

*Self-empowering to maintain and enhance personal
identity as an older adult with depression*

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Abstract

Australians have one of the longest life expectancies in the world, but up to 15% of older Australians living at home experience depression. Increasing attention is being paid to understanding the clinical aspects of depression in older age. However, less is known about how older Australians living in the community experience and self-manage depression, and the factors that influence these processes. The purpose of this qualitative grounded theory study was to explicate the self-management strategies used by older adults diagnosed with depression to optimise their well-being. Data collection and analysis were informed by Corbin and Strauss' (2015) approach to grounded theory. Data were collected through 32 individual interviews, observations and questionnaires. The key conceptual findings of the study comprise a core problem, a core category and three related categories. The basic social psychological problem was conceptualised as *Struggling to maintain personal identity as an older adult with depression*. The core category, *Self-empowering to maintain and enhance personal identity as an older adult with depression*, was abstracted through simultaneous data collection and analysis, and constant comparison. This goal was achieved through the three interlinked strategies of *Taking Stock*, *Accessing Support* and *Reclaiming Self-identity*. Participants' efforts were influenced by three contextual determinants: *Perspectives on age and depression influencing help-seeking*, *Ability to navigate and access the health care system*, and *Individual capacity for self-management*. When drawn together, these elements comprise a substantive theory that reflects a shift from a narrow biomedical discourse of depression in older age to a broader experiential focus on individuals as experts for managing long-term conditions. The findings of this study have implications relating to policy, professional practice, the portrayal of age and depression, older adults and their significant others, and future research.

Doctor of Philosophy declaration

I, Meg Polacsek, declare that the PhD thesis entitled *Self-empowering to maintain and enhance personal identity as an older adult with depression* is no more than 100,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signature

A solid black rectangular box used to redact the signature of the author.

Date

8 October 2018

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Table of contents

Abstract	ii
Doctor of Philosophy declaration	iii
Acknowledgements	iv
Table of contents	v
List of abbreviations	x
List of tables	xi
List of figures	xii
List of appendices	xiii
List of publications	xiv
 Part A: Introduction to the study	 1
 CHAPTER 1: Introduction	 2
1.1 Introduction	2
1.2 Background	2
1.3 Research question and aims	3
1.4 Justification for the study	3
1.5 Terms and definitions	5
1.6 Structure of the thesis	7
 CHAPTER 2: Context of the study	 9
2.1 Introduction	9
2.2 The concepts of older age and ageing well	9
2.2.1 Definitions of older age	9
2.2.2 The concept of ageing well	15
2.3 The experience of depression	19
2.3.1 Defining depression	20
2.3.2 Depression in older age	21
2.3.3 Help-seeking for depression	25
2.3.4 Treatment options for depression	31
2.4 The concept of self-management	43
2.5 Summary	46

CHAPTER 3: Methodology	48
3.1 Introduction	48
3.2 The qualitative research paradigm	48
3.2.1 Ontology and qualitative research	51
3.2.2 Epistemology and qualitative research	52
3.2.3 Methodology and qualitative research.....	53
3.3 Grounded theory.....	57
3.3.1 Defining a grounded theory	59
3.3.2 Features of grounded theory	60
3.3.3 Presenting a grounded theory	72
3.3.4 Critique of grounded theory	73
3.3.5 Justifying the use of Corbin and Strauss' approach to grounded theory..	78
3.4 Summary	80
CHAPTER 4: Methods of study.....	81
4.1 Introduction	81
4.2 Ethical considerations	81
4.2.1 Respect for human beings	83
4.2.2 Privacy, confidentiality and anonymity.....	86
4.2.3 Research merit and integrity.....	87
4.2.4 Justice	87
4.2.5 Beneficence	88
4.2.6 Reimbursement.....	90
4.3 Data storage, access and disposal.....	92
4.4 Assumptions and expectations	92
4.5 Data collection and analysis	95
4.5.1 Methods of data collection	95
4.5.2 The study population	104
4.6 Data management.....	108
4.6.1 Data preparation	109
4.6.2 Data analysis.....	109
4.7 Rigour in qualitative research	112
4.7.2 Quality in grounded theory.....	117
4.8 Summary	119

Part B: Results of the study	120
CHAPTER 5: Overview of the study	121
5.1 Introduction	121
5.2 Participant characteristics.....	121
5.2.1 Setting for the study	121
5.2.2 Screening of participants	121
5.2.3 Socio-demographic characteristics	122
5.2.4 Self-assessment on SMAS-30	122
5.2.5 Observations in the field.....	125
5.3 Overview of the theory.....	126
5.3.1 Core problem	126
5.3.2 Core category	128
5.3.3 Categories and strategies	129
5.3.4 Contextual determinants	130
5.4 Outline of the findings chapters	131
CHAPTER 6: Contextual determinants	132
6.1 Introduction	132
6.2 The study's context and contextual determinants	132
6.2.1 Perspectives on age and depression influencing help-seeking	134
6.2.2 Ability to navigate and access the health care system.....	138
6.2.3 Individual capacity for self-management	140
6.3 Summary	142
CHAPTER 7: Core problem.....	143
7.1 Introduction	143
7.2 Struggling to maintain personal identity	143
7.3 Summary	146
CHAPTER 8: Taking Stock	147
8.1 Introduction	147
8.2 The context of <i>Taking Stock</i>	147
8.2.1 Evolving beliefs and expectations	148
8.2.2 External influences	151
8.3 Strategies for <i>Taking Stock</i>	152

8.3.1	Evaluating well-being.....	153
8.3.2	Coming to terms with the diagnosis	155
8.4	Summary	158
CHAPTER 9: Accessing Support.....		159
9.1	Introduction	159
9.2	The context of Accessing Support	159
9.2.1	Personal preferences	160
9.2.2	Support availability and opportunities	161
9.3	Strategies for Accessing Support	163
9.3.1	Overcoming barriers.....	164
9.3.2	Becoming informed and engaged.....	171
9.3.3	Harnessing formal support	174
9.3.4	Optimising informal support	178
9.4	Summary	180
CHAPTER 10: Reclaiming Self-identity		181
10.1	Introduction	181
10.2	The context of Reclaiming Self-identity	181
10.2.1	Individual capacity	181
10.2.2	Resources to support self-management	182
10.3	Strategies for Reclaiming Self-identity	182
10.3.1	Empowering myself	183
10.3.2	Striving for a meaningful existence.....	186
10.4	Summary	190
CHAPTER 11: Core category and theory		191
11.1	Introduction	191
11.2	Self-empowering to maintain and enhance personal identity	191
11.3	Transitions.....	194
11.3.1	Transitional themes	197
11.4	Theoretical integration	200
11.5	Summary	203
CHAPTER 12: Discussion		204
12.1	Introduction	204
12.2	Principal findings	204

12.2.1 The substantive theory.....	205
12.3 Self-management of depression in older age	223
12.4 Summary	226
CHAPTER 13: Implications and conclusion.....	228
13.1 Introduction	228
13.2 Strengths and limitations of the study	228
13.2.1 Strengths	228
13.2.2 Limitations.....	230
13.3 Implications of the study findings	231
13.3.1 Implications for policy	232
13.3.2 Implications for professional practice	236
13.3.3 Implications for the portrayal of age and depression	241
13.3.4 Implications for older adults and their significant others.....	244
13.3.5 Implications for research	246
13.4 Concluding statement.....	248
References	249
Appendices	294

List of abbreviations

CBT	Cognitive Behaviour Therapy, a form of psychological therapy for depression.
GP	A general practitioner (GP) is a medical doctor. In Australia, GPs are typically the first point of access to care in the health context. They care for patients of all ages across all disease categories. They also provide advice and education on health care and refer patients to other specialists (www.racgp.org.au).
K10	The Kessler Psychological Distress Scale (K10) is a 10-item checklist developed to measure a person's level of psychological distress in the past 30 days (Kessler et al., 2002).
Obs.	Observations conducted in the field.
SMAS-30	The Self-Management Ability Scale (SMAS-30) is a 30-item questionnaire developed to measure unique features involved in the self-regulation of well-being in older adults.
SSRI	Selective serotonin reuptake inhibitors, a frequently prescribed medication for depression.
U3A	The University of the Third Age (U3A) is an international organisation for life-long education organised by and for retired adults.

List of tables

Table 1: Main differences between Glaser, Corbin and Strauss, and Charmaz	74
Table 2: Fragmentation of data and conceptual labelling	110
Table 3: Conceptualising the strategy of <i>Harnessing formal support</i>	111
Table 4: Questions to guide data collection and analysis.....	118
Table 5: Overview of the theory.....	128

List of figures

Figure 1: Illustration of the grounded theory process	72
Figure 2: The process of recruiting participants.....	106
Figure 3: Summary diagram of the core category and theory	127
Figure 3: Contextual determinants of the study	133
Figure 4: The influence of public and self-stigma on help-seeking	137
Figure 5: Taking Stock	153
Figure 6: Accessing Support	164
Figure 7: Reclaiming Self-identity	183
Figure 8: Diagrammatic representation of the core category and theory	192

List of appendices

Appendix A: Information flyer.....	295
Appendix B: Sample of organisations asked to promote call for participants	296
Appendix C: Participant information document	298
Appendix D: Participant consent form	300
Appendix E: Interview schedule	301
Appendix F: Kessler Psychological Distress Scale	303
Appendix G: Participant data and Self-Management Ability Scale.....	304
Appendix H: Audit trail for the study	309
Appendix I: Published papers.....	310

List of publications

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Part A: Introduction to the study

CHAPTER 1

Introduction

1.1 Introduction

This thesis presents a study into the self-management strategies used by older adults with moderate depression (hereafter, depression)¹ to optimise their well-being. The study involved adults aged 65 years and older who had received a formal diagnosis of depression and were living in their own homes in Victoria, Australia. Using Corbin and Strauss' (2015) approach to grounded theory as the methodological framework, data were collected through interviews, observations and questionnaires.

The thesis is divided into two parts. In Part A, the background and context of the study are presented, as well as the methodology and method. In Part B, the results and implications of the study are presented. In this chapter, the study is introduced. The research question and aims of the study are presented, followed by a justification for the study. Key terms are then defined. Finally, the overall structure of the thesis is presented.

1.2 Background

Depression is the leading cause of global disability (Malhi et al., 2018; World Health Organization, 2017). It is the most prevalent mental disorder among older adults and is considered a major global public health challenge (Pocklington, 2017; Sunderland, Anderson, Sachdev, Titov, & Andrews, 2015; World Health Organization, 2016). A considerable body of quantitative work illustrates the complexity and magnitude of the problem of depression overall, and in older age (Almeida, Flicker, & Rees, 2014; Blackburn, Wilkins-Ho, & Wiese, 2017; Gilbody et al., 2017; Ten Have et al., 2016). However, less is known about the everyday experience of older adults with depression, the influence of social and contextual factors on their experiences (Ludvigsson, Milberg, Marcusson, & Wressle, 2015; Van Beljouw et al., 2015) and the self-management strategies they use to optimise their well-being (Dear et al., 2015; Pejner, Ziegert, & Kihlgren, 2015; Shepardson, Tapio, & Funderburk, 2017). In the current study, a

¹ In this study, older adults who met the inclusion criteria for moderate depression were recruited to participate. See 4.5.2.1 (Selection and recruitment of participants).

predominantly qualitative approach to data collection and analysis allowed the emphasis to be placed on the subjective experience of depression and the processes by which individuals sought to optimise their well-being.

1.3 Research question and aims

The research question for the study was:

What self-management strategies do older adults diagnosed with depression use to optimise their well-being?

The broad aim of the study was to explicate the self-management strategies used by older adults diagnosed with depression to optimise their well-being. Specific aims were to:

- Identify their self-management strategies;
- Explore the contextual determinants that influenced their ability to self-manage; and
- Develop a substantive theory that explained how they self-managed their depression to optimise their well-being.

1.4 Justification for the study

Up to 15% of older Australians living in the community experience depression (Pirkis et al., 2009). Depression in older adults is associated with a decline in overall well-being, daily functioning and independence, and increased disability, suicidal ideation and mortality (Almeida et al., 2014; Chachamovich, Fleck, Laidlaw, & Power, 2008; Staples, Fogliati, Dear, Nielssen, & Titov, 2016). Globally, older adults with depression report the highest mean number of health conditions, and those with depression visit a general practitioner (GP) and hospital emergency departments more frequently, use more medication, incur higher outpatient charges, and stay longer in hospital (Arias et al., 2017; Vasiliadis et al., 2013). In Australia, health care costs of older adults with depression are higher than those of their non-depressed peers, and they visit their GP more often than those who do not have depression (Prina, Huisman, et al., 2014; Searby, Maude, & McGrath, 2016). Thus, the effect of a diagnosis of depression extends beyond individuals, as they draw on formal and informal supports to manage their symptoms and improve their quality of life. From this perspective, treatments for depression are more likely to

succeed when affected individuals are actively involved in managing their condition (Chambers et al., 2015; Luck-Sikorski et al., 2017). Consequently, an appreciation of the meaning they attach to their experience of depression, and a clear understanding of the strategies they use to cope, are needed. These should underpin integrated and informed approaches that aim to enhance well-being, while simultaneously reducing demands on the health care system (Chambers et al., 2015; Musekamp, Bengel, Schuler, & Faller, 2016). Self-management is one such approach.

In theory, self-management reflects a person's capacity to manage the symptoms, treatment, consequences and lifestyle issues associated with living with a chronic condition (Houle, Gascon-Depatie, Bélanger-Dumontier, & Cardinal, 2013). In practice, it gives people more choice and control over treatment options, and a greater role in recovery and maintaining their health (Lucock et al., 2011). Older adults who are treated according to their personal preferences and are supported to take control of their health demonstrate improved well-being and overall quality of life (Helvik et al., 2016; Luck-Sikorski et al., 2017). Accordingly, it is becoming increasingly important for older adults to be proactive in their own care for as long as possible (Cramm & Nieboer, 2015). By facilitating ownership of their health, self-management may help them remain independent and healthier for longer (Cramm, Hartgerink, et al., 2012), while moderating the risk of a chronic condition worsening (Washington, Zimmerman, & Browne, 2016).

From policy and service provision perspectives, it is becoming increasingly important to support the self-management of chronic physical and mental conditions (Shepardson et al., 2017). The implication is that effective self-management may assist in ameliorating growing demands on health services (Fisher, Croxson, Ashdown, & Hobbs, 2017). In the current context, this requires a shift from the biomedical discourse of depression in older age to a broader focus on supporting individuals to self-manage their depression. The potential contribution of this study lies in explicating the experience of depression in older age, identifying patterns of help-seeking behaviour and explaining the self-management strategies used to optimise well-being.

1.5 Terms and definitions

This thesis contains several terms that should be defined and contextualised at the outset:

- **Ageing well** is a paradigm in which older adults define for themselves what it means to age well, and, therefore, what they need to age well (Bowling, 2005). The concept encompasses an individual's overall well-being, as well as lifestyle, behaviour and social environment (Kendig, Browning, Thomas, & Wells, 2014).
- **Contextual determinants**, in the current context, are factors which moderate the individual's capacity for self-management of depression. They include a person's individual characteristics and their social, physical and economic environment (Corbin & Strauss, 2015).
- **Depression** is an affective, or mood, disorder characterised by feelings of depressed mood, lack of energy and loss of capacity for interest or enjoyment. Common symptoms include disturbed sleep, poor appetite, reduced concentration and fatigue after minimum effort are common. Feelings of guilt or low self-worth are also common. Depending on the number and severity of the symptoms, a depressive episode may be assessed as mild, moderate or severe (World Health Organization, 2018).
- **Formal support** refers to services provided by private or public health providers, including individual health professionals, hospitals, health or community services, and local councils (Shiba, Kondo, & Kondo, 2016).
- **Help-seeking**, in the health care context, is an adaptive coping process by which the individual actively seeks formal and informal support, and engages with treatment (Rickwood, Thomas, & Bradford, 2012).
- **Informal support** constitutes the support provided by an individual's network of significant others (see below), religious institutions, other non-professionals, or the broader community (Shiba et al., 2016). For individuals, it includes receiving social, emotional, instrumental and/or informational support that influences their experiences and perceptions of well-being and quality of life (Allen & Wiles, 2014; Yu, Saltus, & Jarvis, 2017).²

² Social support refers to social connectedness and relationships, while emotional support is evidenced by expressions of empathy and caring towards individuals, and a sense of feeling valued and loved (Morelli, Lee, Arnn, & Zaki, 2015). Instrumental support includes receiving material aid, such as help with tasks, transport, or financial assistance (Morelli et al., 2015). Informational

- **Mental health literacy** refers to personal beliefs and attitudes that influence how mental illness is recognised and treated (Jorm, 2000; Jorm et al., 1997). It includes knowledge and beliefs about risk factors, sources of information and support, and treatment options for mental health conditions (Farrer, Leach, Griffiths, Christensen, & Jorm, 2008; Jorm, 2000).
- **Older adults** are individuals aged 65 years and older. Although there is no general agreement on the age at which a person becomes “old”, the age of 65 years is generally considered the starting point to define “old” or “elderly” (World Health Organization, 2015a).
- The **recovery approach** recognises the individual’s strengths, including coping skills and resilience, and capacity for self-determination (Ashman, Halliday, & Cunnane, 2017; Department of Health, 2009). In developed countries, there is an increasing expectation for mental health service providers to work within a recovery-oriented framework (Pincus et al., 2016).
- **Self-determination** refers to the capacity of individuals to make decisions that affect their well-being. It requires a certain level of insight, confidence, competence and motivation (Corrigan et al., 2012).
- **Self-efficacy** encapsulates individuals’ beliefs in their ability to accomplish a task or succeed in a specific situation. Expectations of self-efficacy determine whether coping behaviour will be initiated, how much effort will be expended, and how long the behaviour can be sustained (Bandura, 1997; Richard & Shea, 2011).
- **Self-management** refers to a person’s capacity to manage the symptoms, treatment, consequences and lifestyle issues associated with living with a chronic condition (Houle et al., 2013).
- **Self-management ability** refers to the core behaviours and cognitive abilities which presumably contribute to the sustainable well-being of older adults (Schuermans et al., 2005).
- **Significant others** are those with whom an established relationship exists, including partners, family members, close friends, colleagues and/or neighbours (Thoits, 2011). Significant others frequently provide informal support (see above).

support refers to the provision of advice or information aimed at helping the individual cope with their current circumstances receiving useful advice and/or information (Rickwood et al., 2012).

- **Substantive theory**, in grounded theory methodology, is a theory that is topic-specific and seeks to explain a social process within a clearly defined context (Birks & Mills, 2015; McCann & Clark, 2003a).
- **Transition** is a multifaceted concept that describes “the experience of individuals who are confronting, living with, and coping with ... a situation that requires new skills, sentiments, goals, behaviours or functions” (Meleis, 2015, p. 363).
- **Well-being** is an individual’s subjective state of existence, characterised by health, happiness and prosperity. As an optimal state of being, it is associated with self-perceived health, productivity and longevity (Carpentieri, Elliott, Brett, & Deary, 2017). It has been conceived as the balance point between an individual’s psychological, physical and social resources, and life challenges (Dodge, Daly, Huyton, & Sanders, 2012).

1.6 Structure of the thesis

This thesis is presented in 13 chapters. Part A of the thesis contains four chapters which detail the background and conduct of the study. In this introduction (Chapter 1), the background and aims of the study are set out. In Chapter 2, the context of ageing, depression and self-management is considered. In Chapter 3, the methodology is discussed, including an exploration of the qualitative research paradigm and the theoretical framework of symbolic interactionism. The use of grounded theory is considered, followed by a justification for selecting Corbin and Strauss’ (1990, 2015) approach to grounded theory. The methods of the study are described in Chapter 4.

Part B of the thesis is organised into nine chapters. In Chapter 5, the study setting and participant characteristics are explained. An overview of the findings is then given, with an explanation of how they are organised in the following chapters. Chapter 6 contains the core problem of *Struggling to maintain personal identity as an older adult with depression*. The contextual determinants that influence the findings of the study—*Perspectives on age and depression influencing help-seeking*, *Ability to navigate and access the health care system* and *Individual capacity for self-management*—are described in Chapter 7. In Chapter 8, an analysis is undertaken of the first category, *Taking Stock*, and its related strategies of *Evaluating well-being* and *Coming to terms with*

the diagnosis. In Chapter 9, analysis and discussion of the second category, *Accessing Support*, takes place, focussing on the strategies of *Overcoming barriers*, *Becoming informed and engaged*, *Harnessing formal support* and *Optimising informal support*. In Chapter 10, the third category of *Reclaiming Self-identity* is considered, with analysis and discussion of the strategies of *Empowering myself* and *Striving for a meaningful existence*. Following the examination of the categories, strategies and sub-strategies that comprise the study, Chapter 11 contains a discussion on the core category of *Self-empowering to maintain and enhance personal identity as an older adult with depression* and its transitional themes of *Accepting a change in wellness-illness status*, *Adapting to the changeable nature of depression*, and *Creating new meaning*. The overall findings of the study are discussed in Chapter 12. Finally, in Chapter 13, the strengths and limitations of the study are presented, as well as the implications of the findings in relation to the self-management of depression in older adults.

CHAPTER 2

Context of the study

2.1 Introduction

The broad aim of this study was to explain the self-management strategies used by older adults diagnosed with depression to optimise their well-being. The purpose of this preliminary review of literature is to establish the background and context of the study. An initial review of literature serves to justify the need for a study, orientate the researcher to the field and promote theoretical sensitivity³ about the phenomenon being studied. This chapter commences with a discussion of the concepts of older age and ageing well, and the implications of an ageing population. The experience of depression generally and then in older adults is considered, after which the concept of self-management is presented.

2.2 The concepts of older age and ageing well

There is no consensus on the age at which a person becomes old (Stuart-Hamilton, 2011). In addition, the common use of chronological—or calendar—age to mark the threshold of old age presupposes an equivalence with biological age, even though it is generally accepted that these two are not necessarily synonymous. Like the concept of “being old”, there is also no unanimous definition of what it means to age well in practical, measurable terms (Lacruz et al., 2010). However, broad acceptance of these concepts is needed to inform policy and practice.

2.2.1 Definitions of older age

The concepts of age and ageing are social constructions that vary over time and are shaped more by culture, beliefs and traditions, than biology (Cruikshank, 2013). Although most people have individual frames of reference for what old age and ageing mean to them, these personal, societal and cultural concepts are often difficult to define. Notwithstanding challenges in establishing an objective definition of old age and ageing, population projections are needed to inform planning for the future. These require

³ See 3.3.2.1 (Theoretical sensitivity).

accurate collection and analysis of demographic data, including along predetermined age thresholds. Accordingly, most developed countries currently accept the age of 65 years as a way to define “elderly” or “old” (World Health Organization, 2015a). This seemingly arbitrary definition of old being “65 years and over”⁴ is often associated with the earliest pension schemes in Europe, where it was set as the minimum age to qualify for an old-age pension (Pachana, 2016). To facilitate their studies into different groups of older adults, gerontologists⁵ typically divide the decades after the age of 65 years into different bands. “Young old” refers to those aged between 65 and 74 years; “old old,” those aged 75 to 84 years; and “oldest old,” those aged 85 years and over (Pachana, 2016). Other conceptualisations of age include “Third Age” and “Fourth Age”. Varying definitions of these suggest that the Third Age ranges from 50 to 80 years, and the Fourth Age from 80 years onwards (Van Dyk, 2016; Weber et al., 2015). The parameters of the Third and Fourth Ages are bounded by work and family life stages, and health, rather than chronological age (Gilleard & Higgs, 2011). From another perspective, Cruikshank (2013) proposes that “it is not the changes in our bodies that define ‘old’, but the societal meanings given to those changes” (p. 6). Edgar (2013) echoes this sentiment, commenting that “we who are old do not see ourselves as society defines us” (p. 8). Against this backdrop, Kendig (2017) posits that “... our images of ageing and the life chances of ageing people are inseparable from the periods of history in which they have lived their lives” (p. 13). These images and chances are linked inextricably to life expectancy.

2.2.1.1 *Life expectancy*

The World Health Organization (2016) estimates that the proportion of adults over 60 years of age⁶ will almost double by 2050. In Australia, life expectancy⁷ for both genders has improved steadily in the last century and is now one of the highest in the world (Australian Bureau of Statistics, 2016). Records indicate that, between 1901-10 and 1999-2001, the average life expectancy of newborns in Australia increased from 55 to 77 years for boys and from 59 to 82 years for girls (Australian Bureau of Statistics, 2004). Between

⁴ This is the age inclusion criterion for the current study. See 4.5.2.1 (Selection and recruitment of participants).

⁵ Gerontologists explore the biological, social, cultural, psychological and cognitive aspects of old age and ageing.

⁶ The United Nations (2015) uses the benchmark of 60 years of age or above to refer to older adults, as this lower age category is representative of developing countries, where life expectancy is often lower than in developed countries.

⁷ Life expectancy measures how long, on average, a person is expected to live from birth, based on current age and gender-specific death rates. It is expressed as the number of years of life a person born today is expected to live (Australian Institute of Health and Welfare, 2017a). In contrast, “longevity” describes a person’s typical length of life (living a long life), while “life span” refers to an individual’s age at death.

1996 and 2016, the proportion of people aged 65 years and over⁸ increased from 12 to 15.3% (Australian Institute of Health and Welfare, 2017b), while the number of people aged 85 years and over almost doubled (Australian Bureau of Statistics, 2015a). In 2014-16, life expectancy at birth was 80.4 years for males and 84.6 years for females (Australian Bureau of Statistics, 2017). In Australia, the number of adults aged 65 years and over is expected to more than double by 2055, with predictions indicating that there will be approximately 40,000 people aged over 100 years old in 2054-55, well over the 122 Australian centenarians in 1974-75 (Commonwealth of Australia, 2015).

For Aboriginal and Torres Strait Islander peoples, however, poorer health status and higher incidence of chronic diseases are manifested as significantly lower life expectancy than Australia's non-Indigenous population (Pachana, 2016; Phillips et al., 2017). By 2055, life expectancy for Aboriginal and Torres Strait Islander peoples is predicted to reach 69.1 years for males and 73.7 years for females (Australian Institute of Health and Welfare, 2016), considerably less than non-Indigenous people.

Although gender is influenced by biological, social, environmental and behavioural factors, it is one of the strongest predictors of life expectancy (Luy & Minagawa, 2014; Tower, 2017). Detailed population records provided by the Human Mortality Database (www.mortality.org) reveal that women live longer than men in all countries, for every year on record. Hypotheses to explain gender differences in life expectancy include a more responsive female immune system, the protective effect of oestrogen⁹ and compensatory effects of the second X chromosome (Austad & Bartke, 2016; Lindahl-Jacobsen, Zarulli, Christensen, Vaupel, & Oeppen, 2016; Pucci et al., 2017).¹⁰ In addition, men are more likely to engage in risky behaviours, such as cigarette smoking, alcohol use, less safe driving and poorer diet, which elevate their risk of injury, disease and death (Lindahl-Jacobsen et al., 2016). Although women live longer than men, they typically experience poorer health over their lifetime. This health-survival paradox reflects age-related patterns of disease, whereby men experience more life-threatening conditions at a

⁸ The use of the age of 65 years onwards as "old" is often associated with the qualifying age for pension benefits (Pachana, 2016).

⁹ In females, oestrogen may protect against cardiovascular disease by facilitating the elimination of bad cholesterol (Pucci et al., 2017).

¹⁰ For example, the heterogametic sex hypothesis—that is, a species in which the sex chromosomes are not the same—posits that the lack of a second X chromosome in males tends to lead to shorter life spans (Austad & Bartke, 2016). Hence, having a second X chromosome offers females a better resistance to biological ageing (Desjardins, 2004).

younger age, while women face higher rates of less severe chronic diseases (Austad & Bartke, 2016; Luy & Minagawa, 2014). To illustrate, men die earlier from coronary heart disease, cancer and stroke, whereas women experience more, but less healthy, years of life due to autoimmune or rheumatologic conditions (Luy & Minagawa, 2014). Thus, gender differences in the experience of ageing demonstrate the importance of targeting health promotion efforts to men and women (Kendig & Browning, 2016).

Life expectancy is also influenced by prevailing cultural, societal, economic, political and religious conditions (Gilleard & Higgs, 2011; Holmes & Holmes, 1995). Modernisation,¹¹ for example, is identified as a major influence in how old age is conceptualised and experienced, as it is directly related to longevity. The steady increase in life expectancy since the early 20th century has been attributed to lower infant mortality, improvements in living conditions—such as safer water supply and sanitation systems—and improved food quality (Australian Institute of Health and Welfare, 2017a). Other factors that influence life expectancy include socio-economic status, health behaviours,¹² and social activity (Paul et al., 2016; Pynnönen, Törmäkangas, Heikkinen, Rantanen, & Lyyra, 2012). Health literacy and access to high quality health care are also important indicators of life expectancy and mortality (Bostock & Steptoe, 2012). These factors are associated with improved recognition of symptoms, help-seeking and treatment concordance, which enable better health outcomes (Bostock & Steptoe, 2012; Kopera-Frye, 2016).

2.2.1.2 *Implications of population ageing*

Increased life expectancy has a direct impact on society, as changes brought about by an ageing population require a range of social and policy responses (Bateman, 2016). Population ageing affects intergenerational relationships, health services and aged care, and retirement planning (Piggott, 2016).¹³ For policy-makers, the dependency ratio—that is, active workers per dependent pensioner¹⁴—created by an ageing population is a major concern (Bateman, 2016). Tax bases and rates are being changed to meet the increased

¹¹ The term modernisation, often used interchangeably with industrialisation, is used widely to describe the changes which have occurred in developed societies over the last two or three centuries. Both terms most often refer to development and use of mechanical technology, a real or perceived increase in the standard of living, changes to gender roles and political change.

¹² Health behaviours that increase life expectancy include following a healthy diet, undertaking regular exercise, reducing smoking and lowering alcohol consumption (Paul et al., 2016).

¹³ The concept of retirement is found mainly in developed and highly productive societies (Taylor & Earl, 2016).

¹⁴ Typically calculated as the population over 65 years of age divided by those aged between 15 and 64 years (Piggott, 2016).

revenue requirement of a changing population (Piggott, 2016). The qualifying ages for the state age pension and access to superannuation are increasing steadily, as retirement income systems undergo ongoing reform (Bateman, 2016). In Australia, the state pension age of 65 years and six months in 2017 will increase progressively to 67 years by 2023 (Department of Social Services, 2016). This change is consistent with international trends. In the United States, Germany and Iceland, the pension age is or will soon become 67 years (Powell, 2017). In the United Kingdom, plans to increase the qualifying age for the State Pension to 68 years have been brought forward from 2044 to 2037 (Department for Work and Pensions, 2017). Justification for these increases relates to the additional years spent in retirement, shrinking tax-paying working populations and rising health and welfare costs (Hall & Van Gool, 2016).

The impact of demographic ageing is possibly most pronounced in Japan, where almost 27% of the population is currently aged over 65 years (Statistics Japan, 2016). Although it has one of the longest life expectancies in the world, its normal retirement age of 65 years—which is also the age at which individuals may access full pension benefits—is one of the lowest in developed countries (Kitao, 2017).¹⁵ The sustainability of its pension system is a major concern for the Japanese government, as the number of pension recipients and the average number of years receiving pensions increase (Kitao, 2017; Sugie, 2017). At the same time, its labour force is shrinking. Although major reforms to retirement policies are being implemented, the effect of these reforms has been limited by conflicting priorities between government, employers and workers (Higo & Klassen, 2017). For example, the Japanese government encourages employers to re-hire post-retirement workers back into the workforce, but these workers are frequently offered lower pay and fewer, if any, benefits (Higo & Klassen, 2017). They must also compete for work among a growing pool of older and younger workers (Sugie, 2017). Many older adults are unable to secure meaningful work, leaving them to perform low-skill, low-wage jobs, or unemployed (Weller, 2017). One consequence of this has been a marked increase in crimes committed by older adults in Japan, attributed to changes in living conditions—including employment—boredom, isolation and poverty (Hu, 2016; Sugie, 2017; Weller, 2017). Better prison facilities for older adults do little to deter crime, as

¹⁵ Only recently as serious debate on the need to increase Japan's retirement age beyond 65 years commenced (Kitao, 2017).

inmates have access to shelter, food and regular health assessments, that they may otherwise not be able to afford (Hu, 2016).¹⁶

To help governments meet the changing needs of the population, it is necessary to improve the efficiency and performance of health services (Productivity Commission, 2013). Increases in productivity and labour force participation are needed to complement government income (McDonald, 2016). Although redesigning services and optimising use of technology are essential to support the ageing population (Hall & Van Gool, 2016), concerns regarding the funding of age pensions frequently attract the most publicity, much of it negative (Elgot, 2017; Ockenden, 2017). This may represent a fear on the part of policy makers and individuals that existing pension and saving schemes may not be sustainable.¹⁷ However, in an analysis of the national policy challenges associated with population ageing in Australia, Piggott (2016) suggests that Australia is well served by the existing retirement and superannuation framework, and that “while many questions remain unanswered, and there is much room for improvement, the current system is sustainable” (p. 50).

In refuting the discourse of economic burden or blame concerning an ageing population, Edgar and Edgar (2015) emphasise the contribution they made by building Australia’s economy, and continue to make by supporting younger generations through education and child-rearing. Gong and Kendig (2016) also describe the substantial contributions made by older adults beyond paid work, including through child care, caregiving¹⁸ and volunteering. Although the high rate of volunteering among older adults offers broad benefits to the community (Gong & Kendig, 2016), the associated activity and social engagement benefit the volunteers themselves (Kahana, Bhatta, Lovegreen, Kahana, & Midlarsky, 2013).¹⁹ These activities undertaken by older adults that contribute to the economy are also of substantial benefit to their experience of ageing (Kahana et al., 2013).

¹⁶ To accommodate the thousands of older adults in its prisons, the Japanese government is designing and constructing wards that cater to their needs, while additional nursing staff are being employed to assist these older inmates with their activities of daily living (Weller, 2017).

¹⁷ In Australia, this might include state pension schemes and personal and/or employer superannuation contributions.

¹⁸ The economic value of child care and caregiving provided by older adults was estimated at AU\$7 billion in 2009 (National Seniors Australia, 2009).

¹⁹ See 9.3.4.2 (Helping others).

2.2.2 The concept of ageing well

A growing focus on optimising quality of life in older age has heightened interest in understanding what it means to age well. Most discussions on ageing well describe ways in which older adults manage their experiences of ageing and adjust to maintain their sense of self (Hughes & Heycox, 2010). However, the natural experience of ageing is multidimensional: physical changes occur in a particular setting, and are influenced by factors such as gender, ethnicity and the broader social and political climate (Cruikshank, 2013; Kendig & Browning, 2016). Predictors of ageing well include physical activity, diet, social support and low stress (Kendig & Browning, 2016; Kendig et al., 2014).

Formal models of successful ageing began to emerge in the 1970s. At the time, research on ageing was dominated by efforts to distinguish between pathological and “normal” ageing, with little attention given to understanding the upper end of the continuum—that is, successful ageing (Rowe & Kahn, 1987). Although normal ageing is often accompanied by a gradual decline in physical and cognitive function (Kooman, van der Sande, & Leunissen, 2017; Washington et al., 2016), Rowe and Kahn (1987) postulated that many age-related changes associated with ageing were preventable or, at least, manageable. Their alternative model of “successful ageing” comprised a combination of low probability of disease and risk factors for disease, high cognitive and physical functioning, and active engagement with life (Rowe & Kahn, 1997). Staying healthy, reducing risk factors—for example, by following a healthy diet and exercise regimen—and maximising cognitive functioning and social engagement in later life were considered predictors of well-being in older age (Rowe & Kahn, 1997). More recently, Troutman-Jordan (2015) described various degrees of coping processes for successful ageing, which are unique to each person. “The theory of successful aging” (Troutman-Jordan, 2015) considers multiple domains of health and well-being, and the influence of personal choice on the experience of ageing.

Whether viewing ageing as a state of being at a certain moment or as a process, it remains unclear if the construct of successful ageing refers to the absence of disability or to a combination of positive attributes, including well-being (Lacruz et al., 2010). Another prominent model, which focused on behavioural and psychological adaptation to various

forms of loss, described successful ageing in terms of lifespan developmental trajectories (Baltes, 1997). Since then, several studies have used various operationalised definitions to examine the concept of successful ageing (Jeste, Depp, & Vahia, 2010; Troutman-Jordan, 2015). Different nomenclature applied to the concept of ageing well include “active ageing”, “healthy ageing”, “harmonious ageing”, “positive ageing” and “robust ageing” (Jeste et al., 2010; Nosraty, Jylhä, Raittila, & Lumme-Sandt, 2015).

In the current study, the term “ageing well” is used. Although measures of physical and mental health, cognition, social engagement and life satisfaction have been used to explore definitions of successful ageing, the paradigm of ageing well allows older adults to define for themselves what it means to age well, and, therefore, what they need to age well (Bowling, 2005). This may be compared to the concept of successful ageing, which “focuses on individuals to the exclusion of structural, social, gender and cultural explanations of their circumstances” (Kendig & Browning, 2016, p. 139). The concept of ageing well includes complex interactions of lifestyle, behaviour and social environment, as well as physical and mental health, and overall well-being (Bowling, 2005). Older adults themselves rate overall health, functional and cognitive ability, being pain-free and being able to conduct daily tasks as important elements of ageing well (Nosraty et al., 2015). However, individual views and experiences of age and ageing are far more diverse and complex than any single theory or model of ageing (Nosraty et al., 2015). One of the important factors that exerts an influence on the experience of age is the attitudes of older adults themselves towards ageing (Carpentieri et al., 2017; Hoppmann, Infurna, Ram, & Gerstorf, 2015; Wurm & Benyamini, 2014).

2.2.2.1 *Attitudes towards ageing*

The narrative used by older adults when talking about well-being has been associated with health, life satisfaction and quality of life (Carpentieri et al., 2017). Positive attitudes towards ageing are recognised as important drivers of healthy mental and physical ageing, and help-seeking behaviour (Bryant et al., 2012; Levy, Slade, Pietrzak, & Ferrucci, 2018; Wurm & Benyamini, 2014). Carpentieri et al. (2017) reported that older adults who engaged in high levels of constructive self-talk experienced higher well-being, despite low physical function. Similarly, Levy (2018) highlighted how positive age beliefs may

serve as a protective factor in the well-being of older adults. Conversely, negative views and expectations typically have a detrimental effect on the experience of ageing (Coudin & Alexopoulos, 2010; Wurm & Benyamini, 2014). Coudin and Alexopoulos (2010) found that older adults who approached ageing with a sense of pessimism were more likely to experience poorer mental and physical health, and increased loneliness, which led to increased dependency on others. In addition, older adults who anticipate deterioration in physical and mental health—including increased expectation of depression—and loss of independence, may be unaware of the potential of seeking help for common physical or mental health problems in older age (Luck-Sikorski et al., 2017). Hence, negative stereotypes and discrimination may delay or prevent help-seeking, while diminishing older adults' independence and optimism for the ageing experience (Bryant et al., 2012; Han & Richardson, 2015). Given the influence of ageing stereotypes and discrimination on older adults' sense of well-being and help-seeking behaviour, the concept of ageism merits attention.

2.2.2.2 *The experience of ageism*

Butler (1975) originally coined the term “ageism” to describe the process of systematic stereotyping and discrimination on the basis of age. Like racism and sexism, ageism is prejudice or discrimination against a category of people. However, there is a significant difference between racism or sexism, and ageism: unlike a person's race or gender, anyone may become a target of ageism if they live long enough (Malta & Doyle, 2016). It may be experienced through ageist jokes, patronising language and a prevailing sense of being a burden on family or society (Palmore, 2009; Schroyen et al., 2018).

Ageism is inextricably linked with cultural influences (Löckenhoff et al., 2009). Although ageism is widespread in many developed societies (Blancato & Ponder, 2015; Han & Richardson, 2015), old age is still honoured and respected in more traditional cultures, which value inter-dependence and mutual support among individuals (Bergman, Bodner, & Cohen-Fridel, 2013). In a study of the perception of ageing across 26 cultures on six continents, Löckenhoff et al. (2009) found that participants from Asian cultures generally hold more positive societal views of ageing than their Western counterparts. Similarly, more respect is accorded to elders in Australia's Aboriginal and Torres Strait Islander

communities, where ageing is accepted as an important part of the cycle of life (Ranzijn, 2015). From a government and institutional perspective, ageism may involve discrimination in public policy, such as age discrimination in the workplace, involuntary retirement and the portrayal of the ageing population as a burden on society (Bergman et al., 2013; Chrisler, Barney, & Palatino, 2016). Australia's first survey of older workers, conducted in 2015, revealed that more than a quarter of respondents aged 50 years and over had experienced some form of age-related discrimination in the last two years (Australian Human Rights Commission, 2015). The most common types of discrimination concerned reduced opportunities for employment, promotion or training due to age, the perception that the skills of older workers were outdated, and age-related jokes or derogatory comments from colleagues or managers. In the United States, employment-related age discrimination is the top category—25% of the caseload—of cases addressed by the Equal Opportunity Commission each year (Blancato & Ponder, 2015). Although policies are slowly changing to reflect the increased presence of older workers, a change in attitudes towards older adults in the workforce is needed (Gong & Kendig, 2016).

In the health care setting, it is in the interaction between health professionals and older patients that ageism most frequently occurs (São José, Amado, Ilinca, Buttigieg, & Taghizadeh Larsson, 2017). Ageism may also be reflected in organisational culture and broader health policies (São José et al., 2017). There is ample evidence of health professionals patronising older patients,²⁰ listening less to their views, giving less time to clinical interviews and attributing symptoms to age rather than to treatable conditions (Blancato & Ponder, 2015; Chrisler et al., 2016; Makris et al., 2015; Schroyen et al., 2018; Wilson et al., 2017). There is also a danger of over- or under-treatment of mental and physical conditions in older adults (Ouchida & Lachs, 2015; Schroyen et al., 2018). Regarding over-treatment, Berwick and Hackbarth (2012) found that older patients were subjected to tests and treatments that lacked evidence of benefit. These treatments included excessive use of antibiotic medication and surgery, rather than close monitoring, and intensive care at the end-of-life that was inconsistent with individuals' wishes

²⁰ Health professionals often communicate with older adults using “elderspeak”, which is characterised by a patronising tone, slower or louder speech, and simplified sentences (Schroyen et al., 2018).

(Berwick & Hackbarth, 2012). Health assessments and treatment recommendations were based on the older adult's chronological age, rather than their personal preferences, functional status or other co-morbid conditions (Berwick & Hackbarth, 2012). Alternatively, under-treatment occurs when health professionals assume that ailments are age-related (Ouchida & Lachs, 2015). Compared to younger patients, health professionals are more likely to recommend against diagnostic tests or medical treatment for older patients (Ouchida & Lachs, 2015; São José et al., 2017). To illustrate, in a study into ageism as a reason for under-treatment of back pain, Makris et al. (2015) found that medical providers dismissed or under-estimated their patients' pain, based on assumptions they made regarding health expectations at an advanced age.

Regarding mental health, health professionals frequently misattribute common depressive symptoms such as a loss of interest in life, chronic unexplained pain, poor sleep or impaired memory to old age, dementia or poor health (Han & Richardson, 2015; Law, Laidlaw, & Peck, 2010; Ouchida & Lachs, 2015; Webb, Cui, Titus, Fiske, & Nadorff, 2018). This risk increases if health professionals lack the skills to diagnose depression in older adults, and/or conflate an apparently high prevalence of depression with the natural consequence of ageing (Ouchida & Lachs, 2015; Von Faber et al., 2016).

2.3 The experience of depression

The term "depression" is used commonly to describe a range of symptoms, disorders or illnesses characterised by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, fatigue and poor concentration (Jorm, Allen, Morgan, Ryan, & Purcell, 2013). In contrast to usual mood fluctuations or passing emotional responses to everyday challenges, depression can substantially impair an individual's ability to function or cope with daily life (Kitchener, Jorm, & Kelly, 2017).

There is no single, exact cause of depression (Kitchener et al., 2017). However, its development is generally associated with a combination of family history, severe life stressors and serious medical illness (Jorm et al., 2013; Kitchener et al., 2017). Depression may be transient, long-lasting or recurrent, with some types driven by genetic and biological factors, and other types being a response to major life events or socio-structural

factors (Townsend, 2015). Ongoing difficulties, such as long-term unemployment, loneliness or stress, are also more likely to lead to depression than individual events or recent stresses (Jorm et al., 2013; Read, Cartwright, Gibson, Shiels, & Magliano, 2015).

2.3.1 Defining depression

The most widely used classification systems for depressive disorders are the World Health Organization's (2018) International Classification of Diseases (ICD-11) and the American Psychiatric Association's (2013) Diagnostic and Statistical Manual (DSM-5).²¹ Under slightly different headings, both systems classify depression as mild, moderate²² or severe on the basis of the severity of episodes, the number and severity of symptoms, and whether psychotic features are present. The difference between the two classification systems relates mainly to the lower threshold of symptom requirements for the ICD-11 (World Health Organization, 2018),²³ compared to the DSM-5 (American Psychiatric Association, 2013).²⁴

²¹ Depressive symptoms can also be measured by a number of self-reported inventories, such as the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the Self-Rating Depression Scale (Zung, 1965).

²² The inclusion criteria for the current study required participants to be screened for moderate depression. See 4.5.2.1 (Selection and recruitment of participants).

²³ According to the ICD-11 (World Health Organization, 2018), moderate depression (6A71.1) means "there is currently a depressive episode of moderate severity, and there are no delusions or hallucinations during the episode. A depressive episode is characterized by a period of almost daily depressed mood or diminished interest in activities lasting at least two weeks accompanied by other symptoms such as difficulty concentrating, feelings of worthlessness or excessive or inappropriate guilt, hopelessness, recurrent thoughts of death or suicide, changes in appetite or sleep, psychomotor agitation or retardation, and reduced energy or fatigue. In a moderate depressive episode, several symptoms of a depressive episode are present to a marked degree, or a large number of depressive symptoms of lesser severity are present overall. An individual with a moderate depressive episode typically has considerable difficulty in continuing with work, social, or domestic activities, but is still able to function in at least some areas" (para. 1).

²⁴ Under the DSM-5 (American Psychiatric Association, 2013), the criteria for major depressive disorder may be summarised as:
"A. Five (or more) of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure:
1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful).
2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation.)
3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day.
4. Insomnia or hypersomnia nearly every day.
5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
6. Fatigue or loss of energy nearly every day.
7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.
B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
C. The episode is not attributable to the physiological effects of a substance or to another medical condition" (pp. 160-161).

A plain English description of the symptoms of moderate depression, offered by Townsend (2015), lists alterations in the following four areas of functioning:

- Affective: feelings of sadness, helplessness, hopelessness and low self-esteem. The person also has difficulty experiencing pleasure in activities.
- Behaviour: including psychomotor retardation, slowed speech and limited verbalisation. Social isolation and self-destructive behaviour may also be present, as well as decreased interest in personal hygiene and grooming.
- Cognitive: including repetitive thoughts of pessimism and negativism, and retarded thinking processes. Suicidal ideation may also be present.
- Physiological: including sleep disturbances, pain—typically in the form of headache, backache, chest pain or abdominal pain—decreased libido and fatigue.

2.3.2 Depression in older age

Depression is the most common mental disorder in older adults (Herron & Mitchell, 2018; World Health Organization, 2015c). In developed countries, it is experienced by between 10 and 40% of community dwelling older adults (Blackburn et al., 2017; Keshavarzi, Ahmadi, & Lankarani, 2015).²⁵ In the United Kingdom, rates as high as 35% have been reported (Herron & Mitchell, 2018), while in Australia, up to 15% of older adults living in the community experience the disorder at any one time (Haralambous et al., 2009).²⁶ Despite the significance of these figures, it is likely that the prevalence of depression in older adults living in the community remains under-estimated and under-treated (Arias et al., 2017; Arokiasamy et al., 2017; Luck-Sikorski et al., 2017; Tanner, Martinez, & Harris, 2014). This is significant, because depression is a risk factor for other adverse health outcomes, particularly in older adults (Maust, Sirey, & Kales, 2017). However, establishing the incidence of depression in older Australians living in the community is challenging, with variability in estimates attributed to researchers' use of different instruments, sample sizes, age parameters and age-related screening bias (Pirkis et al., 2009; Snowdon, Almeida, & O'Connor, 2016; Sunderland et al., 2015). In addition,

²⁵ This includes late-life and long-term depression. Late-life depression generally refers to the development of depressive symptoms and a diagnosis in adults aged over 60 years (Blackburn et al., 2017; Han & Richardson, 2015). In long-term depression, the person has a history of depression.

²⁶ Older adults living in residential aged care facilities experience depression at significantly higher rates than those living in the community (Australian Institute of Health and Welfare, 2013; Stargatt et al., 2016). However, the focus of the current study is on community-dwelling older adults.

studies frequently report data and procedures that combine depression with anxiety (Dear et al., 2015; Titov et al., 2016). Australian studies have also considered the association of depression with a comorbid condition, such as vision loss (Holloway et al., 2018) or pain (Sharpe et al., 2017), or in relation to influencing factors, including cultural diversity (Haralambous et al., 2016) or geographical location (Dawson et al., 2017). This makes it difficult to determine the prevalence of depression alone.²⁷ Hence, the estimate of up to 15% continues to be cited widely (Pirkis et al., 2009).

Although it is a serious condition at any age, depression is a particularly complex problem for older adults (Dear et al., 2015; Pirkis et al., 2009). The prognosis is often poor, as it follows a more chronic course²⁸ and displays higher relapse rates than depression earlier in life (Mitchell et al., 2011; Von Faber et al., 2016). Depression in older adults is also more likely to persist, if left untreated (Almeida et al., 2012). Left undiagnosed and untreated, it also often produces adverse effects such as physical illness, a decline in functioning and loss of independence (Aylaz, Aktürk, Erci, Öztürk, & Aslan, 2012; Blackburn et al., 2017; Law et al., 2010). In addition, reciprocal associations²⁹ between depression in older adults and increased falls (Lee et al., 2017) and overall frailty (Soysal et al., 2017) have been reported. Depression in older age is also associated with greater self-neglect (Hansen, Flores, Coverdale, & Burnett, 2016; Livingston et al., 2017).³⁰ Older adults with depression may feel overwhelmed and unable to cope, resulting in a decrease in self-care and increased risk of self-neglect (Hansen et al., 2016; Tanner et al., 2014). In a study into self-neglect in older adults, Hansen et al. (2016) identified an urgent need to improve understanding and interventions to address the correlates of depression and self-neglect, and to determine the most appropriate treatment and support for these individuals. There are also indications of a link between long-term depression and cognitive impairment, including dementia (Do Couto et al., 2016; Malhi et al., 2015).

²⁷ In a recent *Older Australia at a Glance Report* (Australian Institute of Health and Welfare, 2017b), the lack of overarching data on mental health is attributed to the diversity of mental health services provided through different pathways. However, older adults accounted for 9% of all community mental health service contacts in 2013–14.

²⁸ Depression is often, but not always, chronic (that is, persistent or recurring) (Malhi et al., 2015; Mitchell, Rao, & Vaze, 2011).

²⁹ That is, each is associated with an increased prevalence and incidence of the other, and may increase the risk of developing the other (Soysal et al., 2017).

³⁰ Self-neglect refers to failure or refusal to address one's own basic physical, emotional and/or social needs. It is manifested by a lack of self-care and protection in relation to food, water, clothing, hygiene, living environments, personal safety and medication (Hansen et al., 2016).

Those aged 50 years and over are reported to fear dementia—commonly associated with older age—more than any other illness (Langa et al., 2017; Verhaeghen, 2011). Although the number of people with dementia is increasing globally due to ageing populations, the prevalence of dementia in developed countries may be trending downwards (Langa et al., 2017; Livingston et al., 2017; Wu et al., 2017). A study conducted in the United States reported a significant decline in the prevalence of dementia from 11.6% in 2000 to 8.8% in 2012, which translates to about a million fewer individuals with the condition (Langa et al., 2017). Similarly, the incidence of age-specific dementia is declining in the United Kingdom (Ahmadi-Abhari et al., 2017). In addition, despite improved life expectancy, the increase in the number of people with dementia is not as large as previously predicted (Ahmadi-Abhari et al., 2017). These declines may reflect improvements in living conditions, education, health behaviour and health care (Wu et al., 2017). Declining rates of dementia in Sweden have been associated with higher education (Skoog et al., 2017), while better control of blood pressure and diabetes may decrease the risk of age-related memory problems and stroke (Langa et al., 2017). However, the evidence for dementia rates in developing countries is inconclusive (Almeida et al., 2014). In a study into dementia prevention, intervention and care, Livingston et al. (2017) included the need for active treatment of depression as a strategy for delaying or preventing dementia.³¹

Depression in older age is also associated with a greater likelihood of death by suicide (Draper, 2014; Heisel & Flett, 2016; Webb et al., 2018). Age-specific data indicate that Australian men aged 80 years and above are most likely to die by suicide than other age groups (Australian Bureau of Statistics, 2015b), while data published by the World Health Organization (2014) show that suicide rates are highest in men and women aged 70 years and over in almost all regions of the world.

A multitude of social, demographic, biological and psychological factors contribute to the older person's experience of depression (Northwood, Ploeg, Markle-Reid, & Sherifali, 2018; Stoeckel & Litwin, 2015). Common risk factors for depression in older age include a history of depression, poor self-rated health, medical problems, low

³¹ Other strategies for delaying or preventing dementia include active treatment of hypertension in middle aged (45–65 years) and older adults (over 65 years), reducing smoking, managing hearing loss and diabetes, undertaking regular exercise and maintaining social engagement (Livingston et al., 2017).

education, being female and being unmarried (Pocklington, 2017; Ylli et al., 2016).³² Increased risk of depression is also associated with the loss of a partner, family member, close friend or pet, loss of independence, poverty, and having care-giving responsibilities for others with major illness (Blackburn et al., 2017; Cloutier-Fisher, Kobayashi, & Smith, 2011; Saito, Kai, & Takizawa, 2012). Concerning the impact of retirement on older adults' mental health, the data are inconsistent: some studies have found an increase in depression and/or anxiety, while others have reported an improvement in mental well-being (Djukanović & Peterson, 2016). Social isolation and loneliness of older adults are also recognised as major influences on quality of life (Bartlett, Carroll, Warburton, Lui, & Peach, 2013).

As the population continues to age, social isolation and loneliness are expected to affect the well-being of increasing numbers of older adults, particularly those who are single, live alone and have poor self-reported health (Bartlett et al., 2013; Saito et al., 2012). However, the lived experience of social isolation should be considered within individual contexts of everyday life, important life events and life course transitions (Cloutier-Fisher et al., 2011). For example, some older adults prefer small social networks, whereas others consider them a marker of social isolation (Cloutier-Fisher et al., 2011). A study by Allen and Wiles (2014) found that childless participants had developed support networks that suited them, even though others perceived them to lack support. Notwithstanding these findings, there is ample evidence that social support and involvement in community activities mitigate against the experience of depression (Sheridan et al., 2014; Turner, Realpe, Wallace, & Kosmala-Anderson, 2015). Thus, it should not be assumed that significant life events or losses are necessarily followed by depression in older age, nor that older adults with depression have experienced them (Haralambous et al., 2009). Above all, depression should not be considered a universal or normal part of ageing (Law et al., 2010; Ludvigsson et al., 2015). This view may lead to delays in help-seeking by the individual, or in the appropriate treatment being offered by the health professional.

³² Older Aboriginal and Torres Strait Islander peoples are generally at greater risk of depression than non-Indigenous communities (Brown et al., 2013; Shen et al., 2018). However, depression diagnosis and treatment may be impeded by different languages and conceptualisations of depression, and the lack of culturally-sensitive screening tools (Ranzijn, 2015; Shen et al., 2018).

2.3.3 Help-seeking for depression

Used frequently in reference to health behaviour, help-seeking concerns the way in which help is actively sought from other people (Rickwood, Deane, Wilson, & Giarrochi, 2005) and as all stages of the process by which individuals access care (Kovandžić et al., 2011). Despite its common usage, few sources define the term, leaving its meaning to be implicit or self-evident. However, Rickwood et al. (2012) proposed a universal operational definition that incorporates the diverse elements of the help-seeking process within the mental health context: “Help-seeking is an adaptive coping process that is the attempt to obtain external assistance to deal with a mental health concern” (p. 6).

The major factors that influence help-seeking for a mental health concern include dispositional factors—that is, an individual’s personal, social and cultural characteristics (Kessler, Agines, & Bowen, 2015; Van Zoonen et al., 2015)—severity of symptoms (Rickwood et al., 2012; Woodward & Pachana, 2009), prevailing attitudes towards depression, such as the influence of stigma, (Conner, McKinnon, Ward, Reynolds, & Brown, 2015), previous negative experiences of help-seeking (Chew-Graham et al., 2012) and access to support (Paul et al., 2016; Scogin, Moss, Harris, & Presnell, 2014). The help-seeking process is also influenced by an individual’s capacity and motivation (Coventry, Fisher, Kenning, Bee, & Bower, 2014; Culph, Wilson, Cordier, & Stancliffe, 2015), as well as health professionals’ knowledge and skills to diagnose and treat depression in older adults (Rhee, Capistrant, Schommer, Hadsall, & Uden, 2017). Improved understanding of the determinants of help-seeking would contribute to efforts to reduce barriers and increase facilitators to help-seeking in older adults with depression.

2.3.3.1 *Help-seeking barriers*

Older adults frequently encounter difficulties obtaining a diagnosis and appropriate treatment for depression (Choi, DiNitto, Marti, & Kunik, 2016; Xiang, Danilovich, Tomasino, & Jordan, 2018). Common help-seeking barriers include attitudes of older adults and health professionals towards depression in older age, poor motivation to seek help, stigma, inconsistent screening for depression and difficulty accessing formal support and previous negative experiences (Rhee et al., 2017; Xiang et al., 2018).

At a fundamental level, older adults' views and knowledge of depression affect whether treatment is sought, accepted and maintained (Fiske, Wetherell, & Gatz, 2009; Woodward & Pachana, 2009). Help-seeking is delayed or prevented when negative views of ageing, or the belief that pain, fatigue and increased dependency on others are normal parts of ageing, are held by older adults (Burroughs et al., 2006; Law et al., 2010), significant others (Vassilev, Rogers, Kennedy, & Koetsenruijter, 2014) or health professionals (Ouchida & Lachs, 2015). A series of interviews with older adults and health professionals, conducted by Burroughs et al. (2006), revealed that both groups endorsed perceptions of depression in later life as understandable and justifiable, with consequent low expectations of treatment options and outcomes. In addition, those who do report symptoms of depression to a health professional have been found to disproportionately underutilise mental health services, compared to younger adults with similar symptoms (Kessler et al., 2015; Pocklington, 2017; Sjöberg et al., 2017). Poor motivation, a lack of confidence and decreased decision-making capacity due to depression also constitute barriers to help-seeking (Culph et al., 2015; Searle et al., 2014). Although difficulty with motivation often inhibits older adults with depression from accessing support (Pocklington, 2017), those whose daily activities are impaired by their depression are more likely to recognise the value of treatment and seek help (Culph et al., 2015; Raue, Weinberger, Sirey, Meyers, & Bruce, 2011). To do so, they must first overcome stigma as a barrier to help-seeking (Zivin & Kales, 2008).

Misconceptions about mental illness and negative attitudes towards depression are common, exacerbated by the belief that those with depression are unpredictable, difficult to engage, incompetent or weak (Griffiths, Christensen, & Jorm, 2008; Reavley & Jorm, 2015). Public stigma occurs when people are labelled as different and are devalued by being attributed a lower status than the general population (Hamilton & Russo, 2006). A significant outcome of public stigma is that individuals who would benefit from professional help are frequently reluctant to disclose their symptoms to others, including health professionals, as they grapple with feelings of shame, distress and hopelessness (Griffiths et al., 2008). In this way, public stigma is internalised as self-stigma.³³ Self-

³³ Self-stigma is most commonly reported in individuals with diagnoses of schizophrenia or bipolar disorder. However, it is also evident in individuals with depression (Sirey, Franklin, McKenzie, Ghosh, & Raue, 2014).

stigma occurs when negative stereotypes are internalised. It is typically experienced as shame, secrecy, feeling devalued and withdrawing from social activities, and has a direct effect on a person's willingness to seek help (Conner et al., 2015; Corrigan et al., 2010). In a study into stigma of depression, Barney et al. (2009) found that fear of being ridiculed by family members, friends or work colleagues constituted a significant barrier to help-seeking. Participants in that study also raised concerns about how friends or family might react if they learned that help was being sought from mental health professionals (Barney et al., 2009).

The causes of stigma associated with depression are unclear, as depression is generally not associated with being a danger to others (Geller, 2012), which is a common misconception regarding mental illness (Corrigan, Bink, Fokuo, & Schmidt, 2015). Concerning the current study, older adults tend to attach a greater level of stigma to depression than the general population and appear to be particularly vulnerable to stigma and discrimination, as they also contend with other challenges associated with getting older (Griffiths et al., 2008). These include experiences of ageism and the misconception that depression is a normal part of ageing (Ouchida & Lachs, 2015). There is also a reciprocal association between age discrimination and depression. For example, perceived age discrimination may be a risk factor for developing depression in older age, as the person develops self-critical thoughts about ageing (Han & Richardson, 2015). In those who do seek help, stigma may also influence treatment concordance. In a study of treatment preferences of older adults with depression, Raue et al. (2011) found that those with lower self-stigma were more likely to engage actively in their treatment. Conversely, those who experience high levels of stigma are more likely to discontinue treatment early (Sirey, Greenfield, Weinberger, & Bruce, 2013; Yanos, Roe, & Lysaker, 2010). However, problems with treatment concordance presuppose that the individual has access to appropriate services and support in the first place.

The multifaceted concept of access constitutes another influence on help-seeking. In the health care context, access has been defined as the ability to obtain appropriate support in a timely manner (Paul et al., 2016), and the opportunity or ease with which an individual or community are able to use appropriate services in proportion to their needs (Levesque,

Harris, & Russell, 2013). In a review of patient-centred access to health care, Levesque et al. (2013) defined access as the way an individual perceives, seeks, reaches, pays for and engages with health services in a timely manner, and without obstacle. Appropriate access includes the availability of appropriate services or support, the opportunity to access that support, and the personal resources to access them (Goodman, Onwumere, Milam, & Peipert, 2017). Common barriers to access include financial costs, excessive travelling distance and/or waiting time to reach service providers, and a lack of providers (Goodman et al., 2017). In a study of access to primary mental health care for hard-to-reach groups, Kovandžić et al. (2011) identified the distance of services from consumers' homes and an associated need for transport as barriers to access. Similarly, Levesque et al. (2013) referred to "ecological obstacles" (p. 7) when describing access difficulties associated with the location of services and travel distances and time.

In the current context, additional problems concerning access include a lack of health professionals who specialise in depression in older adults (Prina, Marioni, et al., 2014), a general dearth of appropriate services for older adults with depression, and failure of health professionals to refer older adults to existing services (Clement et al., 2015; Woodward & Pachana, 2009). In a study of help-seeking for mental health problems, Clement et al. (2012) distinguished between stigma-related and non-stigma-related barriers to help-seeking. Non-stigma-related barriers included instrumental and attitudinal barriers, such as not knowing where to go for help, the cost of services, perceived lack of effectiveness of treatments or hoping the problem would resolve itself (Clement et al., 2012).

The presence of help-seeking barriers may delay or prevent the diagnosis and treatment of depression. Comparing depression treatment in older and younger adults, Sanglier et al. (2015) found that older adults were at higher risk of delayed treatment for depression. Furthermore, those that did receive a diagnosis were less often prescribed antidepressants or referred for psychotherapy³⁴ than younger adults (Sanglier et al., 2015). Similar findings were reported in a study into age group differences in the rates of diagnosis and

³⁴ Psychotherapy encompasses a range of therapies provided by counsellors, psychologists or psychiatrists, which aim to explore an individual's feelings, thoughts and behaviours, with a view to improving personal understanding and coping strategies (Miller & Reynolds, 2012).

treatment of depression (Choi et al., 2016). Presenting mostly to general practice clinics, older adults were less likely to receive a diagnosis of depression than younger adults, and only a third were recommended for antidepressants or psychotherapy. Although effective treatment options for depression in older adults are readily available (Choi et al., 2016; Janssen et al., 2017), they often receive suboptimal levels of care (Fiske et al., 2009; Han & Richardson, 2015; Law et al., 2010). In a study of depression diagnosis and treatment in older home health service users, Xiang et al. (2018) reported that less than 40% of participants who had screened positive for depression were receiving appropriate treatment. Of those, less than 10% reported receiving psychotherapy (Xiang et al., 2018).

2.3.3.2 *Help-seeking facilitators*

In contrast to help-seeking barriers, several factors have a positive influence on the help-seeking process. Help-seeking facilitators include personal responsibility and motivation, mental health literacy, positive relationships with health professionals, and support from significant others.

Accepting personal responsibility and becoming motivated to seek help are crucial to positive health behaviour, including help-seeking and treatment concordance (Ellis et al., 2017; Taylor et al., 2016). In a study of patient and practitioner views of barriers to self-management, Coventry et al. (2014) highlighted the importance of personal motivation on the individual's commitment to and capacity for adopting positive health and lifestyle behaviours. Motivation is also strongly associated with a sense of self-determination, which supports the individual's willingness to adopt self-management practices (Coventry et al., 2014). Examining behaviour change in patients, Ng et al. (2012) found that adjustments to illness lasted longer and were more effective when individuals were autonomously motivated through a sense of self-determination. However, individuals' motivation and capacity to recognise and self-manage their depression require an understanding of its symptoms and treatment options (Yeung, Feldman, & Fava, 2010). This understanding has been conceptualised as health literacy.

Broadly, health literacy reflects individuals' ability to access, understand and use information in a way that enables them to make informed and appropriate decisions

regarding their health (Kopera-Frye, 2016; Lauber, Nordt, Falcato, & Rössler, 2003).³⁵ It is an indicator of appropriate health behaviour and the effectiveness of interventions (Geboers, De Winter, Spoorenberg, Wynia, & Reijneveld, 2016). High health literacy is associated with improved treatment concordance and better health outcomes (Kopera-Frye, 2016). Conversely, a study of health literacy and mortality in older adults, conducted by Bostock and Steptoe (2012), reported an association between low health literacy and poorer health outcomes, including lower overall health, more frequent hospitalisation and higher mortality rates. More specifically, high mental health literacy is associated with early help-seeking, and better recognition and understanding of mental health issues (Farrer et al., 2008; Kim, Rhee, Lee, Park, & Sharratt, 2017). In a study of older South Korean adults with depression, Kim et al. (2017) indicated that improved mental health literacy would result in higher health service utilisation, thereby increasing the potential for positive health outcomes. Similar findings about the positive outcomes of improved mental health literacy were reported in a study of help-seeking behaviour of older Mexican adults with symptoms of depression (Pérez-Zepeda et al., 2013). Individuals who research their symptoms and potential treatments prior to visiting a health professional are also better positioned to participate actively in discussions and decision-making about their well-being (Andersson et al., 2012; Leuchter, Hunter, Tartter, & Cook, 2014). They are also more likely to follow treatment plans and implement strategies that promote and maintain good mental health (Moncrieff, 2015).

The empowerment provided by improved health literacy is best applied when collaborative relationships are formed with preferred health professionals (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016; Hansberry, Agarwal, & Baker, 2015). There is substantial evidence of the importance of a positive therapeutic relationship—that is, the therapeutic alliance—between individuals and their health professionals (Hansberry et al., 2015; Jaffray, Cardy, Reid, & Cameron, 2014; Mace et al., 2017). In a study of the relationship between therapeutic alliance and treatment outcomes for chronic depression, Arnow et al. (2013) found that the quality of the professional relationship significantly predicted positive health outcomes. Similarly, in a study of the influence of

³⁵ Health literacy is an important component of self-management, as the process involves identifying a problem, generating and implementing possible solutions, and evaluating their effectiveness on an ongoing basis (Raven, 2015; Serper et al., 2014).

the therapeutic alliance on the treatment of depression in older adults, Mace et al. (2017) reported that greater understanding and acceptance by therapists predicted a reduction of depression symptoms. A successful therapeutic alliance depends on shared common values and beliefs,³⁶ as well as respect for the expertise of each person who contributes to the management plan (Holm & Severinsson, 2014a). However, some health care professionals may find it challenging to share their expertise and sense of control with other colleagues and across disciplines, as they form partnerships and engage in productive interactions that enable effective self-management (Cramm & Nieboer, 2015; McCann, Baird, Clark, & Lu, 2008). With acute illness, the patient is typically inexperienced. The health professional, as the expert, applies their knowledge to the passive patient. Those roles change in cases of chronic illness, as the patient is more likely to become an active participant in treatment (Ellis et al., 2017; Holman & Lorig, 2004). Enlisting informal support from significant others also supports help-seeking efforts. To illustrate, a study of older adults' experiences of depressive ill-health and family support, conducted by Lyberg et al. (2013), reported that higher informal support was associated with formal help-seeking, improved recovery, better treatment concordance and reduced duration of depression.

2.3.4 Treatment options for depression

Once the symptoms of depression have been recognised, formal and/or informal support should be sought as soon as possible (Jorm et al., 2013). GPs are the first point of access to care in most countries (Schäfer, Boerma, Schellevis, & Groenewegen, 2017), including Australia (Stanners, Barton, Shakib, & Winefield, 2012). Hence, they are largely responsible for diagnosing and treating depression, as well as providing referrals to specialist services (Chew-Graham et al., 2012; Maust et al., 2017; Schäfer et al., 2017). Prior to making a diagnosis, GPs should seek to identify contributing factors and may provide brief counselling when discussing treatment options, prescribing medication and/or referring the individual to a mental health specialist (Jorm et al., 2013).

³⁶ A treatment is more likely to work when it matches an individual's beliefs and values (Burnett-Zeigler et al., 2014; Zivin & Kales, 2008).

In its clinical practice guidelines for depression, the Royal Australian and New Zealand College of Psychiatrists (Malhi et al., 2018) recommends psychological management alone as first-line treatment for depression, and a combination of psychosocial and pharmacological management for moderate to severe depression. Healthy lifestyle changes are also recommended, including techniques to manage stress and facilitate sleep (Malhi et al., 2018).³⁷ These recommendations reflect a chronic illness model, in which the individual and health professional collaborate to reduce the symptoms of depression, recognise triggers, improve self-management skills and limit the risk of self-harm (Gilbody et al., 2017; Malhi et al., 2015; Zimmermann et al., 2016). Extensive evidence exists to support this collaborative approach. Katon (2012) cites 69 studies that demonstrate the effectiveness of the chronic illness model in improving quality of care and outcomes. The chronic illness model is also more cost-effective than treatment as usual, which is generally limited to GP-led pharmacotherapy (Katon, 2012).

Treatment options for depression range from pharmacotherapy—using prescription medication as treatment—and psychotherapy, to physical activity, meditation and diet (Raue et al., 2011; Yeung et al., 2010). Although the changeable nature of depression typically requires a flexible treatment approach that can accommodate fluctuating symptoms (Cuijpers, Karyotaki, Pot, Park, & Reynolds, 2014; Stanhope & Henwood, 2014), the literature offers the strongest evidence for antidepressant medication (Cipriani et al., 2018; Miller & Reynolds, 2012) and psychotherapy (Cuijpers et al., 2014; Jayasekara et al., 2015), or a combination of the two (Choi et al., 2016; Cuijpers, 2017).³⁸

2.3.4.1 *Pharmacotherapy*

Antidepressant medication is frequently used to treat mood and anxiety disorders (Malhi et al., 2018; Manson, Gordon, & Baldwin, 2016). By improving neuroplasticity—the process by which the brain’s neural pathways are altered to compensate for injury and disease—antidepressants may enhance cognitive and emotional functioning, including learning and memory (Harmer, Duman, & Cowen, 2017; Kraus, Castrén, Kasper, &

³⁷ The decision of which treatment approaches to detail in this chapter was guided by these guidelines (Malhi et al., 2015).

³⁸ However, evidence in favour of one treatment does not necessarily mean that it will work well for each person (Jorm et al., 2013).

Lanzenberger, 2017). However, for antidepressants to be most effective, they must be administered at an appropriate dose for a reasonable period (Malhi et al., 2015).³⁹

The consumption of antidepressants has increased steadily since 2000 in many developed countries (Organization for Economic Cooperation and Development, 2015). Iceland reported the highest antidepressant consumption in 2013, followed by Australia, Portugal and Canada (Organization for Economic Cooperation and Development, 2015). The level of antidepressant prescription and consumption depends on depression prevalence in different countries, how depression is diagnosed and treated, local guidelines and other available therapies (Moore et al., 2009; Organization for Economic Cooperation and Development, 2015). For example, in the United Kingdom, Mars et al. (2017) suggest that the substantial increase in the prescription of antidepressants over the past 20 years is due to more people receiving long-term treatment.

Social issues may also be driving increased antidepressant use (Ridge et al., 2015; Spence, Roberts, Ariti, & Bardsley, 2014). A cross-sectional study by Wemakor et al. (2014) found that antidepressant use increased with age and socio-economic deprivation. An increase in antidepressant prescriptions and use may also reflect a lack of available formal services, such as psychologists, particularly in remote areas (Doebler, Ryan, Shortall, & Maguire, 2017), or a view that medication is a cheaper or easier treatment option (Cartwright, Gibson, Read, Cowan, & Dehar, 2016). The influence of sponsorship on prescription rates should also be considered (Cleare et al., 2015; Sinyor et al., 2012). In a Cochrane Review on industry sponsorship and research outcomes (Lundh, Lexchin, Mintzes, Schroll, & Bero, 2017), evidence was presented that studies sponsored by the pharmaceutical industry tend to favour sponsors' drugs over those without industry sponsorship. In a review of 58 randomised control trials concerning antidepressant treatment for major depression, Sinyor et al. (2012) found that sponsored drugs were prescribed at higher doses than non-sponsored drugs, while higher dosing was associated with better sponsor drug outcomes.

³⁹ The Royal Australian and New Zealand College of Psychiatrists' *Clinical practice guidelines for mood disorders* acknowledge that establishing duration and dosage of medication during any phase of treatment is challenging, due to the individual nature of each person's diagnosis and response (Malhi et al., 2015). However, it is generally accepted that most individuals should show improvement from antidepressant treatment within two to three weeks (Malhi et al., 2015; Malhi et al., 2018).

Notwithstanding ongoing criticism and ethical debate concerning sponsorship and associated publication biases (Sinyor et al., 2012; Wang et al., 2017), evidence for the efficacy of antidepressants in treating or preventing relapse of depression has been reported widely (Cipriani et al., 2018; Harmer et al., 2017; Thorlund et al., 2015). In a systematic review of randomised controlled antidepressant trials of older adults with depression, Kok et al. (2012) found that all classes of antidepressants were more effective than placebo. Similarly, Cipriani et al. (2018) reported that 21 different antidepressant drugs were more efficacious than placebo in adults with major depressive disorder. For those undertaking an antidepressant regimen, signs of improvement may be experienced in days or weeks (Harmer et al., 2017). These signs include improved sleeping, decreased anxiety and improved energy levels (Miller & Reynolds, 2012). Mood and libido usually take longer to improve (Miller & Reynolds, 2012).

The benefits of antidepressants stem from how they act by targeting certain circuits and chemical messengers, called neurotransmitters, in the brain, although it is not known precisely how they exert their therapeutic effect (Jorm et al., 2013; Malhi et al., 2015). The theory is that these neurotransmitters—which include serotonin, dopamine and norepinephrine—affect mood and emotion by passing signals from one cell to another in the brain (Malhi et al., 2015). Different types of antidepressants work in different ways, but they all affect chemicals in the brain (Miller & Reynolds, 2012). The most commonly prescribed antidepressants for older adults are selective serotonin reuptake inhibitors (SSRIs), followed by tricyclic antidepressants (Extavour & Perri, 2018; Herron & Mitchell, 2018; Thorlund et al., 2015). There is some evidence for the use of ketamine as a potential antidepressant, although its effects are short-term and often transient (Al Shirawi, Kennedy, Ho, Byrne, & Downar, 2017; Harmer et al., 2017; Malhi et al., 2015). Older agents, such as monoamine oxidase inhibitors, are much less frequently prescribed, due to tolerability and safety concerns (Herron & Mitchell, 2018; Malhi et al., 2018). These concerns include dangers associated with overdose and toxic interactions with foods high in tyramine (such as strong or aged cheeses, cured or processed meats, dried or overripe fruits and some alcoholic beverages) (Cleare et al., 2015).

Despite evidence in their favour and their widespread use, questions have arisen concerning the effectiveness of antidepressants for treating depression in general (Buus, 2014; Manson et al., 2016) and in older adults (Coupland et al., 2011; Read, Gibson, & Cartwright, 2016; Tham et al., 2016). In a systematic review of randomised, placebo-controlled trials of antidepressants, Tham et al. (2016) found only low or moderate evidence of their effectiveness for treating depression in older adults. In many cases, SSRIs were no more effective than placebo in acute treatment of depression, although they were more effective for maintenance and/or preventing relapse (Tham et al., 2016). Read et al. (2016) found that older adults were prescribed antidepressants when presenting with lower levels of depression and fewer symptoms, and were more likely to remain on them for longer than younger people. The potential for over-treatment of older adults has also been identified, with several studies indicating that GPs had prescribed antidepressants in the absence of a formal diagnosis of depression or in response to fewer symptoms (Maust et al., 2017; Moncrieff, 2015).

The issue of side-effects of antidepressants should also be considered. Although SSRIs have fewer side-effects than tricyclic antidepressants, common adverse effects include headache, nausea, weight gain, drowsiness, sleeplessness, agitation and sexual problems (Jorm et al., 2013; Miller & Reynolds, 2012). These may not be experienced at all or may last for only a short time. However, the risk exists that some side-effects could themselves constitute risk factors for depression, such as loss of sexual functioning and reduced interest in social or physical activities (Read, Cartwright, & Gibson, 2014). If side-effects cannot be tolerated, the individual may be prescribed another medication, or need to consider other treatment options (Buus, 2014). Antidepressants may also interact with medications for other conditions. It is not unusual for older adults to receive long-term prescriptions for medications for multiple conditions, such as diabetes, arthritis and heart disease (Coupland et al., 2011; Mock, Norman, & Olver, 2010). Polypharmacy—taking five or more medications at one time—is further complicated by the use of over-the-counter medications, herbal supplements or other complementary health interventions (Biswas et al., 2018; Stanners et al., 2012). This may make it difficult to distinguish between symptoms of the pre-existing illness and the side-effects of antidepressant

medication in those with multiple physical and/or mental comorbidities (Mock et al., 2010; Pocklington, 2017).⁴⁰

To mitigate against adverse effects, concordance with prescribed medication regimens is important. In a study into the influences on early discontinuation—within six months—of antidepressant medication, Jaffray et al. (2014) identified the importance of effectively managing side-effects. Participants in that study were more likely to continue taking their antidepressants if they felt in control of the management of their depression, knew what changes to expect and understood how long it would take for the medication to be effective (Jaffray et al., 2014). It is also important for the health professional to address common myths about antidepressant medications. Erroneous beliefs about antidepressants frequently lead individuals to discontinue their medication too soon (Chakraborty, Avasthi, Kumar, & Grover, 2009; Jaffray et al., 2014). These beliefs include fears that antidepressants will change a person's personality, that they will instantly relieve low mood or lack of energy, that they can be taken only as needed, like pain killers or antibiotics, or that there is a link between antidepressant use and increased suicidal tendencies (Miller & Reynolds, 2012). Misunderstandings about how quickly and well antidepressants might work, and concerns about becoming addicted, constitute additional barriers to medication concordance, even when explanations about the nature of depression and the appropriateness of antidepressant medication were given (Jaffray et al., 2014). Psychoeducation to improve mental health literacy should be offered as early as possible, to assist individuals in the interpretive and adaptation process of embarking on a regimen of antidepressant medication (Malhi et al., 2015).

2.3.4.2 *Psychotherapy*

For mild to moderate depression, psychological management is recommended initially, especially early in the illness course (Malhi et al., 2018). For moderate to severe depression, pharmacotherapy should be accompanied by psychoeducation, as a minimum, or some form of psychotherapy, to enhance the effectiveness of treatment (Malhi et al.,

⁴⁰ Coupland et al. (2011) note that older adults are often under-represented in clinical trials of antidepressants, making it difficult to derive reliable or precise estimates of the incidence of adverse side-events in this group. In addition, criteria for antidepressant trials frequently exclude older adults with comorbid conditions (Manson et al., 2016).

2015; Malhi et al., 2018). Psychoeducation refers to the process of providing information and education to individuals seeking or receiving mental health services. In the current context, it concerns the development of knowledge as a tool to help individuals manage depression. In a systematic review of its effectiveness for depression, Tursi et al. (2013) concluded that psychoeducation had a positive effect on treatment concordance, depression course and broader psychosocial functioning. Psychoeducation regarding the nature of depression and the rationale and benefits of treatment is also associated with improved capacity for self-management (Yeung et al., 2010). However, any form of education should be appropriate to the individual's capacity for insight, comprehension and action (Martinez, Williams, Whitfield, & Dafters, 2008). Similar requirements concerning the individual's health-literacy-related strengths and limitations apply to psychotherapy (Batterham et al., 2016).

Psychotherapy is an effective treatment for depression in older adults (Cuijpers, 2017; Janssen et al., 2017; Jayasekara et al., 2015). The main aim of psychotherapy is to help individuals see their predicament clearly, weigh options for change and find fulfilment in life (Miller & Reynolds, 2012). The most effective types of psychotherapy for older adults with depression include Cognitive Behaviour Therapy (CBT), behavioural therapy, reminiscence therapy, bibliotherapy and mindfulness-based cognitive therapy (Blackburn et al., 2017; Jorm et al., 2013). Of these, CBT has the strongest empirical support for the treatment of depression, including older adults (Laidlaw, 2010; Scogin et al., 2014).⁴¹

In CBT, individuals work with a therapist to identify patterns of thinking—that is, cognitive patterns—and behaviour that influence their tendency towards developing depression, and their recovery from depression (Jorm et al., 2013). CBT may be undertaken in a group⁴² or individual setting, and may include psychoeducation, relaxation techniques, positive imagery and mindfulness exercises. The aim of this practical, problem-solving approach is to enhance the individual's thinking through learned techniques and improved problem-solving skills (Laidlaw, 2010; Marquett et al.,

⁴¹ Although the effectiveness of CBT is not in doubt, it enjoys the greatest weight of evidence in its favour, as it is the most studied psychotherapy for depression (Cuijpers, 2017; Cuijpers et al., 2013).

⁴² A range of therapies may be delivered in a group setting. However, specific support or self-help groups that bring together people with common problems are also popular. By providing an opportunity to be understood by others who can comprehend the problem and remain non-judgemental, participation may help to reduce feelings of isolation in a forum in which knowledge, coping skills and self-esteem may be increased (Karp, 2017; Kitchener et al., 2017).

2013). Recognising unhelpful negative or self-critical patterns of thinking enables the individual to adopt more realistic and problem-solving thoughts that promote good mood and better coping (Jorm et al., 2013). By learning to identify and alter negative thoughts, the individual is left with fewer reasons to feel depressed (Miller & Reynolds, 2012). Positive reinforcement is used to increase functional and pleasurable behaviour, while decreasing depressed behaviour (Janssen et al., 2017). CBT is a viable choice for those who are reluctant to accept antidepressant medication, or who may be unable to tolerate their side effects (Jayasekara et al., 2015). An additional benefit is that it can be delivered by a range of health professionals—such as psychotherapists, mental health nurses or social workers—thereby improving its accessibility and cost effectiveness (Janssen et al., 2017; Richards et al., 2016).

Reminiscence therapy is also effective for older adults with depression. Through structured dialogue and interaction with a therapist or in a group setting, older adults look back on life, while also focussing on the present and future (Djukanović, Carlsson, & Peterson, 2016). A focus on positive memories offers individuals the opportunity to accept the “meaning and purpose to the life lived” (Djukanović et al., 2016, p. 993). Its appropriateness in later life is evidenced in the way reminiscing can foster a sense of well-being about an accomplishment or provide validation for overcoming difficult experiences (Miller & Reynolds, 2012). In a study into the effectiveness of reminiscence for treating depression in older adults, Meléndez et al. (2015) reported statistically significant reductions in depression symptoms and improvements in psychological well-being. Similar findings were reported by Su et al. (2012), whose older study participants showed significant reductions in depression symptoms after reminiscence therapy.

Another form of psychotherapy that is effective in improving symptoms and overall well-being of adults with depression is bibliotherapy, or therapy in book form (Scogin et al., 2014; Songprakun & McCann, 2012). As a form of self-help,⁴³ bibliotherapy provides information, homework exercises and strategies for coping with depression, usually following the principles of CBT (Gualano et al., 2017; Seeley, Manitsas, & Gau, 2017).

⁴³ Self-help refers to strategies that can be applied by individuals without the essential need for professional guidance (Morgan & Jorm, 2008). Other forms of self-help include physical activity, yoga and meditation.

It may be available in the form of books, self-help manuals, other written material or computerised psychotherapy (Yeung et al., 2010). In a systematic review of its long-term effects, Gualano et al. (2017) reported that bibliotherapy was effective in reducing the symptoms of depression in the long term. Bibliotherapy often involves a minimal amount of contact with a health professional, often by telephone, or participation in group therapy sessions, with individuals reading materials to supplement routine treatment (Songprakun & McCann, 2012).⁴⁴ Gualano et al. (2017) suggest that bibliotherapy may be particularly useful for individuals whose help-seeking is delayed or deterred due to fears of prejudice or stigma. For example, it could be used to help individuals accept their depression diagnosis and seek help in the future (Gualano et al., 2017). However, issues of usability and readability should be considered, with content tested in clinical practice (Martinez et al., 2008), while ensuring that the individual's reading skills, concentration and/or motivation are appropriate for the intervention (Morgan & Jorm, 2008).

Mindfulness-based cognitive therapy combines the essentials of cognitive therapy with meditative practices. It is based on an integration of aspects of CBT with components of a mindfulness-based stress reduction program, whereby individuals pay attention to the present moment, clear their heads, slow down their thoughts and accept themselves and their experiences (Kabat-Zinn, 2003; Uebelacker et al., 2017). It involves education about depression, simple breathing techniques and mindfulness meditation, aimed at improving a range of health conditions and overall quality of life. By enabling individuals to focus on the present moment and stop the train of negative thoughts, mindfulness-based cognitive therapy helps individuals recognise negative thinking patterns before they have become fixed (Jorm et al., 2013). In a secondary analysis of data from a randomised controlled trial of mindfulness-based stress reduction for older adults living in the community, Elliot et al. (2018) reported that mindfulness was associated with fewer depressive symptoms, greater positive affect and improved physical well-being.

Despite evidence of the effectiveness of psychotherapy for older adults with depression, referrals remain low, compared to younger adults with similar symptoms (Han &

⁴⁴ The evidence for computerised interventions appears promising, particularly when it is supported by a health professional (Berger, Krieger, Sude, Meyer, & Maercker, 2018; Staples et al., 2016). One advantage of computerised psychotherapy is that it can be interactive, providing instant scores on questionnaires or assessments, and feedback on skill-building exercises (Berger et al., 2018).

Richardson, 2015; Sanglier et al., 2015; Stanners et al., 2012). In a matched cohort study of depression treatment in older and younger populations, Sanglier et al. (2015) found that older adults were at higher risk of delayed or non-treatment. Evaluating access to psychological interventions, Prina et al. (2014) found that GPs were less likely to refer older adults for psychotherapy, than younger adults with similar symptoms (Prina, Marioni, et al., 2014). Hence, the limited number of trained therapists who specialise in depression in older age and the commonly held belief by many health professionals that older adults are less likely to benefit from psychotherapy than medication constitute barriers to treatment (Jayasekara et al., 2015; Laidlaw et al., 2008; Titov et al., 2016). To overcome these barriers, health professionals should consider the beliefs, needs and preferences of older adults when determining the most appropriate treatment (Read et al., 2015). The onset and progression of depression should also guide decisions about treatment. In moderate depression, for example, psychological therapy alone may be effective, especially in the early stages, whereas episodes of greater severity or those that run a longer course may require medication (Hollon et al., 2014).

2.3.4.3 *Electroconvulsive therapy*

For more severe and/or drug-resistant depression, electroconvulsive therapy (ECT) may be indicated (Kellner et al., 2012; Malhi et al., 2018). The immediacy of its effect is a significant factor when deciding to undergo ECT (Kellner et al., 2012). In ECT, a carefully controlled electrical current is used to cause a temporary seizure that is thought to restore correct balance of electrochemical functions in the brain (Miller & Reynolds, 2012). ECT may be effective than medication in the treatment of major depression in older adults (Kerner & Prudic, 2014; McCall et al., 2018). It is recommended in severe depression, where there is a very high level of distress and suicide risk (Malhi et al., 2015). It may also be used for those who have not responded to antidepressant medications, or who have an intolerance to medication (Malhi et al., 2018; McCall et al., 2018). An initial course of high dose ECT has been associated with improved health outcomes in older adults (Kerner & Prudic, 2014; McCall et al., 2017). Following initial treatment, maintenance ECT is effective in preventing relapse after the administration of an acute course of ECT, including in older adults with depression (Kellner et al., 2012). In a randomised clinical trial into the effects of maintenance ECT on the quality of life of

older adults with depression, McCall et al. (2018) reported the beneficial effects of ECT on indicators of health-related quality of life, such as mental health, physical and social functioning, general health and vitality.

Although ECT is an appropriate treatment for older adults with depression (McCall et al., 2018), its effectiveness should be balanced against potential side-effects, which increase with increasing doses (Malhi et al., 2015). These include headache, nausea, muscle pain, temporary confusion and memory impairment (Kerner & Prudic, 2014). However, these side-effects are usually not severe and generally transient (Kerner & Prudic, 2014).

2.3.4.4 *Social support*

There is extensive evidence for the beneficial effects of social support on physical and mental health (Lyberg et al., 2013; Thoits, 2011; Werner-Seidler, Afzali, Chapman, Sunderland, & Slade, 2017).⁴⁵ Cohen (2004) defines social support as the “provision of psychological and material resources intended to benefit an individual’s ability to cope with stress” (p. 676). Social support has also been defined as the functions performed by significant others to benefit an individual (Thoits, 2011). For Hupcey (1998), it encompasses an interpersonal act, the provision of support by loved ones or members of the community, and/or an exchange of resources. Common to these conceptualisations is the aim of family or friends to improve another’s sense of well-being.

Ideally, significant others offer understanding and support, while encouraging and assisting individuals to seek appropriate professional help and follow prescribed treatment (Hatfield, Hirsch, & Lyness, 2013; Kamen, Cosgrove, McKellar, Cronkite, & Moos, 2011). They are also in a strong position to help individuals make lifestyle improvements and build resilience (Berk, Jorm, Kelly, Dodd, & Berk, 2011; McCann, Lubman, & Clark, 2012). Results of a survey of older adults’ resilience, happiness, depression and life satisfaction confirmed the positive influence of close social relationships on resilience and well-being (Smith & Hollinger-Smith, 2015). In a study into the meaning of family support among older adults with depression, Lyberg et al. (2013) found that family relationships, as a source of emotional and practical support,

⁴⁵ Social support is a component of informal support. See 0 (Terms and definitions).

enabled older adults to manage their mental health more effectively. Significant others are also often the first to notice a change in a person's behaviour and/or identify the symptoms of depression (Yeung et al., 2010). Examining the influence of family support on depressive symptoms over the course of 23 years, Kamen et al. (2011) reported that effective relationships influenced positively participants' experience of, and recovery from, depression. Similar findings were reported by Hatfield et al. (2013), who identified a correlation between perceived satisfaction with the quality and frequency of social support and quality of life. In addition to family members, having close and trusting friend-as-confidante relationships significantly lowers older adults' depressive symptoms, while improving their self-rated health (Bookwala, 2017; Thomas, 2016). An investigation into the association between depression and social support, conducted by Werner-Seidler et al. (2017), also confirmed the moderating effect of social support for depression. Conversely, family dysfunction, criticism and a lack of support are associated with a longer course of depression (Lyberg et al., 2013; Stoeckel & Litwin, 2015). Thus, it is not only the availability of support from significant others that matters, but the nature and quality of relationships (Gardner, 2011; Hatfield et al., 2013).

2.3.4.5 *Complementary and lifestyle interventions*

Complementary and lifestyle approaches to managing depression range from natural therapies, such as aromatherapy and massage, to avoiding sugar and getting a pet (Jorm et al., 2013). However, two of the main lifestyle strategies for managing depression are physical exercise and meditation (Azizan & Justine, 2016; McPherson et al., 2014; Searle et al., 2014). Although yoga and meditation are most effective when used in conjunction with medication and/or psychotherapy (Cramer, Lauche, Langhorst, & Dobos, 2013; Uebelacker et al., 2017), lifestyle changes, such as improving nutrition, increasing exercise and engaging in pleasurable activities, should be encouraged. There is increasing evidence that supports the positive association between higher levels of physical activity and depression (Blumenthal, Smith, & Hoffman, 2012; Heesch, van Gellecum, Burton, van Uffelen, & Brown, 2016; Park, Han, & Kang, 2014; Schuch et al., 2015). In a study into the effect of exercise on symptom severity of major depression, Schuch et al. (2015) concluded that exercise was a safe and efficacious adjunct to treatment, improving depressive symptoms and quality of life. Similarly, Park et al. (2014) found that exercise

therapy was effective in reducing depressive symptoms in older adults, while improving their self-esteem and quality of life.

The development and use of tailored exercise programs for older adults with depression are prudent. However, initial acceptance of and motivation for exercise is often a challenge in this cohort (Blumenthal et al., 2012; Schuch et al., 2015). In a review into the viability of exercise as a treatment for depression, Blumenthal et al. (2012) found that individuals affected by depression-related fatigue, loss of interest, indecisiveness or low self-esteem tend to delay or avoid exercise, even when they had experienced its benefits. Although the support of a health professional may be required to encourage and facilitate regular exercise (Blumenthal et al., 2012), physical exercise as a treatment for depression is frequently neglected. This may be because diagnosing depression in older adults is often confused with symptoms of physical illness (Kessler et al., 2010), or because of a prevailing view that older adults are less capable or motivated to optimise their physical health (Blancato & Ponder, 2015).

2.4 The concept of self-management

Self-management is a dynamic, interactive process by which individuals seek to meet their everyday social, emotional, psychological and physical needs (Chambers et al., 2015; Eikelenboom, Van Lieshout, Wensing, Smeele, & Jacobs, 2013). The term was originally used to refer to active participation in treatment (Creer, Renne, & Christian, 1976). Since then, it has been used widely to describe how a person engages in the day-to-day management of a long-term and/or chronic condition (Lorig, Ritter, Pifer, & Werner, 2014).

The fundamental skills for self-management identified by Lorig and Holman (2003) include problem-solving, decision-making, resource utilisation, the formulation of a patient-provider partnership, action planning, and self-tailoring. Coventry et al. (2014) identify capacity, responsibility and motivation as the requirements for effective self-management. Although it includes significant others, community and health care professionals in practice, the overall concept acknowledges the person as self-determining and respects the expertise they bring to the management of their condition

(Lorig & Holman, 2003). However, the lack of a standard definition of self-management and different interpretations of the scope and potential of self-management may result in some confusion in the health professional, whose role, purpose and responsibility are unclear, as they balance a duty of care with efforts to promote self-management (Holm & Severinsson, 2014a). Notwithstanding this challenge, optimal self-management requires that people participate actively and effectively in their own health care on an ongoing basis (Chambers et al., 2015).

The principles of self-management have been applied successfully to manage a range of chronic conditions, including diabetes (Lorig et al., 2016), heart disease (Jaarsma, Cameron, Riegel, & Stromberg, 2017), asthma (Pinnock et al., 2015), chronic pain (Damush et al., 2016) and depression (Chambers et al., 2015). Underpinned by the constructs of self-efficacy and self-determination, self-management is most often recognised as a form of patient empowerment (Ellis et al., 2017; Raven, 2015). Processes of self-management concern the ways in which people can realise and sustain their well-being, even when their resources decline (Musekamp et al., 2016; Schuurmans et al., 2005). Often a life-long task, elements of self-management are frequently attached to health promotion and patient education programs, particularly for chronic illness (Lorig et al., 2014). In a qualitative study of the self-management of longer-term depression, Chambers et al. (2015) reported that self-management was more than a process of neutralising loss, as it reflected the ability to look ahead and invest in resources which contributed to well-being in the long run. Examples of appropriate resources include engaging in good health behaviour and maintaining positive social relationships (Chambers et al., 2015).

From a health system perspective, the main benefits that may be derived from improved self-management of chronic illness include long-term cost savings through reduced health complications and more efficient health service utilisation (Fisher et al., 2017). Consequently, health care policy in developed countries is focusing increasingly on promoting the self-management of long-term health conditions (Ellis et al., 2017; Fisher et al., 2017). Given that depression is often recurring and chronic, self-management

appears to be a promising approach by which the person may achieve the highest level of functioning and the lowest level of symptoms (Chambers et al., 2015; Houle et al., 2013).

The nature of depression requires specific interventions that transfer knowledge and skills to the person, to equip them to maintain their well-being (Houle et al., 2013). Turner et al. (2015) found that a co-produced management program improved psychosocial outcomes for people living with depression. Improved knowledge about depression and the use of appropriate self-management strategies resulted in significant improvements in health status and health-related quality of life (Turner et al., 2015). Similar results were reported in a cluster randomised controlled trial on the implementation of a self-management intervention for participants with depression (Zimmermann et al., 2016). Study participants reported improved motivation to engage in self-help and help-seeking behaviour, and an enhanced sense of self-efficacy and empowerment (Zimmermann et al., 2016). A wide range of strategies identified by Van Grieken et al. (2013) to self-manage depression included taking a proactive attitude towards depression and treatment, explaining depression to others, remaining engaged in social activities and giving attention to oneself. These findings align with the recovery approach in mental health,⁴⁶ which involves people making sense of their experiences in a way that allows them to maintain a sense of personal efficacy or control (Chambers et al., 2015; Turner et al., 2015). In addition, each of these studies highlighted the need for health professionals to encourage individuals to take active roles in self-managing their mental and physical health (Chambers et al., 2015; Turner et al., 2015; Van Grieken et al., 2013; Zimmermann et al., 2016). The extent to which health professionals understand the individual's needs and illness representations is associated with self-management behaviour (McSharry, Bishop, Moss-Morris, & Kendrick, 2013). Indeed, self-management forms part of a complex process of understanding and managing health (McSharry et al., 2013). The need for health professionals to recognise and address the complexities of ageing with depression has been identified, particularly in considering the individual's personal, social and environmental circumstances (Cruwys et al., 2013).

⁴⁶ A recovery approach is a process and an outcome that emphasises empowerment, autonomy, choice and hope. It represents “a personal journey toward a new and valued sense of identity, role and purpose together with an understanding and accepting of mental illness” (Department of Health, 2009, p. 26).

Despite broad acceptance for the effectiveness of self-management for chronic conditions, there is some criticism of the increasing expectation on individuals to self-manage chronic conditions (Brijnath & Antoniadis, 2016; Redman, 2007). Redman (2007), for example, questioned whether the push towards self-management placed unreasonable responsibility on the older adult with depression. In a study into the association of a disease management program and health behaviours, self-management ability and quality of life, Cramm and Nieboer (2015) found that a focus on clinical and functional outcomes did little to improve participants' overall quality of life and well-being. Although participants' health behaviours and physical quality of life improved, broader self-management abilities or mental quality of life were not maintained (Cramm & Nieboer, 2015). An additional concern is that much of the evidence in favour of self-management focuses on people with a single chronic disease, whereas older adults frequently experience multiple comorbidities (Rijken, Jones, Heijmans, & Dixon, 2008). Self-management studies have been conducted on people who have had a stroke (Boger, Demain, & Latter, 2013), experienced kidney disease (Washington et al., 2016) or are living with dementia (Martin, Turner, Wallace, & Bradbury, 2013). However, the self-management of co-morbid mental and physical conditions, particularly in older age, is more challenging (Musekamp et al., 2016; Stanhope & Henwood, 2014) and requires that individuals and health professionals share common values and beliefs about the illness and treatment approaches, including self-management (Holm & Severinsson, 2014a).

2.5 Summary

Most developed countries use the age of 65 years to define “elderly” or “old”. However, the concepts of age and ageing are difficult to define, as they change progressively and vary from one culture to another. Depression is the most common mental disorder in older adults. Although depression is a serious condition at any age, it is a significant problem for this cohort. Even mild depression has a deleterious impact on the older adult's quality of life. The views and knowledge held by older adults about depression influence whether a diagnosis is sought, and treatment maintained. The approach selected by individuals to manage their depression is influenced by their personal views and preferences, availability of formal and informal support, and personal resources. A combination of antidepressant medication and psychotherapy is often the most effective treatment.

Lifestyle changes and support from significant others are also important contributors to well-being. Given that depression is often chronic and/or recurring, self-management appears to be a promising intervention. Self-management refers to a person's capacity to manage the symptoms, treatment, consequences and lifestyle issues associated with living with a chronic condition. The central aim of self-management is to optimise well-being.

CHAPTER 3

Methodology

3.1 Introduction

The selection of a qualitative or quantitative methodology is a fundamental decision when planning a study. This chapter on methodology commences with a discussion on different principles of and approaches to research. An overview of the tenets of qualitative research, including its ontological, epistemological and methodological foundations, supports the selection of a qualitative approach in the current study. An analysis of interpretivism and symbolic interactionism provides context for a discussion on grounded theory methodology, after which the origin and features of grounded theory are discussed. Explanations are given for the selection of grounded theory, and for choosing Corbin and Strauss' (1990, 2015) approach. The chapter concludes with a critique of grounded theory.

3.2 The qualitative research paradigm

Qualitative and quantitative approaches hold important positions in the field of research. However, they differ in several major ways, and the selection of an approach should be based on the nature of the research question and the researcher's philosophical stance, knowledge and skills (Holloway & Galvin, 2016). The research question itself also guides the researcher's choice of methodology, method, sample, sample size, and approaches to data collection and analysis (Lipowski, 2008).

In acknowledging the paradigmatic differences between qualitative and quantitative research, attention should be given to their ontology, epistemology and methodology. These three interconnected, generic assumptions define the research process, whereby the researcher approaches the subject with a set of ideas (ontology or theory) that give rise to specific questions (epistemology or method) to be examined (methodology or analysis) (Denzin & Lincoln, 2013). Indefinite and non-linear by nature, these beliefs or values relate to the types of evidence researchers use to make claims (epistemology) and how they consider the concepts of existence and reality (ontology). Thus, they guide the researcher's thoughts on how legitimate knowledge can be acquired. Posing specific

questions or hypotheses, quantitative researchers typically use numbers and statistical analysis to obtain information and interpret results. This approach is appropriate when the researcher is searching for causal explanations or focusing on proving or disproving a hypothesis based on a large sample of data from which conclusions can be drawn (Blackstone, 2012). Qualitative researchers, on the other hand, adopt an interpretive, naturalistic approach to the world, as they seek to generate knowledge of human experiences and lives, and the meaning given to them (Denzin & Lincoln, 2013). This approach allows participants' experiences to be understood in context and in greater depth than is possible with quantitative study (Denzin & Lincoln, 2013). The outcomes of quantitative research are usually measurable and testable, whereas qualitative researchers generate knowledge grounded in human experience. Researchers in both traditions use a wide range of methods to collect and analyse data (Holloway & Galvin, 2016).

Considered particularly appropriate to the health care sector, a qualitative approach allows researchers to straddle disciplines, fields and subject matter (Holloway & Galvin, 2016). Researchers in this tradition use a person-centred, holistic perspective to explore the uniquely personal aspects of living with illness, pain or disability (Holloway & Galvin, 2016). In the current instance, the choice of a qualitative approach reflects the researcher's interest in a naturalistic, interpretive approach to explore and understand the subject matter.

Qualitative research operates within a complex historical context. Precursors to qualitative research have been recorded since the ancient Greeks, with evidence of scholarly studies on phenomena⁴⁷ such as morality, culture and human lifeways. Knowledge of nature was reported descriptively, including the physics of Aristotle and the medicine of Galen (Erickson, 2013). Thus, qualitative research crosscuts at least eight historical moments (Erickson, 2013). The traditional moment⁴⁸ of qualitative research spanned from 1900 to 1950, followed by the modernist, or golden, age⁴⁹ that continued

⁴⁷ A phenomenon is the central concept to be researched. The term refers to a fact or situation—that is, an aspect of reality—that can be sensed or experienced, and observed to exist or happen, especially one whose cause or explanation is being studied (Holloway & Wheeler, 2010).

⁴⁸ This period was characterised by positivism, with researchers striving for objectivity in their field work and reports. A fundamental line of distinction was drawn between the researcher and those who were observed as passive participants in the research enterprise (Erickson, 2013; Patton, 2002).

⁴⁹ In this phase, qualitative researchers emphasised methodological rigour. By formalising their methods, they sought to counter the postpositivist emphasis on interpretivism and achieve acceptance within social science (Denzin & Lincoln, 2013).

into the 1970s. This was followed by blurred genres (1970-1986),⁵⁰ the crisis of representation (1986-1990),⁵¹ the postmodern (1990-1995),⁵² post-experimental enquiry (1995-2000),⁵³ the methodologically contested present (2000-2010)⁵⁴ and the future (2010 onwards) (Denzin & Lincoln, 2013).⁵⁵ While some overlap exists between these perspectives, important differences reflect varying experiences and emphases within the history of qualitative research (Patton, 2002).

Given the overall aim of addressing a gap in knowledge about the self-management of depression in older adults—a problem which is relatively new and under-researched—the selection of a qualitative methodology was considered appropriate. By its very nature, an approach that is context-bound and gives primacy to the data is suitable for this study (VanderStoep & Johnson, 2008). However, the value-laden interpretations and explanations given to justify a specific qualitative study do not necessarily extend to other studies, nor should they be interpreted as a criticism of other approaches.

⁵⁰ During this phase, alternative interpretative approaches to qualitative research emerged as a response to debates about ontological, epistemological and methodological issues associated with the postpositivist paradigm, such as symbolic interactionism, hermeneutics, ethnomethodology, phenomenology and feminism. Disputes about the rigour of qualitative research emerged, coupled with questions about the role of the researcher (Erickson, 2013; Patton, 2002).

⁵¹ This phase focused on issues of reflexivity, power, race, gender and socioeconomic class, which undermined qualitative researchers' traditional notions of validity and neutrality. Interpretive theories—rather than grounded theories—became more prominent, as debate emphasised the problematic issues of objectivity, reliability, validity and generalisability (Patton, 2002).

⁵² In the postmodern (and later the postexperimental) moment, theories were viewed in narrative terms. These periods were defined by a concern for literary and rhetorical devices, for storytelling and for composing ethnographies in new ways. The notion of the impartial researcher was undermined, as many researchers presented themselves as advocates or collaborators with the people being studied (Denzin & Lincoln, 2013; Erickson, 2013).

⁵³ In this phase, the boundaries of qualitative research were expanded to include creative nonfiction, autobiographical ethnography, poetic representations and multimedia presentations (Patton, 2002).

⁵⁴ This was a time of tension and conflict among researchers as they considered different ways of knowing and the most suitable qualitative methods with which to achieve this. It included an appreciation for the dominant perspectives of the past periods, as alternative evaluative criteria were sought (Denzin & Lincoln, 2013; Erickson, 2013).

⁵⁵ In response to the methodological backlash associated with the evidence-based movement, this period is concerned with moral discourse and calls for critical conversations about democracy, race, gender, class, freedom, globalisation and community (Denzin & Lincoln, 2013).

3.2.1 Ontology and qualitative research

Ontology is a branch of philosophy that concerns the nature of being and the nature of reality. It refers to the way in which we can understand the things that constitute the world (Blackstone, 2012).

Each research study is based on a specific theoretical or philosophical view that is rooted in a certain idea about the world and the nature of knowledge (Wuest, 2011). The ontological differences between qualitative and quantitative research paradigms revolve around the perceived nature of reality. Qualitative researchers seek to understand multiple constructed realities that generate different meaning for different individuals, whereas quantitative researchers believe in a single reality that can be measured using scientific principles (Holloway & Galvin, 2016).⁵⁶ In their search for meaning, qualitative researchers deploy a range of interconnected research practices, whose interpretations depend on their particular perspective and aim (Denzin & Lincoln, 2013). Qualitative researchers are influenced by phenomenology, a philosophy which explores the meaning of lived experience through individuals' own descriptions (Holloway & Galvin, 2016).

There are three major streams of phenomenology,⁵⁷ but it was Martin Heidegger [1889-1976] who developed phenomenology into the interpretive philosophy that has become the basis for several methods of enquiry which influence health researchers (Pursley-Crotteau, Bunting, & Draucker, 2001). With the aim of discovering meaning and achieving understanding of everyday lived experiences, Heidegger's (1953) hermeneutic perspective focuses particularly closely on people and the context of their existence, and goes beyond description to interpretation. True understanding, therefore, is only possible through human engagement (Heidegger, 1953). Hence, as a research method, hermeneutics rests on the ontological assumption that all experience is an interpretive process (Holloway & Galvin, 2016).

⁵⁶ Despite these different approaches, both research traditions seek to uncover the realities that exist.

⁵⁷ The other two main streams are Edmund Husserl's [1859-1938] descriptive phenomenology and the existentialist phenomenology of Maurice Merleau-Ponty [1908-1961] and Jean-Paul Sartre [1905-1980] (Holloway & Galvin, 2016).

3.2.2 Epistemology and qualitative research

Epistemology refers to beliefs about the nature of knowledge and assumptions about how different forms of knowledge can be acquired. The epistemological perspective—or theoretical stance—adopted by the researcher relates to the ways in which we can know the world. Since a specific research paradigm guides the domain of the study, the intentions and philosophical underpinnings of each different approach should be considered in sufficient depth to enable the researcher to arrive at an epistemological position that supports a study's empirical claims (Holloway & Galvin, 2016).

Quantitative researchers seek to generate and explain knowledge through objective, structured means. Basing their approach to enquiry in a positivist belief in universal laws and rules, they strive for objectivity and distance between themselves and their subjects (Holloway & Galvin, 2016). Scientific methods based on the epistemology of positivism have long been used in the social sciences, where they have added significantly to medical knowledge. However, these methods do not collect information about contextual factors. Rather, it is through qualitative research that complex, dynamic and multi-dimensional realities and relationships may be understood (Blackstone, 2012).

Qualitative researchers focus on the process by which knowledge is constructed. With their roots in philosophy and the human sciences, they typically follow an inductive reasoning approach which proceeds from a study of the specific to the general. This interpretivist paradigm⁵⁸ is considered particularly important and appropriate in the health professions, which focus on caring, communication and interaction (Holloway & Galvin, 2016). Interpretivist approaches are informed by constructivist ontology, which reflects the belief that human beings construct their social reality and that the social world cannot exist independently of human beings (Sandelowski, 2004). Multiple truths or realities exist, which the researcher seeks to explain through the construction of knowledge (Blackstone, 2012).

⁵⁸ Interpretivism is examined in more detail later in this chapter.

The interpretivist view can be traced back to the work of sociologist Max Weber [1864-1920] in the 19th century and his concept of *Verstehen* (Denzin & Lincoln, 2013).⁵⁹ Arguing that understanding in the social sciences differs from explanation in the natural sciences, Weber (Weber, 1947/1964, 1981) identified the single individual and their actions as the basic unit of study. By approaching knowing as a process rather than a product, the researcher acknowledges that social reality depends on its context and is derived from individuals' experiences and interpretations (Koro-Ljungberg, 2008). Interpretivism centres on the subjective reality of human beings and their ability to interpret meaning from the social world, that is, the way they make sense of their experiences and lives (Weber, 1947/1964). The epistemology of constructionism, which is closely linked to the theoretical paradigm of interpretivism, assumes that individuals construct their social reality, and that the researcher and participants construct meaning together through the research process (Holloway & Galvin, 2016).

Notwithstanding epistemological explanations for selecting an interpretivist approach to acquiring knowledge, the paradigm debate does not reflect the interactive continuum of quantitative and qualitative research, nor the number of similarities between the two approaches (Blackstone, 2012; Holloway & Galvin, 2016). For example, both paradigms include the use of a research question, which is addressed through some type of observation. Researchers from both paradigms also use specific techniques to interpret, analyse and verify data. Both approaches use different methodologies to make valuable contributions to evidence-based practice in health care.

3.2.3 Methodology and qualitative research

Methodology refers to the framework of theories and principles that underpin the methods and procedures of a study. It constitutes the underlying logic of how research should proceed, including the assumptions, principles and procedures of a certain approach (Holloway & Galvin, 2016). As a way of approaching and studying social phenomena, a qualitative methodology encompasses the theoretical perspectives and practical considerations that underpin a study, including the choice of method and its suitability to the research aims (Corbin & Strauss, 2015). There are several different methodological

⁵⁹ A German word meaning the experience of understanding something in context.

approaches within the wider framework of qualitative research, but they share the main aim of wanting to understand, describe and interpret social phenomena as experienced by the study participants (Wuest, 2011). Participant interviews and observation are typically used in interpretivist studies, with the researcher as the main research tool. The qualitative researcher collects, analyses and interprets data that are not easily reduced to numbers. Rather, these data relate to the social world and the concepts and behaviours of people within a specific context. Using an inductive approach, the qualitative researcher aims to generate knowledge from the ground up. In this way, hypotheses can be generated by exploring phenomena in their natural setting. Notwithstanding its name, inductive reasoning includes a combination of inductive, deductive and abductive thinking to account for the way in which the researcher can make abstract statements from the specific (Birks & Mills, 2015). Induction refers to the reasoning process in which the researcher proceeds from specific instances to general, abstract principles, whereas deduction is the process of testing a general hypothesis to explain a specific case. Abduction reasoning begins with an examination of the data, after which hypotheses are confirmed or disproved during the process of analysis, until a plausible interpretation of the observed data has been reached (Bryant & Charmaz, 2007b).

The interpretivist paradigm in general, and symbolic interaction, in particular, are considered appropriate to explain the processes by which older adults with depression self-manage their depression and optimise well-being.

3.2.3.1 *Interpretivism*

The assumptions that underlie social research can, in their most basic form, be grouped into the positivist and interpretivist paradigms. Quantitative research is based on a positivist approach in which knowledge is observable, measurable and objective (Blackstone, 2012). Interpretivism, as the basis for qualitative research, focuses on human beings and the way they make sense of their reality. The acceptance of an individual's subjective reality is central to interpretivism, with Weber (1981) asserting that meaning could be found in an individual's intentions and goals. Research that is situated within the interpretivist paradigm focuses on understanding human experience within a broader life context, thereby acknowledging a person's reality as a social construction

(VanderStoep & Johnson, 2008). By accepting that there are multiple interpretations of reality, interpretivist researchers strive to generate meaning as understood by participants in a natural setting. One of the branches of interpretivism, symbolic interactionism, is particularly closely aligned to the study of human behaviour (Handberg, Nielsen, Lomborg, Thorne, & Midtgaard, 2015).

3.2.3.1.1 Symbolic interactionism

The foundations for symbolic interactionism were laid in the 1920s, but it was only in the early 1930s that George Herbert Mead [1863-1931] articulated the notion that the self was defined through social roles, expectations and broader societal perspectives (Mead, 1934). Drawing from behaviourism, Mead (1934) defined human behaviour as a response to interpretations of the world, rather than to the world itself. He expounded that behaviour and behavioural choices were influenced, but not determined, by context, history and social structures (Mead, 1934). In asserting that knowing occurs within the context of experience, Mead was concerned with the social act as the fundamental process from which all behaviour emerges (McKinney, 1955). The social nature and origin of the individual was that *self* is defined through a combination of social role expectations and perceptions imposed on the individual by society and groups within society (Mead, 1934). In other words, the self begins to develop when individuals interact with others and play particular roles in that interaction (Baumann, 1967).⁶⁰ From this perspective, meaning is created through the individual's own internal dialogue and interactions with others (Milliken & Schreiber, 2001).

Herbert Blumer [1900-1987], a former student of Mead, also viewed the concept of self as constructed through social interaction. He refined and extended the notion of symbolic interactionism as theory about human behaviour and an approach to enquiry into human behaviour, and has been credited with coining the term (Blumer, 1969; MacDonald, 2001). At the time, Blumer's theory of symbolic interactionism was viewed as an opposition to mainstream sociology, which was dominated by quantitative and deductive

⁶⁰ By proposing that the self is a result of experiential relations between the individual and the broader social group, Mead is considered the father of role theory (Baumann, 1967).

approaches to social research (Puddephatt, 2009). Blumer's (1969) three basic premises were:

That human beings act towards things on the basis of the meanings that things have for them ... the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows ... that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters (p. 2).

According to Blumer (1969), the actions and social lives of humans are based on a continuous process of interpretation. The premise that the self emerges out of social structures and social situations is supported by Denzin (1969), who agrees that social interaction forms human conduct, rather than merely being a means of expressing it. These interactions rest on common meanings and shared understanding that are achieved through the use of symbols or symbolic systems, of which language is considered the most common (Handberg et al., 2015). In other words, interaction is symbolic, as it is made possible through symbolic tools, such as language and gestures. By viewing people as active participants engaged in practical activities in their worlds, symbolic interactionism focuses on how they accomplish these activities. Social scientists in this tradition assert that human complexity can only be understood through inductive enquiry (Oliver, 2012). This is the process by which the researcher moves from specific observations to general principles and theories. By defining, labelling and naming actions and events, symbolic interactionism provides a perspective for developing a dynamic understanding of the process under investigation (Charmaz, 2014). In this way, symbolic interactionism orients enquiry to how people act and interact in their daily lives (Oliver, 2012). Indeed, Denzin (1972) notes that methods of social research are not simply tools, but are a means of responding to and making sense of the environment.

By claiming that qualitative research was the only real way of understanding and explaining how people perceive, understand and interpret the world, Blumer's (1969) classic symbolic interactionism takes a micro-sociological perspective, in that it considers only the question of the individual in society, not the shape of society itself (Oliver, 2012). This stance that meaning is generated only through social interaction is inconsistent with Mead's epistemology, which allowed individuals to adjust their action to other people

and their physical environment, within the context of their historical traditions and time constraints (Puddephatt, 2009). Although the inseparability of the individual and the context in which the individual exists are fundamental features of symbolic interactionism (Handberg et al., 2015), there is some debate around whether the process of making meaning should be limited to the sphere of social interaction (Puddephatt, 2009). However, Blumer's assumptions form a popular foundation for the work of generations of symbolic interactionists who contribute to an improved understanding of the social and interactive nature of everyday life (Oliver, 2012).

The epistemological basis of symbolic interactionism makes it particularly relevant in the health care environment, as the individual and service providers find themselves in an interactive process of meaning making that is based on active engagement and communication within a specific context. As a theory about human behaviour and an approach to enquiring into human conduct, it is highly compatible with the qualitative research methodology of grounded theory (Anells, 1996; Bryant & Charmaz, 2007b). By engaging in symbolic interaction, the grounded theory researcher aims to illuminate and explain the actions and interactions of participants as they manage a particular social problem (Milliken & Schreiber, 2001).

3.3 Grounded theory

Grounded theory is one of the most widely used qualitative research methods across a range of disciplines and subject areas and is considered particularly useful in the social sciences (Corbin & Strauss, 2015). Grounded theory was developed in the 1960s by Barney Glaser and Anselm Strauss for the purpose of improving social scientists' capacities for generating theory from data. The publication in 1969 of their seminal work, *The Discovery of Grounded Theory: Strategies for Qualitative Research*,⁶¹ marked a dramatic breakthrough in research in the social sciences at a time when the broader scientific community viewed qualitative research as anecdotal and unsystematic (Hall, Griffiths, & McKenna, 2013). Through this publication, the two sociologists from very different backgrounds—Glaser trained in quantitative methods, whereas Strauss had a background in qualitative research—presented their argument for grounding theory in

⁶¹ Often referred to simply as *Discovery*.

social research itself, and provided procedures for generating grounded theory (Glaser & Strauss, 1969). They challenged the predominant positivist assumptions about research methodology, proposing that qualitative research could move beyond pure description, and be used to develop theoretical explanations of human behaviour (Hall et al., 2013). Rather than dismissing the contribution of quantitative research, they proposed that a grounded theory should “be clear enough to be readily operationalised in quantitative studies when these are appropriate” (Glaser & Strauss, 1969, p. 3).

Researchers who use grounded theory typically focus on social processes, structures or interactions, as they seek to transcend simple description and exploration by generating a theory that explains the phenomenon under study (Sandelowski, 2004). Glaser and Strauss (1969) emphasised the existence of a basic social process that researchers discover in the field. This process becomes apparent in the categories and strategies constructed from the data, and the relationships between them (Birks & Mills, 2015). An example of a process is the way in which individuals respond to and manage a change in wellness-illness status. Grounded theory is unique among qualitative methods in that the researcher does not begin with a pre-identified list of concepts, but explicates concepts from the data during simultaneous data collection and analysis, and constant comparison (Corbin & Strauss, 2015). This process demands flexibility and openness on the part of the researcher.

Since its conception in the 1960s, grounded theory has been the subject of a series of academic debates around its core tenets. This has resulted in three dominant and divergent configurations of grounded theory, often referred to by the names of their originators: Glaser’s classical or traditional approach, Corbin and Strauss’⁶² more structured approach, and Charmaz’s constructivist version. However, with any variant of grounded theory, researchers aim to discover basic social processes within the data—that is, they trace actions, the consequences of those actions and how patterns of social interaction combine to give rise to particular social processes (Birks & Mills, 2015). The resultant theory must be grounded in the data and not predetermined by any theoretical perspective. In other words, the data must have primacy. By immersing themselves in the data,

⁶² By 1990, Strauss had formed an academic alliance with Juliet Corbin, a researcher with a nursing background.

grounded theory researchers use conceptual density or thick description⁶³ to develop detailed portrayals of participants' experiences that allow them to uncover feelings and meanings related to their experiences and actions (Morse, 2015). Thick description also supports credibility of findings, as the details about specific events and behaviours provide a way to test emerging theories (Onwuegbuzie & Leech, 2007). To achieve conceptual density, researchers explore the "emic", or insider's, perspective, as they seek to uncover the meaning people give to their experiences and the way in which they interpret them (Holloway & Galvin, 2016). Using the emic perspective, researchers interpret participants' meanings and seek to explain events and actions (Holloway & Galvin, 2016).⁶⁴ In this way, travelling a path with the participant, the grounded theory researcher accounts for complex processes in a specific context and develops a rich portrayal of the phenomenon under study (Morse, 2001).

3.3.1 Defining a grounded theory

The grounded theory methodology gets its name from the way in which a theory is constructed from data collected during the research process (Corbin & Strauss, 2015). As a foundation for explaining phenomena, a grounded theory denotes a set of well-developed categories, whose properties have been systematically developed and interrelated (Corbin & Strauss, 2015). A theory differs from descriptive qualitative research in that it provides an overarching framework that explains why and how things happen. The grounded theory researcher's job is not to provide a perfect description of a phenomenon, but to develop a theory that accounts for it (Glaser & Strauss, 1969). This is achieved by collecting data for comparative analysis, generating conceptual categories and their properties from the data, and generating a theory.

Completed grounded theory studies have a distinct style and form (Morse, 2001). In their original work, Glaser and Strauss (1969) distinguished between substantive and formal theory. Although both types of theory must be grounded in the data and integrated around a core, or central, category, they are distinguished by their levels of generality (Glaser &

⁶³ Thick description means a detailed description of the context, people and process of the study. It allows readers to understand the processes and interactions of the research context, empathise with participants and reach similar conclusions as the researcher (Holloway & Galvin, 2016).

⁶⁴ In contrast, an etic perspective takes the outsider's point of view (Holloway & Galvin, 2016).

Strauss, 1969). Both are middle-range, in that “they fall between the minor working hypothesis of everyday life and the all-inclusive grand theories” (Glaser & Strauss, 1969, p. 33). However, in any study, the researcher should focus on generating either a substantive or a formal theory (Glaser & Strauss, 1969). A substantive theory is topic-specific and seeks to explain a specific social process within a clearly defined context (Corbin & Strauss, 2015). Examples of substantive theory include a study by Pejner et al. (2015) into older patients’ experiences of emotional support from registered nurses, and Cooney’s (2012) grounded theory study of the factors that are critical to older adults in long-term care settings. The current research is considered substantive as it focuses on understanding a specific phenomenon in a clearly defined situation; namely, how older adults with depression self-manage their illness to optimise their well-being. Most grounded theory studies result in the development of a substantive theory (Birks & Mills, 2015). Developed to a higher level of conceptual abstraction, formal theory encompasses concepts that span several substantive areas (Morse, 2001). A formal theory explains a set of phenomena that have broad social applicability and specifies the links between general concepts. It is not specific to a group or place, but applies to a range of concerns across situational contexts (Corbin & Strauss, 2015). An example of formal theory is Elisabeth Kübler-Ross’ (1973) theory of the stages of dying, which has wide application beyond its original scope (Birks & Mills, 2015). Although a single study may generate formal grounded theory, most examples are derived from existing substantive theory, whereby the core category is expanded through additional data (Birks & Mills, 2015). Kearney (2001) explains that grounded formal theory is typically comprised of middle-range theory that is grounded in substantive qualitative research. The more substantive theories a researcher can refer to, the higher the level of formal theory that can be achieved (Kearney, 2001).

3.3.2 Features of grounded theory

Although grounded theory is best viewed as a family of methods, seven criteria are considered integral to the method: theoretical sensitivity, theoretical sampling, constant comparison, coding and categorising of data, review of literature, integration of theory, and theoretical memos (McCann & Clark, 2003b). The grounded theory researcher uses these seven elements of grounded theory in a systematic, yet flexible manner to collect

and analyse qualitative data, to construct a theory. The three main approaches to grounded theory—Glaser, Corbin and Strauss, and Charmaz—differ in the degree to which these elements are applied, although the main aim remains the generation or modification of theory from the data (Cooney, 2010).

3.3.2.1 *Theoretical sensitivity*

Theoretical sensitivity refers to the ability to have insight in discerning participants' words and actions (Corbin & Strauss, 2015). Instrumental in the development of a grounded theory, a researcher's level of theoretical sensitivity⁶⁵ reflects the insight they have into themselves and the area of research. Using theoretical sensitivity, the researcher seeks to understand and give meaning to the data, detach the relevant from the irrelevant, and conceptualise and formulate a theory as it is abstracted from the data (McCann & Clark, 2003a). In this way, theoretical sensitivity enables the researcher to enter the field "with an awareness of the subtleties of the data" (McCann & Clark, 2003a, p. 10). It is an ongoing process that extends throughout the course of the research, as the researcher asks such questions as "What does the theory do? How is it conceived?" (Glaser & Strauss, 1969, p. 46).

In the current study, a preliminary review of literature, complemented by the researcher's professional experience in the aged and community care sector, provided sensitising cues about the subject area. Although background, knowledge and experience allow the researcher to develop and increase their sensitivity to concepts in the data, they also enable the identification of connections between concepts (Corbin & Strauss, 2015). By entering the field with an awareness of the subtleties of the data, the researcher should be able to recognise and extract elements that are relevant to the emerging theory. Thus, sensitivity is demonstrated by how they interact with participants, ask questions and respond to the data. In so doing, researchers take the role of the other, while acknowledging the interplay between the data and the personal, professional and experiential history they bring to the analysis. Approaching the data from different vantage points, asking questions, making comparisons, following leads and building on ideas also support theoretical sensitivity (Charmaz, 2014).

⁶⁵ Corbin and Strauss (2015) later referred to the concept simply as "sensitivity".

Theoretical sensitivity is intrinsically linked to the researcher's degree of reflexivity (Birks & Mills, 2015).⁶⁶ This is the active process by which insights into the data are systematically developed and then guide ongoing interpretation and action throughout the research process (Birks & Mills, 2015). By scrutinising the research experience, a reflexive stance informs the reader how the researcher conducted the research, related to participants and represented them through the study (Bryant & Charmaz, 2007b).

3.3.2.2 *Theoretical sampling*

Two types of sampling are used in a grounded theory study. Recruitment of participants commences through purposive sampling using predetermined criteria. In this initial stage, preliminary decisions about the sampling and recruitment of participants must be made. However, sampling does not continue in terms of drawing samples of specific groups of individuals, but in terms of the emerging theory (Corbin & Strauss, 1990). The sequential process begins with purposive sampling and moves progressively into theoretical sampling.

Theoretical sampling refers to the process of collecting data for comparative analysis in order to generate substantive and formal theory (Glaser & Strauss, 1969). Theoretical sampling commences as soon as the first set of data have been analysed and is used to collect new data to compare emerging categories (Birks & Mills, 2015). Unlike other sampling in qualitative research, theoretical sampling is not planned before the study starts, but continues in line with progressive data collection and analysis. In this way, the emerging theory is used to guide further decisions about participants, sample size, settings and the type of data to be collected (McCann & Clark, 2003a). These decisions are part of the process of theory development. This concept-driven approach to sampling is particularly important when studying an area which is new or under-researched, as it allows the exploration of issues from different angles (Corbin & Strauss, 2015). Sampling becomes more specific as data collection and analysis progress. It is through theoretical sampling that the researcher achieves representativeness of concepts and consistency of data (Corbin & Strauss, 1990, 2015). To achieve this, questions should be asked that aim

⁶⁶ See 4.4 (Assumptions and expectations).

to identify people who have not yet been represented by a tentative category, or who may contribute to further development of a theoretical category (Tweed & Charmaz, 2012).

The circular process of data collection, data analysis and development of concepts continues until the point of theoretical saturation, when all major categories have been fully developed, show variation and are integrated (Corbin & Strauss, 2015). Achieved by joint collection and analysis of data, theoretical saturation depends on the correct application of the principles of theoretical sampling, to ensure a diverse range of data (Glaser & Strauss, 1969). Although this is a goal that largely determines sample size in a grounded theory study, the quality of the data is more important than the frequency with which it occurs (McCann & Clark, 2003a). At the point of theoretical saturation, no new categories or relevant themes are identified, and the links between categories can be clearly explicated and validated (McCann & Clark, 2003a). The theory should be dense and logical, with no unexplained gaps (Corbin & Strauss, 2015).

3.3.2.3 *Constant comparative analysis*

In grounded theory, data collection and analysis take place simultaneously: they are linked from the outset of the research, proceed in parallel and interact continuously (Holloway & Galvin, 2016). Using constant comparative analysis, each unit of data is compared to all preceding units, to establish if they are similar or different in meaning (Corbin & Strauss, 2015). The four stages of constant comparative analysis require researchers to (i) compare incidents that apply to each category; (ii) integrate categories and their properties; (iii) delimit the theory; and (iv) write the theory (McCann & Clark, 2003a). In practice, this means that data are broken down into manageable parts, before being compared for similarities and differences. This comparative process includes reference to the literature. As analysis continues, concepts are grouped together and labelled to form categories, while constant comparative analysis drives theoretical sampling and the ongoing collection of data (Birks & Mills, 2015). Approaching the data from different vantage points, asking questions, making comparisons, following leads and building on ideas also support sensitivity, one of the essential elements of grounded theory (Charmaz, 2014).

A combination of inductive and abductive thought is used when making decisions during concurrent data collection and analysis (Birks & Mills, 2015). Induction is the reasoning process by which the researcher moves from the specific to general principles, whereas abductive reasoning begins when the researcher examines inductive data, observes a finding that cannot be explained, and forms or tests hypotheses to achieve the most plausible interpretation of that data (Charmaz, 2014; Reichertz, 2007). Charmaz (2014) asserts that the researcher brings creativity into the research process through abductive reasoning. The combined reasoning is one of the features that distinguishes grounded theory from other forms of qualitative description, as it allows the researcher to build a conceptual framework, presented as a theory, from the data (Reichertz, 2007).

3.3.2.4 *Coding and categorising data*

In grounded theory, all data are coded. Coding is a cyclical process during which researchers move back and forth between different phases of coding, throughout the process of data collection and analysis (Kenny & Fourie, 2015). The researcher uses this fundamental analytic process to identify and name concepts or themes, before they are transformed and reduced to build categories (Birks & Mills, 2015). Initial codes may be provisional, and later modified or transformed as data analysis progresses. Conceptually similar incidents are then grouped together to form categories and strategies (Birks & Mills, 2015).

Unlike other methodologies in which coding is a discrete stage, the coding process in grounded theory spans the duration of the research: the process of coding and categorising data is the start of theory development (Charmaz, 2014). This means that the researcher might be simultaneously coding at several levels. Once patterns in the data have been coded, conceptual labels are assigned to individual incidents that are related to a phenomenon (McCann & Clark, 2003a). This process of conceptualisation of data is the foundation of a grounded theory and stops only when the researcher is unable to find new information on a specific category, can comprehensively describe the properties of each category, and can establish firm links between categories (Glaser & Strauss, 1969). The major category which links all others is identified as the core category.

Although the basic coding procedure of Glaser and Strauss' (1969) original approach to grounded theory has been maintained, contending coding procedures are apparent across the three main approaches to grounded theory (Kenny & Fourie, 2015). Glaser (2013) maintained a distinction between substantive and theoretical coding, Corbin and Strauss (1990) went on to propose three levels of coding—open, axial and selective—in their efforts to develop a more systematic and rigorous coding structure to create, rather than discover, a theory (Cooney, 2010; Kenny & Fourie, 2015). Their coding structure has been criticised by Glaser and Charmaz, who argue against “forcing” the data or following “a maze of techniques” (Kenny & Fourie, 2015, p. 1277). From a different perspective, Corbin and Strauss' approach has been commended for providing clear direction to neophyte researchers (Kenny & Fourie, 2015).⁶⁷ In contrast, Charmaz (2008) advocates the use of highly adaptable coding guidelines which enable “imaginative engagement with data” (p. 168). However, her technique neglects to explain the smaller steps between coding and analysis (Kenny & Fourie, 2015).

Despite the points of divergence regarding coding and coding conventions, in practice the coding methods overlap. The dividing line between each approach could be seen as somewhat artificial, as the researcher moves back and forth between different phases of coding in a cyclical manner throughout the process of data collection and analysis (Kenny & Fourie, 2015). As the current study uses Corbin and Strauss' approach to grounded theory, it is appropriate to describe their coding procedure in more detail, with some reference to other views on coding, including those of Glaser and Charmaz.

3.3.2.4.1 Open coding

Also known as Level I or initial coding, open coding is the interpretive process by which the researcher breaks down raw data into discrete parts, identifies concepts and discovers properties (Birks & Mills, 2015). In this early stage of data analysis, it is usual for the researcher to identify a large number of descriptive categories from a small amount of text. This is because there is not yet sufficient data to allow the abstraction of broader underlying concepts and recurring patterns. Commencing with line-by-line analysis of interview transcriptions or field notes, to break down the data, this concentrated approach

⁶⁷ A neophyte refers to someone who is new to a subject or activity. In this case, the PhD candidate is a neophyte researcher.

requires that researchers examine the data in minute detail, while asking questions of the data (Corbin & Strauss, 1990, 2015). The purpose of these questions is to identify elements of process or action, contextual influences and primary stakeholders. Coding may progress by sentence or paragraph, although the researcher should revert to line-by-line coding if a new concept or category is identified. Charmaz (2014) recommends the use of gerunds⁶⁸ when coding, as they provide a sense of action and sequence, and allow the researcher to discern implicit connections in the data.

Once the data have been broken into manageable pieces, the researcher reflects on the data in memos, and conceptualises the data based on their interpretations of the meaning of that data. This is a particularly reflexive activity, as generative questions are asked of the data, comparisons made, and possible themes or categories delineated (Corbin & Strauss, 2015). By fracturing the data, the researcher is forced to examine any preconceived notions and break through any subjectivity or bias (Corbin & Strauss, 2015). Theoretical sensitivity supports efforts to generate concepts from the data and relate them to others (Holton, 2007). As categories become increasingly dense, the researcher may begin to develop sub-categories which may, in turn, be subsumed under increasingly abstract higher order categories (Kenny & Fourie, 2015).

To facilitate the abstraction of new, context-specific theories, category labels should be grounded in the current data. Analysis typically commences with line-by-line *in vivo*⁶⁹ coding of interview transcripts, field notes and other data. The list of *in vivo* codes and shorter phrases is then grouped and named. By using *in vivo* codes which capture the exact words or phrases used by participants in the study, the researcher avoids importing existing theory into the analysis (Saldaña, 2013).⁷⁰ This process continues until categories begin to form. These categories form the basis for theoretical sampling.

⁶⁸ Verbs that finish with 'ing'. Charmaz (2014, p. 123) cites examples such as "gaining medical access" and "remaining unheard".

⁶⁹ A Latin term which indicates that participants' words are used to encapsulate a broader concept in the data (literally: "Within the living") (Birks & Mills, 2015).

⁷⁰ However, a complicating factor when deciding how many and which quotes to use to exemplify a theme is that some participants are invariably more or less articulate, or share more relevant experiences than others (Karp, 2017).

3.3.2.4.2 Axial coding

Axial coding, also known as theoretical or Level II coding, represents the process by which links are forged between a category and its emerging sub-categories (Kenny & Fourie, 2015). Axial coding takes analysis into medium-level concepts, whereby the researcher brings the data back into a coherent whole, having previously fractured it through open coding. By making connections between and within categories, concepts are elevated to provisional categories (McCann & Clark, 2003a). A category serves as an axis around which the researcher can delineate relationships and specify dimensions by testing them against other data (Bryant & Charmaz, 2007b). Consequently, each sub-category has properties that can be linked to an overarching category, which grows in density and precision as the research progresses.

It is during axial coding that theoretical sampling becomes particularly important as a means of addressing questions that arise during category development and integration (Birks & Mills, 2015). The researcher should check the emerging theory by sampling incidents that may support or challenge its claims. In this way, theoretical sampling supports the refinement and, ultimately, saturation of existing categories (Tweed & Charmaz, 2012).

Corbin and Strauss (2015) advocate the use of a coding paradigm to demarcate the sub-categories of causal conditions, context, intervening conditions, action-interactional strategies and consequences (Birks & Mills, 2015; Kenny & Fourie, 2015). By representing a group of abstract theoretical terms, the aim of the paradigm model is to help the researcher develop categories from the data, find relations between them and reassemble the data as a coherent whole (Bryant & Charmaz, 2007b). In this way, it forms a skeleton for the developing categories and their relations (Kelle, 2007). In contrast, Glaser argued against using a coding paradigm, which he maintained would force meanings onto the data (Kelle, 2007). Charmaz (2008) also criticised the rules used by Corbin and Strauss, asserting that axial coding in particular detracts from participants' experiences. However, Corbin and Strauss (2015) defend their coding procedure, maintaining that it should be used flexibly and adapted to different circumstances and studies. Warning that the researcher should not become fixated on the specifics of the

paradigm, and risk rigidifying the analytic process, Corbin and Strauss (2015) contend that the coding paradigm should facilitate the abstraction of a tightly woven explanatory theory that reflects the reality it represents.

3.3.2.4.3 Selective coding

Selective coding is the process by which all categories are unified around a core category (Corbin & Strauss, 1990). It is through selective coding, also known as advanced or Level III coding, that data ultimately become a theory. This stage mainly involves theoretical coding and memo writing, which allow the researcher to review the data theoretically instead of descriptively (McCann & Clark, 2003a). By integrating categories with a higher level of abstraction, a dominant core category is identified which is broad enough to integrate other categories and represent the components of the phenomena. Abstraction of a core category is dependent on “constant comparative analysis with the data, persistent questioning and painstaking analytical thinking” (McCann & Clark, 2003a, p. 14). Corbin and Strauss (2015) provide a list of criteria and several analytic techniques for determining the core category:

- It must be sufficiently abstract to constitute the overarching explanatory concept that ties the other categories together;
- It must appear frequently in the data and be logical and consistent with the data; and
- It should grow in depth and explanatory power as each of the other categories is justified through statements of relationships.

Other techniques to facilitate the process of integrating findings around the core category include explicating the storyline,⁷¹ relating subsidiary categories around the core category, relating categories at the dimensional level, validating relationships against the data and filling in categories that need refinement (Birks & Mills, 2015). As selective coding is likely to occur in the later phases of a study, any modifications at this point are mainly about clarifying and elaborating details of properties to formulate the theory (Holton, 2007).

⁷¹ A narrative framework that contextualises and integrates the various elements of the theory, thereby stimulating integration (Birks & Mills, 2015).

Although grounded theory researchers seek to abstract a core category from the data, it is possible for different types of core categories to exist. Glaser and Strauss (1969) and Glaser (1978) sought to identify a single over-riding process, which would be conceptualised by the subsequent grounded theory. By examining behaviour from the perspective of an emergent basic social process, the grounded theory researcher would come to a new understanding of the phenomenon under study. The core category—which could be a process, activity, state or implication, or multidimensional—constitutes a process that ties the stages of the theory together, that is, the theory is built around a basic social process (Glaser, 1978).⁷² Identifying the risk that the researcher may force data into a process at the expense of developing emergent categories, Glaser (2013) later moved away from the search for a single basic social process.⁷³ Similarly, Corbin and Strauss (2015) also refer to processes in general as a distinguishing feature for grounded theory, rather than basic social processes, while Charmaz (2014) refers to unfolding temporal sequences linked in a process, which lead to change. Although the precise descriptor may vary between different schools of thought, it remains the aim of the researcher to explicate from the categories and sub-categories within the data a process that takes place and can evolve over time. By separating essential concepts from less important ideas, the researcher strives to abstract a theory that is parsimonious, or simple,⁷⁴ but true to the core insights gained from the data (McCann & Clark, 2003a). The resultant core category—or theory—should be dense, testable, logically coherent and explain variations in the categories (Gehman et al., 2017).

3.3.2.5 *Theoretical memos and diagrams*

Theoretical memos and diagrams are essential tools in grounded theory, as they capture the researcher's internal dialogue. As part of the process of analysis, memoing is fundamental to the development of grounded theory (Birks & Mills, 2015). Memos provide information on the research process and the substantive findings of the study. Field notes form the basis for the construction of memos. A researcher who neglects

⁷² It could be a basic social psychological process, which emphasised social psychological processes (such as empathising, interacting or reflecting), or a basic social structural process, which relates to broader structural influences (such as medical dominance or legalisation (Glaser, 1978).

⁷³ In other words, the researcher may be at risk of diluting fit and relevance by forcing a theoretical code onto a theory of a process that may not exist in the data (Glaser, 2013).

⁷⁴ Hutchinson (1993) defines a parsimonious theory as one that is comprehensive without being unwieldy. The theory should comprise more categorical codes than theoretical codes. Most codes should be substantive.

memoing to move directly from coding to writing loses a great deal of conceptual details and will be unable to develop a fully grounded theory (Corbin & Strauss, 1990).

The researcher should commence memoing as soon as data are collected and continue writing memos throughout the research process. Memos will vary in style, length and complexity, but generally begin as basic representations of the researcher's thoughts and then grow in complexity, density and accuracy as the research progresses (Corbin & Strauss, 2015). All memos should be dated, contain a heading and indicate the sections of data they were inspired by. As reflections of analytic thought, memos force the researcher to work with concepts, rather than merely recording data. It is also useful for the researcher to periodically compile summary memos that reflect the information on a specific concept. By capturing the major ideas of the research, these memos help with the final integration of the theory (Corbin & Strauss, 2015).

Many of the guidelines for memoing can be applied to diagrams. Although diagramming is typically done less frequently than memo writing, it can be used to conceptually map analysis throughout the research process and to visually represent the conceptual relationships between categories (Corbin & Strauss, 2015). Through the process of drawing and redrawing diagrams, the researcher can stand back and conceptualise the full theory, which can then be checked against the data. These diagrams include maps, charts and figures that locate concepts and directs movement them (Charmaz, 2014).

3.3.2.6 *Review of literature*

It is common for researchers to commence their studies with a detailed review of existing literature. However, in their original work, Glaser and Strauss (1969) argued against conducting a comprehensive literature review in the early stages of the research process, citing the risk that researchers might superimpose their preconceived ideas onto the data. In the ensuing decades, Strauss' position in relation to the literature review changed significantly, evidenced by the way in which he, with Corbin, came to advocate an early, cursory review of relevant literature (Dunne, 2011). However, theoretical development must be guided by concepts that are abstracted from the data and not those that appear in extant literature (Yarwood-Ross & Jack, 2015). As Strübing (2007) suggests, the issue

lies not in whether previous knowledge should be used, but in how to make proper use of that knowledge.

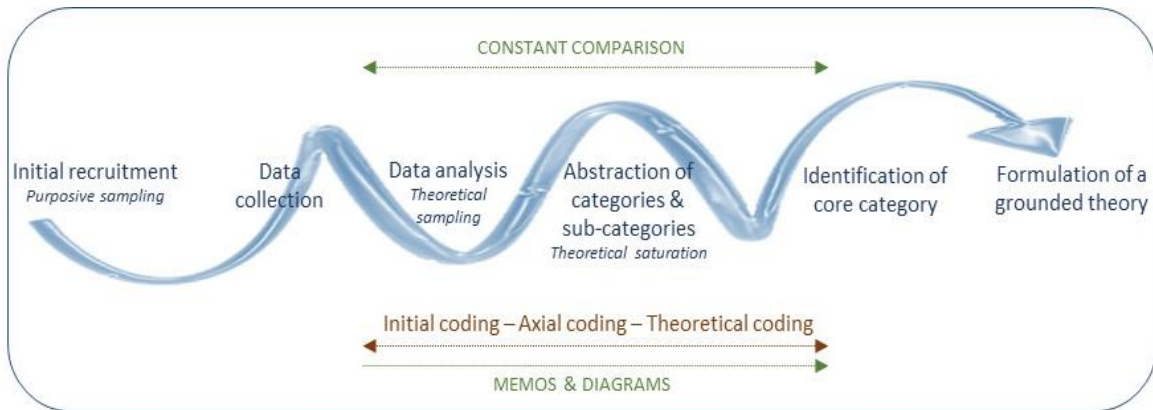
Although its role in grounded theory research is contentious, the benefits of using the literature include that it can enhance theoretical sensitivity, serve as a useful source of secondary data, raise questions about the data, support theoretical sampling and offer an approach to validating the theory (McCann, Boardman, & Polacsek, in press). However, there is consensus between the different schools of thought that a review of the literature review be undertaken at some point, but that it should neither limit creativity, nor allow the researcher to impose existing ideas on the data (Corbin & Strauss, 2015). A cursory review of the literature undertaken prior to data collection and analysis should justify the need for the study, orient the researcher and inform the development of sensitising concepts (McCann & Clark, 2003a). The main literature review is an ongoing process that helps the researcher clarify ideas, make comparisons and identify connections between the new and existing research (Corbin & Strauss, 2015). In this way, ongoing engagement with the literature serves to enhance rather than constrain analysis. Using existing literature as a source of secondary data also allows for comparisons and connections to be made along conceptual lines. Finally, once the theory has been developed, the literature can be used to validate the theory (Corbin & Strauss, 1990). Regardless of the grounded theory approach adopted, researchers should explain the role and timing of the literature review (Dunne, 2011).

3.3.2.7 *Integration of theory*

Integration of theory depends on continuous data collection and analysis throughout the entire research process. Thus, the construction of a grounded theory begins as soon as data collection and analysis commence (Figure 1). The quality of the final product of the research depends on the researcher's ability to move conceptual renderings to the level of an integrated grounded theory (Morse, 2001). By creating robust categories and insightful analyses through engaging in theoretical sampling, saturation and sorting, the researcher seeks to develop an explanatory scheme—that is, a theory—comprised of a set of categories that are related to each other and tightly linked to the data (Birks & Mills, 2015). Glaser and Strauss (1969) posit that integration of the theory should emerge by

itself, providing the essential processes of grounded theory have been followed. Thus, the grounded theory is abstracted by showing the dynamic relationships between and among emerging concepts (Gehman et al., 2017).

Figure 1: Illustration of the grounded theory process



In theoretical integration, a larger number of smaller categories are reduced into larger ones, and a selective sampling of the literature is integrated into the emerging theory (McCann & Clark, 2003c). These larger categories are then linked around a core category which represents the main theme of the research and is sufficiently abstract and broad to adequately represent all study participants (Morse, 2001). In this final step of analysis, the focus shifts from exploring to summarising. This involves reviewing the theory for internal consistency and logic, filling in any gaps, removing extraneous concepts and accounting for outlying cases (Corbin & Strauss, 2015). Once it has been identified, the researcher must integrate the study's findings around the core category. Techniques to facilitate the integration process include writing a descriptive summary memo—that is, the storyline of the data—or writing a conceptual summary memo of the research findings, and using integrative diagrams to sharpen the relationships between categories (Corbin & Strauss, 2015).

3.3.3 Presenting a grounded theory

The processes of thinking and writing are inextricably linked in the construction of a grounded theory. Writing serves an important role in preserving and presenting the process and outcome of the analytic work involved in generating a grounded theory. Furthermore, research is not complete until it has been disseminated, and at some point,

the researcher must focus on communicating rather than analysing findings. Charmaz (2014) refers to “rendering” as the process by which the researcher achieves a particular writing style when presenting a grounded theory. In this way, writing goes beyond an analysis of data, as it represents participants’ experiences in a way that transforms the subjective into the collective (Charmaz, 2014). Thus, grounded theory methodology suits researchers who prefer to write with the aim of generating new theory, compared to those who prefer to read about and then test existing theory (Birks & Mills, 2015).

Although guidelines for presenting a grounded theory exist, the writing process should not be rigidified. The researcher should first decide on the main analytic message, and then give enough conceptual detail and descriptive quotations to give the reader a comprehensive understanding of the study (Corbin & Strauss, 2015). Using plain language and straightforward ideas makes theory readable, while tone and pace lead the reader into the topic (Charmaz, 2014). Despite the traditional use of the third person or passive voice when writing about research, judicious use of the first person may be used to identify and acknowledge the role of the researcher (Gilgun, 2005). As with all qualitative research, the grounded theory should contain direct and verbatim quotes from participants, as they give insight into people’s experiences and the meaning they give to them (Patton, 2002). The use of quotes also helps the reader to judge how the findings were derived from the data, thereby establishing the credibility of the emerging theory (Charmaz, 2014).

3.3.4 Critique of grounded theory

In the years since Glaser and Strauss (1969) first presented their new method for generating theory from data, grounded theory has served as a major method for conducting qualitative research. Developed against a backdrop of debate around fundamental philosophical and methodological approaches to research, particularly in the social sciences, grounded theory continues to evolve in the light of the current epistemological landscape (Bryant & Charmaz, 2007a). However, the philosophical and methodological differences between the three main configurations of grounded theory—Glaser, Corbin and Strauss, and Charmaz—often create confusion for researchers, and supporters and critics abound in each version (Kenny & Fourie, 2014) (Table 1).

Table 1: Main differences between Glaser, Corbin and Strauss, and Charmaz

Element	Glaser	Corbin and Strauss	Charmaz
Epistemology	<ul style="list-style-type: none">· Critical realist ontology· Post-positivist paradigm· More positivistic	<ul style="list-style-type: none">· Social constructivist and poststructuralist, or postmodern paradigm· Less positivistic	<ul style="list-style-type: none">· Relativist ontology· Pragmatist philosophy· Constructivist
Researcher's role	<ul style="list-style-type: none">· Independent	<ul style="list-style-type: none">· Dialectic and active	<ul style="list-style-type: none">· Active
Theory	<ul style="list-style-type: none">· Emphasis on theory generation	<ul style="list-style-type: none">· Emphasis on verification and validation of theory and hypotheses	<ul style="list-style-type: none">· Emphasis on co-construction of a theory
Focus in the field	<ul style="list-style-type: none">· Main emphasis on symbols, interactions and context· Emphasis on socially constructed world of participants (micro)	<ul style="list-style-type: none">· Emphasis on structural, contextual, symbolic and interactional influences· Emphasis on describing cultural scene (macro) and socially constructed world of participants (micro)	<ul style="list-style-type: none">· Emphasis on constructing a conceptual interpretation of the phenomenon
Literature review	<ul style="list-style-type: none">· Main review to support emerging theory	<ul style="list-style-type: none">· Preliminary review to enhance theoretical sensitivity· Main review to support emerging theory	<ul style="list-style-type: none">· Preliminary review to enhance theoretical sensitivity· Main review to support emerging theory
Research question	<ul style="list-style-type: none">· Emerges in study	<ul style="list-style-type: none">· Personal experience· Suggestion by others· Literature· Emerges from the data	<ul style="list-style-type: none">· Personal experience· Suggestion by others· Literature· Emerges from the data
Data collection and analysis	<ul style="list-style-type: none">· Principles and practices of qualitative research· Guided by participants and socially constructed reality	<ul style="list-style-type: none">· Rules and procedures· Rigorous coding framework	<ul style="list-style-type: none">· Flexible coding guidelines· Less structured, impressionistic coding
Evaluation	<ul style="list-style-type: none">· Fit, work, relevance and modifiability	<ul style="list-style-type: none">· Deference to canons of qualitative research outlined by other qualitative researchers	<ul style="list-style-type: none">· Credibility, originality, resonance and usefulness

(McCann et al., in press)

The main criticism of grounded theory concerns the lack of clarity around beliefs about the nature of knowledge and assumptions about how knowledge can be acquired—that is, its epistemology (McCann & Clark, 2003b). In this regard, the absence of a clearly explicated epistemological framework has left room for confusion among less experienced grounded theory researchers. Issues have also arisen over the use of language, conflicting terminology and sociological jargon within the discourse of grounded theory (Glaser, 2009; McCann & Clark, 2003b).⁷⁵ The jargon on methodology and procedures can also be particularly mystifying for neophyte grounded theory researchers and outsiders (MacDonald & Schreiber, 2001). The term *grounded theory* itself may cause confusion, in that it refers to the method used in the research process and the result of the research process (Bryant & Charmaz, 2007b). Thus, grounded theory has been positioned as positivist, constructivist, interpretivist, pragmatist, realist and neo-empiricist (Holton, 2007), while the researcher is assumed to be simultaneously objective and subjective, and use inductive and deductive thinking (McCann & Clark, 2003b).

There is also uncertainty around the position of symbolic interactionism in grounded theory. Although symbolic interactionism is almost universally cited as the theoretical foundation for grounded theory (Handberg et al., 2015), its actual position in grounded theory is unclear. Glaser (2005) has dismissed the applicability of any specific philosophical position, including symbolic interactionism, believing that it would reduce the potential of grounded theory. In contrast, Corbin and Strauss (1990, 2015) maintain that symbolic interactionism underpins grounded theory, although they explain that the researcher does not necessarily have to subscribe to these philosophical and sociological orientations to use grounded theory. Charmaz (2014) considers symbolic interactionism to be “the major theoretical perspective associated with grounded theory” (p. 261), while others suggest that it is inherent in grounded theory research, whether or not the researcher is aware of it (Milliken & Schreiber, 2001).

Remaining true to the original version of grounded theory, Glaser continues to focus on methods rather than a specific theoretical position, although his views are underpinned by critical realism, post-positivism and objectivity (Kenny & Fourie, 2015). Strauss, on

⁷⁵ For example, one researcher’s conceptual framework may resemble another’s theory.

the other hand, was influenced by the more pragmatic philosophy of symbolic interactionism, and he documented his personal transformation from a realist view to a more relativist perspective (Hall et al., 2013; MacDonald & Schreiber, 2001). Together with Corbin, Strauss refined certain features of classic grounded theory to display a shift towards a relativist approach with constructivist leanings (Corbin & Strauss, 1990). Rejecting the view of theory waiting to be discovered, they saw reality as a product of interpretation and construction by the researcher (Hall et al., 2013). To this end, questions are open and focused on social processes. However, formulating a good research question is often one of the most challenging aspects of a study, particularly for neophyte researchers (Doody & Bailey, 2016). A good research question should be flexible and open-ended, researchable, and relevant and appropriate to the field (Holloway & Galvin, 2016). It should also be of interest to the researcher (Doody & Bailey, 2016). In grounded theory, the initial research question identifies the phenomenon to be investigated. This allows a theory to be abstracted progressively from interviews and observations in the real world (Corbin & Strauss, 2015). Thus, a grounded theory study should not begin with an explicit hypothesis, but with broad sensitising questions that guide data collection. Notwithstanding Glaser's (1998) criticism of their model as too prescriptive, Corbin and Strauss (2015) offer clear guidelines and techniques for data collection and analysis, which are useful to the neophyte grounded theory researcher. They also warn against taking a rigid approach, reminding the researcher that qualitative research should be interpretive and dynamic (Corbin & Strauss, 2015).

Although Corbin and Strauss showed signs of a paradigm shift, Charmaz was the first to unequivocally name her work as constructionist (Charmaz, 2014). Constructivist grounded theory adopts the original inductive, emergent approach, but highlights the flexibility of grounded theory and resists its mechanical application (Charmaz, 2014). Despite contrasting philosophical frameworks, contending coding procedures and conflicting use of the literature, all three approaches acknowledge the same origin and embrace several of the original methodological techniques of grounded theory.

In line with their contending philosophical frameworks, there is disagreement between Glaser, Corbin and Strauss, and Charmaz on the timing and extent to which existing literature may be used during a grounded theory study (Dunne, 2011; Kenny & Fourie,

2015). Glaser (1998) has argued that it is essential not to refer to relevant academic literature before or during the research process, to avoid imposing preconceived ideas on the work, and that the literature should be consulted at the end of the study for the purposes of constant comparison (Dunne, 2011). Rather, the researcher should engage with literature outside the topic area (Birks & Mills, 2015). However, it is highly unlikely that a researcher would enter the field completely unfamiliar with relevant literature. At the very least, a researcher would have to justify the need for the study and submit some form of study proposal. Corbin and Strauss (Corbin & Strauss, 2015) distinguish between technical and non-technical literature, where the former refers to research reports and other theoretical or philosophical papers, while the latter refers to material such as letters, diaries, memoirs or newspapers (Corbin & Strauss, 2015). Although an early literature review should provide a cogent rationale for a study, ongoing consultation with the technical literature should be used to making comparisons, enhance sensitivity, provide descriptive materials, inspire questions for observations and interviews, stimulate analytic questions and confirm findings (Dunne, 2011; Kenny & Fourie, 2015). Non-technical literature may be used to authenticate findings or supplement interviews and observations. In contrast, Charmaz advocates that the literature review be delayed to allow researchers to articulate their own ideas (Yarwood-Ross & Jack, 2015). To provide context, the final version of the literature review should be tailored to fit the specific purpose and argument of the study (Charmaz, 2014).

Notwithstanding areas of tension, grounded theory is an appropriate and effective methodology for investigating individuals' experiences, actions and interactions, as well as their perceptions and thoughts about them. Indeed, Charmaz (2008) maintains that most criticisms of grounded theory turn on misunderstandings or misuse of the method, pointing out that weaknesses in using the method have been erroneously equated as weaknesses inherent in the method. However, researchers planning to use grounded theory inevitably must choose an approach. This decision demands considerable time and effort, for the researcher to appreciate the similarities and differences between approaches before deciding which one to follow. The reason for the decision should be presented with the study.

3.3.5 Justifying the use of Corbin and Strauss' approach to grounded theory

Over the years, grounded theory has continued to mature and branch as its appeal as a qualitative research methodology has grown (Holloway & Galvin, 2016). The three main approaches to grounded theory—those of Glaser, Corbin and Strauss, and Charmaz—share similar characteristics, but emphasise certain aspects of the tradition. To illustrate, Glaser directs the researcher to allow the emergent nature of the analysis to dictate the study's direction; Corbin and Strauss suggest the use of a systematic matrix for coding; and Charmaz views the researcher as integral to the process of data collection and theory development (Birks & Mills, 2015). Although much has been made of the schism between Glaser and Strauss, in particular, as well as Glaser's criticism of Charmaz, the flexibility of the grounded theory method has allowed it to retain its relevance as it has evolved (Birks & Mills, 2015). However, it is important to present and justify the choice of approach. This justification should not be interpreted as a criticism of other versions of grounded theory, but as an explanation of the suitability of the chosen approach to the researcher's aims and views.

Several personal philosophical learnings and practical considerations influenced the decision to use Corbin and Strauss' (1990, 2015) approach to grounded theory in the current study. From an initial review of the different philosophical perspectives of the three main approaches to grounded theory, the researcher acknowledged that the critical realist ontology and postpositivist paradigm of classic grounded theory did not resonate strongly with her. This paradigm asserts that an objective, external reality exists, and that the researcher is independent from those being researched (Kenny & Fourie, 2015). While Glaser and Strauss' (1969) original work proposed that the research problem itself should emerge, clarification was sought on Glaser's (1992) later view that research functions from a position of "abstract wonderment" (p. 21), whereby the researcher enters the field with nothing more than a general curiosity in an area of interest, before trying to identify participants' main concern. However, given that a research proposal typically requires a defined research question, a justification for the study and some degree of context—such as through a literature review—the researcher who approaches a study with little more than wonderment is likely to encounter difficulties (Yarwood-Ross & Jack, 2015).

There are several reasons that Corbin and Strauss' (2015) approach to grounded theory was selected for the current study. Aligning with a social constructionist ontology and the poststructuralist paradigm pragmatism, their approach makes explicit the influence of symbolic interactionism (Corbin & Strauss, 1990). Their revision of the original precept of a natural emergence of theory from data to one that is discovered by the researcher was considered appropriate for this neophyte grounded theory researcher. Corbin and Strauss (2015) emphasise the context in locating and explaining action-interaction. Taking account of micro and macro influences on a phenomenon, context includes events, the circumstances that make up a situation, the meanings given to these, the action or interaction that people take to manage or achieve the desired outcome, and the actual consequences that result from their action (Corbin & Strauss, 2015). By linking concepts, context enhances a theory's ability to explain a phenomenon; ignoring context only tells part of the story and leads to description, rather than theory (Corbin & Strauss, 2015). Consideration of the mutually interdependent micro and macro realms is highly relevant in health care research, as individual, face-to-face care is located within broader health practices and social conditions (Holloway & Galvin, 2016; MacDonald, 2001). This applies to the current study. Although most of Corbin and Strauss' (2015) premises were derived from pragmatist and interactionist philosophies, their shift toward social constructivist ontology and postmodernism is also compatible with current thinking (Cooney, 2010).⁷⁶ Indeed, theoretical knowledge must be relevant to time and place, and be updated to keep pace with change over time (Corbin & Strauss, 2015).⁷⁷

Practical considerations also influenced the selection of Corbin and Strauss' (2015) approach to grounded theory. A more structured approach to data collection and analysis was considered appropriate for this neophyte researcher, as step-by-step guidelines and techniques could be followed throughout the research process. Corbin and Strauss (1990, 2015) allow for a preliminary review of the literature that allows the researcher to enter the field with an awareness of the subtleties of the data. Although boundaries are established around what is to be studied, a preliminary review of the literature allows the researcher to consider broader contextual issues that influence the phenomenon being

⁷⁶ Although Charmaz's (2014) constructivist worldview interested me, her emphasis on multiple realities and local complex situations highlights the importance of a researcher's experience.

⁷⁷ For example, through creative and critical responses to feminist, indigenous and political conditions (Denzin, 2007).

studied (Cooney, 2010). However, the researcher should not develop preconceptions or constrain analysis of the data with extant codes and concepts (Birks & Mills, 2015).

The final consideration in choosing to use this approach to grounded theory relates to its potential for research translation. The emphasis on explaining process means that theories developed from data may be more readily translatable to evidence-based practice. Corbin and Strauss (2015) assert that grounded theory studies offer insight, enhance understanding and provide a meaningful guide to action in the form of policy change, practice change or knowledge development. Certainly, the researcher in the current study hopes that her work is relevant beyond academia, as she seeks to explain how older adults with depression strive to optimise their well-being.

3.4 Summary

A fundamental decision when planning a study concerns the selection of a qualitative or quantitative approach, or a combination of both. Once a qualitative approach has been chosen to answer the research question, a decision regarding the methodology and approach is needed. In this chapter, the theoretical assumptions and practical considerations that underpin this study were described. The rationale for using a qualitative approach was given, followed by an explanation of symbolic interactionism as the underpinning philosophy of grounded theory. Grounded theory is particularly useful in health care settings and is considered an appropriate approach to explain how older adults with depression self-manage their illness to optimise their well-being. The core features of grounded theory were explained, with reference to different schools of thought. As with most other methodologies, grounded theory is constantly evolving. Therefore, it is important for the researcher to identify and justify the particular version of grounded theory to be used in a study. Following careful consideration of its merit and application, the decision to follow the approach of Corbin and Strauss (1990, 2015) was justified.

CHAPTER 4

Methods of study

4.1 Introduction

In this chapter, the methods of study used to investigate the research question of how older adults with depression self-manage their illness to optimise their well-being are discussed. The chapter commences by locating the pursuit of knowledge within a sound ethical framework. Requirements for data management are outlined, followed by a description of the methods of data collection and analysis in grounded theory. The selection and recruitment of participants is described, with reference to the aim of the study to understand the self-management strategies used by older adults with depression to optimise their well-being. The chapter concludes with a discussion of rigour in qualitative research.

4.2 Ethical considerations

Ethical considerations apply to all research. However, the primary concern in any research study should be to protect the dignity, rights, safety and well-being of participants (Holloway & Galvin, 2016). A range of principles, rules and standards exists to guide all of those involved in conducting research.

Efforts to establish international rules for ethical conduct in research stem from the time after World War II, when abuses under the name of research were made public in the Doctor's Trial in the German city of Nuremberg in 1946-47 (Nuremberg Military Tribunals, 1946). The disregard for human dignity that occurred in German concentration camps during the War—which included assigning 'patients' to clinical interventions without their knowledge or consent—shaped the research ethics process (Kaufman, 1997).⁷⁸ The trial verdict adopted 10 points, known as the Nuremberg Code, to define and govern legitimate medical research (Nuremberg Military Tribunals, 1946). The guiding principles of the Nuremberg Code are enshrined in the Declaration of Helsinki, which has

⁷⁸ Although the literature on the German trial is abundant, other reports of unethical conduct that took place during World War II include medical researchers in the United States of America injecting hospital patients with radioactive plutonium to learn its effects on the human body (Kaufman, 1997).

directed research on human participants since 1964.⁷⁹ Compiled by the World Medical Association primarily for physicians, this statement of ethical principles is now adopted generally in research involving human beings (World Medical Association, 2013). It asserts that the quest to generate new knowledge should never take precedence over the rights and interests of research participants, and that all medical research should follow ethical rules of practice that promote and ensure respect for participants, while protecting their health and rights (World Medical Association, 2013). Research should also be of benefit to researchers and their subjects.

In Australia, the National Statement on Ethical Conduct in Human Research (2018b) articulates principles and guidelines for those conducting research and for those involved in its ethical review. These principles are located within the overarching values of respect for human beings, research merit and integrity, justice and beneficence (National Health and Medical Research Council, 2018b). Although these values provide a substantial and flexible framework for the principles that guide the design, conduct and review of ethical research, the underlying imperative is for researchers to treat participants with respect, care and sensitivity, and to conduct their research with integrity (Oliver, 2008). Hence, the research must align with the principles and practices of the Australian Code for the Responsible Conduct of Research, which was issued jointly by the National Health and Medical Research Council, the Australian Research Council and Universities Australia (National Health and Medical Research Council, 2018a). As this research study involved human participants, the researcher was also required to comply with the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2018b).⁸⁰

The five main ethical and research integrity issues related to the current study were:

- Respect for human beings, including the requirement for informed consent;
- The right of participants to withdraw from the study;
- Privacy, confidentiality and anonymity;

⁷⁹ The first version was adopted in 1964. It has been amended seven times since then, most recently in October 2013 (World Medical Association, 2013).

⁸⁰ These statements and codes, together with individual human research ethics committees, serve to operationalise the principles of the Nuremberg Code (1946) and Declaration of Helsinki (World Medical Association, 2013).

- Research merit and integrity, justice and beneficence, which encompass the requirement to minimise the risk of harm to participants and the researcher; and
- Appropriate data storage, access and disposal.

In the current study, these ethical considerations and proposed approaches to managing them were articulated in the *Application for ethical review of research involving human participants*, submitted to the Victoria University Human Research Ethics Committee after the proposal for the study had been approved. Data collection commenced only after approval was gained from the Human Research Ethics Committee (Approval no.: HRE15-280). However, by their very nature, issues relating to research ethics and integrity are often complex, and increasing attention is being given to the mismatch between procedural ethics, as mandated by policies and committees, and ethics in practice (Ellis, 2007). Although numerous papers articulate the complexities of research ethics, there remains an expectation that ethical behaviour and the specific research setting can be standardised (Ellis, 2007; Speer & Stokoe, 2014). This may be particularly challenging in qualitative research, in which the researcher approaches data collection with an openness that aims to discover participants' views and experiences, and does not prescribe what will constitute relevant data (Holloway & Galvin, 2016). For example, it may be more useful for a researcher to ask, "What should I do now?" rather than follow an instruction that could not have foreseen the context or interpersonal engagement that occurs in each different interview (Ellis, 2007). Nonetheless, there is a clear expectation that researchers draw on sound ethical principles and rules to guide their research decisions and conduct (Patton, 2002). In addition, the onus remains on the researcher to be ethical, even if or when participants are unaware of or unconcerned with formal ethics requirements (Ellis, 2007). Indeed, ethical dilemmas are concerned not only with making the right decision, but in justifying that decision (Speer & Stokoe, 2014).

4.2.1 Respect for human beings

In the research context, respect for human beings refers to recognising the intrinsic value of research participants, while having due regard for their welfare, beliefs, perceptions, customs and cultural heritage (National Health and Medical Research Council, 2018b). This value includes respecting a person's capacity to decide whether to participate in

research—commonly known as the requirement for informed consent— based on sufficient information and adequate understanding of the proposed research. It also refers to the privacy and confidentiality of participants, and decisions about payment or reimbursement.

4.2.1.1 *Informed consent*

The requirement for informed consent is grounded in the notions of autonomy and respect for human beings, and is one of the best known procedural principles in research ethics (Oliver, 2008). According to Sim (2010), the fundamental components of informed consent are:

- Disclosure: the adequacy of the information provided to the prospective participant;
- Comprehension: the extent to which that information is understood;
- Competence: the person's capacity to give consent; and
- Voluntariness: the absence of coercion or inducement in making a decision regarding participation.

The National Statement on Ethical Conduct in Human Research (2018b) requires a person to have sufficient information on and understanding of the proposed research to give informed consent. The person must also understand the implications of participating in the research, and the decision to participate must be voluntary. If one or more of these components is inadequately fulfilled, consent may be considered invalid (Sim, 2010). A finding that a person is not competent to give consent, for example, may lead to the removal of their fundamental rights, while consent obtained from a person who does not have capacity is not valid (National Health and Medical Research Council, 2018b). Although provision is made for a third party to give consent on a participant's behalf, those whose decisional capacity may be impaired must be protected.

Although the need for regulation of research is clear, processes relating to research governance are often approached in an administrative manner, and obtaining consent does not necessarily make research ethically acceptable (Pollock, 2012). For example, a participant may experience or perceive interactional pressure, or subtle coercion, if information and consent documents are written in a way that assumes a consenting

response, or when alternative options are unevenly weighted or difficult to enact (Speer & Stokoe, 2014). One of the most effective ways to ensure the integrity of the consent process is for trained researchers to take responsibility for the procedure (Pollock, 2012). In the case of neophyte researchers, guidance from experienced researchers or supervisors is recommended (Holloway & Wheeler, 2010).

In this instance, the researcher was responsible for all research activities, including recruitment, providing information and gaining consent. The information provided to and discussed with prospective participants before they decided whether to participate in the research included the purpose of collecting the information, how it would be used, the questions to be asked during the interview, how data would be managed, confidentiality, and risks or benefits associated with participation.⁸¹ Care was taken to ensure that participants genuinely understood the purpose of the research and its potential risks and benefits. The researcher discussed the documents with prospective participants, using plain English and providing opportunity for questions and answers. If a prospective participant appeared unsure, reluctant or confused about participating, the researcher offered to discuss or repeat information, or leave the information with the person, to review in their own time. Informed consent was required before data collection commenced.⁸²

4.2.1.2 *Withdrawing consent*

General requirements for consent include the right of research participants to withdraw from a study at any time (National Health and Medical Research Council, 2018b). They must be informed of their right to withdraw from a study at any time and no reason for their withdrawal is required. In addition, the researcher may not exert any pressure on a participant who wishes to withdraw. Participants may also request that information provided by them be destroyed. They are also entitled not to answer certain questions.

The information and consent documents for the current study explained participants' right to withdraw from the study at any time. They were also informed that any decision

⁸¹ See Appendix C (Participant information).

⁸² See Appendix D (Participant consent form).

whether or not to take part, or to take part and then withdraw, would not have negative consequences for them, such as preventing any treatment or support they were receiving at the time. None indicated a wish to withdraw from the current study.

4.2.2 Privacy, confidentiality and anonymity

At its most basic level, privacy refers to a domain in which the individual is entitled to be free from the scrutiny of others (National Health and Medical Research Council, 2018b). In Australia, the Commonwealth *Privacy Act 1998* (Privacy Act) regulates the handling of personal information about individuals (Office of the Australian Information Commissioner, 2015). Under the Privacy Act, 13 Australian Privacy Principles set out the standards, right and obligations relating to handling, holding, using, accessing and correcting personal information.

In the research context, the assurance of privacy is essential to earning the trust that encourages people to become involved in research (Lowrance, 2012). The Privacy Act allows individuals to know why their personal information is being collected, how it will be used and who it will be disclosed to (Office of the Australian Information Commissioner, 2015). It also provides the option of not being identified or using a pseudonym. The National Statement on Ethical Conduct in Human Research refers to the Privacy Act in articulating the right of research participants to privacy, confidentiality and anonymity, and the handling of sensitive information (National Health and Medical Research Council, 2018b). These principles are related in many ways: privacy refers to the way personal information is handled, confidentiality refers to the people who might be able to access data, and anonymity refers to the participant not being linked to or identified in the data. Strategies to manage these issues relate closely to how data and primary materials are managed and stored, including the requirement for secure storage and retention of electronic and printed material, restricted access to data by others, and safe and secure disposal (Lowrance, 2012).

Before commencing data collection, participants were informed of the purpose of the study and how their information would be used. They were assured that all data would be treated in the strictest confidence. Participants were informed that only the researcher and

study supervisors would have access to their personal details and the raw data that was collected in the field.⁸³ Participants' anonymity was further protected by the use of pseudonyms. No identifying details have been or will be disclosed.

4.2.3 Research merit and integrity

The involvement of human participants in research can only be ethically justified if the proposed research has merit—through value and validity—and the researchers conducting the research have integrity (National Health and Medical Research Council, 2018b). Research has merit if it is justifiable by its potential benefit, such as its anticipated contribution to knowledge or to improved social welfare and individual well-being. The methods used in a research study must also be appropriate for achieving its aims. Research integrity is demonstrated through a commitment to searching for knowledge and understanding, complying with recognised principles of research conduct and conducting research in an honest manner (National Health and Medical Research Council, 2018a). Results should also be disseminated in ways that contribute to knowledge and understanding, and that permit scrutiny.

4.2.4 Justice

The principle of justice implies that research strategies and procedures are fair and just, and that the benefits and burdens of research are distributed fairly (Christians, 2013). In the research context, procedural justice demands fair treatment in the recruitment of participants and the review of that research, while distributive justice refers to the fair distribution of the benefits and burdens of research (National Health and Medical Research Council, 2018b). The research methodology should explain the selection of participants and demonstrate a fair method of recruitment, for example, by explaining inclusion and exclusion criteria for participants. The research results and outcomes should be disseminated in a timely manner.

⁸³ Although a professional service was commissioned to transcribe interview recordings, the audio files were de-identified prior to transcription.

4.2.5 Beneficence

In research, the principle of beneficence—in concert with the principle of non-maleficence—demands that the benefits of a study outweigh the risks to an individual or wider society (Holloway & Galvin, 2016). Beneficent actions are understood in a dual sense, whereby the researcher must avoid harm altogether or, if risks are involved for achieving significant benefits, minimise the harm as much as possible (Christians, 2013). In other words, researchers must establish a favourable risk-benefit ratio. In minimising risks and enhancing the potential benefits of their work, researchers must be sensitive to the welfare and interests of those involved in their research, while considering any social and cultural implications of their work. Concerning the current study, older adults and those with a mental illness rate depression as a priority research topic and are highly motivated to participate in research (Banfield, Barney, Griffiths, & Christensen, 2014; National Ageing Research Institute, 2013). Thus, the benefits to society are an important result of research, but they should be achieved through just means, be distributed fairly, and present no unjust burdens (National Health and Medical Research Council, 2018b).

The significance and contribution of the current study have been outlined elsewhere.⁸⁴ In this study, harm pertains to the way in which the researcher assessed and took account of the risks of harm or discomfort to participants. Whereas there was no physical risk of harm to participants, participating in a qualitative interview may provoke distressing memories (Alexander, 2010; Holloway & Wheeler, 2010). Given the focus of the study, there was a foreseeable risk of participants experiencing distress as they recounted their experiences around diagnosis, treatment and management of depression. A protocol was in place to guide the researcher's response if this occurred. Initially, the researcher would offer initial emotional support and offer to pause the interview. If the participant preferred not to proceed, the interview would be terminated. A psychologist based at the university had been briefed on the study and was available to provide formal support, at no cost to participants.⁸⁵ This service was not requested by any participant. Although several became mildly distressed during their interviews, they remained articulate and expressed the desire to continue with the interview. This behaviour is consistent with evidence that

⁸⁴ See 1.4 (Justification for the study).

⁸⁵ The psychologist, an academic staff member of Victoria University, agreed to assume this role, if necessary.

interview participants generally find it helpful to share their experiences and insights on a personal level, even when they may experience a level of discomfort or distress (Wolgemuth et al., 2015). This was evidenced on one occasion, when a participant became angry and tearful as he recalled the circumstances around his sudden retrenchment, which resulted in early retirement. When the researcher offered to pause the interview, Nick (a pseudonym) clearly expressed his wish to continue with the interview. By the time the interview concluded, Nick was showing no signs of distress and thanked the researcher for the opportunity to share his experiences and strategies for managing his depression.

4.2.5.1 *Non-maleficence and vulnerable participants*

The principle of beneficence stipulates that research should produce recognisable benefit to participants and the wider community. Non-maleficence requires us not to do things that may be harmful to others (Sim, 2010). This principle prohibits researchers from causing or allowing psychological or physical harm to research participants, including indignity, deception or being used as an object (Pollock, 2012).

Depending on the research, setting and participant characteristics, the risks and potential harms of qualitative research are often considered to be lower than in some intervention studies (Pollock, 2012). However, the imperative to balance the pursuit of knowledge with ethical responsibilities is especially important for researchers working with vulnerable populations (Bay-Cheng, 2009). Although there is a lack of consensus on what it means to be vulnerable, the term typically applies to children, older adults, those with mental disorders or learning difficulties, those who lack the mental capacity to give consent and those in a dependent or unequal relationship (Alexander, 2010; Bay-Cheng, 2009). Patients receiving palliative care are also vulnerable (Alexander, 2010). The sensitivity of the topic of research should also be taken into account.⁸⁶ Qualitative research that explores sensitive topics in depth may involve emotional and other risks to participant and researcher (Wolgemuth et al., 2015). However, the process of participating in research can be empowering and cathartic for participants, with several

⁸⁶ In research, a sensitive topic is one which poses a potential risk to those involved, which may make the collection, holding or dissemination of data problematic for participants and/or researchers (Decker, Naugle, Carter-Visscher, Bell, & Seifert, 2011). Examples include childhood sexual abuse, domestic violence, trauma or grief (Decker et al., 2011; Wolgemuth et al., 2015).

studies reporting the likely benefits to participants across a wide range of sensitive study topics, participant samples and methodologies (Decker et al., 2011; Warburton, Bartlett, Carroll, & Kendig, 2009; Wolgemuth et al., 2015).

Although no risks of physical harm were identified in the current study, there was a low risk that participants may become mildly distressed when sharing their experiences of ageing and depression. The risk of psychological harm to participants can be minimised by the researcher following the principles of respect for human dignity and justice. Clear protocols, approved by the Human Research Ethics Committee, were in place to respond to any distress that might be experienced by participants. In the event, none elected to contact the researcher or her supervisors to seek emotional support. This was confirmed with the psychologist who had made himself available for this purpose. However, one participant wrote a follow-up letter to the researcher, suggesting that a second interview may have been appropriate, as a way of addressing any issues that had arisen from the first interview. In consultation with her supervisors, the researcher contacted the participant by telephone, to discuss her experience of the interview and invite additional comments. The participant appeared satisfied by the conversation and the researcher's explanation of the limitations of the study in terms of number of interviews, and there was no further contact.

4.2.6 Reimbursement

It is generally considered appropriate to offer a form of payment or reimbursement for costs to participants taking part in a research study, provided that payment is not disproportionate to the time involved and does not serve as a form of inducement to participate (National Health and Medical Research Council, 2018b; Polacsek, Boardman, & McCann, 2016). However, there is an absence of clear guidelines concerning the ethical and practical issues associated with paying patient and caregiver participants in research. In response to this gap, the researcher, in collaboration with her supervisors, published a paper on the topic (Polacsek et al., 2016). In this paper, a set of guiding principles was presented to support researchers in their decision-making around participant reimbursement (Polacsek et al., 2016).

The researcher must take several ethical issues into account when considering whether to reimburse participants, and what form or value that reimbursement might take. The ethical principles of respect and beneficence require recognition of the intrinsic value of the individual, as well as recognition that participation in research is voluntary, while the potential benefits must justify any risks (National Health and Medical Research Council, 2018b). For example, the requirement of respect would not be met if a prospective participant's decision to participate in research is motivated by the promise of a payment. It is incumbent on the researcher to ensure that the requirement for voluntary participation is met and that consent is given freely, regardless of any reimbursement offered to participants. The proposed reimbursement should also be reviewed by an ethics committee before the research commences (Polacsek et al., 2016). Above all, it is imperative that the parties involved understand their underlying responsibilities (VanderWalde & Kurzban, 2011).

Consideration should also be given to what the payment may mean for participants' relationship to the research (VanderWalde & Kurzban, 2011). A number of studies have raised the concern that payments could prompt participants to give false information to be eligible for a study,⁸⁷ manufacture accounts or identities when payments are involved, or tell the interviewer what they think they want to hear (Head, 2009; Roche, King, Mohan, Gavin, & McNicholas, 2013).⁸⁸ In contrast, some researchers now view making payments as a mark of ethically sound research, claiming that it is a way of equalising the uneven power relationships between the researcher and participants (Head, 2009).

In the current study, each participant was given a gift voucher to the value of \$30 as a form of reimbursement for their time and inconvenience. The voucher was from a well-known retailer which could be easily accessed by participants, the cost of which was factored into the approved budget for the study. The intention to provide a token payment in the form of a voucher was reviewed and approved by the Human Research Ethics Committee before the study commenced.

⁸⁷ To illustrate, a research participant on a low income might feel coerced to participate if the level of reimbursement is too great to refuse (Head, 2009).

⁸⁸ These risks are reported to be greater in clinical trials, particularly if medical patients are desperate to benefit medically from access to experimental treatment (Wertheimer, 2013).

4.3 Data storage, access and disposal

Researchers must ensure that proper arrangements are made for the security and storage of confidential data. The procedures and protocols for ensuring the confidentiality of participants and the information they provide, including data management, storage, retention and disposal, are typically included in applications made to ethics committees or other review boards (Holloway & Galvin, 2016). In line with university policy, a research data and materials plan was compiled for the current study.

Participants were informed of the strategies in place to secure and maintain their data.⁸⁹ All participant data were securely stored either in locked cabinets or in password protected electronic files, with keys and passwords held by the research team only. Electronic and hard-copy participant data were de-identified through the use of a participant identifier and/or use of pseudonyms. Interview recordings, field notes and memos were coded numerically to avoid identification of participants or third parties. The Australian Code for the Responsible Conduct of Research (2018a) requires researchers and institutions to safely and securely dispose of primary materials and research data. The requirements of Victoria University's Research Data and Materials Plan align with the Code in defining a standard retention period of five years from completion of a research project or after the date of published results, whichever is later. At this time, the data, materials and records will be shredded and all electronic data destroyed.

4.4 Assumptions and expectations

In qualitative research, the researcher is a central figure who influences the collection, analysis and interpretation of data. Every researcher brings their own perspective, biases and assumptions to the research process (Corbin & Strauss, 2015). Hence, the process and findings of qualitative research are affected by social, ethnic, cultural or economic differences between researchers and participants. Without some understanding of these effects, the researcher's work may lack in thoroughness, accuracy or explanatory power (Birks & Mills, 2015).

⁸⁹ See 4.2.2 (Privacy, confidentiality and anonymity).

Reflexivity refers to the way in which researchers engage in an active, systematic process to gain insight into their work (Birks & Mills, 2015). It encompasses the continual evaluation of subjective responses, interpersonal dynamics between the researcher and participants, and the research process itself (Holloway & Galvin, 2016). In grounded theory, taking a reflexive approach to data analysis helps the researcher to avoid subconsciously applying familiar codes during initial coding, while at the same time appreciating and developing theoretical sensitivity (Glaser, 1978). The insight gained through this thoughtful, conscious self-awareness guides the researcher's actions and interpretations.

Through self-reflection, the researcher gained a clearer insight into and appreciation of her values, experiences and commitments. In this instance, three broad factors influenced her assumptions and expectations. The first influence related to her professional experience in aged care, where the experience of ageing—with or without depression—is frequently viewed negatively. The concept of an older adult's capacity for self-management was seldom highlighted. Her post-graduate studies in aged services⁹⁰ were also an influence, as she learned more about the tensions between older adults' preferences for services or support, and the practical challenges of policy, regulatory and funding mechanisms that provide them. Through her personal, hands-on work in aged care and her academic experience, she recognised the need to increase the evidence base for the self-management of long-term or chronic illnesses. The third influence was her personal experience of depression. This led her to challenge assumptions about the experience of living with depression and the difficulty of providing individual services or support within a health system of limited resources. These notions and expectations highlight the importance of engaging in reflexive practice.

For the neophyte researcher, reflexivity may be easier said than done. Although research students learn and practice skills related to data collection, analysis and reporting, they should also develop a set of dispositions that support careful and systematic qualitative research. These dispositions include a commitment to flexible, open-ended enquiry, a

⁹⁰ Master of Health Sciences (Aged Services) completed at Victoria University in 2014.

reflexive stance on their individual subjectivity and position as researcher, and ethical behaviour in the conduct of research (Holloway & Galvin, 2016).

The first level of reflexive practice requires that researchers make explicit their chosen theoretical perspective and methodology. In the current study, grounded theory was selected. In grounded theory, the awareness of one's own preconceptions through the iterative process of collecting and coding data enriches the process of analysis (Charmaz, 2014). However, the researcher remained cognisant of the importance of mitigating the risk of introducing bias into the study, as she trod the fine line between interpreting data and imposing a pre-existing frame on it. While coding, for example, she was careful not to identify familiar topics instead of participants' actions and processes, or to pursue personal rather than participants' concerns.

Although there is some debate about the ability of the researcher to have insight into themselves, reflexivity is a valuable tool to examine the influence of the researcher's position, perspective and presence (Kvale & Brinkmann, 2015). For Chambers et al. (2015), practical ways to enhance reflexivity include doing reflective exercises to examine any personal beliefs around the research area, and using research diaries to combine field and personal reflections. The use of a journal may also foster self-awareness, by recording thoughts and any biases, reactions to what is being said or done, and the influence that participant and researcher may have on each other (Corbin & Strauss, 2015).

The grounded theory methodology itself contains a set of checks and balances that can help control for the intrusion of biases, or negate assumptions (Corbin & Strauss, 2015). By making constant comparisons throughout the research, the researcher matches data for similarities, differences and consistency, while checking how the data are being conceptualised. For the current researcher, open coding was a particularly reflexive activity, whereby she constantly interrogated herself about the early analytical decisions she was making and reflected deeply on the contents and nuances of her data.

4.5 Data collection and analysis

Grounded theory has gained popularity as a method of mental health research and it has frequently been used to analyse the accounts of those individuals and groups typically perceived as marginalised (Tweed & Charmaz, 2012). In grounded theory, data collection and analysis are linked from the outset of the research, proceed in parallel and interact continuously (Corbin & Strauss, 2015). Approaching the data from different vantage points, asking questions, making comparisons, following leads and building on ideas also support sensitivity, one of the essential elements of grounded theory (Charmaz, 2014).

4.5.1 Methods of data collection

Consistent with its aim to gather data that are as rich as possible, there are many alternative sources of data in grounded theory research (Charmaz, 2014). Data for a single study may include interviews, observations, drawings, filmed material, biographies and different kinds of written documents, such as diaries (Corbin & Strauss, 2015). Data from interviews consist of direct quotations from people about their experiences, views, feelings and knowledge. Data from observations include detailed descriptions of activities, behaviours, actions and interactions, whereas data from written documents comprise people's descriptions of their experiences, thoughts and feelings.

In the current study, data were collected mainly through interviewing participants. Field observations and questionnaires were also used. These different forms of data contributed to the development of a detailed, nuanced grounded theory about the processes used by older adults with depression to self-manage their illness to optimise their well-being.

4.5.1.1 Interviews

Interviews are the most common form of data collection in qualitative research, of which one-to-one interviews consisting of questions and answers are the most common (Holloway & Galvin, 2016).⁹¹ Participant interviews are the most common source of data in grounded theory studies, as the researcher seeks to explain the world of the individual from their particular perspective (Birks & Mills, 2015). As a method of data collection in

⁹¹ Other types include focus groups and narrative interviews (Holloway & Galvin, 2016).

which one person asks questions of another person, the use of interviews offers the researcher an inside view of the phenomenon under study (DiCicco-Bloom & Crabtree, 2006; Qu & Dumay, 2011). For Glaser and Strauss (1969), the collection of qualitative data was virtually synonymous with interviews and fieldwork. Corbin and Strauss (1990, 2015) also consider interviews as essential to the grounded theory method, confirming the popularity of interviews and observations among grounded theory researchers. The use of interviews as the main source of data was considered appropriate in the current study, as the researcher sought to understand process and change in situations where a problem is new, under-researched and complicated.

Qualitative interviews may be structured, unstructured or semi-structured. In a structured, or standardised, interview, the interviewer asks a series of pre-established questions which allow only a limited number of response categories (Qu & Dumay, 2011). All participants are asked the same questions in the same sequence, with the researcher deviating as little as possible from the script. The premise is that correctly phrased questions will uncover all the information relevant to the topic (Qu & Dumay, 2011). However, it is uncommon for qualitative researchers to use structured interviews, as they resemble a written survey questionnaire, and are typically used to generate quantitative rather than qualitative data (DiCicco-Bloom & Crabtree, 2006; Whiting, 2008). It is considered inappropriate to use structured interviews in grounded theory studies, as they limit the flexibility the researcher needs to follow the data and develop theory (Corbin & Strauss, 2015). At the other end of the continuum of interview methods, unstructured interviews can be moulded to the individual situation and context (Qu & Dumay, 2011). Although the guided conversation format of unstructured interviews generates the richest data for building theory, they also have the highest drop rate (Holloway & Galvin, 2016).⁹² In addition, unstructured interviews are particularly challenging for the less experienced interviewer, as they take practice and experience to listen with an open mind and an open agenda (Corbin & Strauss, 2015). The semi-structured interview occupies the intermediary space on the interview continuum. Using semi-structured interviews, the researcher maintains some consistency over the concepts to be covered during the interview, while allowing flexibility to ask additional questions (Corbin & Strauss, 2015).

⁹² The amount of material that is of limited use to the researcher.

Frequently used by researchers in the health care field, semi-structured interviews are personal encounters in which open, direct questions are used to elicit participants' experiences and the meaning they give to them (Kvale & Brinkmann, 2015). The questions are contained in an interview guide—or *aide memoire*—but the sequencing of the questions can be adapted to the process of the interview and in response to individual statements. The semi-structured interview approach was selected in the current study, as it allowed the researcher to modify the style, pace and ordering of questions to evoke the fullest possible responses in participants' own language. All interviews were conducted on a one-to-one basis between the researcher and each participant. The open-ended nature of questions in one-on-one interviews encourages depth and vitality, and allows new concepts to arise in discussions (Misoch, 2015). Following an interview guide, questions and associated prompts moved from the general to the particular, commencing with broad, open-ended questions before focussing on more specific questions.⁹³ The researcher used prompts to delve more deeply into different aspects of the research issue. In line with the iterative nature of the qualitative interview, the flexibility afforded by semi-structured interviews allowed the researcher to revise the questions and prompts after several interviews to accommodate the emergent nature of grounded theory research.

Notwithstanding the importance of well-designed questions, the outcome of qualitative interviews depends largely on the skills and qualities of the researcher. As it takes strategy, flexibility and practice to gain the skills needed to conduct smooth interviews, neophyte researchers may refer to guidelines and seek expert advice when developing and refining their interview skills. The uninitiated researcher may, for example, find it difficult to face periods of silence, jumping in with questions or comments that break the participant's thought process (Corbin & Strauss, 2015). Although practice interviews may be useful, interacting with a person with a colleague or friend does not reflect a research interview situation (Whiting, 2008). For example, in a genuine interview, researchers must consider how to introduce themselves, give the participant an outline of the study and the interview, and obtain participant consent.

⁹³ See Appendix E (Interview schedule).

By approaching the interview as an encounter, rather than a tool, the researcher should aim to understand the described events, beliefs and feelings from each participant's point of view. Although all interviews are conducted with the purpose of knowing participants better, the purpose of that knowing varies according to the research question (DiCicco-Bloom & Crabtree, 2006). In the current study, the overall aim was to understand the self-management strategies used by older adults diagnosed with depression to optimise their well-being. The specific aims of the study were to identify their self-management strategies, understand the contextual determinants that moderate their ability to self-manage, and explain how they self-manage depression to optimise well-being. While the act of listening is arguably the most important element of interviewing, the researcher must also absorb non-verbal cues and responses, and formulate new questions based on previous answers (Kvale & Brinkmann, 2015). However, the researcher's questions or prompts should not lead participants in the interview process. In addition, the researcher must remain relatively neutral concerning what participants tell them.⁹⁴ This delicate process of meaning-making is facilitated when effective rapport can be established.

It is through rapport that a participant's willingness to share personal experiences and feelings may be enhanced (Mealer & Jones, 2014). The development of rapport is particularly important in interviews and observations, as a means of enhancing authentic communication (Mealer & Jones, 2014; Patton, 2002). Anthropologist James Spradley (1979, 1980) highlighted the importance of rapport when describing the steps to qualitative interviewing.⁹⁵ Rapport is an essential component of the interview, as it allowed the researcher to attain meaningful information, while conveying empathy and understanding, without judgement (Spradley, 1979). Spradley (1979) conceived four stages in the rapport process as apprehension, exploration, cooperation and participation. The initial stage of apprehension is characterised by uncertainty, as the researcher and participant find themselves in a strange context. It is often useful for the researcher and participant to engage in general conversation before the interview commences, to reduce apprehension (Whiting, 2008).

⁹⁴ Interpretivists focus on understanding human experience within a broader life context and eschew neutrality in favour of acknowledged subjectivity (Greene, 2012). From Corbin and Strauss' (2015) perspective, the researcher has an active role in the field. It is therefore impossible for the researcher to remain completely neutral, objective and dispassionate.

⁹⁵ These steps remain relevant today and are still commonly cited (Holloway & Galvin, 2016; Whiting, 2008).

The wording of the opening question is particularly important in encouraging the participant to begin to feel comfortable and talk (Kvale & Brinkmann, 2015). It should be broad, open-ended and non-threatening, followed by a prompt about the central concept under study. Rapport begins to be established in the exploration stage, in which the participant becomes engaged in an in-depth conversation that is accompanied by learning, listening and a sense of bonding and sharing (Spradley, 1979). It is in the cooperative stage that a comfort level is reached, based on mutual trust. At this point, the researcher may clarify certain points and the participant may correct the researcher as they make sense of the participant's world. The participation stage represents the greatest level of rapport, in which the participant guides and teaches the researcher (Whiting, 2008). However, this stage is not always reached, often due to the short length of an interview.

Recognising the importance of thorough planning before, during and after research interviews, the researcher in the current study scheduled interviews in advance at a designated time and place that best suited each participant. At the same time, the researcher gave participants an estimation of the time required for the interview. Although the length of time for an interview is an important consideration that depends on the participants, the topic and the methodology (Holloway & Galvin, 2016), there are differing views about how long an interview should last. A review of studies on similar topics and cohorts indicated that the planned interviews might last up to 90 minutes.⁹⁶ The number and content of the questions and prompts contained in the interview guide gave the researcher a broad indication of how long each interview might take. The researcher also timed a practice interview. On this basis, the duration of the interview was estimated and agreed upon with each participant prior to commencing the interview. In the current study, interviews lasted between 60 to 90 minutes.

The interview setting is also important, as the choice of site influences the dynamics, direction and content of the interview (Qu & Dumay, 2011). For example, conducting an

⁹⁶ In a study of older women's experiences of depression, the interviews conducted by Allan and Dixon (2009) lasted between 60 and 120 minutes, whereas those conducted by Van Beljouw et al. (2014) in their study of loneliness in older adults with depression lasted between 30 and 90 minutes. Other qualitative studies on older adults and/or those with a mental illness describe interviews lasting between 25 and 60 minutes (Ludvigsson et al., 2015), an average of 60 minutes (McCann, Bamberg, & McCann, 2015), or up to 90 minutes (Stanhope & Henwood, 2014).

interview in the researcher's workplace tends to shift the perceived balance of power towards the researcher, whereas participants being interviewed in their own homes are generally more relaxed and in some position of control (Holloway & Galvin, 2016). This allows the researcher to gain rich data. The researcher can also identify areas for further investigation through observation in the interview setting.

With participants' consent, all interviews were audio-recorded. Audio-recording provides an accurate record of the interview and access to verbatim quotes that can be used to defend coding decisions and to illustrate the final grounded theory (Birks & Mills, 2015). The use of audio-recorded interviews also allows the researcher to concentrate on the conversation, listen carefully and note any non-verbal cues, such as facial expressions or gestures, while capturing the exact words of the interview and any other verbal cues, such as laughter or hesitation. In this way, the use of recording devices allows researchers to give their full attention to participants (Charmaz, 2014). Discrete notes were also taken during interviews, mainly to help the researcher formulate new questions and to serve as prompts to clarify earlier statements made by participants. Notes were also taken immediately after each interview to record non-verbal communication and other observations, and to facilitate analysis by locating important issues that arose during the interview.

Despite the usefulness and popularity of participant interviews in qualitative research generally, the grounded theory researcher may wish to supplement interview data with additional data. One way of increasing the depth of the data is to conduct observations.

4.5.1.2 *Observations*

It is through observations that the researcher aims to collect data about social processes in a natural or typical setting, in which the focus is on what people do, and not on what they think and report about what they did. Participant observation as fieldwork is a way of collecting data in a relatively unstructured manner in a naturalistic setting (Dewalt, Dewalt, & Wayland, 2000). By placing them in the centre of the action, observations allow researchers to see and hear what is going on (Corbin & Strauss, 2015).

Participant observation as an approach to data collection stems from anthropology and sociology. The phrase “participant observation” was originally coined by Eduard Lindeman [1885-1953] (1924), a social scientist who described how to explore a culture from the inside. Lindeman (1924) asserted that observers do not participate in a study as such, but in the activities of those being observed. This view was later echoed by Blumer (1940), who noted that social observation requires “[a] judgment based on sensing the social relations of the situation in which the behaviour occurs and on applying some social norm present in the experience of the observer” (p. 715). However, it is Bronislaw Malinowski [1884-1942] (1922) who is usually credited with developing the approach to data collection which emphasises everyday interactions and observations, rather than direct enquiries into participant behaviour. Participant observation is closely linked to symbolic interactionism,⁹⁷ with Blumer (1969) referring to the premises of symbolic interactionism as “simple ... they can be readily tested and validated merely by observing what goes on in social life under one’s nose” (p. 50). In identifying social phenomena through observation, researchers rely on noticing familiar gestures, while also listening to the people under study. The act of making observations is, in itself, symbolic, as there are no objective observations, but only those that are socially situated in the worlds of the observer and the observed (Denzin & Lincoln, 2013).

When they first described the grounded theory methodology, Glaser and Strauss (1969) included participant observation as a source of data, and its use remains popular in grounded theory studies (Birks & Mills, 2015). It is particularly useful in situations in which there is little information about a phenomenon, as it provides access to the social context and to the ways in which people act and interact. In this instance, the use of interviews and observations provided different perspectives to the research question, thereby also supporting the rigour of the study. Corbin and Strauss (2015) list several recommendations for doing observations in grounded theory, such as letting the scene unfold, taking discreet notes that describe the setting, participants, routine activities, interactions and so on, and asking questions about specific incidents. The role and acts of the observer must also be considered. The four types of overlapping observer involvement

⁹⁷ See 3.2.3.1.1 (Symbolic interactionism).

described by Gold (1958) remain relevant and are still used widely to identify the role of the observer in the field (Holloway & Galvin, 2016; Holloway & Wheeler, 2010):

- The complete participant takes the role of an insider, is fully part of the setting and often observes covertly;
- The participant-as-observer negotiates their way into the setting, by virtue of having a reason for being part of the setting;
- The observer-as-participant has only minimal involvement in the setting; and
- The complete observer does not take part in the social setting at all, for example, by observing from behind a two-way mirror.

Spradley (1980) later described five modes of participant observation according to a continuum that reflects the researcher's level of involvement:

- Non-participation, which involves acquiring cultural knowledge without active interaction with people, such as by watching television or reading diaries;
- Passive participation, involving observation, with limited participation;
- Moderate participation, which involves greater participation than the passive role, but is still somewhat limited because the observer attempts to maintain a balance between emic and etic experiences;
- Active participation, whereby the observer seeks to do what others are doing, to gain acceptance in the setting and learn appropriate behaviour; and
- Complete participation, whereby the researcher joins the group under study.

4.5.1.3 *Questionnaires*

In the current study, questionnaires were used to screen participants, gather socio-demographic data and determine their assessment of their self-management ability. The use of questionnaires to obtain additional data facilitated the qualitative research process by corroborating—or not—the data obtained from interviews and observations. The sets of data collected through questionnaires also served as a form of data triangulation, in which the researcher used different data sources to enhance the depth, rigour and validity of the study (Holloway & Galvin, 2016).

4.5.1.3.1 The Kessler Psychological Distress Scale

The Kessler Psychological Distress Scale (K10) (Kessler et al., 2002) was used to confirm participants' eligibility to participate in the study.⁹⁸ The K10 was developed to yield a global measure of psychological distress, based on questions about anxiety and depressive symptoms (Kessler et al., 2002).⁹⁹ It constitutes a 10-item checklist that measures a person's level of distress in the past 30 days, using a five-point Likert type response scale. Participants answer questions concerning feelings of hopelessness, nervousness, restlessness, worthlessness and depression, experienced in the past four weeks, ranging from 1 (none of the time) to 5 (all of the time).¹⁰⁰ The minimum possible score is 10, while the maximum possible score is 50. Higher scores indicate higher distress. Several studies have demonstrated the K10's suitability to assess the common symptoms of depression and anxiety (Boerema et al., 2016; Chamberlain, Goldney, Delfabbro, Gill, & Dal Grande, 2009; Cornelius, Groothoff, Van der Klink, & Brouwer, 2013), including in older adults (Vasiliadis, Chudzinski, Gontijo-Guerra, & Prévile, 2015). It is publicly available and is frequently applied in community surveys and health research, due to its sensitivity and specificity, and simplicity of administration (Chamberlain et al., 2009).¹⁰¹ The K10 demonstrates high levels of reliability and validity, with good to excellent internal consistency of 0.919 (Cronbach's alpha) (Cornelius et al., 2013; Stallman, McDermott, Beckmann, Kay Wilson, & Adam, 2010).

4.5.1.3.2 Socio-demographic data

Participants were asked to provide basic socio-demographic data, including their age, gender, marital status, highest level of education and work history. They were also asked to explain their current living arrangements and the approximate year or age at which that their depression had first been diagnosed. These questions preceded administration of the Self-Management Ability Scale.¹⁰²

⁹⁸ See Appendix F (Kessler Psychological Distress Scale).

⁹⁹ Although the K10 was designed to measure symptoms of psychological distress, several studies have confirmed its high specificity for detecting depression (Conway et al., 2016; Van Zoonen et al., 2015).

¹⁰⁰ Despite being used widely as a measure of psychological distress, there is no international standard for presenting K10 scores. Thus, there is some discrepancy in the way in which scores are calculated across different studies and countries (Enticott et al., 2017). For example, similar scoring algorithms for the K10 have been used, but with different starting points of 0 and 1 (Enticott et al., 2017). In the current study, scoring started at 1, which is consistent with the approach used by most Australian surveys (Australian Bureau of Statistics, 2012b).

¹⁰¹ In Australia, national level information on psychological distress using the K10 was first collected in 1997. Since then, it has been included in the 2001, 2004-05, 2007-08 and 2011-12 National Health Survey as a predictor of depression and anxiety disorders (Australian Bureau of Statistics, 2015c).

¹⁰² See Appendix G (Participant data and Self-Management Ability Scale).

4.5.1.3.3 Self-Management Ability Scale

The Self-Management Ability Scale (SMAS-30) was used to assess the core behaviours and abilities which may contribute to sustainable well-being in later life (Cramm, Strating, De Vreede, Steverink, & Nieboer, 2012; Schuurmans et al., 2005). Developed in the Netherlands specifically for use in older adults, the SMAS-30 measures unique features involved in the self-regulation of well-being in older adults as a composite concept of abilities systematically linked to dimensions of well-being in adults aged 65 and over. Its sub-scales reveal a profile of inter-related abilities (Schuurmans et al., 2005). Used in studies of older adults with depression, it has been used to highlight the importance of identifying the repertoire of self-management abilities that influence a person's sense of well-being (Cramm, Hartgerink, et al., 2012). It has also been used to study self-management ability in chronic obstructive pulmonary disease (Dulohery, Schroeder, & Benzo, 2015) and chronic kidney disease (Washington et al., 2016). Its validity, reliability and internal consistency have been tested by means of structural equation modelling using Cronbach's alpha (α), exploratory Mokken Scale Analysis and Principal Component Analysis (Schuurmans et al., 2005). The SMAS-30 demonstrates a high internal consistency of 0.85 (Cronbach's alpha) (Schuurmans et al., 2005).

4.5.2 The study population

4.5.2.1 *Selection and recruitment of participants*

A study population consists of people to whom the researcher can gain access and who have the appropriate knowledge and experience for the research topic (Holloway & Galvin, 2016). In selecting and recruiting participants, the researcher was guided by the research question and the methodology selected for the study. Consistent with grounded theory methodology, recruitment commenced through purposive sampling. This type of sampling is criterion-based. As data collection and analysis progressed, theoretical sampling was used to collect new data to compare emerging categories. Theoretical sampling was sampling based on the emerging theory and continued until saturation was reached, that is, until no new categories or relevant themes were identified (Corbin & Strauss, 2015).

The inclusion criteria used in the current study were:

- Men and women aged 65 years and over;
- Living in their own home;¹⁰³
- Not in full-time paid employment;
- Self-reported diagnosis of depression for which treatment and/or support is currently being received from a treating clinician, such as a GP, mental health nurse, psychiatrist or psychologist;
- A score of at least 25 on the K10, which indicates moderate depression; and
- Ability to communicate in conversational English.

The exclusion criteria used in this study were:

- Currently receiving inpatient treatment for an acute episode of depression; and
- Suicide intent or attempt within the past week.

Participant recruitment took place between January and September 2016 (Figure 2). To assist recruitment, the researcher developed an information flyer explaining the study and inviting contact from interested individuals.¹⁰⁴ Recruitment occurred mainly through community organisations that provided services or support to older adults, or to people with mental health issues. Organisations identified for this purpose included community centres, neighbourhood houses, lawn bowls clubs, Probus clubs and senior citizens' groups. The researcher asked to attend regularly scheduled meetings of groups of older adults, at which information about the study was presented to those who were present. She also left information and contact details about the study at these meetings.¹⁰⁵ Requests were made to professional organisations, such as the Council on the Aged (Victoria Branch) and the Association of Independent Retirees, to circulate information on the study to their members. Moderated online forums and email networks were also used to promote the study to prospective participants. In all, the researcher contacted 128 organisations over nine months to recruit 32 participants.¹⁰⁶ On contacting the researcher,

¹⁰³ This criterion refers to people who own, rent, share or otherwise occupy a home in the community; that is, they do not live in a supported or residential facility.

¹⁰⁴ See Appendix A (Information flyer).

¹⁰⁵ People were not asked to indicate their interest in these social settings, as a way to protect their anonymity.

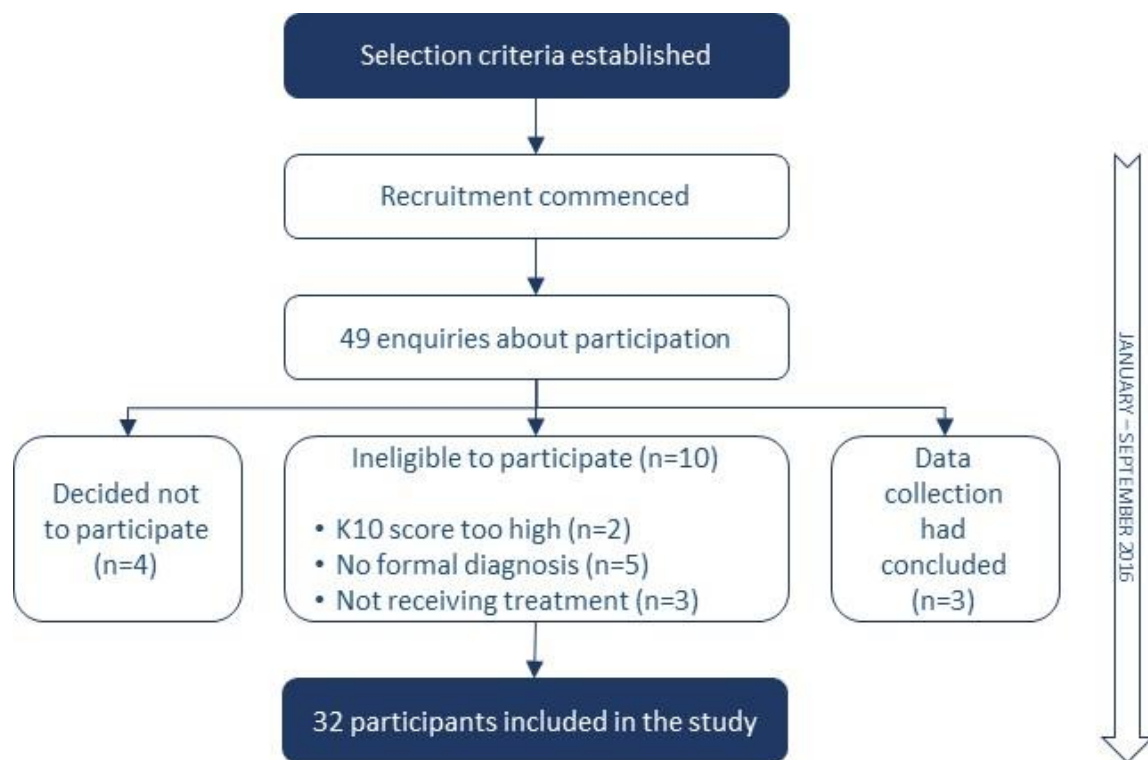
¹⁰⁶ See Appendix B (Sample of organisations asked to promote call for participants).

prospective participants were given a detailed explanation of the study, during which they were assured that their participation was voluntary and that their information would be treated as confidential. The researcher invited questions to be asked about the study and suggested that they take their time before deciding to participate. Written consent was required prior to the collection of any data.

Ten individuals were ineligible to participate in the study, because:

- Their score on the K10 was too high (n=2);¹⁰⁷
- They had received no formal diagnosis of depression (n=5); and
- They were not currently receiving treatment and/or support for depression (n=3).

Figure 2: The process of recruiting participants



The final number of participants required to achieve data saturation of the main categories is considered a strength of the study.¹⁰⁸ However, the recruitment process was challenging and several targeted calls for participants were unsuccessful. To illustrate, the researcher

¹⁰⁷ See 5.2.2 (Screening of participants).

¹⁰⁸ See 13.2.1 (Strengths).

was welcomed into several branches of Men's Sheds¹⁰⁹ and U3A groups,¹¹⁰ where members spoke openly about their knowledge of depression. However, no participants were recruited through these networks. Difficulties in recruiting participants may have been due to stigma and an associated reluctance of individuals with depression to share their experiences (Conner et al., 2015; Sjöberg et al., 2017). Other frequently cited deterrents to participation include time demands, medical problems and concerns about confidentiality (Blackstone, 2012). In the current study, the researcher sought to overcome these challenges by using a wide range of recruitment strategies, as described above.

4.5.2.2 *Entering the field*

For most researchers, qualitative data is virtually synonymous with fieldwork, interviews and background documents that put the research into context (Denzin & Lincoln, 2013). Field researchers use the strategies of questioning, observing and listening to immerse themselves in the real world of the participants (Holloway & Galvin, 2016). They also map the scene and observe patterns, arrangements and activities (Blackstone, 2012). The extent of these activities varies according to the methodology, participants and setting.¹¹¹

The grounded theory researcher most commonly collects data in the usual environment in which the phenomenon occurs—that is, in the field—through interviews and observations. The fundamental aspect of fieldwork is to position researchers as close as possible to their participants (Blackstone, 2012). Fieldwork yields very detailed data and emphasises the role and relevance of each participant's social context (Blackstone, 2012). As researchers become acquainted with the research setting, they seek to discover and explain what people do in their everyday lives and what their actions mean to them (Erickson, 2013). In this way, fieldwork enables a greater understanding of the intricacies and complexities of daily life, with a focus on the phenomenon under investigation. It also offers flexibility, as researchers can extend data collection to establish and fully

¹⁰⁹ Men's Sheds are community spaces created for older men to socialise while participating in a range of practical activities, often woodwork or other maintenance and/or repair tasks (Culph et al., 2015).

¹¹⁰ U3A is an international organisation for non-competitive life-long education and the pursuit of knowledge for its own sake (U3A Network Vic, 2016). Each learning community is organised by and for people who are active in retirement (the so-called Third Age of their lives).

¹¹¹ For example, Dewalt et al. (2000) suggest that ethnographic research requires at least one year of fieldwork to gain sufficient insight through participant observation.

explore different views, diversify their sample to analyse differences in experiences or focus on a certain point of interest (Blackstone, 2012).¹¹² The flexibility inherent in fieldwork assumes special importance in grounded theory, as data often lead the researcher in unanticipated directions (Charmaz, 2014). However, fieldwork can be challenging. It is extremely time intensive and, by demanding a great deal of involvement on the part of the researcher, it can be emotionally taxing (Blackstone, 2012). The researcher must also address logistical issues, such as negotiating entry to the field. Because of time, resource and other practical considerations, entry to the field occurs to varying degrees.

After gaining approval from the university's Human Research Ethics Committee, the researcher contacted organisations to recruit participants and negotiate access to events which potential participants may attend, such as meetings or social activities. Fieldwork consisted of interviewing participants in their own homes or in neutral settings,¹¹³ and attending events at which observations could be conducted. Upon entering the field, the simultaneous collection and analysis of data commenced. This required careful and efficient management of the data.

4.6 Data management

The management of data is one of the general concepts that permeates the entire grounded theory research process (Birks & Mills, 2015). Concurrent collection and analysis of data make it essential for grounded theory researchers to establish effective processes and tools to record, store, retrieve, analyse and manage their data. This system should be logical and secure.¹¹⁴ The amount of data to be managed in a grounded theory study depends on the number of interviews and observations undertaken by the researcher. The actual number of participants and time spent in the field are determined by theoretical saturation, that is, the point at which all major categories have been fully developed and integrated

¹¹² Grounded theorists begin with general research questions. In the event that those questions become irrelevant in the field, they can develop new, suitable ones or find another field (Charmaz, 1990).

¹¹³ Two chose to meet the researcher in a neutral setting. One requested to meet in a coffee shop, as she could speak more freely without her husband at home. The other suggested meeting in the courtyard of a shopping centre, as she lived some distance away and was attending another appointment there at the time. On both occasions, a place that suited the participants was secured for the interview.

¹¹⁴ The correct application of grounded theory methods safeguards procedural logic, which is essential for achieving a quality end-product (Birks & Mills, 2015).

(Corbin & Strauss, 2015). In the current study, fieldwork data were collected from 32 individual, audio-recorded interviews and the researcher's attendance as an observer at five events. In all, the researcher spent approximately 50 hours conducting interviews and 15 hours informally observing and interacting with older adults in group settings.

4.6.1 Data preparation

Although qualitative data is usually collected from a relatively small number of participants, the amount of data can be extensive. In the current study, data were collected from audio-recorded interviews, observations and questionnaires. Field notes, memos and diagrams were also compiled by the researcher. All interviews were audio-recorded, allocated a pseudonym and transcribed by a professional transcription service, in most cases within several days of the interview. When the transcriptions were returned, the researcher first read the printed record while listening to the interview recording. This process served to identify any errors in transcription, while allowing the researcher to immerse herself in the words of participants. Referring to field notes, the researcher read and re-read transcriptions before commencing the coding process. This combination of verbatim transcription and researcher notes is integral to the quality of a grounded theory study (Birks & Mills, 2015).

4.6.2 Data analysis

The grounded theory researcher explicates concepts from the data during simultaneous collection and analysis, and constant comparison (Corbin & Strauss, 2015).¹¹⁵ By using the fundamental process of coding, the researcher analyses, identifies and names concepts or themes, before they are reduced to build categories (Birks & Mills, 2015). Strauss (1987) stressed the importance of coding well and early, saying “the excellence of the research rests in large part on the excellence of the coding” (p. 27). Although an explanation of the coding process may give the impression of a smooth, orderly process, in practice the researcher typically moves back and forth between different phases of data collection and analysis.

¹¹⁵ See 3.3.2.3 (Constant comparative analysis).

The coding process commenced with open coding, during which the researcher reflected on the contents and nuances of the data. In qualitative research, a code is most often a word or short phrase that captures the essence of a concept (Saldaña, 2013). While reading transcripts or field notes, listening to recordings or conducting observations, the researcher identified concepts that underpinned incidents in the data. It was to these concepts that a code was applied. In this way, codes constituted a form of shorthand used by the researcher to identify conceptual reoccurrences and similarities in patterns in the data (Birks & Mills, 2015). Open coding was done by hand initially, during which the researcher highlighted text while reading and listening to participant interviews, taking notes of themes and phenomena in the margins. During this line-by-line analysis, the data were carefully examined and questioned, before being broken down—or fragmented—into discrete parts (Table 2). As the researcher became more familiar with the data, whole sentences or paragraphs were sometimes coded, although line-by-line coding was used if a new concept arose.

Table 2: Fragmentation of data and conceptual labelling

Data	Memo extract	Conceptual label
I think I can put on a face that I'm quite all right. I've got a mate that doesn't believe there's a thing wrong with me (Roger, 82 years)	<ul style="list-style-type: none"> · Most participants to date are discerning about whether to disclose their diagnosis, and to whom · There is not necessarily a strong sense of shame or stigma about depression, but rather taking control of what they share with others 	Putting on a happy face
I'm the sort of person who tries to get the best that I possibly can out of my life ... I'm very determined to do the best I can for me (Rita, 67 years)	<ul style="list-style-type: none"> · Strong sense of being an individual, going against generalisations, seeking my own meaning, doing what works for me in terms of age and depression 	Getting the best I can out of life

Various computer programs are available that can be used to organise and manage qualitative data, and the use of computer software to aid in the coding process is now considered mainstream for grounded theorists (Birks & Mills, 2015). Although qualitative data analysis software programs can enhance the organisation, management and analysis of data, they do not replace the role of the researcher in developing ideas that lead to the

development of theory (Hutchison, Johnston, & Breckon, 2010). Hence, many researchers find a combination of manual and computerised coding to be most helpful (Bazeley & Jackson, 2013). In this instance, the researcher chose to code the data manually in this initial stage, as several reports indicated that computer programs could assign hundreds of codes to full interviews, making data analysis mechanistic to the detriment of intuition and creativity, and creating the risk that the researcher may focus more on learning a new software program than exploring the data (Birks & Mills, 2015; Saldaña, 2013). Initial codes were then entered into QSR NVivo (Version 10; QSR International, Victoria, Australia). As the raw data were being broken into manageable parts, the researcher used memos to make comparisons, identify possible themes or categories, and ask generative questions. Questionnaire data were analysed initially using Microsoft Excel. These data were then also transferred into NVivo, to ensure that all concepts, categories and strategies were included in data analysis and interpretation. Broad conceptual labels were linked into more abstract categories, as their properties and dimensions were identified (Table 3). Gerunds were used in the coding process.¹¹⁶

Table 3: Conceptualising the strategy of *Harnessing formal support*

Conceptual label	Example of elements represented
Securing services	<ul style="list-style-type: none"> · Identifying services · Needs and preferences · Types of services or support · Positive experiences · Negative experiences
Establishing a therapeutic alliance	<ul style="list-style-type: none"> · Preferred health professional · Establishing a relationship of trust · Working as a team

During axial coding, the fragmented data were synthesised and brought back into a coherent whole. With the category serving as an axis, links were made between categories and sub-categories. During selective coding, the third part of the coding process, major categories were developed. Relationships between categories were identified, refined and linked together. Through this advanced coding process, a dominant core category was identified that unified all categories. Theoretical memos and diagrams were particularly

¹¹⁶ See 3.3.2.4.1 (Open coding).

useful at this stage of analysis. As the different threads of the research were drawn together to construct an explanatory framework, the data ultimately became a theory.

4.7 Rigour in qualitative research

Regardless of the purpose and process of a study, methodological thoroughness and the adherence to certain standards are central to high quality qualitative research (Patton, 2002). Thus, researchers should not only consider the value of their work, but also establish its trustworthiness. However, there is little consensus on what constitutes an appropriate set of evaluation criteria for qualitative research (Morse, 2015; Onwuegbuzie & Leech, 2007), while various disciplines refer to different standards for conducting research and for the acceptability of its evidence (Charmaz, 2014; El Hussein, Jakubec, & Osuji, 2015).

In the 1980s, Guba (1981) and Guba and Lincoln (1989) expounded the criteria of dependability, credibility and transferability to determine the trustworthiness of qualitative research. These criteria and associated strategies for achieving trustworthiness replaced the dominant terminology used for achieving rigour at the time; namely, reliability, validity and generalisability (Morse, 2015). Sandelowski (1986) built on Guba and Lincoln's (1981; 1989) concepts of truth value, applicability, consistency and neutrality, while Burns (1989) proposed using the standards of descriptive vividness, methodological congruence, analytic preciseness, theoretical correctedness and heuristic relevance to critique qualitative research. In the early 1990s, Beck (1993) developed a framework and checklist to assist the transition of the entrenched quantitative terms of internal validity, external validity and reliability to those of credibility, fittingness and auditability, respectively. Cooney (2011) expanded Beck's (1993) criteria of credibility, fittingness and auditability to enhance and demonstrate rigour in a grounded theory, and it is these expanded criteria which were applied to the current study from the outset. This decision was based on two main factors: contemporary literature still draws on Beck's (1993) three standards, and several grounded theory studies in the field of nursing explain the practical application of Beck's criteria (Chiovitti & Piran, 2003).¹¹⁷

¹¹⁷ See, for example, grounded theory studies by Abdu, Stenner and Vydellingum (2015), Khankeh, Hosseini, Rezaie, Shakeri and Schwebel (2015), and Kneafsey, Clifford and Greenfield (2013).

4.7.1.1 *Credibility*

In qualitative research, credibility measures how vividly and faithfully a phenomenon is described and how well categories represent the data (Holloway & Galvin, 2016). This criterion refers to the truth—trustworthiness—of the data and the way in which the researcher represents participant views. The researcher should be able to defend inferences based on valid and reliable data (Holm & Severinsson, 2014b), and the theory should be recognisable to participants (Corbin & Strauss, 2015). In this way, a person who has had that experience would immediately recognise it as their own, while researchers or practitioners should be able to recognise the experience when they encounter it, having only read about it (Cooney, 2011). Referring to Beck's (1993) evaluation criteria for qualitative studies, Chiovitti and Piran (2003) present several strategies to enhance the credibility of a grounded theory study, which are considered below.

4.7.1.1.1 Let participants guide the research process

To demonstrate that participants have guided the research, there should be evidence that concepts introduced by them are used to modify and develop questions (Cooney, 2011). In the current study, the interview guide was modified in response to incoming information from participants. To illustrate, the original interview guide contained a question about social support and living arrangements, with a prompt to ask about loneliness. Loneliness is cited frequently as a challenge for older adults living in the community and is associated with depression (Aylaz et al., 2012; Hawkey & Kocherginsky, 2017; Ong, Uchino, & Wethington, 2016). After collecting and analysing data from the first interviews, it became apparent that neither the concept nor the experience of loneliness resonated with participants.¹¹⁸ Rather, they reported that they enjoyed being alone and actively sought time alone. Consequently, the researcher probed whether being alone was a way of self-managing their depression. By adapting the question to the emerging data, the researcher could better understand the ways in which solitude and loneliness were experienced.

¹¹⁸ See 10.3.2.1 (Seeking solitude).

The interview guide also contained a question that invited participants to suggest additional questions the researcher should ask.¹¹⁹ In this way, concurrent data collection and analysis enhanced the credibility of the study. However, they were not asked to review preliminary findings, as grounded theory does not aim to describe participants' experiences, but to produce an abstract representation that explains a common process experienced by all participants (Cooney, 2011).

4.7.1.1.2 Check the theory against participants' meanings of the phenomenon

In a grounded theory study, theoretical construction must be checked against participants' meanings of the phenomenon. Another criterion, therefore, is cross-checking the data (Cooney, 2011). Codes and relationships between codes were checked and verified through direct questioning as the theory was abstracted from the data. At the end of each section of the interview, and at the end of the interview, the researcher confirmed the developing understanding of their experiences. This verification activity increased the credibility of the study (Lincoln, Lynham, & Guba, 2011). Similarly, conducting observations across different settings gave the researcher multiple opportunities to observe or question views and experiences of depression in older adults. Credibility of the findings of a grounded theory study is also enhanced by the collection of interview and observational data, as the researcher presents descriptions that are vivid and recognisable to those familiar with the field (Kneafsey et al., 2013). By corroborating one source of data by another, the trustworthiness of the findings can be strengthened. In this way, validation of the emerging theory occurred during stages of the research process.

4.7.1.1.3 Use participants' actual words in the theory

In the first stage of the coding process, the researcher identifies and assigns conceptual labels to the data. These labels¹²⁰ can either be words informed by participants' language—so-called *in vivo* codes—or notions drawn from sociological terminology (Kelle, 2007). *In vivo* codes have imagery, as they closely reflect the language of participants and the substantive field, thereby giving meaning to the data (Strauss, 1987). Although

¹¹⁹ Most participants found the interview comprehensive. However, several suggested that it may be useful to ask questions about the experiences of their main support person, or whether they had considered self-harm or suicide. These suggestions were considered within the scope of the current study and were taken into account in subsequent interviews.

¹²⁰ See 3.3.2.4.1 (Open coding).

sociological constructs constituted by data from the field and the researcher's knowledge and expertise allow a more scholarly conceptualisation of the analysis than *in vivo* codes, a greater level of imagery can typically be elicited from *in vivo* codes (Strauss, 1987).

By using *in vivo* codes, the researcher used participants' actual words to encapsulate a broader concept. This aided the development of theory and added to the credibility of findings by providing an accurate representation of participants' meanings. Each word or expression was supported with excerpts from interview data, to mitigate against the researcher inadvertently distorting or misinterpreting an intended meaning. During the coding process, the researcher examined hidden assumptions in both her own and participants' language. By preserving their words as accurately as possible and using verbatim quotes in the written report, the researcher demonstrated how findings were derived from the data. In addition, examining how participants used language offered the researcher greater insight into their situations. To illustrate, time-related words typically denote a change in perception or activity, which are important when identifying process (Corbin & Strauss, 2015). Similarly, their use of metaphors or similes may convey emotions associated with events or activities.

4.7.1.1.4 Articulate the researcher's views and insights

To enhance credibility when reporting a qualitative study, researchers should describe their experiences of collecting, analysing and engaging with the data (Cope, 2014). Corbin and Strauss (2015) recommend the use of a reflective journal to control the intrusion of the researcher's perspectives, biases and conjecture. In the current study, the researcher used a journal to record personal reactions to what was being said or done, such as excitement or surprise. In this way, she could identify early in the study how any preconceptions or personal constructions might affect the research process. By making the research process visible, the use of a journal also demonstrated the researcher's reflexivity.¹²¹ Regular meetings between the researcher and her supervisors throughout the research process also contributed to the credibility of the study. In addition, material relevant to the study was presented for critique and discussion with peers and colleagues.

¹²¹ See 4.4 (Assumptions and expectations).

These opportunities to test emerging hypotheses and explore reflexivity also strengthened the credibility of the data.

4.7.1.2 *Fittingness*

Fittingness, also termed transferability, deals with the extent to which the research findings can be applied to other settings.¹²² The concept of fittingness originally related to the extent to which the results of a quantitative study could be generalisable to other populations. In qualitative research, it refers to the ability of the researchers to demonstrate that findings may have meaning to others in similar situations (Beck, 1993; El Hussein et al., 2015). In the current study, fittingness is demonstrated through the comprehensive description of the subject, participants, data collection and data analysis. This allows readers to judge the similarity of the study setting to other settings or contexts, and to consider whether the findings are meaningful and applicable in terms of their own experience (Cooney, 2011). However, the extent of fittingness depends on the degree of similarity between different settings or contexts (El Hussein et al., 2015).

In addition to describing its scope and context, the researcher should identify the level of theory generated by the study (Chiovitti & Piran, 2003).¹²³ A theory must be grounded in the data and integrated around a core category, but is distinguishable by its level of generality (Glaser & Strauss, 1969). For example, a substantive theory is topic-specific and seeks to explain a specific social process within a clearly defined context, whereas a formal theory spans several substantive areas, and is developed to a higher level of conceptual abstraction (Birks & Mills, 2015). If the level of theory generated by research is not explained, the reader is insufficiently informed about the scope of the theory, which, in turn, impedes an assessment of its fittingness (Chiovitti & Piran, 2003). The current theory is considered substantive as it focuses on understanding a certain phenomenon in a clearly defined situation. Chiovitti and Piran (2003) also suggest describing the literature that pertains to each category that comprises the theory. By highlighting

¹²² This is considered the most contentious criterion related to validity. It has its origin in random statistical sampling procedures used in quantitative research, and generalisation is not the purpose of qualitative research (Corbin & Strauss, 2015; Holloway & Wheeler, 2010). However, Beck (1993) asserts that fittingness measures how well a working hypothesis fits into a context other than the one from which it was generated.

¹²³ See 3.3.1 (Defining a grounded theory).

similarities between new findings and those in extant literature, the researcher has demonstrated the potential transferability of the phenomenon to other situations.

4.7.1.3 *Auditability*

For a study to be auditable, another researcher should be able to follow the decision or audit trail which encompasses all the decisions made by the researcher at every stage of data analysis (Beck, 1993). Auditability is sometimes referred to as confirmability or trustworthiness, as it “holds up to scrutiny the methodological and theoretical decisions made throughout the research process” (Bowen, 2009, p. 305).

Audit trails are a principal technique for verifying the research process (Bowen, 2009). According to Lincoln and Guba (1985), an audit trail serves to establish or increase trustworthiness in a naturalistic study. Audit trails comprise a collection of materials and notes used in the research process that detail the researcher’s decisions and assumptions (Cope, 2014). In the current study, the researcher presented a record of data sources, sampling decisions, analytical procedures and their implementation. This required the researcher to maintain explicit records and to document decision trails. The trail should be sufficiently detailed to make it possible for other researchers to replicate the same study in the same setting and draw the same conclusions (Beck, 1993; Cooney, 2011). Beck (1993) recommends checking that the researcher has established the typicality of participants and their responses, and that theoretical sampling produced in a range of participants who experienced the phenomenon under study. Accordingly, the researcher specified how and why participants in the study were selected, including how they were identified and recruited, how sampling decisions were made and how data saturation was reached. Auditability can also be enhanced by delineating the standard questions the researcher consistently asks of the data during analysis (Chiovitti & Piran, 2003).

4.7.2 **Quality in grounded theory**

In grounded theory, quality is built into the method (Corbin & Strauss, 2015). For Corbin and Strauss (2015), the conditions that foster quality in a grounded theory study include methodological consistency, sensitivity to participants and the data, reflexivity and clarity of purpose. These different perspectives reflect three broad conceptualisations of rigour:

methodological rigour—that is, best practice in the conduct of research—interpretive rigour—trustworthiness of the interpretations—and a combined focus, whereby the reliability of data is based on consistency and care in the application of the methodology (Cooney, 2011). Corbin and Strauss (2015) recommend asking four sets of questions of the data (Table 4).

Table 4: Questions to guide data collection and analysis

Type of question	Purpose	Example
Guiding questions	<ul style="list-style-type: none"> · Used to guide interviews and observations, and analysis 	<ul style="list-style-type: none"> · Can you tell me about your experience of being an older adult? · Can you tell me what it's like, in general, to live with depression?
Practical questions	<ul style="list-style-type: none"> · Provide direction for theoretical sampling · Help with developing the structure of the theory 	<ul style="list-style-type: none"> · How well developed are the concepts? · Where, when and how do I go next to gather data for the evolving theory? · Is my developing theory logical? · Have I reached data saturation?
Theoretical questions	<ul style="list-style-type: none"> · Help the researcher to identify process and variation, and to make connections between concepts 	<ul style="list-style-type: none"> · What is the relationship of a concept with another? · What would happen if ...? · What are the larger structural issues here?
Sensitising questions	<ul style="list-style-type: none"> · Attune the researcher in to possible meaning of data 	<ul style="list-style-type: none"> · What is going on here? · How do participants define the situation, and what does it mean to them? · How similar or different are the actions of various participants and in different situations?

In the current study, these questions allowed the researcher to audit her approach during the research process and leave an audit trail for other researchers.¹²⁴ In addition, the write-up of a grounded theory study should provide information on the criteria for assessing its data, research process and empirical grounding (Corbin & Strauss, 2015). By interweaving these details in the method and findings, the reader may consider the process and product of the study when determining its quality and credibility.

¹²⁴ See Appendix H (Audit trail for the study).

4.8 Summary

It is incumbent on the researcher to ensure that a study is conducted within a sound ethical framework. The guiding principles and practices of this framework balance risk and benefit associated with the research, whereby the involvement of human participants is justified by the merit of what is being studied and the integrity of how it is being studied, in this instance a grounded theory study of how older adults with depression self-manage their illness to optimise their well-being. The central role of the researcher in the collection, analysis and interpretation of data was made explicit, with reference to the importance of researcher reflexivity in qualitative research. A description of how participants were selected and recruited was followed by an explanation of the method of concurrent data collection and analysis. Finally, consideration was given to rigour in qualitative research and the ways in which trustworthiness can be enhanced in a grounded theory study.

Part B: Results of the study

CHAPTER 5

Overview of the study

5.1 Introduction

In this chapter, an overview of the study is presented. The chapter commences with a summary of participant characteristics and a review of the proposed substantive theory,¹²⁵ comprising a synopsis of the core problem, core category, categories and strategies, and contextual determinants. The chapter concludes with an outline of the findings chapters.

5.2 Participant characteristics

5.2.1 Setting for the study

The study took place in the state of Victoria, Australia. In line with the inclusion criteria for this study, participants were older adults who were still living at home.

5.2.2 Screening of participants

The use of the K10¹²⁶ questionnaire to screen prospective participants was explained in the participant information and consent form and discussed with individuals. At this time, participants were reminded that participation was voluntary and that all information collected during the study was confidential. The researcher screened each prospective participant, asking questions over the telephone. Telephone screening, including use of the K10, is increasingly used in clinical and research settings (Kelly et al., 2010; O'Connor, Beebe, Lineberry, Jobes, & Conrad, 2012; Stallman et al., 2010). A score of at least 25 indicates moderate distress (Kessler et al., 2002). Participants' mean score on the K10 was 26.6, with a range of 22 to 31.

Those who scored higher than 30 were checked against the exclusion criteria for the study—that is, if they were currently receiving inpatient treatment for an acute episode of depression or had experienced suicide intent/attempt within the past week. Consistent with other studies that have used the K10 to screen or evaluate participants (such as

¹²⁵ See 3.3.1 (Defining a grounded theory).

¹²⁶ See 4.5.1.3.1 (The Kessler Psychological Distress Scale).

Stallman et al., 2010), a protocol was established to manage these instances. Those who seemed very distressed, or at high risk for suicide, would be referred to their GP, an appropriate telephone support service or a local hospital psychiatrist for management. Based on their K10 scores, two individuals were considered ineligible to participate in the study. The first, who scored 36, recognised his need to re-engage with his current psychologist for support. The second, who scored 50 on the K10, also acknowledged his symptoms and committed to making an appointment to see his GP without delay. Both had previous experience of receiving support for their depression and assured the researcher that formal support would be accessed. The researcher immediately reported these discussions to her supervisors, who confirmed that the instances had been managed appropriately. No further contact was made by the individuals or the researcher.

5.2.3 Socio-demographic characteristics

Thirteen males and 19 females participated in the study.¹²⁷ The mean age of participants was 71.3 years, ranging from 65 to 82 years. The mean age at which they received their first formal diagnosis of depression was 50.6 years, ranging from 16 to 81 years. Twelve lived with their partners (wife or husband), 18 were divorced or widowed, and two had never married. Twenty lived alone. Sixteen participants had a tertiary (university) education,¹²⁸ 13 had completed secondary school, two had received vocational education (trade) and one had completed primary school. Only one identified as coming from a culturally and linguistically diverse background.

5.2.4 Self-assessment on SMAS-30

The SMAS-30¹²⁹ was used to measure core behaviours and cognitive abilities which may regulate well-being in older adults (Cramm, Strating, et al., 2012; Schuurmans et al., 2005). The questionnaire comprises six sub-scales of five questions each, totalling 30 questions that measure the older adult's inter-related self-management abilities related

¹²⁷ The high number of males who participated in the current study is noteworthy, as depression is under-diagnosed in men (Culph et al., 2015). This may be due to stereotypical views of masculinity and an associated reluctance to seek a diagnosis and support for depression.

¹²⁸ Eleven of the tertiary-educated participants were degree-qualified, one had a PhD and four had Masters degree qualifications.

¹²⁹ See 4.5.1.3.3 (Self-Management Ability Scale).

explicitly to the dimensions of well-being specified in Social Production Functions theory, on a Likert scale.¹³⁰ According to Schuurmans et al., (2005), the six abilities are:

- Taking initiatives: the ability to be instrumental or self-motivating to realise the dimensions of well-being (six-point scale, ranging from “Never” to “Always”);
- Self-efficacy: the ability to gain and maintain a belief in personal competence with regard to achieving well-being (six-point scale, ranging from “I can not” [*sic*] to “I always can”);
- Investment behaviour: the ability to invest in resources for longer term benefits (six-point scale, ranging from “Never” to “Always”);
- Positive frame of mind: the ability to keep a positive perspective regarding the future, rather than focusing on loss (five-point scale, ranging from “No!” to “Yes!”);
- Multi-functionality: the ability to gain and maintain resources or activities which serve multiple dimensions of well-being (six-point scale, ranging from “Never” to “Very often”); and
- Variety: the ability to maintain variety in various resources for each dimension of well-being (six-point scale, ranging from “None” to “More than six”).

The SMAS-30 has a maximum score of 175. A higher score is associated with better perceived health, higher life satisfaction, less frailty, greater self-efficacy and higher overall well-being (Schuurmans et al., 2005). A lower score indicates the opposite. Participants were asked to answer the questions before being interviewed, either by completing the questionnaires themselves or with the assistance of the researcher. The lowest participant score was 87 (50%) and the highest was 156 (89%). The mean score was 123.1 and the standard deviation 18.55. Although the SMAS-30 is well suited to measuring changes in self-managing ability over time, or to test the effectiveness of self-management interventions (Schuurmans et al., 2005), it was used in the current study to enhance depth and perspective. In this way, it contributed to the rigour of the study, as the general flexibility of the semi-structured interview allowed the researcher to probe items of interest that arose from participants’ responses to the 30-item questionnaire.

¹³⁰ According to the theory of social production functions (SPF), successful ageing is a life-span process of realising and sustaining well-being. Successful self-management of ageing is based on this theory (Schuurmans et al., 2005; Steverink & Lindenberg, 2006).

Hence, theoretical sensitivity¹³¹ was enhanced by the researcher reviewing completed questionnaires before interviews commenced. By identifying high or low-scoring items, the researcher used sensitising questions to understand and give meaning to the questionnaire data.¹³² To illustrate, Vera selected the highest score for Question 10 on the SMAS-30 (*Are you able to have friendly contact with others?*), indicating that she “always can” have “friendly contact with others”. However, during the interview, she stated that:

It doesn't bother me that I sit here alone, but I'm always pleased when anybody pops in. I'd much rather they came to me than I went to them. I don't like the feeling of imposing myself, I guess because I just don't have enough confidence to think that anybody would really want to see me. (Vera, 69 years)

This apparent contradiction presented the researcher with the opportunity to ask further probing questions to explore Vera's experience of social contact. She explained that she engaged in daily casual conversations with other dog owners, while she walked her dog in nearby parks. However, few of these interactions developed into friendships. Another occasion on which the SMAS-30 was used to improve sensitivity concerned Bea. She scored herself as “almost never” on Question 23 (*I participate in my hobbies with others*), but in the interview, described several regular activities she enjoyed sharing with friends, including participating in—and, in one case, coordinating—three different music groups in her local community. More focused discussion allowed Bea to clarify her understanding of the term *hobbies*, as she identified her social activities as being part of her local community, rather than hobbies. Thus, Bea's overall low score on the SMAS-30 may be attributable to her low motivation at the time of interview (“The willingness is there, but it doesn't translate into action”), rather than her actual capacity for practical self-management.

I used to always look after myself fairly well, but that's all sort of stopped, which is a pity, because I really should be looking after myself a bit better ... but I can't be bothered. (Bea, 67 years)

These examples illustrate the different dimensions of well-being, as interpreted and prioritised by participants. Their overall scores are also of interest here, as a higher score

¹³¹ See 3.3.2.1 (Theoretical sensitivity).

¹³² One of the benefits of grounded theory is that it gives researchers the flexibility to explore concepts as they arise.

is positively related to general self-efficacy, which is associated with self-determination and self-management.¹³³

5.2.5 Observations in the field

Having gained permission from relevant gatekeepers and participants, observations¹³⁴ for the current study occurred in open settings, including community centres, neighbourhood houses or social activity groups that provide services or support to older adults. In line with the grounded theory method, these settings were identified during the research process, as the selection of sites for conducting observations should be concept-driven (Corbin & Strauss, 2015). Moving around freely, while observing the settings in detail and depth, the researcher found it appropriate to adopt Gold's (1958) role as observer-as-participant, during which Spradley's (1980) mode of moderate participation was most frequently used. This level of participation involved only occasional interaction with participants, as the researcher essentially "commuted" to the field to observe the everyday activities of study participants (Dewalt et al., 2000, p. 262). In so doing, the researcher was guided by Spradley's (1980, p. 78) nine dimensions of social situations, namely:

- Space: the physical place or places;
- Actor: the people involved;
- Activity: a set of related acts people do;
- Object: the physical things that are present;
- Act: single actions that people do;
- Event: a set of related activities that people carry out;
- Time: the sequencing that takes place over time;
- Goal: the things people are trying to accomplish; and
- Feeling: the emotions felt and expressed.

Accordingly, each type of participation occurred within a continuum of involvement, which varied throughout the study, depending on the participants, specific situation, opportunities available and permission given to the researcher. At the outset, broad descriptive observations captured as much as possible of the setting. Observation then

¹³³ See 2.4 (The concept of self-management).

¹³⁴ See 4.5.1.2 (Observations).

focused on important areas or aspects of the setting, which contributed to answering the research question, while selective observation centred on specific issues (Spradley, 1980).¹³⁵ To illustrate, a range of attitudes towards depression was demonstrated in small group discussions, whereas different types of social support were apparent in various settings. Attending a social activity arranged by a regional U3A group, the researcher found members keen to talk about her study, with some sharing their personal experiences of depression (Obs. 5). One man spoke openly about his depression diagnosis and described the social support he received from other group members. Although members of this group offered to promote the call for participants, none were recruited through them. The openness with which depression was discussed in this group contrasted with the behaviour of members of another U3A group. At a previous meeting of U3A members, a member told the researcher, “Nobody here has the time to be depressed”, to which another member winked at the researcher and whispered, “We all know that’s not true” (Obs. 1). On another occasion, the researcher noted a prominent display of posters promoting the importance of depression diagnosis and treatment (Obs. 3).

5.3 Overview of the theory

The proposed substantive theory is conceptualised as *Self-empowering to maintain and enhance personal identity as an older adult with depression*. The theory is comprised of a basic social psychological problem—the core problem—a core category, three categories and related strategies, all of which are moderated by contextual determinants. These elements are summarised in Figure 3¹³⁶ and Table 5. A synopsis of each follows.

5.3.1 Core problem

The core problem is an abstract concept that allows sufficient flexibility for the researcher to follow the data and explore the topic in depth. This becomes apparent to the researcher as data are collected and analysed (Corbin & Strauss, 2015). In the current study, the core problem was conceptualised as *Struggling to maintain personal identity as an older adult with depression*. Although the problem was experienced in individual ways, a lack of a

¹³⁵ The progressive focusing of observations is also referred to as grand-tour observations (rich descriptions of a social situation) and mini-tour observations (detailed descriptions of smaller units of experience) (Spradley, 1980).

¹³⁶ A detailed diagram is presented in Chapter 11.

sense of personal identity, or individuality, was shared by participants, as they sought a diagnosis and ongoing support for depression.

Several internal (individual) and external factors contributed to the experience of the core problem. Participants' individual characteristics, for example, were evident in how they recognised and responded to a diagnosis of depression. This process reflected their personal history and individual capacity. External factors included individual and community perceptions of age, and the attitudes of health professionals towards older adults, specifically those who presented with symptoms of depression. The availability and quality of support also influenced how the core problem was experienced.

Figure 3: Summary diagram of the core category and theory

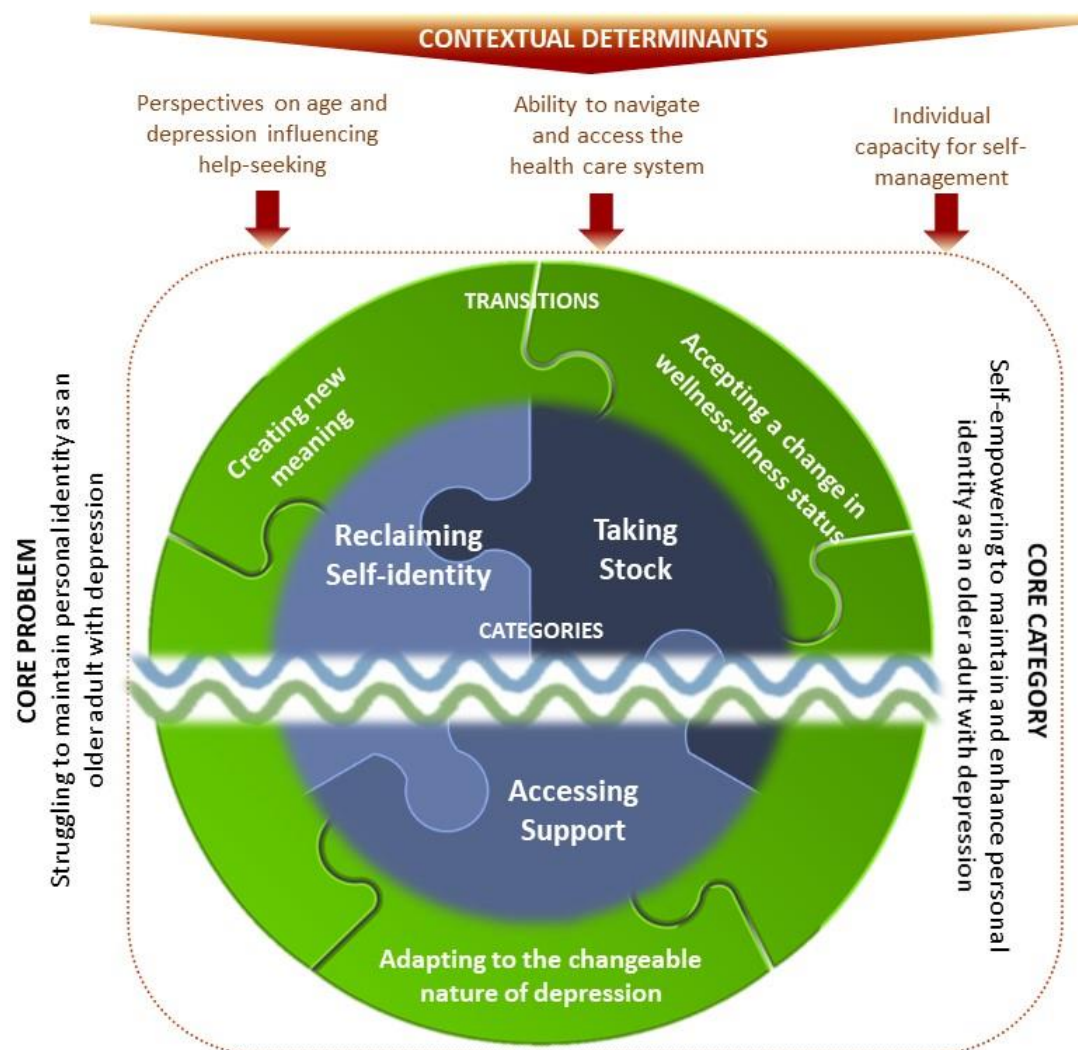


Table 5: Overview of the theory

Core problem	<i>Struggling to maintain personal identity as an older adult with depression</i>		
Core category	<i>Self-empowering to maintain and enhance personal identity as an older adult with depression</i>		
Transitional themes	Accepting a change in wellness-illness status	Adapting to the changeable nature of depression	Creating new meaning
Categories	Taking Stock	Accessing Support	Reclaiming Self-identity
Strategies and sub-strategies	<i>Evaluating well-being</i>	<i>Overcoming barriers</i>	<i>Empowering myself</i>
	· Challenging assumptions about age and depression	· Resolving personal barriers	· Fostering self-determination
	· Seeking answers	· Addressing external barriers	· Embracing self-management
	<i>Coming to terms with the diagnosis</i>	<i>Becoming informed and engaged</i>	<i>Striving for a meaningful existence</i>
	· Accepting the diagnosis	· Improving mental health literacy	· Seeking solitude
	· Taking personal responsibility	· Making informed decisions	· Setting my own pace
		<i>Harnessing formal support</i>	· Planning for the future
		· Securing services	
		· Establishing a therapeutic alliance	
		<i>Optimising informal support</i>	
		· Maximising positive relationships	
		· Helping others	
Contextual determinants	Perspectives on age and depression influencing help-seeking	Ability to navigate and access the health care system	Individual capacity for self-management

5.3.2 Core category

As the central phenomenon, the core category represents the main theme of the research. To tie all the other categories together, the core category must offer significant explanatory power. In Glaser's (1978) words, the core category must have "grab" and "carry through" (pp. 94-95). The core category, *Self-empowering to maintain and enhance personal identity as an older adult with depression*, recurs frequently in the data and represents the central process by which participants responded to the problem of *Struggling to maintain personal identity*. The processual nature of how they responded to this central concern was characterised by three interrelated phases, or transitions:

Accepting a change in wellness-illness status, Adapting to the changeable nature of depression and Creating new meaning. The core category in the current study is a basic social psychological process, as it connects the sequences of individual behaviours and interactions, as they relate to the core problem. It comprises interlinked conceptual elements, relating to empowerment, personal identity and self-management. Evident in the ways in which participants embraced self-determination and self-management, empowerment is closely associated with a sense of personal identity. By integrating their sense of self into strategies for managing depression, they reported increased confidence in improving their well-being.

5.3.3 Categories and strategies

Three categories are embedded in the core category: *Taking Stock, Accessing Support and Reclaiming Self-identity.* Together, these categories incorporate the strategies and sub-strategies used by older adults to address the core problem. A different, but related and complementary, process is represented by each category. In many ways, each category facilitates or augments the other two categories, as each one informs and enhances the effectiveness of the others.

5.3.3.1 *Taking Stock*

The first category, *Taking Stock*, reflects participants' judgements about their well-being and quality of life, and their efforts to adapt to a diagnosis of depression. The abstraction of *Taking Stock* reflects the ways in which current circumstances were evaluated and expectations moderated in response to changes in wellness-illness status following the diagnosis of depression. Although *Taking Stock* is a subjective experience, it occurs within a broader biopsychosocial framework comprised of biological, psychological and social influences. Participants employed the strategies of *Evaluating well-being* and *Coming to terms with the diagnosis* as initial steps to making sense of their current circumstances. *Evaluating well-being* involved making judgements about their well-being and quality of life by *Challenging assumptions about age and depression* and *Seeking answers*, while *Coming to terms with the diagnosis* involved *Accepting the diagnosis* and *Taking personal responsibility*. These strategies represent the starting point

from which participants sought to harness support to manage their unique experience of depression.

5.3.3.2 *Accessing Support*

The second category, *Accessing Support*, captures participants' efforts to improve their mental health literacy, access formal support and optimise informal support. However, they had to overcome personal and external barriers before they could harness support. Through the strategy of *Becoming informed and engaged*, they sought to improve their capacity to take an active role in discussions and decision-making about their treatment options. This facilitated their efforts towards *Harnessing formal support* and *Optimising informal support*. These strategies represent the ways in which they identified services and maximised the benefits of those services that met their needs and preferences. *Accessing Support* also relates to informal support provided by significant others, while helping others was a way of connecting with the broader community.

5.3.3.3 *Reclaiming Self-identity*

The third category, *Reclaiming Self-identity*, represents the related aspects of participants' views and behaviours, and reflects their efforts and actions in the previous categories of *Taking Stock* and *Accessing Support*. The two main strategies within this category were *Empowering myself* and *Striving for a meaningful existence*. Drawing on individuals' autonomy and expertise, the concept of empowerment reflected their efforts to master their current circumstances in ways that improve well-being. Within this category, the concepts of self-determination and self-management were explored. The strategy of *Striving for a meaningful existence* reflects participants' need for solitude, the importance of a daily routine and a way to prioritise tasks, and anticipation of future needs.

5.3.4 **Contextual determinants**

In a grounded theory study, each participant's actions-interactions towards a specific phenomenon can be located and explained by examining the context in which they take place. Participants typically express contextual determinants as explanations or reasons for what they feel, think, say and do in response to a problem (Corbin & Strauss, 2015).

In this way, contextual determinants influence—positively or negatively—their experience of the phenomenon under study. To illustrate, personal and environmental contexts influence the meanings individuals assign to experiences, and the ways in which they respond to them. Three over-arching contextual determinants shaped their efforts to establish a sense of self by managing their experience of depression: *Perspectives on age and depression influencing help-seeking*, *Ability to navigate and access the health care system* and *Individual capacity for self-management*. In addition, each category was influenced by its own contextual determinants that influenced the way they experienced transitions between wellness-illness states.

5.4 Outline of the findings chapters

The data are presented in a sequence that should facilitate a comprehensive understanding of the study. In Chapter 6, the contextual determinants that influence the self-management of depression in older adults are presented. In Chapter 7, the basic social psychological problem—that is, the core problem—of *Struggling to maintain personal identity as an older adult with depression* is put forward, before each of the study's three categories is examined in detail. In Chapter 8, the first category, *Taking Stock*, and the two strategies of *Evaluating well-being* and *Coming to terms with the diagnosis*, are discussed. In Chapter 9, the second category, *Accessing Support*, is presented, together with the four strategies of *Overcoming barriers*, *Becoming informed and engaged*, *Accessing formal support* and *Optimising informal support*. The third category, *Reclaiming Self-identity*, and its two strategies of *Empowering myself* and *Striving for a meaningful existence*, are discussed in Chapter 10. In Chapter 11, an explication of the core category, *Self-empowering to maintain and enhance personal identity as an older adult with depression*, is complemented by an exploration of the three transitional themes of *Accepting a change in wellness-illness status*, *Adapting to the changeable nature of depression* and *Creating new meaning*. In Chapter 12, a discussion on the study findings is presented. Finally, in Chapter 13, the study's strengths and limitations are presented, followed by a discussion on the implications of the study for policy, practice and future research, as well as concluding statements.

CHAPTER 6

Contextual determinants

6.1 Introduction

The purpose of this chapter is to explore the context in which study participants' experiences took place and to discuss the main contextual determinants that influenced the process of *Self-empowering to maintain and enhance personal identity as an older adult with depression*. Through this background, the reader's understanding of the study's more focused conceptual findings may be enhanced. The chapter commences with an explanation of the meaning of context and contextual determinants in a grounded theory study. Contextual determinants that relate to the current study are then explicated.

6.2 The study's context and contextual determinants

Corbin and Strauss (2015) define context as the conditions that locate and explain an event or a set of circumstances, the meanings given to them, and the action-interaction taken by individuals to respond to them.¹³⁷ These sets of conditions—known as contextual determinants—contributed to the core problem and influenced the core category. Individually or in concert, they enhanced or constrained the way in which the problem was experienced and influenced participants' actions and interactions in response to the core problem of *Struggling to maintain personal identity*.

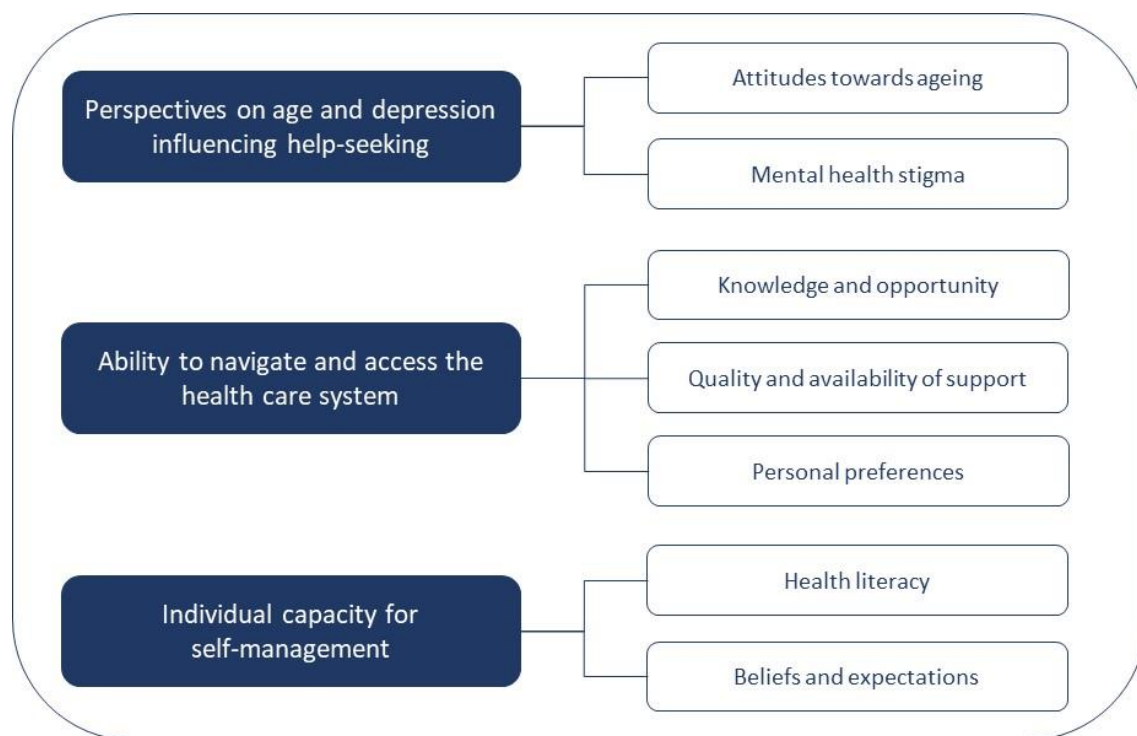
It is through the process of axial coding¹³⁸ that grounded theory researchers code for context by locating and linking action-interaction between and within categories and sub-categories. In this way, researchers abstract contextual determinants that explain or rationalise how participants felt about and respond to a problematic situation. Thus, a full understanding of context allowed for the abstraction of a theory from the data. Conversely, ignoring the influence of context leaves the researcher with only a description of individual experiences, and no theory (Corbin & Strauss, 2015).

¹³⁷ See 3.2.3.1.1 (Symbolic interactionism) for a discussion on the importance of context in interpretivist research, specifically in relation to symbolic interactionism.

¹³⁸ Also known as theoretical or Level II coding. See 3.3.2.4.2 (Axial coding).

Contextual determinants are the factors which moderate individuals' capacity for self-managing depression. They reflect the social, physical and economic environment, and individual characteristics (Corbin & Strauss, 2015). However, most situations reflect a complex interplay between them, and they may occur simultaneously, concurrently or consecutively. In the current study, contextual determinants reflected individual *Perspectives on age and depression influencing help-seeking*, *Ability to navigate and access the health care system*, and *Individual capacity for self-management* (Figure 4).

Figure 4: Contextual determinants of the study



Perspectives on age and depression influencing help-seeking reflect the prevailing views about older age and mental health, and the ways in which these views influence individuals' help-seeking efforts. This contextual determinant influenced decision-making processes when seeking a formal diagnosis and support for depression. *Ability to navigate and access the health care system* concerned the individual's ability to identify and access the different services and providers across public, private and non-government sectors. This ability was affected by prevailing Commonwealth and state government health policies, the quality and availability of support that met individuals' needs and

preferences, and issues concerning access.¹³⁹ The third contextual determinant, *Individual capacity for self-management*, reflected individual views on self-determination and self-management, and their practical capacity for self-management in terms of health literacy and physical resources.

6.2.1 Perspectives on age and depression influencing help-seeking

Individual perspectives on age and depression exert a strong influence on the help-seeking process. The term “help-seeking” refers to the process by which individuals seek and obtain help from others (Kovandžić et al., 2011).¹⁴⁰ Andersen (1995) distinguished three main influences on help-seeking, grouped into predisposing, enabling and need factors. Predisposing factors include individual characteristics (such as age, gender and personality). Enabling factors reflect the individual’s knowledge of and access to services, whereas need factors relate to individual perspectives on the need for care (Andersen, 1995). Broadhurst (2003) also proposed three essential elements of help-seeking: first, a problem must be defined; second, the individual must decide to seek help; and third, the individual must actively seek help. In the current study, these components of help-seeking were considered from perspectives of age and depression.

Positive perspectives on older age and the process of ageing are associated with improved well-being (Carpentieri et al., 2017; Prior & Sargent-Cox, 2014). Those who approach ageing with a sense of optimism are more likely to engage actively in health promotion activities and help-seeking behaviour to optimise well-being (Carpentieri et al., 2017; North & Fiske, 2015; Wurm & Benyamini, 2014). Conversely, negative perspectives and low expectations have a detrimental effect on the experience of ageing (Coudin & Alexopoulos, 2010; Ouchida & Lachs, 2015). In addition, older adults who hold negative views of ageing are less likely to seek help for physical and/or mental health problems (Ouchida & Lachs, 2015). When they do seek help, the diagnosis and treatment of depression are frequently delayed, as health professionals are often slow to recognise and treat depression in older adults (Kessler et al., 2010; Ludvigsson et al., 2015; Mitchell et al., 2011). It is common for the symptoms of depression to be attributed to ageing, or for

¹³⁹ Access to support is discussed in detail in Chapter 9.

¹⁴⁰ See 0 (Help-seeking for depression).

mental health issues in older adults to remain undistinguished from normal ageing (Luck-Sikorski et al., 2017; White & Casey, 2017). Thus, the erroneous view that depression is a normal part of ageing influences individuals and health professionals (Haralambous et al., 2009; Ludvigsson et al., 2015).

Notwithstanding age-related influences on help-seeking, arguably the strongest influence relates to views of depression, particularly stigma. Mental health stigma is one of the most common barriers to help-seeking, including in older adults (Conner et al., 2015; McKinnon, Conner, Roker, Ward, & Brown, 2017). The concept of stigma brings together negative stereotypes, prejudices and discrimination.¹⁴¹ It is a common barrier encountered by people with a range of mental health conditions (Corrigan, 2004; Corrigan et al., 2015; Manos, Rusch, Kanter, & Clifford, 2009), including depression (Conner et al., 2015; Griffiths et al., 2008; McKinnon et al., 2017). As a social construct, stigma varies by diagnosis, across cultures and over periods of time (Corrigan et al., 2015; McCann, Renzaho, Mugavin, & Lubman, 2017; Schomerus & Angermeyer, 2017).¹⁴² Stigmatising beliefs may be external (public) or internal (self-stigma).

Public mental health stigma refers to negative beliefs, attitudes and conceptions in the general public, which frequently result in stereotyping, prejudice and discrimination against those with mental illness (Conner et al., 2015; Corrigan et al., 2015). It is one of the biggest challenges encountered by individuals and health professionals in the field of mental health (Martinez & Hinshaw, 2016). The media has a particularly deleterious effect on public attitudes towards older age (Edgar & Edgar, 2015) and mental health issues (Zhang, Jin, Stewart, & Porter, 2016).¹⁴³ Edgar and Edgar (2015) call for more positive reporting on older adults, as they rail against the “ageist war” conducted by the media. Regarding the media portrayal of mental health, Zhang et al. (2016) measured how major news outlets in the United States reported on people with depression. Finding that media coverage focused on deficiencies in the individual, while drawing attention from

¹⁴¹ Stereotypes are beliefs about mental illness (for example, that the person is weak or dangerous). Prejudice is manifested in agreement with stereotypes, which produces a negative emotional reaction, such as fear. Discrimination refers to the behaviour that arises from the emotional reaction (such as avoiding the person) (Corrigan et al., 2015).

¹⁴² For example, people with schizophrenia or other psychotic disorders attract greater stigma than those with mood disorders, such as depression (McCann et al., 2017), while older generations are generally less likely to openly discuss mental health issues (Griffiths et al., 2008; Park, Jang, & Chiriboga, 2018).

¹⁴³ See 13.3.3 (Implications for the portrayal of age and depression).

society-level and public health implications, more balanced reporting that promoted understanding through accurate information dissemination was recommended (Zhang et al., 2016).

Most participants had experienced public stigma at some point, often from people within their social circle. This made them cautious about sharing their experience of receiving a diagnosis and living with depression. The way they saw themselves once a diagnosis was received was also influenced by broad social attitudes—macro conditions, in the form of public stigma—and personal views—micro conditions, in the form of self-stigma.

There is stigma, there is ignorance about it. Ignorance comes first, then there's stigma, I think. (Marina, 65 years)

Stigma also influences health professionals, researchers and policy makers (Wolpert, 2001). Focusing on experiences in the health care setting, participants cited examples of what they perceived as service providers' ignorance of mental health issues, failure to diagnose their depression in a timely manner, or misattribution of their symptoms to physical conditions. The inclusion criteria for the current study required participants to be receiving formal treatment. This meant that those who had feared or experienced stigma had already overcome the complex elements of this barrier. In general, they did so by enlisting—often through trial and error—the support of a GP who was sensitive to their needs.¹⁴⁴

My own doctor, he and I are on the same level. We bounce off each other. He's been my doctor for 23 years and he and I have got a good rapport. I have complete and utter faith in him. (Jenny, 77 years)

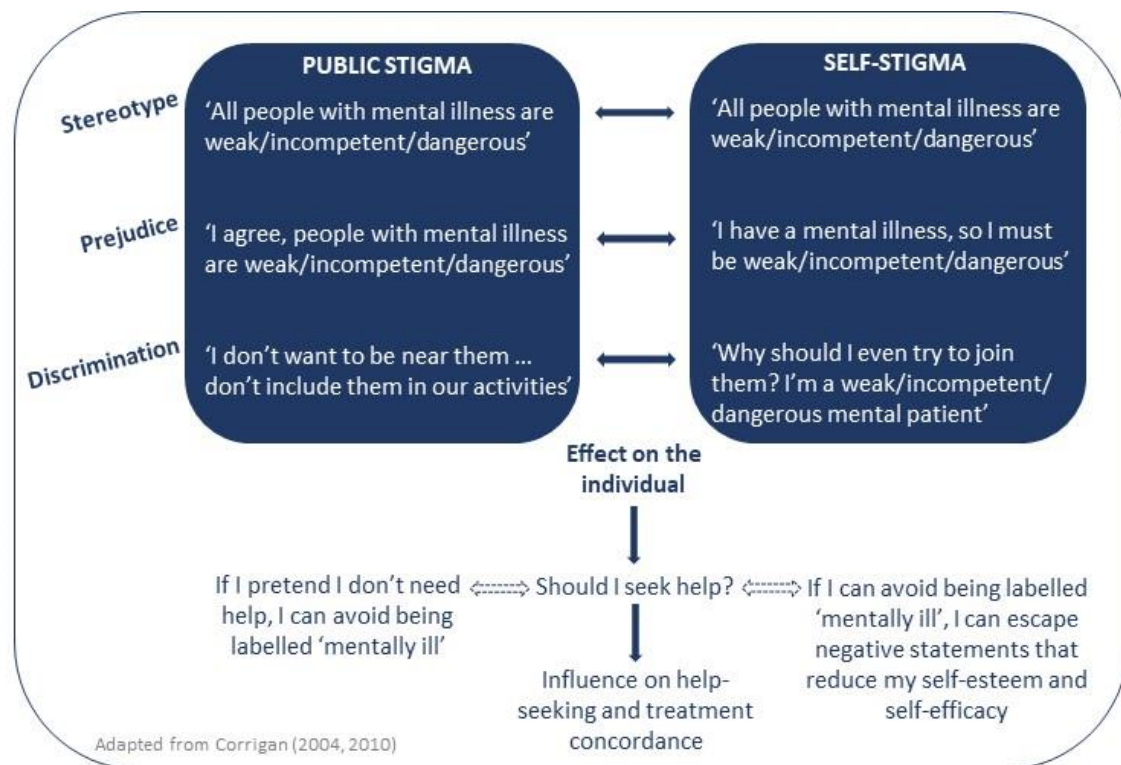
Figure 5 offers a graphical representation of the interaction of public and self-stigma in relation to help-seeking and treatment concordance for people with a mental health issue. The factors outlined in the diagram may be illustrated by several findings from a study of self-management of long-term depression (Chambers et al., 2015). Chambers et al. (2015) reported that several of their participants wished they could refer themselves directly to mental health specialists, rather than having to obtain a referral from their GP.¹⁴⁵ Some

¹⁴⁴ See 9.3.3.2 (Establishing a therapeutic alliance).

¹⁴⁵ In Australia, a GP referral is needed to access specialist services, such as psychiatrists.

chose not to access treatment for depression through a GP, as they did not want it documented in their medical records (Chambers et al., 2015).

Figure 5: The influence of public and self-stigma on help-seeking



Even when people overcome stigma and access support, they may be reluctant to engage fully in treatment regimens. Their attempts to distance themselves from the label of mental illness associated with receiving mental health care frequently result in poorer treatment outcomes (Corrigan, 2004; Quinn, Williams, & Weisz, 2015). On a more positive note, recent research indicates the success of innovative strategies to reduce stigma of depression (McKinnon et al., 2017; Shann, Martin, Chester, & Ruddock, 2018). McKinnon et al. (2017) found that peer educators were effective in reducing public and self-stigma and increasing help-seeking in a sample of older adults with depression. In a randomised controlled trial of the effectiveness of an online intervention to reduce depression-related stigma in organisational leaders, Shann et al. (2018) reported improvements in attitude and knowledge in the intervention group. For participants in the current study, community views about depression also appeared to be changing for the better, as information on mental illness became more available and accessible.

I think people have become less judgemental ... Well, I feel that people are a lot more open about talking about it [depression]. There's more acknowledgement that it's okay to say this is what's happening. (Rita, 67 years)

6.2.2 Ability to navigate and access the health care system

Understanding and accessing the health care system are essential components of self-management. Thus, the second contextual determinant that influenced the experience of self-managing depression in older age concerned individuals' ability to navigate and access the health care system. This ability depends on an adequate understanding of symptoms, and being able to access appropriate and timely information and formal support (Straiton & Myhre, 2017).¹⁴⁶ Broadly, formal support refers to services provided by private or public health professionals or services. The individual's capacity in this regard is strongly associated with health literacy and access to formal support (Ørtenblad, Meillier, & Jönsson, 2017). Conversely, the inability to access and navigate the health care system constitutes a barrier to support (Straiton & Myhre, 2017).

The way in which the health care system is understood and accessed occurs within a broader framework of government policies on health and aged care, and the accessibility of services. The policies established by Commonwealth and state governments direct the funding and delivery of specialised and general health services. *A national framework for recovery-oriented mental health services: Guide for practitioners and providers* articulates the goal for individuals to be able to create and live meaningful and contributing lives in a community of choice (Department of Health, 2015). The framework identifies self-determination and self-management as integral elements of this goal. Similarly, the Commonwealth government's Aged Care Roadmap¹⁴⁷ outlines strategies for realising a sustainable, consumer-led aged care market, in which older Australians have choice and control of the care and support they receive, as well as when, where and how they receive it (Department of Health, 2016).¹⁴⁸

¹⁴⁶ See 9.3.3 (Harnessing formal support).

¹⁴⁷ In April 2015, the Australian Government tasked the Aged Care Sector Committee with developing a roadmap of future reform directions for aged care. The roadmap is informed by important policy documents, including the Aged Care Sector Statement of Principles and the National Aged Care Alliance's (2015) blueprint, *Enhancing the quality of life of older people through better support and care*.

¹⁴⁸ Although this policy statement does not focus on the mental health of older Australians, it is intended to generate discussion regarding future reforms to aged care.

Well, it will depend on the government of the day. I think the way the government are thinking—this could be wrong—their idea is to keep you in the home, and give you the support that you need, as long as you can. (Sarah, 71 years)

Other relevant policy components concern issues such as income support, subsidies for services and medications, community support and housing assistance. Increasing emphasis is being placed on illness prevention and helping people stay independent for longer, while encouraging greater choice for consumers. The increasing focus of policy makers on self-management¹⁴⁹ of chronic, long-term illnesses also influences service delivery. As a result, the quality and availability of formal support for older adults living with depression is linked directly to government policy.

Participants' efforts to access formal support for their depression were also constrained by a range of instrumental barriers. Examples include lack of appropriate services, financial costs, problems with transport and waiting lists (Levesque et al., 2013). Other factors include the quality of the relationship between participants and their health professional (Arnold et al., 2013).¹⁵⁰

At the local medical clinic, I can't establish a bloody GP because none of them have got any consideration whatsoever for mental health. They think it's all a load of gobbledegook [nonsense]. (Greg, 67 years)

I think that [my GP], for all his faults, is a very good general GP. He's just working within the system that he's in. If he can't give me what I need and want, I will search somewhere else. (Evan, 66 years)

This was particularly challenging in the public health system and regional communities.

I've doctor shopped [tried different doctors] a lot ... there's nobody I would trust here [regional town] ... you get regional rubbish, basically. (Marina, 65 years)

I've been waiting for a psychiatrist in [regional town] for over 12 months. (Stephanie, 71 years)

¹⁴⁹ See 2.4 (The concept of self-management).

¹⁵⁰ See 9.3.3.2 (Establishing a therapeutic alliance).

6.2.3 Individual capacity for self-management

The third contextual determinant related to individual participants' capacity to self-manage their depression. Notwithstanding the need to address perspectives on age and depression, and to access appropriate support—the other two contextual determinants—individuals require individual capacity for self-management. This capacity comprises ability, choice and expectations, as participants identify, engage and assess which strategies facilitate their efforts to optimise well-being. It also relates to resources such as finances, environment and social support (Yeung et al., 2010).

The self-stuff is that I'm identifying what the issues might be and then using strategies to manage them. When I go to a psychologist, I am there to learn some strategies to deal with my depression. (Bea, 67 years)

In the current context, personal beliefs related to depression and age, and to the concept of self-management. To illustrate, those who viewed ageing in a positive light were more likely to seek ways to manage their depression that enabled them to optimise their well-being and overall quality of life. Similarly, those who overcame stigma about depression were more likely to maintain their treatment regimen.

I know my default position is one of sadness and slight depression, and accepting that has been one of the greatest difficulties. I think that not accepting that was at the root of the battle. (Evan, 66 years)

A strong sense of personal autonomy was also associated with improved well-being.

I guess, to a point it's up to you. If you want to go out there and conquer the world, well, you will. (Sarah, 71 years)

You determine what you're going to do with yourself and how others deal with you. (Amy, 67 years)

It became apparent early in the process of concurrent data collection and analysis¹⁵¹ that participants had a strong interest in and commitment to self-determination and self-management, although they did not necessarily use those exact terms. Known facilitators of self-management were exhibited, including a proactive attitude towards age and

¹⁵¹ See 3.3.2.3 (Constant comparative analysis).

depression, the establishment of short- and long-term strategies, remaining socially engaged and maintaining physical health (Van Grieken et al., 2013).

You know there's something not right and that's when you either decide you're going to do something about it or you're not ... it means looking after the condition I've got, which is depression. (Paul, 69 years)

Conversely, the absence of these attributes, coupled with as a sense of futility or hopelessness about ageing with depression, would constitute significant barriers to self-management. Those with the capacity to optimise well-being drew on the resources available to them to facilitate effective self-management. Identification of and engagement with these resources depended largely on each person's health literacy.

Health literacy comprises individuals' ability to access, understand and use information in a way that enables them to promote and maintain their health. More specifically, mental health literacy refers to knowledge and beliefs about mental health issues, including risk factors, sources of information and support, and treatment options (Farrer et al., 2008; Jorm, 2000).¹⁵²

I've looked at websites like beyondblue [a national depression website] and I think they're tremendous for anyone who's feeling depressed. It's a great resource to help find your way through some of the rubbish. (Pete, 75 years)

Mental health literacy is associated with early help-seeking, and better recognition and understanding of mental health issues (Farrer et al., 2008). Those with higher levels of mental health literacy are more likely to promote and maintain good mental health (Farrer et al., 2008; Park et al., 2018). For example, concordance with treatment approaches is commonly associated with higher levels of health literacy. Participants reported generally high levels of confidence in their mental health literacy, as they were actively engaged with their treatment for depression. Examples were given of the ways in which information had been sought and accessed, and how that information had served as a prompt to engage with formal services.

I'd probably do all of those things [talk to GP and friends]. But I do use online things. As long as they are good databases, I use them a lot. (Erica, 70 years)

¹⁵² See 2.3.3.2 (Help-seeking facilitators).

The blogs I take with a bit of pinch of salt, but sometimes they're interesting. I rely a lot on the medical facilities [websites]. I have asked [my GP] about things that I've seen online and said, "Is that appropriate for me?" And a discussion has evolved. (Amy, 67 years)

Mental health literacy is essential to effective self-management of depression, as individuals must take responsibility for their day-to-day care (Houle et al., 2013; Lorig et al., 2014). By educating themselves about the symptoms, course, treatment options and lifestyle choices associated with their depression, participants developed their mental health literacy in ways that enabled them to optimise well-being.

6.3 Summary

In this chapter, the context of the study was presented. Three distinctive contextual determinants influenced and moderated—directly and/or indirectly—how the core problem of *Struggling to maintain personal identity* was experienced by participants: *Perspectives on age and depression influencing help-seeking*, *Ability to navigate and access the health care system* and *Individual capacity for self-management*. These contextual determinants constituted the background against which their experiences took place and provided insight into the setting in which the basic social psychological process occurred.

CHAPTER 7

Core problem

7.1 Introduction

The basic social psychological problem abstracted from the data¹⁵³ relates to participants' sense that they were not treated as individuals as they sought to receive and come to terms with a diagnosis of depression. Consequently, they struggled to maintain a sense of personal identity in their efforts to manage their depression in a way that enabled them to optimise their well-being. In this chapter, a definition of the core problem is followed by an analysis of contributing factors.

7.2 Struggling to maintain personal identity

The core problem typically takes the form of an exploratory statement that allows sufficient flexibility for the researcher to follow the data and explore the topic in depth. Although assumptions are made that guide the development of the core problem, the grounded theory researcher should remain open to contradictions to those notions, as issues are explored and further questions posed, based on incoming data (Corbin & Strauss, 2015).

In the current study, the basic social psychological problem that was elicited from the data was articulated as *Struggling to maintain personal identity as an older adult with depression*. While all were receiving treatment and/or support for their depression,¹⁵⁴ they did not perceive they were treated in a way that acknowledged their individuality. For example, they were confronted by assumptions and stereotypes associated with their age and the experience of depression in older age.

The specialists treat you that little bit differently. They treat you like an old lady. I might be an old lady, but I don't want to be treated like that. (Jenny, 77 years)

The components of the core problem were carefully selected to convey participants' experiences. The term *struggle* indicate that effort was needed to overcome a challenge,

¹⁵³ Glaser and Strauss (1969) originally stated that the research problem should *emerge* from the data. Corbin and Strauss (1990) later described the process by which the researcher *discovers* the core problem.

¹⁵⁴ See 4.5.2.1 (Selection and recruitment of participants).

while a sense of personal identity relates to the qualities or characteristics that distinguish one individual from another.

That sort of sense of identity thing ... I mean, some people just seem to sort of go through life without being particularly fussed about their identity or maybe they just don't think about it. It's something that I'm very conscious of. (Bea, 67 years)

The implication of the core problem was that it impinged on their ability to construct a sense of self by managing their experience of depression, which, in turn, undermined their capacity to optimise well-being. Referring to the experience of receiving a depression diagnosis as crossing “an important identity threshold” (p. 60), Karp (2017) describes the interpretive process by which individuals make sense of and seek meaning from their illness. These interpretations are influenced by widely varying contexts, cultural systems and prevailing systems of rules and shared expectations (Karp, 2017).

Several internal and external factors contributed to the experience of the core problem. External factors included perceptions of age and the attitudes of health professionals towards older adults, specifically those who presented with symptoms of depression.

Some doctors patronise you because you're old, some doctors patronise you because you're female. You just laugh and say, 'Yes, dear', 'No, dear' and keep going. (Lorna, 68 years)

The availability and quality of services and support also influenced how the core problem was experienced. The first internal contributing factor related to participants' individual characteristics, particularly their autonomy and ability to influence the process by which they could optimise their well-being and overall quality of life. Individuals are active beings with the capacity for self-direction and self-actualisation, and their level of personal autonomy is strongly associated with a sense of meaning, purpose and improved mental health (Nosraty et al., 2015; Piltch, 2016). Participants' individual characteristics were evident in how they recognised and responded to a diagnosis of depression.

Multiple factors play a role in the experience of depression, including genetics, adversity in early childhood, stressful life events and poor social support (Yeung et al., 2010). Gender, low education, poverty, chronic physical illness and disability are also strong risk

factors for depression (Ylli et al., 2016). A survey on beliefs about depression conducted by Read *et al.* (2015) found that depression was most commonly attributed to a chemical imbalance, family and/or work stress, genetics, relationship problems and negative childhood experiences. Most Australians associate depression with a combination of psychosocial and biological factors (Pilkington, Reavley, & Jorm, 2013). However, if these multifactorial and idiosyncratic beliefs about mental health are largely negative or debilitating, they will impinge on the individual's capacity to self-manage depression and inclination to comply with treatment (Buus, 2014; Read et al., 2015). Several studies (Corrigan et al., 2015; Read et al., 2015; Schomerus, Matschinger, & Angermeyer, 2014) have found that negative beliefs about mental health increase fear and decrease expectation of recovery. Hence, how they made sense of the aetiology of depression frequently influenced the overall experience of depression.

I don't like to feel I'm failing, that's really the main thing ... [having depression] is a failure, because I can't put it right. I'm a person who can put things right and yet I can't sort myself out and so I get angry and frustrated. (Fiona, 68 years)

Participants' personal histories also influenced their expectation and experience of a sense of self as an older adult. In older age, a sense of self is frequently influenced by perceived or actual ageism, manifested in negative attitudes towards and stereotypes of ageing in the community, and poor attitudes and behaviour of health professionals towards older adults (Malta & Doyle, 2016).¹⁵⁵ The extent to which these attitudes about age are internalised constitutes a further contributing factor to the basic social psychological problem. To illustrate, negative stereotypes of ageing may reduce older adults' motivation to seek help, as they expect that a decline in their well-being is a normal part of the ageing process. This, in turn, reduces their recognition of the need and motivation to seek help (Coudin & Alexopoulos, 2010; Law et al., 2010). Associated with their personal histories, capacity refers to participants' resourcefulness in managing their experience of depression. This contributing factor encompassed the ability to overcome barriers, improve mental health literacy, access formal support and optimise informal support. Individual capacity was also reflected in their interest in and commitment to self-determination and self-management.

¹⁵⁵ See 2.2.2.2 (The experience of ageism)

Alongside personal history and capacity, external—or structural—constraints appeared as barriers to the experience of *Struggling to maintain personal identity*. Thoits (1995) cites factors such as age, gender, race and social class as structural constraints. Societal-level discrimination associated with mental health stigma may also delay access to diagnosis or support (Corrigan, 2004).¹⁵⁶ Community perceptions of age, and the attitude of health professionals towards older adults, particularly those with depression, contributed to the core problem. In the current study, the common belief that depression is a normal part of ageing frequently impinged on participants' efforts to obtain a diagnosis and receive guidance to self-manage their depression. Several reported difficulty in obtaining a diagnosis of depression, while others shared experiences of poor treatment and/or support by health professionals. One of the main complaints in this regard was that they did not feel that they were treated as individuals, but that assumptions were made about their symptoms, capacity for change and self-management, and overall quality of life.

You sort of get used to having to hunt around for GPs and health professionals who take you seriously. (Lorna, 68 years)

Health professionals who held a narrow frame of reference regarding ageing and/or mental health had a direct effect on the experience of older adults with depression. Other external constraints included lack of availability of services, long waiting lists, or the inability to pay for preferred services. Each of these factors abstracted from the data is highlighted in the categories and/or contextual determinants.

7.3 Summary

The basic social psychological problem encountered by participants was conceptualised as *Struggling to maintain personal identity*. The experience of the problem was influenced by internal and external factors. By improving insight into the nature of the core problem, the potential exists for individuals, health professionals and the broader community to extend their understanding of and response to older adults with depression.

¹⁵⁶ See 2.3.3.1 (Help-seeking barriers).

CHAPTER 8

Taking Stock

I think with depression, so many things seem to be, at times, beyond your control. So, take stock and take stock of what's important to you and try to control that. (Janet, 67 years)

8.1 Introduction

In this chapter, the first category, *Taking Stock*, is presented. The chapter commences with an examination of the broader context in which *Taking Stock* occurs. This is followed by an explication of the strategies and sub-strategies employed to evaluate and then adapt to their individual circumstances.

Taking Stock is an *in vivo* code that relates to participants' efforts to identify, evaluate and adapt to their current circumstances, particularly a change in wellness-illness status. *Taking Stock* typically occurs by making an inventory of different elements of life, reviewing positive and negative experiences, major achievements and challenges. It involves thinking carefully and forming an opinion about a situation, and typically occurs before a decision to take action is made (Piltch, 2016). In this way, the process of *Taking Stock* reflects their views and expectations of age, the experience of ageing with depression and the goal to optimise well-being. By thinking carefully about their situation, they formed opinions and then decided what action to take. Using the knowledge or views garnered through *Taking Stock*, participants could approach their predicament in a more planned, strategic way.

8.2 The context of *Taking Stock*

The way older adults with depression approach *Taking Stock* was influenced by their personal values, as well as prevailing community attitudes. Those who had a positive attitude towards ageing were more likely to report better mental and physical well-being than those who expected ageing to be associated with an overall decline. However, the subjective evaluation of one's own circumstances is influenced by deeply embedded

community attitudes and value systems about ageing and mental health. The effect of the prevailing culture in the perception of ageing and/or depression is closely linked to personal assessments of well-being, which, in turn, mediate how quality of life is defined and evaluated (Chachamovich et al., 2008). Levy (2003; 2018) postulates that internalised negative stereotypes of ageing give rise to individuals' own expectations of ageing, also commonly negative. Similarly, there is a strong relationship between the belief in depression as an inevitable consequence of age and negative self-perceptions of age (Law et al., 2010). Myths and negative stereotypes of age suggest that ageism remains a major challenge for older adults seeking to make sense of and optimise their experience of ageing (Law et al., 2010).¹⁵⁷ Deleterious effects of ageism permeate the mindset of older adults, the attitudes of health professionals and the structure of the health care system (Ouchida & Lachs, 2015). Internalisation of stereotypes about ageing and depression have a strong influence on how older adults assess, evaluate and respond to their personal experiences and expectations.

The strategies participants used to take stock of their current circumstances were moderated by two main contextual determinants: *Evolving beliefs and expectations*, and *External influences*.

8.2.1 Evolving beliefs and expectations

At a fundamental level, participants' beliefs and expectations influenced their lived experience of aging and depression, and informed their help-seeking behaviour. In *Taking Stock* of their experience of ageing, participants questioned the seemingly arbitrary definition of "old". Although most developed countries, including Australia, accept the age of 65 years as the delineation of being old, this label did not resonate with participants. Participants accepted that health policies were often based on formal definitions of different age categories, but rejected the notion that they should feel or behave a certain way because of their chronological age.

I actually feel hardly any different internally than I did in my 30s. I mean, I look different, I know that when I look in the mirror, but I don't feel any different. (Mia, 66 years)

¹⁵⁷ See 2.2.2.2 (The experience of ageism).

I can't believe that I'm almost 80, I really can't. I have great difficulty thinking in terms of being almost 80. (Nick, 79 years)

Several reported how their perceptions of age had changed throughout the life course. They referred to how they had perceived older age when they were younger and made comparisons between generations.

When I was younger, I would have thought 67 was old, but I don't feel old. I think as you get older age becomes irrelevant. I think older people nowadays aren't as old as they used to be when my grandmother was old. They have the chance to do a lot more things than they did 50 years ago. (Amy, 67 years)

Questioning broad assumptions or generalisations about what it meant to be old, participants approached ageing in their own way, drawing on their own expectations, values and goals. The meaning that they gave to ageing well¹⁵⁸ influenced the process of *Taking Stock*.

I think of myself as 37. I'm almost 74 and I just think of myself as being young and I'm going to live to 100. (Tony, 73 years)

I don't know about age anymore ... it's a state of mind, I think, more than anything. It's only a number. I feel how I live my life is right for me. (Sandra, 67 years)

However, some participants expressed negative views about the experience of ageing. These comments were mainly focused on physical changes associated with ageing and frequently reflected negative stereotypes of ageing, with participants reporting negative expectations of ageing, not necessarily personal experiences.

Age is a bit of a worry, because you start to feel aches and pains that you didn't have before, and your skin starts to go saggy and wrinkly ... and your brain cells start dying, and so you forget things. (Sue, 68 years)

For some participants, negative expectations about ageing led to a sense of resignation and frustration. The negative images of older adults and/or people with depression frequently portrayed in the media were mentioned by some.

¹⁵⁸ See 2.2.2 (The concept of ageing well).

Very, very rarely we'll pick up a copy of a seniors' newspaper sort of thing ... you read the first couple of pages and you throw it away. (Nick, 79 years)

Sue suggested the potential of the media to facilitate a broader conversation about age and/or mental health, while Sean hoped for the opportunity to share the experiences he had gained over his lifetime.

A lot of creative people you see on the news ... even actors, you know ... happy people have had a life of depression, and reading their autobiographies and how they coped and didn't cope, and learning from other people's mistakes. (Sue, 68 years)

The ageing process should be used especially to look back at the people coming through, whether they're your children or your children's children ... to say to young people, "I don't know much, but what little I have, please may I share it with you?" (Sean, 74 years)

As the focus of the interviews moved from the broad topic of ageing to a more defined discussion on ageing with depression, participants considered the extent to which their evolving beliefs and expectations about depression influenced how they took stock of their lives. In *Taking Stock* of their current circumstances, several reported a sense of shame, or failure.

My shame ... I just feel so ashamed that I have it. Honestly, [the shame] is a daily thing, and I try to pretend I don't have it [depression]. (Fiona, 68 years)

For some, negative self-perceptions were exacerbated by an expectation by others—that they should be able to “snap out of” their depression. Most participants could recall occasions on which someone had made insensitive comments that made them feel worse about themselves.

My mother said, "I don't know why she just doesn't pull herself together, and just get on with it". It's very easy for people who don't suffer it to say, you know, "Just get on with it". They don't understand sometimes how debilitating it can be ... it can be just awful. (Vera, 69 years)

Evolving beliefs and expectations of depression should be considered in light of the place and time of diagnosis. At the present time, speaking openly about depression is increasingly acceptable in developed countries, including Australia (Kokanovic et al.,

2013). However, those who had been diagnosed at a much earlier age—often several decades ago—had faced greater challenges related to stigma, and a dearth of information about depression. These participants reported that they had found it difficult to make sense of how they had been feeling at the time.

I didn't know what depression was. I just felt terrible. I didn't really know what was wrong. I just knew I was unhappy. (Stephanie, 71 years)

Those of us who live with depression know that it's different to having a bad day, or it's different to responding to a normal life event, like a death or something. It's something hanging over you, in the background. (Sue, 68 years)

A third and final set of evolving beliefs and expectations that influenced *Taking Stock* related to perceptions of well-being in older age.¹⁵⁹ Well-being is associated with personal attitudes and behaviours which evolve as individual circumstances change. Those who expect to maintain high levels of well-being are more likely to experience positive health outcomes and are typically more motivated to improve and sustain their well-being.

It got to the point where it was really affecting what I was wanting to do, particularly enjoying retirement. (Adam, 66 years)

Conversely, those who believe that health problems were an inevitable part of ageing may be less likely to engage in behaviour that enables them to optimise well-being.

I'm seeing a specialist again next week. I've got trouble with my wrists and I'll be tossing up whether it's worth having anything else done or not. You know, it's not seriously debilitating, but it's a real pain in the arse. It's like an expectation: "What can I expect at 75?" (Pete, 75 years)

8.2.2 External influences

The subjective process of *Taking Stock* occurred within broad social and environmental frameworks that influenced how participants viewed themselves. Within these frameworks, participants encountered facilitators and barriers to their well-being. *Taking Stock* was influenced by socially pervasive—though rarely explicit—attitudes and beliefs of age and depression at a given place and time. Arguably the strongest external influence when *Taking Stock* was the common Western stereotype of ageing as a time of generalised

¹⁵⁹ See 2.2.2 (The concept of ageing well).

decline (Löckenhoff et al., 2009; Schroyen et al., 2018). Participants described occasions on which health professionals had demonstrated this narrow view.

I went to see somebody else at the clinic, but she was a lot younger ... even though she was well aware of what was happening to me [physically], I just felt it was a battle to get her to acknowledge it [depression]. She just didn't want to listen to me... Oh, it was a battle. (Rita, 67 years)

I'd been going to doctors for 15 years ... I always used to say, "I get agitated, I feel as if I'm not with it", and they'd just say, "No, your blood pressure is up a bit again". I don't know if it was my age ... they just seemed to think there was nothing wrong. (Roger, 82 years)

For Rita and Roger, the assumption that depression was a normal part of ageing resulted in delayed diagnoses and treatment of depression. If health problems are considered an inevitable part of ageing, individuals may be less motivated to engage in behaviour that enhances their well-being (Law et al., 2010; Searle et al., 2014). In addition, when an external negative stereotype of ageing becomes a negative self-perception—in other words, a self-stereotype—the person's experience of depression may be exacerbated as they experience self-fulfilling limitations and reduced expectations of their well-being (Levy, 2003). To illustrate, several reported how negative views of ageing could lead to a sense of futility about their efforts to maintain their physical and mental health.

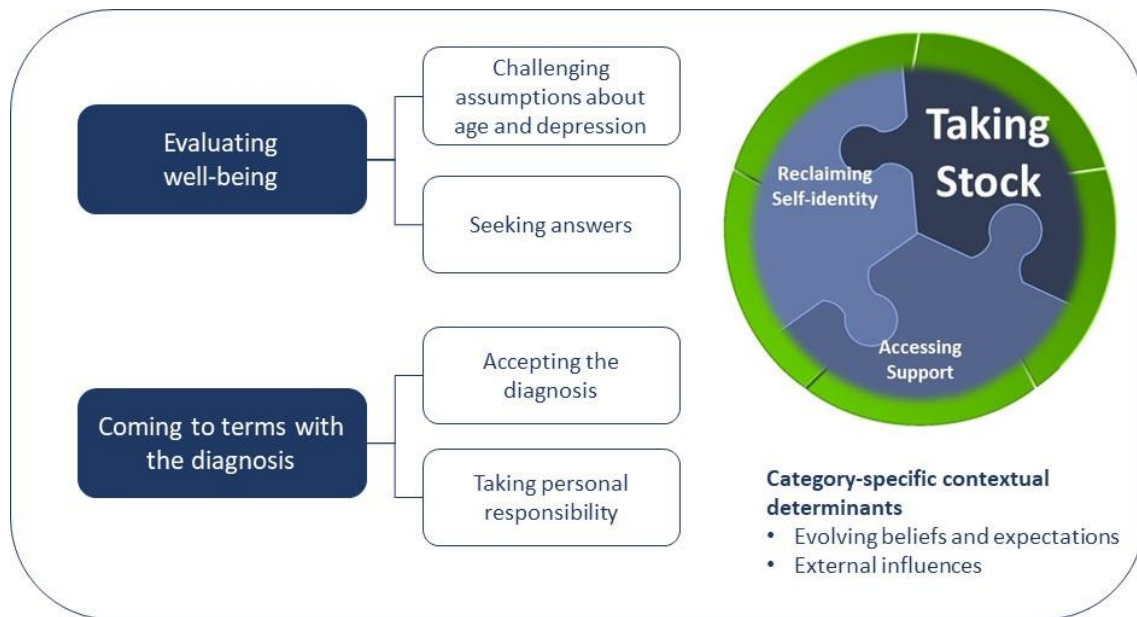
As far as I'm concerned, there's nothing to look forward to really. Just life getting harder, rather than easier. (Vera, 69 years)

How participants negotiated these external influences while *Taking Stock* enhanced or constrained their efforts to evaluate and adapt to their circumstances.

8.3 Strategies for *Taking Stock*

It was through reviewing and making sense of their experience of ageing with depression that participants sought to pursue opportunities to optimise well-being. Participants engaged in two main strategies when *Taking Stock* of their current circumstances: *Evaluating well-being* and *Coming to terms with the diagnosis* (Figure 6).

Figure 6: Taking Stock



8.3.1 Evaluating well-being

Evaluating well-being represents the process by which participants made a judgement about their current sense of well-being and perception of quality of life. There are many concepts and measures of well-being,¹⁶⁰ and this self-assessment is highly subjective and cannot be inferred by or on behalf of others. Rather, participants reviewed and put into perspective their experiences and circumstances in a way that was meaningful to them. Participants evaluated themselves through the two interconnected strategies of *Challenging assumptions about age and depression* and *Seeking answers*.

8.3.1.1 *Challenging assumptions about age and depression*

By *Challenging assumptions*, participants evaluated their views and expectations of ageing and depression, within the context of well-being and quality of life. In acknowledging themselves as an older adult with depression, they considered their own personal and broader social expectations of age, the process of ageing, and of ageing with depression. Where a dissonance was identified between their expectations and experiences, participants were motivated to seek help. In this way, they gauged whether they felt they were ageing well or whether action should be taken address their difficulties.

¹⁶⁰ See 2.2.2 (The concept of ageing well).

This process was strongly influenced by participants' attitudes and expectations age, as positive attitudes towards ageing are important drivers of healthy mental and physical ageing (Levy et al., 2018; Nosraty et al., 2015). Most participants exhibited positive attitudes towards ageing.

The doctor tells me, "You've got this issue, well, you are 66." Within a realistic framework, I don't buy into that stuff. I think it's rubbish ... I created my business after the age of 50. (Evan, 66 years)

How participants interpreted and responded to assumptions about age and depression determined how they evaluated their individual circumstances at a given time and place. Similarly, the explanations they gave to their life patterns rewarded or sanctioned their efforts to optimise well-being. However, these views and explanations did not occur within a vacuum. For example, the media has a direct effect on public attitudes towards older age (Edgar & Edgar, 2015) and mental health issues (Zhang et al., 2016).¹⁶¹

8.3.1.2 *Seeking answers*

Having challenged assumptions about age and depression, participants set out to optimise well-being. A higher expectation of ageing well with depression encouraged them to play an active role in maintaining their physical and mental health. For participants, this process typically commenced by *Seeking answers* when they felt unwell. In his early research on depression, Karp (1994) described a period of time in which his study participants "had no vocabulary for naming their problem" (p. 13). Several participants in the current study were similarly perplexed by their symptoms. Although they knew that they were not well, some could not articulate clearly their symptoms, did not make a connection between their symptoms and depression, or could not conceptualise the meaning of depression.

I knew something was radically wrong with me. I had to talk to someone, I had to do something. (Sandra, 67 years)

I didn't get out of bed for a week and a half ... I fell over big time [collapsed], got hold of the GP and said, "Listen, for God's sake, do something! This is ridiculous!" (Lorna, 68 years)

¹⁶¹ See 2.2.2.2 (The experience of ageism) and 13.3.3 (Implications for the portrayal of age and depression).

Others expected that a health professional might confirm their self-diagnosis of depression. These participants typically sought information on their symptoms before consulting a health professional.

I don't know whether diagnosis is really the word. I think eventually I twigged and I said to my doctor, "You know, I think I'm depressed." (Gillian, 73 years)

However, *Seeking answers* was often not a straightforward process. Depression is particularly complex in older adults, and is often associated with physical illness, a decline in functioning and loss of independence (Dear et al., 2015; Pirkis et al., 2009). Although they knew that they were not well, some could not articulate their symptoms, did not make a connection between their symptoms and depression, or could not conceptualise the meaning of depression. Those who presented to their health professional with physical symptoms found it particularly difficult to obtain a diagnosis of depression. Arguably the most concerning case in the current study was that of Roger, who agitated for an accurate diagnosis for some 15 years. While he assumed that he had an undiagnosed mental disorder, his long-term GP continued to treat him for high blood pressure. It was only when a different GP began working at his local health centre that Roger's depression was appropriately diagnosed.

She was a retired doctor who came and started up again. When I told her my history, she said, "Well, let's start again." (Roger, 82 years)

It was something I pushed for myself. No matter how good they are, don't generally have the time to be able to indulge in actually looking at these things [mental health] properly. (Evan, 66 years)

Once answers had been obtained—either with relative ease or through perseverance—participants commenced the process of *Coming to terms with the diagnosis*.

8.3.2 Coming to terms with the diagnosis

Coming to terms with the diagnosis is the process by which participants calibrated their expectations over time, in response to changes in their health status. Participants exemplified the distinctive and personal nature of depression, as they sought to adapt through the sub-strategies of *Accepting the diagnosis* and *Taking personal responsibility*. For some, these processes were straightforward; for others, they were more challenging.

However, all demonstrated their efforts to be flexible as they navigated the unfolding experience of depression.

I was able to look at myself and say, “Ah, it’s time for you to come to grips with this, Mister ... you do have an emotional problem.” (Sean, 74 years)

8.3.2.1 *Accepting the diagnosis*

Through the process of *Accepting the diagnosis*, participants reflected on how they felt at receiving a formal diagnosis of depression and their subsequent self-perceptions. A formal diagnosis of depression often confirmed participants’ assumptions, particularly those who had lived with undiagnosed depression for an extended time.

I was actually quite relieved, because I knew there was something not quite right, because I’ve always been a very happy-go-lucky person. I knew there was something not right. (Laura, 72 years)

I’m a fairly intense character, so I’ve probably been stressed out a lot which, in turn, has turned a little bit sour. And so, I have had it [depression] for a long time, I think. I just accepted it [the diagnosis] because I thought it was depression all along. (James, 71 years)

Trying to understand the cause of depression was a core strategy in this process. Using cause-and-effect inferences to make sense of the diagnosis, most located the cause(s) of their depression along a continuum of biography or biology (Karp, 2017).¹⁶² Vernon, for example, referred to several major life changes as the cause of his depression, while Sandra regarded her depression as a medical condition.

My career wasn’t going quite as well as I had hoped, and my father died at the same time. I think those were the main things that led to it. (Vernon, 76 years)

The psychiatrist said, “Well, there’s an imbalance in your brain”. So, I’ve got a chemical imbalance in my head and I need to take medication. (Sandra, 67 years)

Several felt that their depression was the result of their childhood experiences.

Somebody should have told me a long time ago that Dad’s violent temper and verbal abuse was going to have a long-term effect on me ... I remember many unhappy times. (Stephanie, 71 years)

¹⁶² The nature/nurture debate reflects longstanding recognition that genes and environments contribute to the etiology of depression (Dunne, 2011).

Although most had come to understand the symptoms, manifestation and treatment of depression as a mental health issue, others had to overcome a sense of failure before they could accept the diagnosis.

I guess I felt like I was a bit of a failure, because all your plans and dreams are shattered. One minute you're going that way, then all of a sudden, you're going the other way. (Mia, 66 years)

For several, making comparisons between their own predicaments and those of others they considered to be at a greater disadvantage reinforced their efforts to accept their diagnosis.

It's annoying, being depressed, and it's annoying having mental problems. But I'm okay, and I'm better than a lot of other people. (Sue, 68 years)

8.3.2.2 *Taking personal responsibility*

Taking personal responsibility typically occurred as a result of *Challenging assumptions about age and depression* and *Seeking answers*. In line with their individual circumstances and resources, participants demonstrated their commitment to taking the first step towards optimising their well-being.

I guess, if you've got depression, it's up to you. I make a bigger effort perhaps to get out more and don't sit at home feeling sorry for myself. (Rhonda, 77 years)

I don't want a miserable life. I want to do the best I can. So, if you're going to look after your health, you might as well, really, do it the best you can. (Sue, 68 years)

Given the focus of the current study on self-management, it was not unexpected that participants would identify *Taking personal responsibility* as a foundation for optimising well-being. From this perspective, they explained how they sought to eliminate blame and not make excuses for themselves.

Forget about who's to blame; let's just simply say, "What's the problem?" Let's identify it, let's see how we can approach it, what are our strategies to overcome it, put that in place. (Sean, 74 years)

Taking personal responsibility reflected participants' commitment to managing their depression over time. Rather than being passive recipients of treatment, they sought to

apply their knowledge and access resources in a way that gave them choice and control. Through an ongoing adjustment process, participants could maintain a sense of control over their individual circumstances, as they took responsibility for establishing and achieving new goals that aligned with their mental and physical health, resources and preferences. In so doing, participants demonstrated their willingness to be flexible as they navigated the unfolding experience of depression. In conceptualising the process of ageing well with depression, participants incorporated a responsibility for their well-being into their conversations about the future. This motivated them to harness support and empower themselves to self-manage their depression.

8.4 Summary

The category of *Taking Stock* is an abstraction that draws together the internal processes and external influences by which participants evaluate and accommodate their current circumstances. *Taking Stock* reflects the personal process by which participants gauged how they felt about their age and the experience of depression. This process is influenced by a complex interplay of social, demographic, biological and psychological factors, as well as life experiences. *Evaluating* their well-being and overall quality of life involved participants actively *Challenging assumptions about age and depression* and *Seeking answers*. It was through *Evaluating well-being* that participants could self-monitor, counter negative thinking, engage in problem-solving and adopt positive behaviour patterns. These strategies, in turn, formed a framework for participants to start *Coming to terms with the diagnosis*, through *Accepting the diagnosis* and *Taking personal responsibility*. By accepting that depression was not a normal or inevitable part of ageing, participants were motivated to explore, identify, initiate and implement action to optimise their well-being and overall quality of life.

CHAPTER 9

Accessing Support

Lay down the strategy, put it into action, make sure it's ongoing and continue to review it ... to me, that is the most important thing. (Sean, 74 years)

9.1 Introduction

In this chapter, the second category, *Accessing Support*, is presented. The chapter commences with a review of the contextual determinants that frame participants' experience of accessing support to optimise well-being, including the preferences and quality of formal and informal support available to them. This is followed by an examination of the four strategies used by participants when *Accessing Support: Overcoming barriers, Becoming informed and engaged, Harnessing formal support and Optimising informal support*.

9.2 The context of Accessing Support

The support preferences of older adults with depression range from active clinical treatment—such as medication and/or psychotherapy—to religious or spiritual activities, to the decision to disengage from formal support altogether (Raue et al., 2011).¹⁶³ The latter may occur when individuals consider themselves to have recovered or when formal support is considered ineffective in treating depression. In addition, several contextual determinants enhance or constrain individuals' efforts to access support.

Briefly, formal support is usually provided by private or public health professionals or services, while informal support refers to the functions performed for an individual by significant others, to enhance the individual's sense of well-being (Thoits, 1995, 2011).¹⁶⁴ Informal support often complements formal support. Where informal support serves as a buffer to stress, for example, an increased positive psychological state may be promoted that induces a positive physiological response (Cohen, 2004). Informal support has also

¹⁶³ Although some older adults with depression may prefer not to engage in formal support, the inclusion criteria for the current study included the requirement for participants to be receiving formal treatment and/or support for depression.

¹⁶⁴ See 0 (Terms and definitions).

been positively associated with treatment concordance and reduced duration of depressive illness (Ibarra-Rovillard & Kuiper, 2011). Conversely, individuals who lack informal support while taking medication or undergoing psychotherapy for depression generally experience poorer health outcomes (Gardner, 2011; Segrin & Rynes, 2009), as exemplified by Vernon's statement about the essential support he receives from his wife.

If I were on my own, I would be no good at all. I would freely admit that my helpmate [wife] is the one that, if you like, keeps me going. (Vernon, 76 years)

The contextual determinants which influenced participants' experiences of formal and informal support were *Personal preferences* and *Support availability and opportunities*.

9.2.1 Personal preferences

Individuals' judgements of their health and support options—in other words, their perceived need for support—reflect their personal, social and cultural characteristics and preferences, as well as their views of the health system (Van Zoonen et al., 2015). Participants' preferences for formal and/or informal support were frequently associated with previous positive or negative experiences. Those who reported positive experiences with formal support, for example, were more likely to maintain the professional relationship, as they saw no reason for interrupting the appropriate and reliable pattern of support they were receiving.

I've got a treasure of a doctor that I've been to for many years. I haven't actually used any other person [health professional]. (Erica, 70 years)

I think we're all on the same page. There's good communication between myself and all those people like the doctor, psychologist ... I think it's all good. (Tony, 73 years)

Predisposing factors also exerted an influence on how participants sought to harness support. These include their personal, social and cultural characteristics, education and relationship status. For example, dispositional factors¹⁶⁵ such as self-confidence, an easy-going disposition and an internal locus of control appear to be positively associated with improved coping in adults living with depression (Helvik et al., 2016). People with a

¹⁶⁵ Also known as internal factors, dispositional factors are individual characteristics that influence a person's behaviour and actions. They include individual personality traits, temperament and genetics.

higher education are also more likely to seek help for their mental health than those with a lower level of education (Parslow, Lewis, & Nay, 2011; Ten Have et al., 2016).

[You need] stamina and sense of humour as you get older. If we didn't have those, we couldn't laugh about the things that happen to us. (Pete, 75 years)

I like to think that I'm intelligent enough, accepting enough, for [a psychologist] to give me advice ... because they are more knowledgeable. (Sean, 74 years)

An important personal preference related to participants' level of willingness to disclose their diagnosis of depression to significant others. Overall, however, confiding in a significant other was their most preferred form of informal support.

I just think that people closest around you need to know ... they know how to help, basically. That's my philosophy. (Laura, 72 years)

My husband has a great sense of picking up on things [with my depression] that are not right. I am always guided by him. (Sarah, 71 years)

Participants' spiritual inclinations also influenced how they viewed and accessed support. Their beliefs related to church-going, meditation or a general sense of a higher being that offered them some level of comfort.

My spirituality is very important to me. Not organised religion, but the way I see the world. Because of my spirituality, I view myself differently. I put a lot of effort into meditation ... into letting go of negativity. (Erica, 70 years)

9.2.2 Support availability and opportunities

Closely related to personal preferences, the second contextual determinant concerned the opportunities participants had to access support. Regardless of their personal preferences, the choice of formal support was sometimes limited to geographical availability.

I'm traveling probably over 100 kilometres between various clinics, trying to find someone that will stop for five minutes and listen to me. (Greg, 67 years)

Financial considerations also influenced whether or how participants could access formal support. Better financial status is commonly associated with subjective improvements in mental and physical health in older adults, and a higher reported quality of life (Bryant et

al., 2012). Participants who had private health insurance encountered fewer difficulties when considering their treatment options.

I have private hospital cover, but not extras [non-hospital treatments]. For some things, I would have had to wait until I might have been able to put money together. (Evan, 66 years)

From the perspective of quality of support, previous negative experiences led several to continue their search for a person or service to meet their needs or disengage with the type of service altogether.

I'm sure there are some very good people out there, but I don't really feel that I've kind of clicked into anyone [established an effective relationship] that's given me the help that I need. (Bea, 67 years)

We changed neurologists because we went in there one day and he said, "Who are you?" I thought, "Shit, he doesn't even know who I am." So, we went to [another one]. We get in there and we're chatting away and he falls asleep! It makes me feel, "What am I doing here?" We're paying for this consultation ... I don't know if I'll go back. (Sarah, 71 years)

Regarding access to informal support, most participants could describe a close relationship with at least one significant other. This trusted confidante was a source of comfort and advice, based on a strong sense of familiarity and comfort. These participants would typically involve a significant other in their decisions about enlisting support.

My very good friend, she has heaps of problems as well, but we just know everything about each other. (Priscilla, 77 years)

Those who actively sought informal support maximised close relationships and frequently engaged in social activities with others. In this way, their positive relations with significant others promoted their mental well-being (Segrin & Rynes, 2009). However, participants faced a range of challenges as they sought to enlist informal support. Rita, who lives with comorbid mental and physical health conditions, explained how she managed while her only child was living overseas.

She's now living [overseas]. She's coming over in May for a month, and then she'll come back again in September for a month. She makes sure she's back for important appointments. (Rita, 67 years)

However, the needs of some for informal support were unmet, often leaving them feeling isolated. To address this sense of social isolation, participants sought to access formal support and empower themselves to optimise their well-being without the immediate help or encouragement of significant others.

People don't talk about depression. We never talk about it. It'd be nice to meet someone who understood it [depression] and what it was like and to be absolutely honest with, as I'm being now about it. (Fiona, 68 years)

Others preferred to keep their diagnosis private, occasionally to the extent that significant others were unaware of the person's depression. Some chose not to disclose their experience of depression to others, to avoid the risk of being treated differently. Behaving in contrast to one's authentic feelings has been described as "a heightened form of impression-management" (Karp, 2017, p. 115). Colloquially, it is frequently articulated as "putting on a happy face"—that is, pretending to be happy (Allan & Dixon, 2009).

I think I can put on a face that I'm quite all right. I've got a mate that doesn't believe there's a thing wrong with me. (Roger, 82 years)

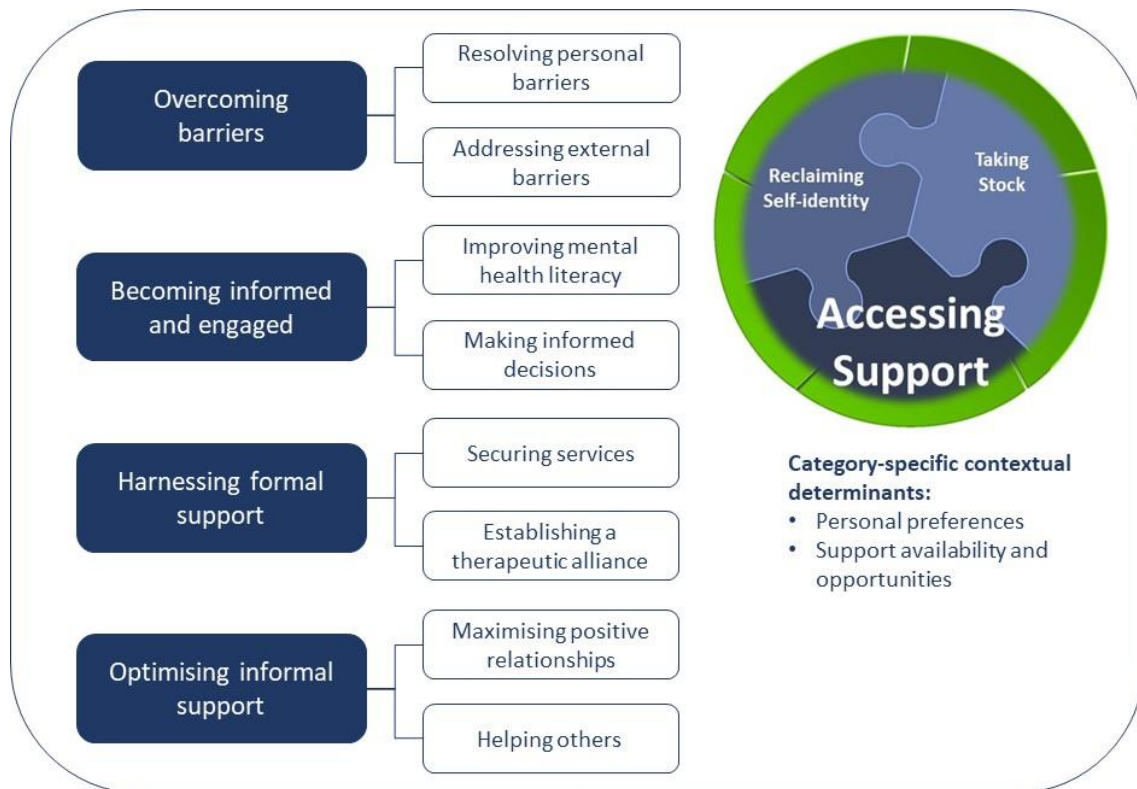
I can be really upset and I don't think anybody would know. I just go around smiling. (Sue, 68 years)

Overall, the contextual determinants described here may simultaneously enhance and/or constrain individual's efforts to harness support. Hence, participants' personal preferences for formal and informal support, and access to that support, influenced how and to what extent they harnessed formal support and optimised informal support.

9.3 Strategies for Accessing Support

Four main strategies for *Accessing Support* were abstracted from the data: *Overcoming barriers*, *Becoming informed and engaged*, *Harnessing formal support*, and *Optimising informal support* (Figure 7).

Figure 7: Accessing Support



9.3.1 Overcoming barriers

Accessing Support is rarely a straightforward strategy, and typically requires that the person first overcomes personal and/or external barriers. *Overcoming barriers* represents the ways in which specific impediments to help-seeking were addressed. This usually occurs in the order in which they are encountered (Stanhope & Henwood, 2014). In the current study, *Overcoming barriers* was achieved through the sub-strategies of *Resolving personal barriers* and *Addressing external barriers*.

9.3.1.1 *Resolving personal barriers*

The most common personal barrier identified by participants was *Struggling to become self-motivated to seek help*. However, the inclusion criteria for the current study required that participants were currently receiving professional treatment and/or support for depression. This indicated that participants had successfully motivated themselves to obtain a diagnosis of depression.

I think, I think, I think, I think. I procrastinate, procrastinate, procrastinate, procrastinate, so my thinking doesn't get converted well enough into doing.
(Sean, 74 years)

For some, getting motivated depended on whether they were “having a good day”.¹⁶⁶ Several reported that, on a bad day, their first challenge was to motivate themselves to get out of bed in the morning. To overcome this challenge, they typically considered what they would say to someone else facing the same problem, or focussed on the knowledge that they would feel better after getting out of bed and engaging in a certain activity.

I've had to push when I get really, really, really depressed. If I was talking to someone else, I'd say, "Get out of your pyjamas!", or "Buy some flowers, or go out and do something!" (Priscilla, 77 years)

Participants also faced an ongoing challenge of remaining motivated to optimise their physical and mental health over the medium and long term.

If I think back to those times when I was at my blackest, there would be days when I could barely walk. I was heavy and stiff and sore. But I would push myself to go swimming, because I just knew on some level it was something positive.
(Evan, 66 years)

I'm sure there are things out there that I would enjoy doing, but I'm just not doing them through lack of motivation. (Bea, 67 years)

Although she acknowledged its influence on her mental health, Bea found it challenging to improve her physical health. However, a recent article in her local community newspaper about treatment options for depression had provided the impetus for her to contact a low-cost counselling service, through which she hoped to enlist support to maintain a healthier lifestyle through exercise and diet.

Another personal barrier concerned stigma. Although participants had overcome public self-stigma to seek help, several were still grappling with self-stigma.¹⁶⁷ Hence, their fundamental views and knowledge of depression determined how a diagnosis was sought initially. Some avoided referring to their depression by name.

¹⁶⁶ For people with depression, “having a good day” might comprise feeling energetic, getting things done at home, engaging in activities outside the home and/or participating in group activities (Ahlström, Skärsäter, & Danielson, 2009).

¹⁶⁷ See 2.3.3.1 (Help-seeking barriers).

I do have a sense of stigma about depression, I do really. [Without using the word 'depression'], I'd say, "I'll just take a day off today from all the things that I normally do." The trigger [impetus to seek help] was when I went into the office and broke down ... my colleague took me to the doctor and she [doctor] immediately said, "Oh, you're depressed." (Priscilla, 77 years)

Personal barriers to *Accessing Support* were frequently overcome by external rather than internal motivation. For some participants, having a network of informal, or social, support played a role in their motivation. Sandra, for example, described how it was the prospect of an unexpected visitor arriving at her home that frequently prompted her to get out of bed in the morning.

Some days, I don't want to get out of bed, but I've made a couple of neighbour friends and it's only the thought that they might call me or call around, that I get out of bed and have a shower. If I hadn't met anybody, I probably would spend a lot of time in bed. (Sandra, 67 years)

Like Sandra, it was an external influence that motivated Vera and Bea to get going in the mornings—their pets. Several had pets who provided them with companionship and joy, while motivating them to get out of bed and to engage in physical activity.

If it wasn't for my dog, I don't know if I'd get out of bed, which is a bit scary. I'd rather get up and make a cup of tea and go back to bed, but we have to run outside, so she gets me up. (Vera, 69 years)

I get up, have a shower, have breakfast. Feed the dog, feed the cat. I look after my animals first ... that often gets me back on track. (Bea, 67 years)

The benefits of pet ownership to people with depression—and other illnesses—are well documented (Cacioppo & Hawkley, 2009; Muldoon, Kuhns, Supple, Jacobson, & Garofalo, 2017). Although participants did not make a direct association between caring for a pet and their experience of depression, it was apparent from the data that having a pet provided impetus to get out of bed in the morning and required physical activity from participants. In addition, having a pet often led to casual conversations with others, when they were walking the dog or obtaining services for an animal.

Once they had motivated themselves into action, participants sought to access and engage with appropriate services and support. Generally, their first step was to obtain information

about depression and appropriate services, which, in turn, allowed them to actively participate in optimising their well-being.

9.3.1.2 *Addressing external barriers*

The most commonly reported external barriers encountered by participants wishing to harness support were stigma of depression in older age, ageism and difficulty accessing formal support. These barriers are consistent with those listed in the literature (Conner et al., 2015; Corrigan et al., 2015; Makris et al., 2015; Ouchida & Lachs, 2015). Although issues related to language and culture are common barriers to accessing support (McCann, Mugavin, Renzaho, & Lubman, 2016), they were not identified by participants.

Stigma associated with mental health issues, including depression, is one of the most common barriers to enlisting support (Conner et al., 2015).¹⁶⁸ Most participants in the current study had experienced public stigma at some point. However, they noted a shift in community views, as information on mental health in general, and depression in particular, had become more available.

I think there is a stigma, because it's perceived as being a mental illness. "He's got depression ... he's mentally ill ... keep away from him." (Vince, 74 years)

Thanks to the Internet, the whole world is being exposed to the concepts and the facts [about depression]. (Pete, 75 years)

Notwithstanding how stigma may prevent or delay help-seeking, participation in the current study required individuals to be receiving formal treatment for depression.¹⁶⁹ The fact that participants had engaged with a health professional to receive a diagnosis and ongoing support indicated that they had managed to overcome the complex elements that constitute stigma. For most participants, the two main strategies for *Addressing external barriers* related to stigma had been to identify and enlist the support of a GP who was understanding and knowledgeable about depression, and to exercise judgement about sharing the diagnosis and experience of depression within informal networks.

¹⁶⁸ Stigma is addressed in detail at 2.3.3.1 (Help-seeking barriers).

¹⁶⁹ See 4.5.2.1 (Selection and recruitment of participants).

As far as GPs and things are concerned, it's trial and error and you just have to ask people and suss [check] them out. I'm dealing with something that I've had for 50 years. (Lorna, 68 years)

Overall, participants had reached a point at which their quality of life was being compromised by their undiagnosed depression. The search for a diagnosis and treatment for their undiagnosed depression became more important than any experience or fear of stigma. To illustrate, Vince described how he had overcome stigma by realising that his overall quality of life was more important than a fear of being judged.

I couldn't get out of bed. I'd be lying there arguing with myself to get out of bed. I'd lie there until 3 o'clock. And so I went over and saw [my GP]. He just picked it [depression] straight away. I think there is a stigma, but it doesn't particularly worry me now. As long as I know about it [depression] now, it [stigma] doesn't worry me. (Vince, 74 years)

Those who felt they were treated differently because of their age found *Accessing Support* even more challenging. Numerous examples were given of health professionals, especially GPs and psychiatrists, patronising participants, listening less to their views and cutting short the clinical consultation time spent with them. This raises concerns of ageism within healthcare professions (Ouchida & Lachs, 2015).

I think they [health professionals] are only too happy to treat you as if you deserve less consideration, or as if you're less intelligent [because of your age]. (Gillian, 73 years)

Those whose depression symptoms had initially been attributed to their age, or confused with “normal ageing”, felt that their age had been a barrier to receiving a timely diagnosis and treatment.

I don't know if it's my age. They [GPs] just didn't think there was anything wrong. Getting the diagnosis [of depression] was the biggest relief I've had for 15 years ... because, see I thought my heart was “crook” [bad]. (Roger, 82 years)

If you get a doctor that truly is interested in you, never let them go, because they're rare at this stage of the game [age]. Everybody treats us like we're old and dumb. (Greg, 67 years)

Ageism as a barrier to accessing support was also indicated by the limited treatment options offered to participants. Although all participants had initially been prescribed antidepressants, few had been referred for psychotherapy. Laidlaw et al. (2008) suggest that relatively low referrals for psychotherapy may reflect the erroneous belief that older adults are less likely than younger adults to benefit from this therapy.

[GPs] could send you off for counselling, but I've never been sent off for counselling. I've never had a GP suggest that I go for counselling or any other form of psychological anything. I've always sorted it out myself. (Sue, 68 years)

Another barrier to be overcome by participants wishing to enlist support for depression concerned the complex concept of access. In the current context, access concerned affordability, physical accessibility—such as availability in a specific geographical area—and acceptability of healthcare services. Consistent with the literature (Haralambous et al., 2009; Patterson-Kane & Quirk, 2014), issues of geographical availability of formal support were most apparent for participants who were living outside the metropolitan area, particularly those in smaller regional or rural communities.¹⁷⁰

Most of the GPs are very second rate. The further you go out from the city centre, the worse the quality becomes. (Marina, 65 years)

You can't do it [get better] without good professional help, but it's pretty hard to find ... you have to really keep chipping away at it. (Adam, 66 years)

No participants had received formal support from mental health nurses. There was little to no awareness of the role of mental health nurses, nor an understanding of how to access them. Consequently, additional barriers to formal support included long waiting times and difficulties establishing new relationships when health professionals relocated or retired.

The trouble is getting to see [my GP]. You've got to be sick three months in advance to try and get him, you know? So, the problem I find these days is actually making an appointment, being able to get an appointment. That's the tricky thing. (Vince, 74 years)

My GP is younger than me, but will no doubt be retiring in the not too distant future. We get on very well together. He and I are of a similar mind and I value

¹⁷⁰ No participants in the current study lived in remote communities, where support and treatment for mental health issues have been identified as major challenges (Haralambous et al., 2009).

and trust his judgment. When he does retire, I have no idea what I'll do. (Vernon, 76 years)

In examining the various aspects of access, Gulliford et al. (2002) highlight the fundamental concept of meeting the needs of different groups of people with equivalent needs. However, even individuals with equivalent needs have their own priorities, values and preferences for support. Thus, each participant's concept and experience of access was complex and subjective, and strategies to overcome barriers to accessing support were highly individualised.

There are various organisations that can help. I don't want this to sound sexist, but some might be for women, some might be for men. It depends. See, men think totally differently to us, very differently. (Sarah, 71 years)

It depends on what sort of counselling you have, but it's got to be an active relationship. You know, we ought to be given an opportunity to assess who is going to provide us with the best support. I think we've got to be able to know which counsellor is going to suit our needs. (Rita, 67 years)

Financial barriers to formal support were identified by several. Notwithstanding a correlation between financial strain and depression (Almeida et al., 2012), none attributed their financial circumstances as a cause of their depression. However, several indicated that they had to carefully manage their financials, in order to access support.

Wherever possible, I go to one of the free services. I went to a woman [psychologist] who charged \$120 for 40 minutes. I can't afford that! That sort of thing is just right out [unaffordable]. (Bea, 67 years)

Maintaining private health insurance coverage was one of the main strategies for overcoming issues relating to financial access to support, although this depended on the type of cover they subscribed to. Another strategy for overcoming financial constraints was to restrict themselves to "bulk billing" services,¹⁷¹ while others sought low-cost or no-cost services.

¹⁷¹ In Australia, bulk billing occurs when health professionals accept the government's Medicare benefit as full payment for a service, as outlined in the Medicare Benefits Schedule (Department of Human Services, 2016). For health professionals who request a greater fee than the Medicare benefit, individuals must contribute to the payment. This out-of-pocket expense, commonly referred to as a "gap payment", is the amount to be paid, over and above what is received back from Medicare or a private health insurer.

I still keep private health insurance, which is getting so expensive. My GP bulk bills me, you know. It must be difficult if you have to pay a huge amount of money. I don't have enough money coming in. (Erica, 70 years)

9.3.2 Becoming informed and engaged

The second strategy for *Accessing Support* is *Becoming informed and engaged*. Approaches to treatment and support are more likely to be effective when the individuals concerned are informed and active participants in discussions and decision-making (Corrigan et al., 2012; Gearing, DeVyllder, Chen, Pogge, & Buccolo, 2014). By planning and equipping themselves to cope with their current diagnosis, participants were also building a buffer against anticipated future challenges associated with ageing and well-being. The sub-strategies for *Becoming informed and engaged* were *Improving mental health literacy* and *Making informed decisions*.

9.3.2.1 Improving mental health literacy

An appropriate level of mental health literacy is needed to access, understand and use information to promote and maintain mental health.¹⁷² Although Farrer *et al.* (2008) identified a need to improve older adults' mental health literacy, most participants felt comfortable and confident in the ways in which they sourced information and resources to support their efforts to optimise well-being.

In my experience, the information is all out there, you just have to pick it up and deal with it. It isn't going to come and knock on your door. (Mia, 66 years)

With the Internet now widely accepted as a source of help (Holzinger, Matschinger, & Angermeyer, 2012), online resources were frequently used to find out about the diagnosis and treatment of depression. However, participants exercised caution when accessing online information, and could distinguish between reputable sources that could be trusted and those that should be avoided. While some had learned which websites to trust through trial-and-error, a U3A meeting attended by the researcher began with an update by the group's computer expert, who informed guests about new websites of interest and alerted

¹⁷² See 2.3.3.2 (Help-seeking facilitators).

them to the risks associated with online activity (Obs. 1).¹⁷³ However, a small number of participants—all of whom had computers and access to the Internet—did not use the Internet to research health-related topics. Rather, they referred to their health professional to meet their needs for information and advice.

Oh no, I never go online. I think information is probably there [on the Internet] and available if you really want it. If you know who to ask, you ask the right person. If I have a problem, I will mention it to the GP. (Vera, 69 years)

I'm of the age where the Internet doesn't become the all mighty know all. I do not trust the Internet at all. I ask the psychologist and she'll run things down for me. (Greg, 67 years)

Although participants were more likely to visit a website than read a self-help book,¹⁷⁴ several showed a keen interest in them.

I have read more self-help books than you could poke a stick at [count]. I've never read one that I didn't get something from, although some are much better than others. (Gillian, 73 years)

I read a lot of self-help books, yes. The new books are better than the old ones, you know, and they sort of work with you. The old ones just tell you this and that ... but you find it doesn't work that way. (Maurice, 82 years)

Health literacy includes the ability to solve problems, including being able to navigate the health system, recall instructions from health professionals, comply with medication regimens and engage in behaviour that promotes well-being (Serper et al., 2014).

My approach is looking at myself and asking, "What is it that I can change in my behaviour to improve what's getting in the way?" Just making those assessments that are going to be meaningful for me. (Rita, 67 years)

Provided information has been given to you authoritatively, provided you have acknowledged it [the diagnosis of depression] within yourself, accept it. (Sean, 74 years)

The recurring nature of depression requires specific interventions that transfer knowledge and skills to the person, to equip them to maintain their well-being (Houle et al., 2013).

¹⁷³ Online risks were a major consideration for participants, as use of the Internet for information and self-guided depression therapy becomes increasingly acceptable (Dear et al., 2015; Medlock et al., 2015).

¹⁷⁴ In a survey of public beliefs about self-help actions for depression, Holzinger et al. (2012) found that older participants were likely to advise against reading a self-help book on depression.

It is by actively participating that the individual may achieve the highest level of well-being and overall quality of life. This aligns with the recovery approach in mental health.

I'm more conscious now of thinking about me and what's best for me and not just going along with the flow ... you determine what you're going to do with yourself and how others deal with you. (Amy, 67 years)

The physical component of health literacy was reflected in participants' efforts to stay active through social and physical activities. High health literacy is strongly associated with engagement in physical activities to maintain overall health, as well as following a healthy diet (Geboers et al., 2016). Most participants engaged in some form of sport or exercise and participated in activities that offered mental or physical stimulation or enjoyment. These activities were identified as a fundamental strategy for managing their depression and optimising their overall well-being.

I walk every day with my dog. By every day, I mean at least six days a week, and that's usually walking for 20 to 35 minutes. I find exercising is actually a job for me ... but when I get back from my exercise, I think, "Thank goodness that's over," and I feel good. (Tony, 73 years)

I joined the gym, and I would go whether I wanted to or not. You automatically start feeling better. Now, I walk twice a day, morning and night, go dancing twice a week, write poetry and creative writing. And I do yoga. So, physically, I'm doing more than I did in my 30s. (Mia, 66 years)

By improving their mental health literacy and following instructions from health professionals, participants fostered their capacity to actively participate in discussions and decisions about their treatment for depression.

9.3.2.2 *Making informed decisions*

Overall, participants described their determination to be involved in decision-making processes related to their self-management of depression. The ability to make informed decisions is an essential factor in self-determination and self-management.¹⁷⁵ However, at a fundamental level, *Making informed decisions* is also a strategy for *Becoming informed and engaged*, as it relates to the ways in which participants sought information about depression and treatment options that met their individual needs.

¹⁷⁵ See 0 (Empowering myself).

I think I ultimately make the decision. I had a recent doubt, if you will, on something which doesn't seem to be working terribly well in my case, for one reason or another. I was thinking of just packing it in, but I asked my GP and he gave me advice which I followed. (Vernon, 76 years)

Most participants felt comfortable and confident to share decisions with their health professionals. However, a small number of participants reported that they still approach decisions about their care in a “doctor-knows-best” manner.¹⁷⁶

I've always been a person that says to my doctor, “You're the expert. You tell me.” That's always been my philosophy. I don't know whether that's the right way to look at it or not, but so far it's worked. (Laura, 72 years)

Notwithstanding individual preferences concerning their level of involvement in decision-making about their treatment, participants generally wanted to be fully informed of their options. This enabled them to enquire about the benefits, risks and side-effects of each option. In response to their enquiries, participants hoped to be involved in appropriate conversation and deliberation.

I'm part of the whole conversation and the decision-making process with them [doctors] about my care ... I wouldn't do something if I didn't want to. (Rhonda, 77 years)

9.3.3 Harnessing formal support

Harnessing formal support represents the third strategy for *Accessing Support*, through which participants identified services that aligned with their current needs and preferences for managing their depression and optimising their overall well-being. There is a substantial body of evidence that supports the use of medication and/or psychotherapy in the treatment of depression in older adults (Fiske et al., 2009; Jayasekara et al., 2015). However, depression in older adults is often managed poorly, largely due to the misguided view that depression is a normal part of ageing, which, in turn, leads to under-diagnosis and inadequate treatment (Arokiasamy et al., 2017; Mock et al., 2010; Ouchida & Lachs, 2015). The progression from acknowledging a mental disorder to *Harnessing formal support* required participants to first overcome barriers¹⁷⁷ and then to become informed and engaged about developing strategies to self-manage their depression. To maximise

¹⁷⁶ Under this more traditional approach, patients passively accept doctors' decisions, often without understanding their right to participate in their health care decisions (McDonald, 2014).

¹⁷⁷ See 2.3.3.1 (Help-seeking barriers).

access to and benefit from these treatments, participants employed the sub-strategies of *Securing services* and *Establishing a therapeutic alliance* with the health professional.

9.3.3.1 *Securing services*

For participants who were not required to overcome barriers related to access or cost, the main decision when *Securing services* concerned their personal preference for the type of health professional, while availability and access to support was also a consideration. Most participants had received their initial diagnosis of depression from a GP, and many continued to use their GPs as the main form of support.

I've got a good relationship with [my GP]. I think he takes a holistic approach to the way he treats. He's informed, he takes care of things, but he's not your touchy-feely [emotional or demonstrative] doctor either, you know. If I need anything, I go and see him and talk to him. (Janet, 67 years)

However, several felt that their GPs did not have the skill or interest to support them in the management of their depression and preferred to visit a psychiatrist or psychologist.

[My GP] is a nice person, but nice does not help when you've got a mental health problem and you want medical knowledge. [The psychiatrist] was good and was experienced. (Marina, 65 years)

Describing disappointing experiences, a few participants no longer saw the benefit in psychotherapy.

Almost every counsellor I ever went to, I said, "I would prefer to be challenged, even though it might upset me at the time." I would much prefer to be really challenged, and nobody ever did. Counselling never did what I thought it could. (Evan, 66 years)

These experiences highlight the fundamental role of the health professional in providing appropriate support to the person with depression. Individuals with depression who access health professionals have complex combinations of beliefs and needs about their illness and treatment. It is incumbent on the health professional to take the time to explore and understand those beliefs and needs, before establishing the most appropriate approach in collaboration with the individual (Read et al., 2015).

For participants, a central strategy for managing their mental health through formal support was to receive the most suitable medication and to comply with their medication regimen. Almost all had been prescribed medication for their depression. Notwithstanding some debate over the prescription and effectiveness of antidepressant medication (Moncrieff, 2015; Ridge et al., 2015),¹⁷⁸ overall participants reported that medication had been effective in improving their mood.

I found the medication was far more helpful than the discussions, because if it's nothing that you can actually do anything about immediately, rehashing the same old reasons why it's happening is not beneficial to me. So, I went on the medication and felt better within five days. (Mia, 66 years)

Although the legitimacy of the pharmaceutical treatment of depression continues to be questioned in professional and lay communities (Ridge et al., 2015), participants who had benefited from antidepressant medication strongly supported its use and did not anticipate discontinuing the medication.

I think I'm happy to stay on this [medication] until the day I die. It's not affecting my ability to do anything and even if I'm taking it unnecessarily, I don't think it's doing me any great harm. (Janet, 67 years)

However, it had frequently been challenging to identify the most suitable medication. Becoming settled on a suitable medication often took time, while those whose medication regimen was effective saw no reason to change it.

I went through about 12 medications before I got the right ones. I knew to persist until I got the right medication. (Marina, 65 years)

I wouldn't like to [change my medication], because I figure when you're on a good thing stick to it; don't mess around. If they did change it, you can bet that I would have a reaction ... so why muck around with that? I mean, it's worked for so many years. (Sarah, 71 years)

9.3.3.2 *Establishing a therapeutic alliance*

The second strategy for *Harnessing formal support* concerned the relationship between participants and their preferred health professional. The positive influence of a therapeutic, or working, alliance between the individual and the health professional is

¹⁷⁸ See 2.3.4.1 (Antidepressant medication).

well established (Arnow et al., 2013; Leuchter et al., 2014). Often associated with psychotherapy, the concept of therapeutic alliance encompasses different approaches to health treatments and/or supports (Andersson et al., 2012). *Establishing a therapeutic alliance* was considered crucial when *Harnessing formal support*. The most common examples given to illustrate the importance of this relationship concerned medication reviews or changes. Most participants negotiated their medication needs with their health professional, at which time they sought to make known their views and experiences of the medication.

Each of them [medication] seems to last about four or five years and then they either lose their effectiveness or I really go downhill and need a change. So, it's probably every four or five years that I'll go and see a GP and say, "It's not working. What can we try now?" (Pete, 75 years)

Reflecting their mental health literacy, several researched their symptoms and potential treatments before visiting their health professional. This enabled them to take the lead in discussions about their treatment, as they collaborated to identify the most effective approach to managing their depression. In addition, individuals are more likely to follow treatment plans when decisions are made in partnership with health professionals, and to comply with medication regimens (Moncrieff, 2015).

I go in with a fist full of academic papers saying, "This treatment isn't working. Here is a bundle of research about this. What do you reckon? Should we try that?" And it's a standing joke with the shrink [psychiatrist] now that, "Oh yes, we've done the A to Z of the antidepressants." Yes, we've gone from Aropax and Zoloft and all points in between [laughs]. (Lorna, 68 years)

I always go in with three or four pages [of information]. He was very interested in getting the information before he would even come back and make a comment. We're both [participant and his wife] proactive in that sense. (Adam, 66 years)

In this context, *Establishing a therapeutic alliance* was also a way for participants to obtain information and learn strategies from a trusted health professional who understood their individual needs.

The most important thing you'll ever do is get education from psychologists and seek help from them now and again. It's hard to do, I know, but once you do and then you identify your triggers and you start to work within them, you find everything falls into place. (Paul, 69 years)

Having engaged with formal support that met their needs and preferences, participants considered the influence of informal support on their management of depression, and their overall well-being.

9.3.4 Optimising informal support

There is extensive literature that confirms the mediating effect of informal support on the experience of depression (Cohen, 2004; Hupcey, 1998; Segrin & Rynes, 2009; Smith, Hill, & Kokanovic, 2015). Consistent with Gardner's (2011) description of informal support as a network of personal relationships that enhance well-being,¹⁷⁹ most participants found that *Optimising informal support* was beneficial to their mental health and overall quality of life. Positive relations with others—that is, informal support—was maintained by *Maximising positive relationships* and *Helping others*.

9.3.4.1 Maximising positive relationships

In the first sub-strategy for *Optimising informal support*, the extent to which participants connected with others depended on the decision to disclose information about their mental health. Most participants exercised caution in deciding who to tell, whereas others were open about their diagnosis of depression.

I worked out that you really need to pick your mark [choose who to tell] and it's surprising who the marks are. You've got to pick your mark, then be very happy to discuss it with the people that are open to you. (Adam, 66 years)

I'm not ashamed. I mean, I don't talk about it to everybody, but it's nothing to be ashamed of. (Erica, 70 years)

There was a consistent theme that maximising close relationships enabled participants to better manage their depression. Pete and Adam highlighted the importance of the support they received from their wives.

I've managed to get this far principally because of support and understanding. The pills go so far, but if I was on my own, I don't know what would have happened. (Pete, 75 years)

¹⁷⁹ See 2.3.4.4 (Social support).

[My wife] would be very encouraging of anything that I thought I should do and she's been very proactive in terms of getting things, or even things from the library, little articles or, you know books or whatever. (Adam, 66 years)

These exemplars correspond with studies that highlight the beneficial role of partners in satisfying individuals' basic psychological needs, particularly in the case of people with depression (Ibarra-Rovillard & Kuiper, 2011; Smith et al., 2015). A few participants reported that they had close relationships with other family members, but preferred to withhold details of their depression to relieve the person of unnecessary worry or burden.

We skim over it. [My daughter] is not aware how bad I've been in the last six months, because I don't want to worry her. A couple of friends and my neighbour across the road are aware of my depression, and I talk to them. (Amy, 67 years)

In addition to maximising close personal relationships, most participants engaged in social activities as a way of staying active and accessing informal support. To supplement participant reports, the researcher attended several social activities at which the benefits of positive interaction and engagement were apparent. At a social activity of a regional branch of the U3A (Obs. 5), several attendees spoke openly about living with depression, while others were empathetic and supportive. The researcher observed similar peer support at a regular craft evening hosted by a suburban branch of the Country Women's Association (Obs. 2), while several members of a large suburban Men's Shed shared their views of depression and gave examples of support they had offered peers, once a diagnosis of depression had been shared with members (Obs. 4).

9.3.4.2 *Helping others*

The second sub-strategy for *Optimising informal support* reflects participants' interest in *Helping others*. For older adults with depression, *Helping others*—typically through volunteering—is a common strategy for engaging with individuals and the broader community (Kahana et al., 2013; Wilby, 2011). By *Helping others*, participants' sense of “giving back” made them feel more connected to their local communities. In turn, participants reported the importance of meaningful engagement with others.

I believe in giving back, you know. I've had a lot of benefits in life from different things, and I think if you can contribute something back, it's worthwhile to do. If I can help someone, then they'll help somebody else. (Nick, 79 years)

I volunteer with the home library service in [my area]. I like to be helpful ... people have helped me throughout my life and I like to help where I can. (Gillian, 73 years)

Helping others has a positive effect on a person's well-being (Kahana et al., 2013; Post, 2005). As a sub-strategy for *Optimising informal support*, *Helping others* contributed to participants' goal to have a meaningful existence and age well with depression.

9.4 Summary

The category of *Accessing Support* represents the strategies and sub-strategies used by participants to manage their depression. Before participants could begin accessing formal and informal support, they first had to overcome personal and external barriers. By improving their mental health literacy, participants felt that they could actively participate in discussions and decisions about their treatment. Through the strategies of *Harnessing formal support* and *Optimising informal support*, participants established relationships and strategies that facilitated their management of depression. It was by *Accessing Support* that participants could begin *Reclaiming Self-identity*.

CHAPTER 10

Reclaiming Self-identity

Maybe, as we get older, there are some benefits in being able to occasionally speak your own truth. (Evan, 66 years)

10.1 Introduction

The third category, *Reclaiming Self-identity*, is presented in this chapter. *Reclaiming Self-identity* encapsulates the interlocking aspects of participants' views and behaviours, and is built on the previous categories of *Taking Stock* and *Accessing Support*. The chapter commences with a discussion on the context in which *Reclaiming Self-identity* occurs. Two main strategies for *Reclaiming Self-identity* as an older adult with depression were extrapolated from the data: *Empowering myself* and *Striving for a meaningful existence*.

10.2 The context of Reclaiming Self-identity

Depending on their individual experiences, skills, values and resources, two contextual determinants moderated the way participants formulated and enacted their strategies for *Reclaiming Self-identity*. These were conceptualised as *Individual capacity* and *Resources to support self-management*.

10.2.1 Individual capacity

To empower themselves and strive for a meaningful existence, older adults must draw on their individual capacity to identify, address and evaluate strategies to optimise well-being. Distinguishing between the knowledge, resources and actions required to take care of oneself, Erickson (2013) posits that “humans are inherently intuitive ... we know what we need” (p. 190). Thus an individual's perception of well-being reflects the ability to adapt to changing circumstances, and not merely the absence or presence of illness (Erickson, 2013). Furthermore, the older adult's well-being benefits from experience and perspective developed over time, as individuals adopt different strategies and processes to facilitate the process of ageing with depression. The capacity for resilience, for

example, is a determinant of how a person may approach ageing with depression.¹⁸⁰ Individual experience and the perception of illness—in this case, depression—also influences each person’s capacity to optimise well-being, as the individual draws on regulatory skills¹⁸¹ that have developed over time to maintain or improve their health status (Charles & Carstensen, 2010; Turner et al., 2015). Conversely, there is a correlation between greater anxiety and negative health consequences and/or symptoms (Charles & Carstensen, 2010). The implication is that greater capacity would strengthen individual efforts towards *Reclaiming Self-identity*.

10.2.2 Resources to support self-management

Assuming individuals have the individual capacity to optimise well-being, they must then draw on the resources available to them to enable effective self-management of depression in older age. The resources considered central to the self-management of depression in general—that is, not only in older age—include a safe and enjoyable neighbourhood environment, availability of healthy food to enable a healthy diet, access to places for physical activity, social support and information on self-help techniques (Yeung et al., 2010). Financial circumstances are also relevant in this regard, as they frequently determine the extent to which individuals can access certain treatment or support. Community resources and services are also integral to optimum self-management, as they assist individuals to manage the medical and psychological elements of their illness (Bartlett et al., 2013; Saito et al., 2012). It is likely that the need for these resources will vary as participants respond to the changeable nature of depression.

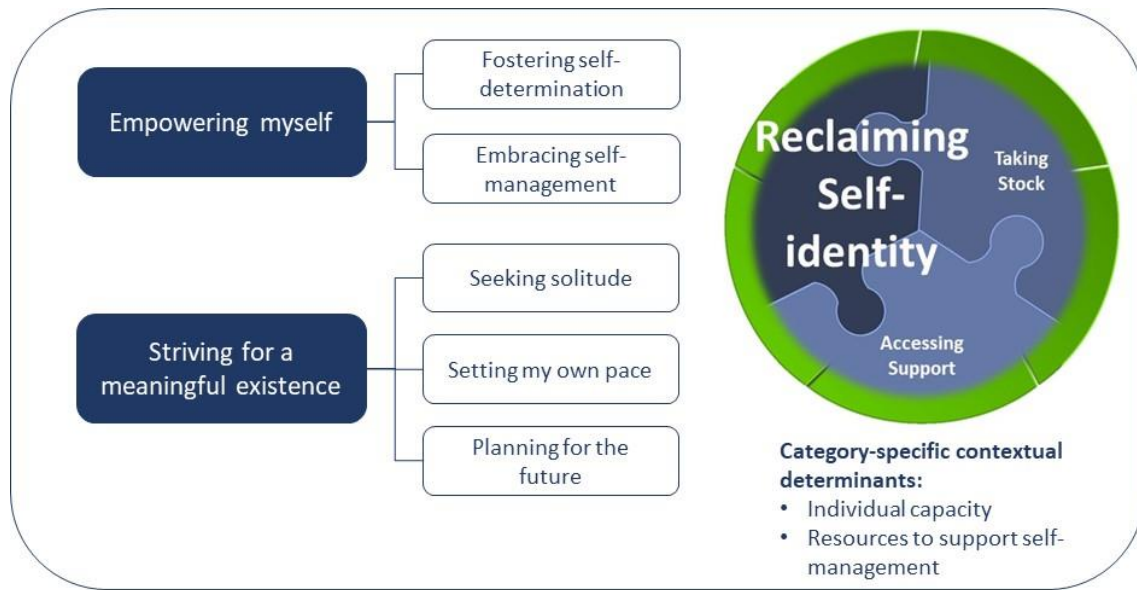
10.3 Strategies for Reclaiming Self-identity

Two main strategies for *Reclaiming Self-identity* were abstracted from the data: *Empowering myself* and *Striving for a meaningful existence* (Figure 8). These strategies represent the ways in which participants focus on the process—rather than the outcome—of optimising well-being as they age with depression.

¹⁸⁰ Despite frequent reference to resilience in health research, there is no universally accepted definition of the term. However, in the current context, resilience implies the ability to overcome adversity, adapt and adjust to a change in health status.

¹⁸¹ Regulatory skills refer to the personal processes that mediate how an individual interprets and responds to changes in life circumstances. For example, older adults typically use life experience to regulate their emotions more effectively (Charles & Carstensen, 2010).

Figure 8: Reclaiming Self-identity



10.3.1 Empowering myself

Broadly, empowerment enables individuals to improve mastery over their individual circumstances, which, in turn, has a positive effect on their overall well-being. Self-empowerment is particularly important for people with chronic or long-term illnesses, including depression, as it promotes their autonomy and expertise in living with the condition (Coulombe et al., 2016; McDonald, 2014). Participants empowered themselves by *Fostering self-determination* and *Embracing self-management*.

10.3.1.1 *Fostering self-determination*

The first strategy for *Empowering myself* was *Fostering self-determination*. Corrigan et al. (2012) define self-determination in a single word: “choice” (p. 170). The choice—and ability—of participants to make their own decisions about optimising their well-being as they aged with depression was a central theme in the data. Within the paradigm of self-determination, participants sought to take control of their decisions and behaviours associated with depression. This allowed them to determine the appropriateness of a treatment, while balancing their perceptions of various interventions with their personal preferences. The capacity to foster self-determination is associated with a certain level of

personal insight, self-confidence, competence (self-efficacy) and motivation (Corrigan et al., 2012; Piltch, 2016).

I try to think about what needs to be done and have a positive outlook on it ... and aim for a positive outcome, because that's the way it will be. (Sarah, 71 years)

Self-determination was fostered by accessing information about the symptoms, diagnosis and treatment of depression, enlisting adequate informal support and enacting a willingness to engage in different interventions and strategies. Participants described the ways in which they explored, identified and initiated the process of self-determination, although few of them used the actual term.

For me, it's not necessarily [about] the implementation [of a strategy], but the capacity to be able to address an issue, identify the aspects of the issue and find it inside yourself—as well as seeking guidance and advice from other people who can be of assistance—to be able to address the issue [depression]. (Sean, 74 years)

Self-determination is closely associated with self-management: adjustments to illness last longer and are more effective when individuals are autonomously motivated (Ng et al., 2012), while a sense of self-determination supports active involvement in managing a chronic illness (Gearing et al., 2014).

10.3.1.2 *Embracing self-management*

The second strategy for *Empowering myself*, *Embracing self-management*, reflects participants' belief and confidence in carrying out behaviours and actions to optimise well-being. Within the current context, self-management encompasses the methods, skills and strategies used by individuals to take care of themselves and manage their depression (Yeung et al., 2010). It typically involved an in-depth understanding of the symptoms, treatment and triggers of depression, and collaboration with a health professional.

The terms used by participants to describe and explain their individual strategies for managing their depression included “looking after myself”, “self-care”, “taking care” and, less commonly, “self-management”. When prompted by the researcher, however,

they acknowledged that the concept of self-management encompassed their strategies for optimising their well-being as they aged with depression.

For me, it's using a very planned approach to it [managing depression], trying to keep yourself reasonably organised and focused and being aware that you do need physical activity. (Adam, 66 years)

I haven't thought of that term, self-management. Self-care, I have. I think it's being kind to yourself, really, and not judging yourself. If you can't do something, well, you can't do it. (Erica, 70 years)

Participants generally associated self-management with actively participating in their treatment and daily activities.

I think I look after myself well. Self-management is not to let yourself go, you know, you dress reasonably well, you keep yourself clean, keep the house in order. (Maurice, 82 years)

I think self-management is looking after yourself to the very best of your ability. It's looking after your health problems, it's trying to be good to other people. It's being good to yourself. To me, that's self-management. (Jenny, 77 years)

However, several explained that their main strategy for self-management of depression constituted avoiding negative influences—in other words, avoiding people or things that made them feel worse about themselves or the world. One of the main strategies used by participants to avoid negative influences was not watching or listening to the news. They also sought to limit the amount of time they spent with people they considered to have negative attitudes about life.

I just turn the news off. It drives me to distraction. Really catastrophic things ... I've had enough of that, not making me feel good. (Sue, 68 years)

You can't afford to spend too much time with people who are depressing. (Gillian, 73 years)

Most associated avoiding conflict or stressful situations with self-management.

I avoid conflict. Saying no to things is also really good. Don't do something you know you can't cope with. And I avoid stressful situations ... [I want] a stable, simple life. Stability is good, when you haven't got the ups and downs. (Sue, 68 years)

I don't like crowded rooms or loud people, you know. I avoid them at all costs. Knowing your triggers is a very important strategy to survive. (Paul, 69 years)

By *Embracing self-management*, participants felt that they could enjoy a better quality of life, than if they were passive recipients of treatment. Becoming informed and engaged, trialling and modifying strategies, and enlisting formal and informal support laid the foundation for participants' individual efforts to self-manage their depression. A sense of empowerment through responsibility and active involvement in managing their illness formed the foundation for participants to build a satisfying and meaningful life. However, a small number of participants did not feel that they were managing their depression particularly well, nor that they were currently optimising their well-being.

I don't think I've managed it. You know, I think I've just kind of sat it out [lived with it]. I'd like to be living differently. (Bea, 67 years)

If I'm really self-managing, it's turning up at the doctors, it's taking the tablets, and it should be eating the right foods and all that sort of thing. Taking responsibility, I suppose ... although I'm not very good at responsibility [laughs]. (Vera, 69 years)

Bea's difficulty in managing her experience of depression was largely due to low motivation, as she struggled to see much purpose in her life at the current time. Illustrating another perspective, Vera's expectations of ageing as a generally negative experience resulted in a lack of motivation to engage in behaviour that may enhance her well-being and overall quality of life. While Bea struggled to maintain and enhance her well-being, Vera presented a sense of resignation about her mental and physical health as she aged.

10.3.2 Striving for a meaningful existence

There is a natural tendency for people to seek meaning in their existence, most noticeably as they get older (Miller & Reynolds, 2012). The perception that life is meaningful is associated with a higher overall quality of life and slower age-related decline in older age (Boyle, Buchman, Barnes, & Bennett, 2010). People who report having meaningful lives are more inclined to employing adaptive coping strategies when unwell (Heintzelman & King, 2014), a finding which resonates with the data collected in the current study.

10.3.2.1 *Seeking solitude*

There is strong evidence that being alone often results in a sense of loneliness, which is strongly associated with depression (Saito et al., 2012; Sheridan et al., 2014; Van Beljouw et al., 2014). In older adults, risk factors for loneliness include being confronted with a partner's decline in health, the death of a partner and reduced social activities due to poor health or disability, often leading to a sense of social isolation (Cloutier-Fisher et al., 2011; Qualter et al., 2015).¹⁸² As a result, the researcher did not expect to hear that most participants preferred living alone and used being alone as a self-management strategy. A clear theme of participants needing and enjoying their own company as a strategy for self-managing their depression was abstracted from the data. Being alone was central to the well-being of most participants, who considered attending to their own unique needs for solitude as a necessary factor in *Striving for a meaningful existence*. Thus, solitude as “a voluntary distancing from one's own social network” should be distinguished from the involuntary experience of loneliness (Ong et al., 2016, p. 444). The need to corral time for themselves was apparent among participants who lived alone or with someone else, including those who were in close personal relationships.

[Living alone is] *wonderful. I have done for 30 years nearly since my marriage broke up. Got totally used to my own presence, my own place, where things are, even if they're a bit of a mess.* (Greg, 67 years)

I love being alone. To me, I savour every second. I love my husband and dog, but when they're out, I love it. There's no noise. You can think. I'll often engage [unplug] the phone for hours because I don't want it to ring. I don't see it [being alone] as a downside ... I absolutely love it. I make sure I have plenty of time on my own. (Mia, 66 years)

For some, the need to be alone influenced decision-making about personal relationships.

I was going out with a lady for quite a while, a lovely girl, but she wanted to move in and stay over, stay on. I didn't want her to stay with me. I prefer my own company. (Vince, 74 years)

Really, I just want to be alone. I wouldn't mind a really nice man, but, you know, just for certain parts of my life. I certainly wouldn't want to share living accommodation with him. (Gillian, 73 years)

¹⁸² See 2.3.2 (Depression in older age).

Through additional probing into whether participants identified a correlation between depression and loneliness, it became apparent that their need for solitude was a positive self-management strategy, and not a reflection of being in a depressed state. Pete, who lives with his wife, explained his belief that his depression was, in fact, the result of trying to meet societal expectations of actively participating in social activities against his will, while Lorna identified living alone as a strategy to manage her everyday responsibilities.

I've always felt I was an observer, rather than a participant in life, and over the years, I guess I haven't really wanted to [fit in]. There was always a lot of pressure on me to do things that I didn't feel I could manage. I think the depression is a result of trying to live with that. (Pete, 75 years)

One of the ways of keeping the depression at bay is to not overload myself with responsibilities, real or imagined. So, living alone is fabulous. I'm living alone because I want to. When you live on your own, you can get away from it all. And if you want to go out and talk to people, it's not hard. (Lorna, 68 years)

These exemplars illustrate the importance of solitude for participants as a strategy for *Striving for a meaningful existence*, while presenting an opportunity for further investigation into when and why older adults with depression sometimes choose to be alone. This finding provided the impetus for the researcher to seek studies that challenged the often-held assumptions about loneliness in older age. These included a study of the resources that compensate for loneliness in older adults, conducted by Zebhauser et al. (2015), which reported that 70% of older adults who lived alone expressed no feelings of loneliness. Similarly, a study into meaning in life in older adults with depression (Volkert et al., 2017) found no association between social isolation and depression.

I'm actually very happy on my own. I keep in touch with a few people up, quite a few really, but I'm never lonely, I'm never lonely. (Tony, 73 years)

10.3.2.2 *Setting my own pace*

Closely associated with *Seeking solitude*, the strategy of *Setting my own pace* was used by participants to plan their time and priorities in a way that allowed maximum comfort or enjoyment, while minimising their stress. Most used diaries, calendars or notes to list their activities and tasks. Participants also set personal goals as a way of motivating themselves and monitoring their progress. However, they were careful not to view any goals they did not achieve as failures.

I have my diary or a pad with me, and I plan what I'm doing every single day. If I don't achieve it, it doesn't matter ... and on the bad days, I stay in bed and watch rubbish on television. (Fiona, 68 years)

The importance of having a routine was highlighted by several. By organising their time in a way that was predictable or by following a familiar sequence, they felt more able to manage their time and overall stress.

For me, it's important to have routine. Every day there's something. I have, you know, a little diary that I write everything in. (Rita, 67 years)

This strategy was particularly important when participants felt more stressed or anxious than usual, or if they felt challenged by a specific responsibility.

What I actually do with any task that looks a bit daunting, is that I break it down to small things. (Janet, 67 years)

I would say part of my self-management is that I've orchestrated my life to have no imperatives. So, I feel I have no pressures, and that's been my personal way of making life pleasant. (Pete, 75 years)

As a younger man, Adam had enjoyed a successful career. With his wife, he had undertaken several major travel adventures. However, he attributed the loss of his ability to effectively plan ahead to his depression. As a result, Adam redefined his expectations of the future in a way that reflected his current capacity, as he sought to establish goals that seemed more appropriate and achievable.

It's about having some targets or goals and writing notes ... and not getting too frustrated when you only get half the list done. (Adam, 66 years)

10.3.2.3 *Planning for the future*

In addition to current needs, participants' perceptions of the future, and the anticipation of future needs, also had implications for subjective well-being. As a strategy for *Striving for a meaningful existence*, participants were *Planning for the future*. These needs ranged from practical support in the home, to health-related and social needs, and financial considerations. With these factors in mind, participants were considering their short- and long-term needs.

I care for myself in that I cook for myself and so forth, but as a little bit of help, I get an hour and a quarter once a fortnight from the council. It does fine, and if I needed more help, I can go there. (Greg, 67 years)

In a study into the health care preparation of older women, Girling and Morgan (2014) found that potential care needs were perceived along a continuum, ranging from proactive, autonomous care to complete avoidance. Participants in the current study who were already accessing a type of support service¹⁸³ felt confident in increasing their current level of support, or sourcing new services, as their needs changed.¹⁸⁴

Somebody came [to a community meeting] and told us all the things that the government can do for you to stay in your own home. In the future, we'll have to put some ramps in, just in case ... so that's planning ahead. I've got a huge envelope of stuff the [government service] can do for us. (Stephanie, 71 years)

I probably would need, just maybe, [help with] shopping ... you know, you need food. And, I guess, showering. Maybe a little bit of cleaning; not too much ... that sort of help. (Sarah, 71 years)

Although most participants hoped to remain in their own homes, several planned to move into a retirement village. None wanted to move into residential aged care.

That's a fear I have, that I may have to go into a home ... I'd rather die before that. (Maurice, 82 years)

10.4 Summary

Reclaiming Self-identity is a category that represents the inter-related and inter-dependent strategies and sub-strategies participants used to empower themselves and have a meaningful existence. A commitment to self-determination and self-management were central to participants' sense of identity, as they sought to manage their depression in a way that enabled them to optimise their overall well-being. Founded on the previous strategies of *Taking Stock* and *Accessing Support*, *Reclaiming Self-identity* was central to participants' efforts to age well with depression.

¹⁸³ Such as domestic help, assistance with shopping or gardening services.

¹⁸⁴ The ability to look ahead and plan for future needs is an element of health literacy and a fundamental component of self-management (Chambers et al., 2015).

CHAPTER 11

Core category and theory

11.1 Introduction

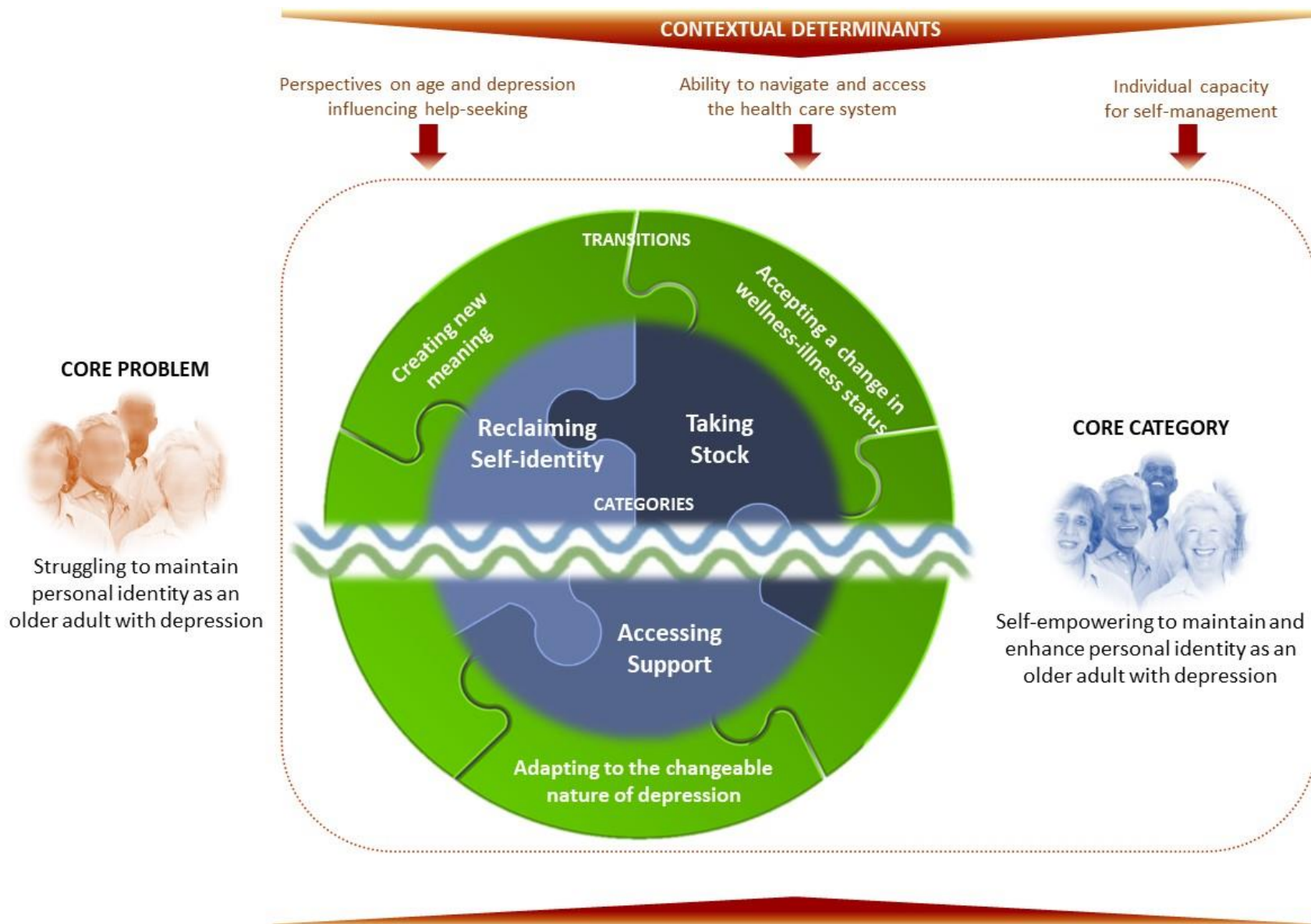
The purpose of this chapter is to present the core category, or theory, before presenting the substantive theory. The core category of the current study was identified as *Self-empowering to maintain and enhance personal identity as an older adult with depression*. This statement represents the central theme of the study, as participants responded to the basic social psychological problem of *Struggling to maintain personal identity*. By linking the central theoretical construct—the core category—with the other categories, strategies and contextual determinants, the study’s findings are raised to the level of theory. The core category is generally representative of the substantive theory.

11.2 Self-empowering to maintain and enhance personal identity

As the central explanatory concept, the core category summarises the main idea expressed in the study, as it connects a frequently occurring variable with each category and strategy to form a theory (Corbin & Strauss, 2015). With this in mind, the researcher was able to identify the major theme of the research in the way that Glaser (2007) articulated: “researchers tend to see their core category everywhere” (p. 14).

The general requirement of a core category—that it addresses the multidimensional factors associated with the core problem—is fulfilled by the conception of *Self-empowering to maintain and enhance personal identity as an older adult with depression* (Figure 9). The conceptual framework is theoretical, in that it is sufficiently abstract to illustrate the most overarching experience of participants. It is also pragmatic, as it explains how participants respond to the diagnosis of depression and adapt their actions and interactions in ways that enable them to optimise well-being.

Figure 9: Diagrammatic representation of the core category and theory



Deliberate selection of the words “maintain and enhance” reflects this ongoing process of action/interaction in response to the problem (MacDonald, 2001; Strauss & Corbin, 1990). Constant change demands a flexible set of responses, by which individuals can determine and respond to a certain need, at a given time. Thus, the core category represents a dynamic, cyclical pattern of responses to the core problem. This process is not linear but follows a course that is influenced by distinctive but mutually related phases, or transitions.

The core category encompasses interlinked conceptual elements relating to empowerment, a sense of personal identity and self-management of depression. Self-empowerment refers to the multi-dimensional social process by which participants sought to gain control over the factors that were shaping their lives. It is typically cultivated when individuals can build the capabilities to gain some level of control over their lives (McDonald, 2014). Essential components of self-empowerment included overcoming barriers to harnessing support and building their knowledge about depression and treatment options, so that participants could become active agents in their lives. Receiving reliable and timely information, and being able to access their preferred formal and informal support, facilitated participants’ efforts to reduce the adverse impact of depression on their overall well-being and quality of life.

By drawing on the internal and external resources available to them as individuals—not simply as members of a group of older adults or people with depression—participants demonstrated a sense of empowerment in their efforts to achieve mastery over their own lives. Self-empowerment is closely associated with self-determination and self-management, both of which were embraced by participants as preferred approaches to meeting their own needs and preferences as older adults living with depression. Consequently, self-empowerment boosts confidence, coping ability and overall health outcomes (McDonald, 2014). It is particularly important for the effective management of long-term or chronic conditions, including depression (Coventry et al., 2014; Ellis et al., 2017). As a highly subjective and individual concept, self-empowerment encapsulates a perception of belonging, achievement and satisfaction in one’s own being. It forms the foundation from which individuals experience their daily lives (Coulombe et al., 2016).

Thieme *et al.* (2013) identify a stable sense of self as essential for achieving mental well-being and improved quality of life, both of which were highlighted as goals for participants. By integrating their sense of self into their strategies for managing depression, participants reported increased confidence in improving their well-being. The concepts of self and identity should also be considered within the context of later life, as goals and aspirations typically change over the life course. These changes are invariably related to transitions (Chick & Meleis, 1986).

11.3 Transitions

People experience multiple transitions throughout their lives. The definition of transitions as passages “from one life phase, condition or status to another” (Chick & Meleis, 1986, p. 239) reflects their inherent sense of movement, direction and flow over time (Schumacher, Jones, & Meleis, 1999). Although the experience is unique and subjective, transitions are often conceptualised as stages of life. Transitions occur over time, but the movement from one situation or life phase to another is triggered by an event which requires new skills or behaviours (Meleis, 2015).¹⁸⁵ The impetus for a process of transition begins at or before the actual trigger event, and extends beyond it (Meleis, 2015). While the change is precipitated by a significant event that represents a turning point for the individual, the transition experience is a more fluid process (Meleis, 2015). In addition, the duration of a transition varies according to the nature of the change event and the extent to which it influences the individual’s sense of identity and patterns of behaviour (Chick & Meleis, 1986). At different junctures, the transition requires a redefinition of self, as individuals develop different views of themselves, their problem and their expectations of the future (Karp, 2017).

Many transitions associated with older age are welcomed and positive, such as starting a new endeavour or enjoying time away from work commitments (Schumacher *et al.*, 1999). However, older adults are also likely to experience negative transitions, such as the loss of a spouse or friends, or the onset of a chronic health condition. Often accompanied by grief, uncertainty and fear, these experiences require that the individual

¹⁸⁵ Strauss (1992) referred to experiences which require individuals to see themselves in a different light as “turning points in identity”.

learn new behaviours and adaptive coping strategies, and access appropriate resources (Meleis, 2015). One example of a transition associated with ageing is the common necessity to change living environments, either by relocating to a more supportive home, or by adapting the current home to the individual's changing needs (Perry, Andersen, & Kaplan, 2013). Another common transition for older adults concerns the subjective experience of retirement. In a study of the impact of retirement on the mental health of older adults, Mosca and Barrett (2016) found that involuntarily retirement, including early retirement due to ill-health, had a particularly strong negative effect on older adults' mental health. Similarly, Dingemans and Henkens (2015) demonstrated an association between involuntary retirement and decreased self-efficacy and life satisfaction in later life. An unhealthy transition into retirement, characterised by feelings of grief, loss of identity and a sense of social disconnection, could have an adverse effect on an individual's overall well-being (Djukanović & Peterson, 2016). Thus, while transitions frequently concern a change in people's health or illness state (Chick & Meleis, 1986), the transition to retirement may increase older adults' risk of health problems (Ducharme, Lévesque, Lachance, Kergoat, & Coulombe, 2011; MacKean & Abbott-Chapman, 2012).¹⁸⁶

Triggers for transition may be developmental, situational or organisational, or health-illness related (Meleis, 2015). Developmental, or lifespan, transitions concern life phases due to age—such as adolescence, ageing or menopause—or changing roles—for example, becoming a parent, getting married or retiring from employment (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Ducharme et al. (2011) describe situational transitions from the perspective of individuals taking on caregiver roles, for which new knowledge and self-confidence are needed to manage a new situation. The experience of migration is another example of a situational transition (Meleis et al., 2000). Examples of transitions linked to organisational rules and functioning include staffing changes, or the introduction of new technology or systems (Meleis, 2015).

Health-illness related transitions are experienced as a change in health or illness status, particularly one that requires formal diagnosis and treatment (Meleis, 2015). Although a

¹⁸⁶ However, voluntary retirement has not been associated with a decline in mental health (Mosca & Barrett, 2016).

transition may commence with a decision, diagnosis, symptom or event, its end—a much more fluid process—occurs when a new skill has been learned or a sense of well-being has been achieved (time or time span) (Meleis, 2015). A successful health transition occurs when cognitive, behavioural and interpersonal processes enable individuals to move towards well-being. Conversely, unsuccessful transitions occur when they move them towards vulnerability and risk (Schumacher et al., 1999). Health care professionals are well placed to facilitate successful transitions, by providing timely and appropriate information, education and support (LaManna, Bushy, Norris, & Chase, 2016). However, older adults and their significant others do not always receive the support they need during a transition (LaManna et al., 2016; Schumacher et al., 1999; Son & You, 2015). Examples include older adults being discharged from hospital without proper home-care supervision arrangements in place (Son & You, 2015) and difficulties associated with transition to palliative care (Martz & Morse, 2017). Thus, is it significant to the current study that successful transition is associated with improved self-management of long-term conditions, including depression (Long, Briggs, Long, & Astin, 2016).

In the current study, the commencement of the transition may have been experienced with some uncertainty, while the diagnosis formalised the transition. Despite the uniqueness of each participants' change event, two common triggers became apparent from the current data: the realisation that something was wrong with how they were feeling, and the experience of receiving a formal diagnosis of depression. Participants' initial evaluation and judgements about their well-being and quality of life provided the impetus for *Seeking answers*. This, in turn, led to *Accessing Support* and *Reclaiming Self-identity*. Finally, the individual, societal or global conditions under which a transition occurs may enable or hinder the achievement of a successful outcome (Meleis et al., 2000). Examples of these influencing factors include an individual's beliefs or expectations, the availability of support or resources, and policies that determine how certain illnesses are diagnosed and treated (Meleis, 2015). In a study of diagnosis and suffering as processes of depression, Petersen and Madsen (2017) considered the ways in which individuals responded to and ascribed meaning to the symptoms, diagnosis and experience of depression. Their finding that individuals “vacillate in and out of various perspectives on handling depression” (Petersen & Madsen, 2017, p. 30) illustrates how a transition

process is experienced, as individuals seek practical and effective strategies that meet their specific needs and preferences. Karp (2017) uses the term “depression career” (p. 73) to describe the discernible stages, turning points and processes individuals experience as they interpret and respond to their depression over time. Similarly, Schumacher et al.’s (1999) earlier work on older adults in transition explains the importance of redefining meaning, modifying expectations, developing new knowledge and skills, restructuring life routines, and maximising opportunities for choice and personal growth. These findings resonate with those of the current study in illustrating how a successful transition may be experienced when the individual gains mastery of, and becomes competent in, managing the new situation (Petersen & Madsen, 2017; Schumacher et al., 1999).

11.3.1 Transitional themes

The process by which the core category is experienced occurs along three inter-connected transitional themes: *Accepting a change in wellness-illness status*, *Adapting to the changeable nature of depression*, and *Creating new meaning*. These themes reflect the sequence of events whereby an older adult receives a diagnosis of depression, accesses support and then seeks to reclaim a sense of self-identity. However, the experience of depression does not have a beginning, middle and end phase.

The first transitional theme, *Accepting a change in wellness-illness status*, typically involved the reconstruction of a sense of self, as participants considered how to best respond to the diagnosis of depression and its impact on their daily lives. In the second transition, *Adapting to the changeable nature of depression*, participants recognised the changeable nature of depression, how they engaged in a process of continuous adaptation to how they were feeling on a given day, and the way in which they planned for the future. In the third transition, *Creating new meaning*, participants sought to identify and enact strategies to improve their well-being and sense of self. These transitions were experienced along a continuum, as participants moved back and forward in response to experiences and change. Although each participant’s interpretation of the depression process was different, regularities in the sequencing of accepting, adapting and creating new meaning were apparent.

11.3.1.1 *Accepting a change in wellness-illness status*

Individuals who receive an illness diagnosis—particularly one for a long-term or chronic illness—frequently experience a change in their sense of identity, as they find themselves having to moderate their responses to a disruption to their lives and redefine their sense of self (Kralik, Visentin, & Van Loon, 2006; Meleis et al., 2000). This interpretive process about the meaning of symptoms often begins before the individual enters the doctor's office (Karp, 2017). In the current study, several reported the experience of receiving a diagnosis of depression as disempowering and depersonalising. These views are consistent with Meleis' (2015) description of the sense of loss or disruption to individuals who receive a medical diagnosis. In the current context, the experience of the change event was exacerbated by prevailing views of older age as a time of decline and loss of independence (Aylaz et al., 2012; MacKean & Abbott-Chapman, 2012). Thus, the first transition for participants was to accept a change in their wellness-illness state, which had been confirmed by the formal diagnosis of depression.

You have to take responsibility for yourself. You cannot leave the whole management of any illness in the hands of the medical profession. It's your body and it's your brain ... only you can rejig [fix] it. (Mia, 66 years)

In addition to context-specific factors, the meaning and values attributed to change triggers and transition processes are further influenced by broader concepts relating to time (or time span), process, experiences, milestones and conditions (Meleis, 2015).

Well, I suppose I'm not the only person in this world, at my age, to be suffering a bit of depression. I suppose each person tackles it in a different way. (James, 71 years)

11.3.1.2 *Adapting to the changeable nature of depression*

The second transition recognised the changeable nature of depression, whereby participants experienced “good days” and “bad days”, and made comparisons between how they felt and “being normal”. Participants described that their efforts to continually adapt to living with depression reflected short and long-term challenges and goals. By detailing their unique experiences and insights, it was apparent that participants had to make daily adjustments—for example, by reducing the number of tasks they expected to

complete in a day—as well as revise their long-term plans, such as renegotiating plans to travel in older age.

I really used to be a planner and structured, systematic person ... it's quite dramatically changed from that point of view. I don't really feel that inclined or as motivated as I would have once been. (Adam, 66 years)

Consistent with transitions theory, the way participants adapted to the change in their wellness-illness status was influenced by their personal beliefs about depression, and the knowledge, skills and resources available to them to optimise their well-being. In addition, the level of engagement by individuals in the change event is an important indicator of how they might engage in the transition process (Karp, 2017; Meleis, 2015).

11.3.1.3 *Creating new meaning*

The third transition reflected participants' efforts to identify and enact opportunities to create new meaning in their lives. This included pursuing practical, short-term strategies for improving their well-being and sense of self, as well as longer-term ways of being. Prevailing attitudes regarding age and depression¹⁸⁷ may also influence the meaning attributed to certain triggers and transitions by individuals, significant others, and health professionals. From this perspective, Meleis (2015) acknowledges the conditions—including ageism—that may promote or inhibit successful transitions. In addition, the meaning derived from their transition may influence individuals' perceptions about their past, current circumstances and future.

Because transitions involve fundamental changes in individuals' views of themselves and the world, their well-being may be affected when their sense of self is disrupted by the meaning and values they attribute to the change event (Meleis, 2015; Meleis et al., 2000). However, new meaning can be created through the adoption of a new identity, which may, in turn, promote adjustment to the transition (Kralik et al., 2006).

I mean, it's no good trying to cure the depression. It's here. I think it's here to stay. What I need to do now is manage my life. And the best way that I can and the way to do that, is getting strategies to deal with stuff. (Bea, 67 years)

¹⁸⁷ See 2.3.2 (Depression in older age).

Creating new meaning allowed participants to integrate a change in their wellness-illness status in a meaningful way. This is consistent with the statement by Kralik et al. (2006), that successful transition depends on the individual's capacity to reconstruct a valued sense of self. A successful transition occurs when feelings of distress are replaced with a sense of well-being and mastery of the situation.

11.4 Theoretical integration

According to Morse (2001), the researcher's ability to raise conceptual findings to the level of an integrated grounded theory determines the quality of the final product. It is through theoretical integration that a theory is formed by linking the study's different conceptual elements around a core category.¹⁸⁸ These elements include contextual determinants, the core problem, the core category, the three categories and their related strategies. In the current study, this process resulted in the generation of the core category of *Self-empowering to maintain and enhance personal identity as an older adult with depression*. Corbin (2015) views this process of theoretical integration as a "research adventure" (p. 187), as the grounded theory researcher discovers concepts and develops theoretical statements that come together to explain the phenomenon under study. By separating essential concepts from less important ideas, the researcher strives to abstract a theory that is parsimonious (simple), but true to the data (Eisenhardt, Graebner, & Sonenshein, 2016).¹⁸⁹

The current theory represents an abstract rendition of the original data, although it is the researcher who interpreted and organised the concepts. Initial codes were entered into a database, while memos and diagrams were used to facilitate the integrative process by which relationships between concepts, and unifying concepts, were progressively organised to support development of the theory. During the process of theoretical integration, the researcher found it particularly helpful to verbalise the research findings with her supervisors, other colleagues and even friends. Through this interactive process, the researcher could develop a coherent and logical story of the research findings. By addressing questions or comments posed by others, the researcher then refined the theory,

¹⁸⁸ See Figure 9: Diagrammatic representation of the core category and theory) in Chapter 11.

¹⁸⁹ See 4.7.1.1 (Evaluating grounded theory research).

creating novel explanations of and adding new insights into the phenomenon. However, it should be reiterated that the researcher's sensitivity to the data remained the central approach to data analysis.

An exemplar case can be used to illustrate how the overarching theory is applied. Mia, 66 years old at the time of interview, was 58 years old when she was first diagnosed with depression. In the weeks leading up to her diagnosis, Mia acknowledged that she had become reluctant to leave her home or answer the telephone, and often found herself sitting quietly for hours. By evaluating her current predicament, Mia made an appointment with her local GP, who confirmed her suspicion that she might have depression. Mia's previous personal and work experience with health professionals enabled her to make sense of and comply with treatment options, and she quickly benefited from her prescribed medication (first transition: *Accepting a change in wellness-illness status*). She sought additional information on depression and treatment options online and from her local council. However, she declined the opportunity to attend psychotherapy, maintaining that talking about her problems would not make them go away. In so doing, Mia sought to enlist support that met her individual needs and preferences. She refused to allow external expectations of her age or the diagnosis of depression to define her. However, she had to change the way she viewed herself, as her initial diagnosis had made her feel like "a failure". She initially tried to fight against the depression, but then accepted the futility of her efforts and realised that she should "try and find how I can fit in my needs with what's happening". Although she felt that stigma about depression was still common, she shared her experiences with friends and family, and benefited from their support.

Mia was motivated and resourceful in the ways in which she sought to optimise her well-being as an older adult with depression. She felt strongly that she should take responsibility for her well-being, but explained that she also allowed herself "a few days to wallow in self-pity ... and then I think, okay, shut up, just get out there and do what you can do" (second transition: *Adapting to the changeable nature of depression*). Mia referred to "self-preservation" when she explained her need for solitude, to attend her daily exercise program and to pursue her creative interests. It was this flexible, responsive

approach to how she experienced and responded to her depression that allowed her to have a meaningful existence (third transition: *Creating new meaning*).

As a second exemplar of how the theory was abstracted from the data, the case of Vince, 74 years old at the time of interview, is presented. Vince worked in a demanding and stressful job for many years. During a major organisational restructure, he experienced what he thought was a panic attack when he was 62. He presented to the emergency department of a local hospital, fearful that he might have a heart attack. No physical issues were identified and he was sent home. Vince thought that health professionals routinely treated older adults differently and felt that his symptoms and frightening experience had been inadequately investigated. For several days, Vince was unable to get out of bed. Mystified by how he was feeling, he finally mobilised himself to see his GP, who took little time in suggesting a diagnosis of depression and prescribed antidepressant medication. Having known his GP for many years, Vince trusted his diagnosis and saw no need to seek more information about depression (first transition: *Accepting a change in wellness-illness status*). Antidepressant medication is the most common treatment administered to older adults with depression, but after several months, Vince asked his GP if he could discontinue the medication, as it made him feel lethargic. He then accessed a psychologist, from whom he learned effective techniques to cope with his depression. One of the techniques was positive visualisation, which allowed Vince to “cleanse himself”. It was through this “form of self-hypnotherapy” that Vince learned to “be careful that [you] don’t fall all the way into that black hole”.

By increasing his self-awareness, Vince realised that he needed to keep himself busy with a fairly structured daily routine. One of his strategies was to go online to identify events or activities that interest him and mark them in his calendar (second transition: *Adapting to the changeable nature of depression*). Although he described himself as a loner, Vince participated in several group activities and felt comfortable with his informal support network. However, his favourite activity was to use public transport to travel to different parts of the city, and to nearby regional towns. He enjoyed the outing, but always carried a crossword puzzle, so that he did not have to engage with strangers. He also regularly looked after his grandchildren, which gave him great pleasure (third transition: *Creating*

new meaning). Vince had identified ways to manage his own experience of depression but remained frustrated by common misconceptions about depression. He cited examples from within his social network, and in the broader community, of depression being viewed as “a bad word”. He also railed against being treated differently or unfairly due to his older age. Hence, Vince found that his age was a greater threat to his sense of identity than his diagnosis of depression.

These two exemplars illustrate that how the basic social psychological problem of *Struggling to maintain personal identity* was experienced by participants but was not necessarily clearly articulated.

11.5 Summary

This is the last of seven chapters that present the findings of the study. In this chapter, the core category is presented, representing participants’ response to the basic social psychological problem. The core category appears frequently in the data and connects all other categories and strategies. It takes place over time, requiring participants to engage in a continuous process of adaptation and change in response to the diagnosis of depression. This process is represented by the transitional themes of *Accepting a change in wellness-illness status*, *Adapting to the changeable nature of depression* and *Creating new meaning*.

CHAPTER 12

Discussion

12.1 Introduction

In this chapter, the results of the study are discussed. The chapter commences with a review of the principal findings, with reference to the research aims. The substantive theory of *Self-empowering to maintain and enhance personal identity as an older adult with depression* is then considered. The three categories that represent the major conceptual processes underpinning the core category are then discussed. Results are considered within the context of the contemporary literature on depression in older age, and new findings situated within a broader knowledge base. The concept of self-management of depression in older age is then considered.

12.2 Principal findings

The overall aim of the current research was to explicate how older adults with depression self-managed their illness to optimise their well-being. This aim was addressed by a substantive theory that defined the core problem, explicated contributing factors and considered interrelated transitional themes that caused or resulted from a change in a person's life, health and relationships. It was extrapolated from the data that each participant responded to the situation of *Struggling to maintain personal identity* by *Self-empowering to maintain and enhance personal identity as an older adult with depression*. As older adults with depression, they sought to optimise well-being through three transitional processes: *Accepting a change in wellness-illness status*, *Adapting to the changeable nature of depression* and *Creating new meaning*. They did so through the three interlinked processes of *Taking Stock*, *Accessing Support* and *Reclaiming Self-identity*. Participants organised their experiences, strategies and preferences into flexible, yet systematic, processes of action and interaction, set within a context of mental health stigma, the health care system and individual capacity for self-management. Conceptually, the core category represents experiences, meanings and actions shared by all participants.

12.2.1 The substantive theory

The substantive theory, presented in detail in the previous chapter, provides a comprehensive understanding of the conceptual links that contribute to the structure and process of the categories of data. All salient properties and dimensions of the data are contained in *Taking Stock*, *Accessing Support* and *Reclaiming Self-identity*. Concepts derived from the data are linked by relational statements that apply generally to all participants (Corbin & Strauss, 2015). These are influenced by three contextual determinants: *Mental health stigma*, *The health care system*, and *Capacity for self-management*. Conceptual density serves as a foundation for a theory that offers precision and explanatory power. Conceptual density is achieved through an examination of the “emic” view of the phenomenon, by which the researcher uncovers the meaning participants give to their experiences.¹⁹⁰ In addition, the current theory accounts for variation, which increases its reach and explanatory power. Variation may be illustrated by the ways in which participants enter, respond to and move between the three transitional themes of *Accepting a change in wellness-illness status*, *Adapting to the changeable nature of depression*, and *Creating new meaning*. As Corbin and Strauss (2015) note, “In other words, a researcher has to do more than come up with a list of categories or themes” (p. 139). The more data are collected, the greater the likelihood of variation in the data, and the denser and more logical the data becomes.

Although the current substantive theory is topic-specific, it has a high level of abstraction. For example, many of its concepts have relevance to other contexts concerning self-management of long-term, chronic conditions. In the main, however, it applies to the circumstances of older adults with depression living in the state of Victoria in Australia and, more broadly, in other developed countries. The current study adds to this knowledge by explaining participants’ experiences, strategies and preferences for managing depression in older age. Importantly, it presents a shift from the biomedical view of depression in older age, by offering a deeper understanding of the individual experience of depression in older age, and the role of individuals as experts for self-managing long-term conditions. Recognising that the defining element of a grounded theory is its

¹⁹⁰ Exploring the emic, or insider’s, view of the phenomenon contributes to conceptual density, as the researcher examines participants’ experiences, feelings and perceptions (Holloway & Galvin, 2016).

explanatory power (Corbin & Strauss, 2015), the current substantive theory links concepts that explain the processes involved in the self-management of depression. In the theory of *Self-empowering to maintain and enhance personal identity as an older adult with depression*, the core category is identified as a basic social psychological process.¹⁹¹ It is the process by which their behaviours and interactions in response to the core problem are connected, and represents the central concern for all participants. It is comprised of a range of categories and strategies, characterised by interrelated phases, or transitions. Discussion of each of the three interlinking categories is now presented.

12.2.1.1 *Taking Stock*

Taking Stock refers to the ways in which participants identified, assessed and adapted to their current circumstances, specifically a change in wellness-illness status. This process occurs within the individual's framework of values, needs, preferences and experiences regarding age, depression and self-management. This framework influences the way in which a change in wellness-illness status is acknowledged, understood and managed. It was through *Evaluating well-being* and *Coming to terms with the diagnosis* that they judged their current predicament against normative and personal ideals, and responded to their change in circumstances.

It is a complex environment in which older adults strive to understand and come to terms with depression. A growing focus on adding quality to the extra years of life associated with increasing life expectancy has heightened interest in understanding what it means to age well.¹⁹² In general, participants spoke of “ageing well” as a state of being at a certain moment or as a process. Concerning their overall well-being, they acknowledged the complex interactions of lifestyle, behaviour and social environment. They also indicated that chronic illness—which may include depression—was not necessarily a barrier to ageing well. This highlights the importance of a positive attitude towards ageing. A study by Kim (2009) into the influence of expectations of ageing found that a higher expectation of ageing was associated with better physical and mental health, as participants were more likely to participate in health-promoting behaviour. This behaviour, in turn, supported

¹⁹¹ See 3.3 (Grounded theory) and 3.3.2.4.3 (Selective coding).

¹⁹² See 2.2.2 (The concept of ageing well).

higher levels of well-being (Kim, 2009). Furthermore, expectations for healthy ageing encourage participants to actively engage in behaviour that would promote well-being (Kim, 2009; Troutman-Jordan, 2015). Conversely, Law et al. (2010) found that those with more negative attitudes to ageing were more likely to endorse a belief that depression was a normal part of getting older. They postulated that such beliefs could lead to a pessimism that hinders the older person from seeking and engaging with treatment for depression (Law et al., 2010). Perceived age discrimination is also an important factor, as it may increase the likelihood of the older person developing self-critical thoughts about ageing, which, in turn, may lead to depression (Han & Richardson, 2015). Perceived discrimination produces significantly heightened stress responses and is related to unhealthy behaviours, coupled with non-participation in healthy behaviours (Pascoe & Richman, 2009).

Overall, participants did not allow their chronological age to act as a determinant of how they felt or behaved. Most felt positive about their age, generally reporting that they did not feel “old” and that they were enjoying being their current age. The importance of a positive outlook and a sense of optimism about the future were abstracted from the data, and underpinned participants’ efforts to optimise well-being. Positive attitudes towards ageing have been recognised as important drivers of healthy mental and physical ageing (Bryant et al., 2012; Prior & Sargent-Cox, 2014; Wurm & Benyamini, 2014). Several studies have found that older adults’ attitudes towards the physical, psychosocial and psychological aspects of ageing mediate the relationship between their subjective health satisfaction and quality of life (Chachamovich et al., 2008; Low, Molzahn, & Schopflocher, 2013). Positive attitudes towards ageing may also serve as a buffer for older adults experiencing challenges to their physical and/or mental health, and increase their health outcomes and overall quality of life (Levy et al., 2018; Wurm & Benyamini, 2014). However, a few participants expressed negative views of ageing. One of the major risks in this regard is that negative stereotypes of ageing frequently reduce expectations of health and overall well-being (Levy, 2003). While all had received a diagnosis and support for their depression, negative attitudes towards ageing may serve as a barrier to seeking help, particularly if depression is viewed as an inevitable consequence of age (Law et al., 2010). Indeed, those who reported the influence of negative views of ageing

were more likely to experience a sense of futility about trying to optimise their well-being and quality of life.

Findings concerning attitudes towards ageing and/or depression highlight the need to challenge stereotypes. Participants faced negative portrayal in two realms: older age and depression. Individual and public perspectives of these issues are influenced by several factors, including knowledge, cultural background and social networks (Corrigan & Kosyluk, 2014). Perhaps the most influential of these, however, is the media, which has a direct effect on attitudes towards older age (Edgar & Edgar, 2015) and mental health issues (Zhang et al., 2016).¹⁹³ Thus, it was incumbent on individual participants to challenge assumptions about age and depression. This was followed by acknowledging a change in their wellness-illness state, which led participants to seek answers and come to terms with a formal diagnosis of depression. Although several felt disappointed at the diagnosis, it was also received with relief, as a diagnosis suggested the possibility of treatment to reduce suffering (Karp, 2017). This was especially significant for those who had spent years unable to name their depression. At this point, the importance of taking personal responsibility for one's own well-being emerged. A study into the experiences and views of older Australians extrapolated that successful ageing was associated with personal responsibility for and acceptance of changing circumstances (Tan, Ward, & Ziaian, 2010). Similarly, a study by Switzer et al. (2006) into depression in older adults reported the importance of personal responsibility in gaining a sense of control and maintaining changes that improved well-being. This focus on the individual's strengths, autonomy and capacity reflects a recovery-oriented approach to depression (Coulombe et al., 2016; Turner et al., 2015).

The main strategies for *Taking Stock*, *Evaluating well-being* and *Coming to terms with the diagnosis*, were directly concerned with how participants perceived and responded to a change in wellness-illness status. However, a final component of this process was for them to redefine their expectations of the future. Consistent with Meleis' (2015) theory of transitions, participants demonstrated flexibility in the way they calibrated their

¹⁹³ There is abundant evidence of the strong influence of the media on public opinion about important health issues, and how it affects health behaviours in the community (Chapman et al., 2014). See 13.3.3 (Implications for the portrayal of age and depression).

expectations of the future in response to the diagnosis of depression. The process of revising existing goals, or establishing new ones, required that they identify and implement actions that would better meet the change in their wellness-illness status. According to Meleis (2015), new behaviours and strategies are required to respond to a transition experience in a way that enhances the well-being of each unique individual. These changes also depend on the individual's resources and capacity. The adjustment of life expectations is essential for maintaining balance and control in life, and to optimising well-being and preserving a positive sense of self (Helvik, Steiring, Iversen, & Hallberg, 2011). By extension, how people think and feel about their condition typically has a significant impact on their capacity to adapt to and manage a change in wellness-illness status (De Silva, 2011). The effective management of a long-term condition, such as depression, requires that individuals use their knowledge, skills and confidence to monitor and manage their health (Ellis et al., 2017). A crucial strategy for doing so is to access support.

12.2.1.2 *Accessing Support*

Accessing Support constitutes the second category that underpins participants' efforts towards *Self-empowering to maintain and enhance personal identity as an older adult with depression*.¹⁹⁴ Although not always a linear process, *Accessing Support* typically follows on from *Taking Stock*, insofar as individuals should acknowledge and take responsibility for a problem, before they begin the process of addressing that problem. However, the path to *Accessing Support* was seldom smooth, and they were frequently faced with *Overcoming barriers* before they could access support.

The most common personal barrier to *Accessing Support* concerned motivation. Motivation is strongly associated with positive health behaviours, such as help-seeking, medication concordance and other activities aimed at improving well-being (Taylor et al., 2016). Difficulty with motivation frequently inhibits depressed individuals from accessing health services (Culph et al., 2015; Heintzelman & King, 2014). It is a significant influence on the capacity and responsibility of an individual to adopt positive lifestyle and health behaviours (Coventry et al., 2014). An Australian study (Culph et al.,

¹⁹⁴ See 0 (*Accessing Support*).

2015) into the experiences of older men with depression of participating in Men's Sheds found that participants' heightened emotions, poor sleep patterns and decreased decision-making capacity adversely affected their motivation to engage in activities of daily living. In the current study, several found it difficult to get out of bed in the morning and motivate themselves to engage in activities of daily living. For some, getting out of bed was a response to external influences, such as the need to walk the dog or the expectation of visitors. However, all participants described how they had overcome poor motivation to seek help and identify strategies for optimising their well-being.¹⁹⁵ They generally did this by challenging assumptions about age and depression and focusing on their desired levels of well-being.

The external barrier most commonly encountered by participants in the current study concerned stigma. Stigma and discrimination are major obstacles to the effective diagnosis, treatment and management of mental health issues, including depression (Zivin & Kales, 2008). Stigmas label people as different and devalue them by attributing a lower status than the general population (Corrigan, 2004). Misconceptions about mental illness and negative attitudes towards depression are common, with many people believing that those with depression are unpredictable, difficult to engage, incompetent, weak or threatening to others (Griffiths et al., 2008; Reavley & Jorm, 2015). People with depression are also often viewed as awkward, insecure, sad, unsociable and defensive (Barney et al., 2009). Issues of stigma and discrimination are also often compounded by preconceptions or judgement about gender, culture and educational level (Burnett-Zeigler et al., 2014). Older adults attach a greater level of stigma to depression than the general population and appear to be particularly vulnerable to stigma and discrimination, as they also contend with other challenges associated with getting older (Conner et al., 2015; Griffiths et al., 2008). Most participants reported experiences of stigma concerning mental health in general, and depression specifically. Stigma had primarily been experienced in their social interactions with significant others. Several occasions of stigma from within the health profession were reported. Initially upsetting to participants, all had managed to address stigma as a barrier to seeking a diagnosis and enlist support.

¹⁹⁵ The inclusion criteria for the study required that participants were receiving professional treatment support depression.

Another barrier to enlisting formal and informal support concerned the multifaceted concept of access. In the health care context, access refers to the availability of adequate services or support, the opportunity to obtain that support and the financial, organisational, social and cultural capacity to access them (Goodman et al., 2017; Gulliford et al., 2002). In addition, services or support should be relevant and effective in order to facilitate positive health outcomes (Gulliford et al., 2002). As a concept and a process, access includes the ability of the population to perceive, seek, reach, pay and engage with health services (Levesque et al., 2013). All participants had accessed treatment for their depression, which required the navigation of different barriers to access. For example, those living outside the metropolitan area were most challenged by distance and availability, in that they found it difficult to identify and engage with appropriate and effective support that met their individual needs. Others found their options for support were influenced by financial constraints.

Once personal and external barriers had been addressed, participants were able to seek formal and informal support. Most typically, the first step they took when *Accessing Support* was to source information about depression and treatment options. In this way, they commenced the strategy of *Becoming informed and engaged* through *Improving mental health literacy* and *Making informed decisions*.

Participants' levels of mental health literacy influenced how depression was recognised and treated. Although mental health literacy is often low in older adults (Park et al., 2018; White & Casey, 2017), participants in the current study reported confidence in their mental health literacy, as they were already actively engaged with their treatment for depression at the time of interview. They described how they had sought and obtained information on depression, treatment options, support services and alternative therapies. Most used the Internet as a source of information, while others sought information from their health professional. A few read self-help books. Thus, they felt more capable and empowered to actively participate in discussions and decision-making to manage the

changeable nature of depression, as they began *Securing services* and *Establishing a therapeutic alliance*.¹⁹⁶

Most participants had received their initial diagnosis of depression from a GP and remained engaged with their GP for ongoing support. In terms of *Harnessing formal support*, participants sought to establish and maintain strategies that met their individual needs. One element they all had in common, however, was that they all expected to be actively involved in the decision-making process about the treatment and strategies to self-manage their unique experience of depression. One of the themes that arose in this regard concerned the relationship with health professionals. It was apparent from the data that a therapeutic alliance¹⁹⁷ between participants and their health professionals was the ideal way to manage their depression. The notion of working as a team was important to participants. Indeed, it is essential that health professionals explore and take into account the beliefs and attitudes of their older clients when considering treatment options and self-management strategies (Law et al., 2010). In addition, understanding individuals' personal views and values, and negotiating a treatment plan that aligns with them, is required for effective self-management (Yeung et al., 2010). However, the assumptions and/or expectations of the therapeutic relationship are often not met, with individuals wanting understanding and warmth, while health professionals focus on symptoms and treatment (Karp, 2017). From this perspective, most participants felt that they did not have enough time to discuss their individual needs and preferences with their health professional, most often their GP. Although several valued the long-term relationships they had with their GPs, their appointments were often rushed. Participants wanted more time to discuss the range of treatment options available to them or how they may be experiencing the changeable nature of depression at a certain point in time. This finding is consistent with the results of focus group discussions conducted by Schmutte et al. (2009) to inform the development of a self-management intervention for adults with serious mental health issues. Participants reported feeling rushed during appointments, which gave rise to concerns about the quality and thoroughness of their care, and increased their sense of powerlessness in improving their well-being (Schmutte et al.,

¹⁹⁶ As improved health outcomes are predicated on the individual being engaged, motivated and proactive, this concept of the "activated consumer" is fundamental to effective self-management (Stanhope & Henwood, 2014, p. 657).

¹⁹⁷ See 9.3.3.2 (Establishing a therapeutic alliance).

2009). There is an apparent paradox that little time was spent by health professionals on discussing the individual's feelings, despite those feelings being the reason for help-seeking (Karp, 2017).

One of the treatment options that warranted careful consideration and discussion related to antidepressant medication. Almost all participants had taken antidepressant medication at some point since their initial diagnosis. They typically began their first course of antidepressants when they reached a time of crisis or had exhausted other treatment possibilities. Regarding its efficacy and side effects, it was often through a protracted process of trial and error that the most suitable medication had been identified. Most participants described a period of experimentation with their antidepressant medication, during which they may have stopped and restarted their medication. Consistent with the literature, this process of experimentation and learning about the benefits and risks of medication supported participants to engage in informed decision-making and led to increased concordance with medication regimens (Karp, 2017; Schofield et al., 2011). In this way, they were able to become "experts" about the medication and dosage that met their needs (Schofield et al., 2011). It was also important to participants that their treatment aligned with their beliefs and preferences. To illustrate, concordance with antidepressant medication is more likely when the health professional considers the individual's views and knowledge on depression and antidepressants, and the individual participates in the decision-making process about treatment (Jaffray et al., 2014). Those who were taking antidepressant medication at the time of interview considered it to be effective and expected to remain on it for the foreseeable future.

Although most participants had used antidepressant medication, several commented about the usefulness of psychotherapy in managing their depression. A combination of medication and psychotherapy is generally considered the most effective approach to managing depression (Cuijpers, 2017; Hollon et al., 2014; Marquett et al., 2013; Scogin et al., 2014). This finding reflects the view that medication alone does not address or enable changes in behaviour that are likely to improve the individual's well-being or overall quality of life (Quinn, Laidlaw, & Murray, 2009). Of the different psychotherapeutic approaches, those that are considered most effective in older adults

include behavioural therapy, CBT, bibliotherapy, brief psychodynamic therapy, and reminiscence therapy (Apóstolo, Bobrowicz-Campos, Rodrigues, Castro, & Cardoso, 2016; Seeley et al., 2017). However, the strongest evidence supports the efficacy of CBT as a treatment for depression in older adults (DiNapoli, Pierpaoli, Shah, Yang, & Scogin, 2017; Scogin et al., 2014). This may be due to its practical, problem-solving orientation and clear principles that aim to enhance the individual's skills (Gaudiano, 2008; Laidlaw, 2010).¹⁹⁸ Several participants named CBT as their preferred approach, as they reflected on the benefits of sharing their feelings and experiences with a mental health professional, most commonly a psychologist. Together, they had developed strategies to improve their mental well-being and optimise their quality of life.

Despite its potential—and recommendations for its use as a first line approach (Malhi et al., 2018)—CBT is often not offered initially as a treatment for older adults with depression (Jayasekara et al., 2015; Laidlaw et al., 2008). Indeed, only a small proportion of older adults with depression and/or anxiety access evidence-based treatments such as CBT (Jayasekara et al., 2015; Sirey et al., 2014; Titov et al., 2016). Focussing on the challenges that affected the referral of older adults to mental health services, Sirey et al. (2014) highlighted the need to address individual and systemic barriers to screening and treatment. Anticipated stigma affected older adults' willingness to seek help, while staff frequently lacked the training to identify depression in and arrange appropriate referral for older adults (Sirey et al., 2014). A prevailing belief in the benefits of antidepressants may also lead health professionals to prescribe medication, rather than refer the individual for psychotherapy (Chakraborty et al., 2009; Jayasekara et al., 2015). In addition, poor diagnosis and management of depression in older age may reflect the inaccurate view of individuals or health professionals that depression is a normal part of ageing (Mock et al., 2010).¹⁹⁹ The relatively low referral for psychotherapy may also reflect an ageist belief that older adults are unlikely to benefit from psychotherapy (Jayasekara et al., 2015; Laidlaw et al., 2008).

¹⁹⁸ This may also be because CBT is the most widely studied form of psychotherapy (Gaudiano, 2008).

¹⁹⁹ See 2.3.2 (Depression in older age).

In the current study, participants generally requested a referral or engaged directly with a psychologist. It was unusual for their GP to suggest psychotherapy, as they tended to recommend antidepressant medication in the first instance. Other strategies used to optimise well-being included physical exercise, yoga and meditation. Several described the importance of exercise for their self-management of depression, with regular walking and gym sessions identified as popular activities. Some engaged in daily swimming and/or cycling. The beneficial role of exercise in improving physical and mental well-being in older adults is well documented (Azizan & Justine, 2016; McPherson et al., 2014; Searle et al., 2014). Tailored exercise programs for older adults with depression have been found to improve depressive symptoms and quality of life (Park et al., 2014). Focusing on older women with depression, Heesch et al. (2016) found a positive association between higher levels of physical activity and quality of life. Even modest levels of physical exercise appear to be associated with reducing depression (Blumenthal et al., 2012). Yoga and meditation were also considered effective at reducing stress and anxiety: some reported the benefits of yoga, while others regularly meditated. They did this on their own at home, or in guided group sessions. Although the literature supports the use of yoga and meditation as an intervention for depression (Pilkington, Kirkwood, Rampes, & Richardson, 2005; Yeung et al., 2010), they are generally considered adjunct treatments used in conjunction with medication and/or psychotherapy (Cramer et al., 2013). None depended only on yoga or meditation to manage their depression.

Another strategy for *Accessing Support* focused on *Optimising informal support*, where participants explained their efforts towards *Maximising positive relationships* and *Helping others*. Considerable evidence associates informal support with improved well-being (Gardner, 2011; Segrin & Rynes, 2009; Smith et al., 2015). A longitudinal study of people with depression by Kamen et al. (2011) confirmed a correlation between family support and improved recovery, a reduction in symptoms and an increase in overall well-being. This finding is demonstrated in other studies, which identify social support as a mediating factor in the recovery from depression (Cloutier-Fisher et al., 2011; Cruwys et al., 2013). In the current study, most participants who lived with a partner or spouse (n=13) benefited from close informal support, although the support from children or wider family networks varied. Mutually beneficial relationships with friends and

neighbours were apparent for most. This finding corresponds with that of a grounded theory study into the experiences of older adults living in the community, which highlighted the importance of neighbourhood networks in enhancing well-being (Gardner, 2011). Consistent with the evidence that social engagement may serve as a mediating factor in depression (Cruwys et al., 2013; Segrin & Rynes, 2009), they also received informal support through their involvement in social activities.²⁰⁰ Several regularly attended community meetings, or local social or sporting clubs.

A different element of informal support was illustrated by participants' interest in *Helping others*. Frequently associated with altruism, the prosocial behaviour of older adults in informal contexts—such as within one's neighbourhood or through community activities—typically reflects a desire to support the welfare of others, to engage in meaningful activity and to maintain social connections (Kahana et al., 2013). The benefits experienced through helping others foster life satisfaction, and have been extensively documented in the literature (Kahana et al., 2013; Wilby, 2011). Helping behaviour may take several forms, including direct support—such as looking after grandchildren, supporting a neighbour or regularly doing volunteer work—or indirect contributions to the community, by way of donations, or other generous and/or compassionate behaviour (Post, 2005). Riche and Mackay (2010) found that older adults frequently helped their friends and neighbours through social and practical support with daily tasks, such as transport and shopping. By helping each other, these older adults felt confident and safe to remain living in their own homes for longer (Riche & Mackay, 2010). Beyond their immediate neighbourhoods, several stayed connected and engaged with their local communities through volunteering. *Helping others* was a form of meaningful activity that contributed to their efforts towards *Striving for a meaningful existence*. For some, volunteering provided a sense of structure for their days and weeks, while providing an outlet for their creativity or skills. The absence of a routine, often related to a lack of employment-related responsibilities and routines, may adversely affect older adults' sense of purpose or self-esteem (Culph et al., 2015).

²⁰⁰ See 9.3.4 (Optimising informal support).

The way in which informal support was sought and received was associated with the extent to which participants disclosed their experience of depression. Decisions regarding disclosure typically related to stigma or fear of being a burden to others. While fear of stigmatisation was a powerful stimulus to secrecy, most participants in the current study had overcome stigma to talk openly about their depression. However, some remained selective in who they told about their depression, explaining that they did not want to be a strain on members of their close personal network, typically their children. Notwithstanding the positive effects of higher family support on depression are well known (Kamen et al., 2011; Miller & Reynolds, 2012), older adults often fear being a burden on others (Lyberg et al., 2013). The perception of being a burden reflects the belief that others would be better off without the person (Jahn, Van Orden, & Cukrowicz, 2013). Although perceived burdensomeness relates most frequently to a person's spouse, Jahn et al. (2013) found that older adults also feared being a strain on their children. In the current study, those who did not want to burden their children reported that they would rather access informal support from their partners or close friends. This finding highlights the need to consider the needs of individuals and significant others, as different levels of support are sought. For example, health professionals should discuss family support preferences, and the quality and availability of family support, when developing self-management strategies with the older adults with depression (Lyberg et al., 2013).

12.2.1.3 *Reclaiming Self-identity*

Participants' experiences, skills, values and resources influenced how they approached the core problem of *Struggling to maintain personal identity*. This process is reflective of the transitional theme of *Adapting to the changeable nature of depression*, as achieving a sense of identity was not an outcome, but an ongoing process by which they were continually redefining and striving towards *Empowering myself* and *Striving for a meaningful existence*.²⁰¹ The first steps in this process concerned the concepts of self-determination and self-management. Self-determination encompasses a person's capacity to self-manage their illness by accessing information, enlisting support and engaging in healthy behaviours (Piltch, 2016). It is manifested in participants' decisions and actions in response to a diagnosis of depression. The capacity of individuals to self-manage a

²⁰¹ See 10.3 (*Reclaiming Self-identity*).

chronic illness, such as depression, reflects their sense of self-determination to manage the condition (Gearing et al., 2014). In the health care context, self-management encompasses the way in which individuals plan, schedule, evaluate and intervene in order to self-manage a chronic condition, including depression (Yeung et al., 2010). The pathway towards self-management is predicated on a person's beliefs, confidence, motivation and ability, which are essential elements of self-determination (Ryan & Deci, 2000). Although the two terms are not interchangeable, there is considerable overlap and congruency between them. To illustrate, Corrigan's (2012) succinct definition of self-determination as "choice" (p. 170) is a fundamental component of self-management. Both notions were considered in the interviews, but few used these actual terms to describe the actions they took to manage their experience of depression in a way that allowed them to optimise well-being.²⁰² Despite the focus of the current study and the use of the term in all recruitment activities, the term "self-management" did not resonate with any participants. Although clearly reflective of the notions of self-determination and self-management,²⁰³ their efforts may reflect an instinctual drive to get well, find meaning and fulfil personal potential, by drawing on internal and external resources (Piltch, 2016). Indeed, they needed the belief, confidence and capacity to self-manage their depression.

Based on their sense of self-determination, participants reported proactive and reactive ways of self-managing their depression. Proactive strategies were typically longer-term approaches to managing their treatment—most commonly in the form of medication concordance—and overall well-being, whereas reactive strategies were often in response to difficult situations. For example, they frequently sought to avoid people or things that had a negative effect on their mood or sense of self. Another example of their self-determination and self-management was the way in which those with high mental health literacy did their own research before meeting with their health professional. They did this so that they could initiate discussions about treatment options, which contributed to their sense of being empowered.

²⁰² Glaser and Strauss (1969) proposed that "the concepts abstracted from the substantive situation will tend to be current labels in use for the actual processes and behaviors [*sic*] that are to be explained, while the concepts constructed by the analyst will tend to be the explanations" (Glaser & Strauss, 1969, p. 107). Thus, a theoretical code is "always implicitly used in the theory, even when not consciously used" (Glaser, 2013, p. 8).

²⁰³ See 0 (Empowering myself).

Health literacy refers to the capacity of individuals to obtain, process and understand basic health information in a way that enables them to make informed and appropriate decisions regarding their health (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Kopera-Frye, 2016). The topic of health literacy has become increasingly important, particularly in the public health arena (Geboers et al., 2016). As in most developed countries, Australia's ageing population and the rise in chronic disease are placing unprecedented demand on health services. The efficient use of resources will depend, in part, on the public's capacity to access and use information and resources; in other words, their level of health literacy (PricewaterhouseCoopers, 2011). An Australian study (Batterham et al., 2016) on the role of health literacy in improving health services and reducing health inequalities confirmed its importance in health service planning, public health education and policy development. According to Cho et al. (2008), however, the role of health literacy in managing a chronic illness yields mixed findings, and the extent to which it affects health status and/or health service utilisation remains unclear (Cho et al., 2008). However, while the relationship between health literacy and self-management capacity requires further research, (Geboers et al., 2016), there are indications that low health literacy is associated with poorer health outcomes, including lower well-being, more frequent hospitalisation and higher mortality rates (Berkman et al., 2011; Cho et al., 2008). Conversely, higher health literacy appears to be associated with improved treatment concordance and better health outcomes (Kopera-Frye, 2016), including in older adults (Geboers et al., 2016; Serper et al., 2014). As such, it may be considered an element of individual empowerment.

After *Empowering myself, Striving for a meaningful existence* was the second strategy for *Reclaiming Self-identity*. The search to make sense of and find meaning in the unique experience of depression motivated participants to adapt to the changeable nature of depression, and is captured in the transitional theme of *Creating new meaning*.²⁰⁴ Although a sense of meaning or purpose does not necessarily protect the individual from developing depression, the experience of meaning in life is generally accepted as an integral component of well-being and improved quality of life, and has been associated with longevity (Boyle et al., 2010; Heintzelman & King, 2014). It follows that the goal

²⁰⁴ See 11.3.1 (Transitional themes).

of *Striving for a meaningful existence* serves as a motivator for effective management of one's health, particularly in chronic illness. Generally accepted as a sense of purpose, meaning also concerns matters of significance to the individual: by its nature, *Striving for a meaningful existence* must make sense to the person living it (Heintzelman & King, 2014). Three essential contributors to participants' sense of meaning were extrapolated from the data: *Seeking solitude*, *Setting my own pace* and *Planning for the future*. These reflect the processes in which they sought meaning, rather than meaning being derived from outcomes. In other words, *Striving for a meaningful existence* depended on these activities being undertaken, not on the achievement of a certain goal.

Seeking solitude was not merely a preference to spend occasional time alone, but was a management strategy, by which they set aside quiet time to gather their thoughts and regain their energy. This finding contrasts with the notion that being alone is necessarily associated with loneliness, which, in turn, is a determinant of depression. A substantial number of older adults experience loneliness (Hawkley & Kocherginsky, 2017). The experience of loneliness is subjective and distressing, as the individual lacks a desired level of social interaction and satisfying relationships (Ong et al., 2016; Pikhartova, Bowling, & Victor, 2016). Loneliness in older age has also been associated with impaired functioning, reduced physical activity and poor physical health (Ong et al., 2016), and with greater mortality (Hawkley & Kocherginsky, 2017). It is also associated with adverse mental health outcomes, including feelings of grief, anxiety and anger (Aylaz et al., 2012). The vulnerability of older adults to loneliness may also be exacerbated by low family support (Hawkley & Kocherginsky, 2017).

Although loneliness has long been considered a factor in depression in older age (Cacioppo & Hawkley, 2009; Ong et al., 2016; Qualter et al., 2015), there are contrasting reports about the level of loneliness in older adults, and some studies have questioned the experience of loneliness in older age. Investigating the social domains of quality of life, Dykstra (2009) found that loneliness levels of older adults had decreased slightly over the past decades. Thus, Dykstra (2009) expounded that other people tended to attribute higher levels of loneliness to older adults, than they themselves experienced. In a study of the association between expectations of loneliness in old age and actual loneliness,

Pikhartova et al. (2016) found that age-related stereotypes in relation to loneliness were significantly associated with reported loneliness. This led to the conclusion that changing stereotypes of older age may be more effective than services that aim to reduce loneliness through practical interventions such as befriending or group-based activities (Pikhartova et al., 2016). There is also some evidence that adolescents and working age people may be more likely to experience loneliness than older adults (Yang & Victor, 2011). It is from this perspective that Tornstam (2007) questioned whether stereotypes of the lonely older person were reflective of pervasive ageism. These contrasting findings confirm the need to distinguish between a preference for solitude and the adverse effect of experiencing isolation or loneliness against one's will (Yang & Victor, 2011). Hence, the discourse regarding older adults' experiences of being alone and loneliness should be expanded to account for influencing factors and individual preferences (Hawkley & Kocherginsky, 2017; Zebhauser et al., 2015).

It is noteworthy that most participants in the current study enjoyed spending time alone. Ren (2016) found that individuals strive to balance their social activity with a need for solitude. Forced solitude is associated with poorer health outcomes, whereas voluntary solitude was found to serve as a protective or sheltering mechanism (Ren et al., 2016). Similarly, a study into the correlation between solitary time and mental health in The Netherlands found that time alone may only be harmful when the individual feels isolated in other respects (Roeters, Cloin, & van der Lippe, 2014). This may be the case in the current study, as they found a positive balance between *Seeking solitude* and *Optimising informal support*. Those who chose to continue living alone, rather than cohabiting with a partner, engaged in positive interactions with others through their social activities, where they received social support and mental stimulation.

The next strategy for *Striving for a meaningful existence* was *Setting my own pace*. More than simply establishing a routine, the notion represents participants' efforts to balance their time between domestic and social activities, while ensuring adequate quiet time on their own. It is closely associated with *Seeking solitude*. Most participants described their use of a diary or calendar to organise their time, while making lists of tasks or priorities was also frequently undertaken. For older adults, daily routines give structure to the day

and make everyday tasks seem more manageable (Victor, Scambler, & Bond, 2009). For participants in the current study, having a routine also served as a motivator, as they planned and prioritised their attendance at scheduled events or activities. Contact with significant others also served to structure the pattern of each week. As a strategy, this has much in common with the behavioural activation approach to treating depression (Dimidjian et al., 2006). To illustrate, behaviourally focused activation strategies include self-monitoring, scheduling daily activities and exploring other enjoyable behaviours (Dimidjian et al., 2006). Activation is a central feature of self-management, evidenced through goal-setting, problem-solving and action planning, based on improved knowledge, skills and confidence (Stanhope & Henwood, 2014; Turner et al., 2015). These components of self-management were described.

The final strategy for *Striving for a meaningful existence* was *Planning for the future* and refers to participants' perceptions of the future. Future needs were generally considered in terms of increasing age, not the experience of depression. This strategy is strongly associated with that of *Becoming informed and engaged*, as decisions about future needs were based on the information and resources currently available to them. By identifying and addressing short- and long-term needs, they demonstrated another element of self-management. An Australian study (Wilhelm, Geerligs, & Peisah, 2014) into the strategies used by "baby boomers"²⁰⁵ to maintain well-being in later life identified planning and proactive strategies as integral to improved quality of life and overall life satisfaction. Considering proactive approaches to ageing, Kahana et al. (2014) emphasised the role of "proactive behavioral [*sic*] adaptations" to maintain psychological well-being (Kahana et al., 2014, p. 467). Planning ahead, "anticipatory moves" and "proactive illness management" were fundamental strategies to support mental and physical health. (Kahana et al., 2014, p. 467). In the current study, similar strategies were used to optimise well-being: having accepted and taken responsibility for their diagnosis, participants accessed formal and informal support, planned ahead and empowered themselves to manage their depression.

²⁰⁵ "Baby boomers" refers to people born between 1946 and 1964 (Australian Bureau of Statistics, 2015a).

12.3 Self-management of depression in older age

Having considered the principal findings of the current study, consideration of the self-management of depression in older age now follows. This discussion reflects the overall aim of the study: to explicate how older adults with depression self-manage their illness to optimise their well-being. It commences with a brief review of the concept of self-management,²⁰⁶ followed by the researcher's interpretation of self-management as it relates to the data and relevant literature.

Now a popular term, self-management describes the actions taken by individuals to manage the impact of chronic conditions on their everyday lives. Early uses of the term stem from the work of Creer et al. (1976), who acknowledged the individual as an active participant in the treatment of chronic illness.²⁰⁷ Although the term has not been consistently defined or conceptualised over the ensuing decades (Ellis et al., 2017), the necessary factors for effective self-management are capacity (the availability of resources, time, knowledge and energy), responsibility (divided between patients and health professionals) and motivation (the willingness of patients to self-manage their illness) (Coventry et al., 2014). These factors are compatible with the tasks identified in a study by Corbin and Strauss (1988) on managing chronic illness at home: medical management (such as concordance with medication or other treatment), role management (creating new meaning by reviewing life roles) and emotional management (managing the emotional effects of living with a chronic condition).

Self-management is, by definition, problem-based, in that the aim is to identify a problem, generate and implement possible solutions, and evaluate their effectiveness on an ongoing basis (Yeung et al., 2010; Zimmermann et al., 2016). The wide range of initiatives to support self-management occurs along a continuum, with the passive provision of information on one end and active interventions on the other (De Silva, 2011). Self-management strategies and support should be targeted to the individual's circumstances, needs and preferences. Self-management support encompasses collaboration with others who provide the individual with the skills, confidence and tools to manage their chronic

²⁰⁶ See also 2.4 (The concept of self-management).

²⁰⁷ Creer et al. (1976) acknowledge the earlier writings of Bandura (1969) in their work on self-management.

illness (Yeung et al., 2010). In the current context, successful self-management requires older adults to develop an in-depth understanding of their depression, to serve as a foundation for monitoring symptoms, adopting healthy behaviours and maintaining treatment regimens.²⁰⁸ Importantly, they should understand and appreciate the benefits of effective self-management of depression, which may be evidenced by a proactive approach to treatment and the adoption of a healthy lifestyle (Van Grieken et al., 2013).

To be most effective, self-management strategies and desired outcomes should be relevant to the individual's everyday life (Boger et al., 2015). Through appropriate education and support, individuals learn techniques to make decisions and take appropriate action to enhance their self-efficacy. In this way, one of the major benefits of self-management is that it has the potential to improve the individual's quality of life through information, empowerment and perceived control (McDonald, 2014; Yeung et al., 2010). A review by De Silva (2011) of more than 550 studies on self-management of chronic conditions concluded that supporting self-management benefited individuals' attitudes, behaviours, symptoms and well-being. Archer (2017) reported that over 90% of patients with long-term conditions wanted to be actively involved in managing their condition, while 75% said that increased formal and informal support would improve their confidence to do so. However, older adults are often not offered the type of support that is relevant to their actual needs (Holm, Lyberg, Lassenius, Severinsson, & Berggren, 2013). Participants in the current study reported that their discussions with their health professional had not focused on self-management, or self-management education. Without tailored self-management support, it appears that they were left to develop their own overall management plans, as they combined information and support from different sources. As the pathway to self-management is not always straight-forward, there is a need for the medical profession to reform working methods to accommodate the time and support needed to promote self-management (Extavour & Perri, 2018; Fisher et al., 2017).

Self-management of chronic illnesses is most effective when health professionals and individuals play complementary roles in a collaborative relationship (Lawn & Schoo, 2010; Redman, 2007). However, several studies have found that GPs often lack the

²⁰⁸ Different health conditions generally require varying self-management approaches (De Silva, 2011).

knowledge or skills to support self-management (De Silva, 2011). Health professionals are also not always fully prepared—in terms of knowledge, skills and/or personal commitment—to support self-management, which may place the individual and service provider at risk (Brijnath & Antoniadou, 2016; Holm & Severinsson, 2014a). Hibbard et al. (2010) identified a need for health professionals to update their views on self-management, while a study by Fisher et al. (2017) into GP workload revealed that GPs did not consider themselves responsible for providing self-management education. Thus, it is necessary for health professionals to broaden their understanding of self-management in general, and in relation to negotiating the most appropriate interventions and strategies for older adults with depression (Holm et al., 2013; Koch, Jenkin, & Kralik, 2004; Raue et al., 2011).

Significant others also play an important role in supporting the individual to self-manage their condition. Self-management is more likely to be effective and successful if support is also provided by the person's informal networks. The potential role of significant others in monitoring and responding appropriately to a change in the individual's well-being has been supported in studies on self-management generally (Archer, 2017; Boger et al., 2013) and in relation to self-management of depression in older age (Holm et al., 2013; Shepardson et al., 2017). Boger et al. (2015) suggest that effective self-management should ideally be co-created with significant others, as the individual's long-term condition often affects close relationships. Similarly, a study by Lyberg et al. (2013) into the experiences of family support for older adults with depression described the importance of "closeness and responsive emotional backup from family members" (p. 3). Conversely, difficulties with self-management may be exacerbated by an absence of informal support (Dulohery et al., 2015).

In addition to the benefits to the individual, effective self-management may result in more efficient health service utilisation (Archer, 2017; De Silva, 2011). Several studies have shown that self-management leads to lower medical expenditure than traditional clinical models (Du & Yuan, 2010; Holman & Lorig, 2004; Washington et al., 2016). This is clearly an important consideration, given that health systems across the world operate in an environment of limited resources (Cramm & Nieboer, 2015; Morgan, Jorm, &

Mackinnon, 2012). Despite favourable cost-benefit analyses of self-management (Du & Yuan, 2010; Washington et al., 2016), more time is needed to determine the extent to which self-management reduces health service utilisation (Battersby et al., 2010; Ellis et al., 2017). Much work also remains to be done in understanding how different stakeholders conceptualise, understand and support self-management, and providing them with the knowledge and skills to embrace it.

Another important consideration concerns the changeable nature of many chronic conditions, including depression. Depending on how they are feeling at a given time, individuals often have shifting experiences of their illness, where a sense of illness or wellness may dominate their thoughts (Lorig & Holman, 2003). Accordingly, self-management strategies should aim to help individuals maintain a wellness perspective. The way in which individuals come to terms with a change in wellness-illness status and adapt to the changeable nature of depression have a direct effect on the way they seek to self-manage their illness. Participants acknowledged the long-term and changeable nature of depression and the role that they took in optimising their well-being. Contradicting the common belief that older adults are not motivated to or capable of learning new ways to look after themselves (Malta & Doyle, 2016; Ouchida & Lachs, 2015), participants in the current study were actively engaged in their treatment and described individual strategies they had developed to self-manage their depression.

12.4 Summary

The aim of the grounded theory researcher is to develop a theory that accounts for a particular phenomenon (Glaser & Strauss, 1969). This is achieved by concurrent collection and analysis of data, generation of conceptual categories and abstraction of a theory. Completion of the present study has enabled the development of a substantive theory that is dense, coherent and true to the data. The theory encompasses a core problem, a core category, three categories and related strategies, and three transitional themes. Contextual determinants are also highlighted.

Overall, the substantive theory offers an optimistic account of the self-management of depression in older age. Rather than being passive recipients of care, participants took an

active role in identifying and accessing the internal and external resources they needed to self-manage depression and improve their quality of life. In many ways, the strategies they used in response to a diagnosis of depression were brought together in ways that gave them a sense of empowerment. Empowerment is closely associated with a person's sense of self, which is essential for achieving mental well-being and improved quality of life (Thieme et al., 2013). Indeed, it was by integrating their sense of self into their strategies for self-managing depression that they gained confidence in improving their individual circumstances.

CHAPTER 13

Implications and conclusion

13.1 Introduction

In this final chapter of the thesis, the strengths and limitations of the study are considered. This is followed by a discussion of the implications of the findings for policy, professional practice, the portrayal of age and depression, older adults and their significant others, and future research. A concluding statement is then presented.

13.2 Strengths and limitations of the study

In the current study, a grounded theory approach to data collection and analysis was selected to address a gap in knowledge about a problem which is relatively new and under-researched. This allowed the researcher to gain insight into the self-management strategies used by older adults with a diagnosis of depression to optimise their well-being. However, as in all research, the method has its strengths and limitations.

13.2.1 Strengths

One of the strengths of the current qualitative study lies in the selection of grounded theory methodology. Popular with qualitative researchers, grounded theory is often considered the method of choice in nursing research (Holloway & Galvin, 2016). The uniqueness of grounded theory is evident in the processes of simultaneous data collection and analysis, and constant comparison, which allow the researcher to abstract an explanatory theory from the data (Corbin & Strauss, 2015). The abstraction of a parsimonious theory is another strength of the current study.²⁰⁹ The merit of a grounded theory study depends on the researcher's faithful adherence to the essential techniques and procedures of each approach (Bryant & Charmaz, 2007a). By adhering to the methodology, the researcher extrapolated meaningful findings from the data, which are presented as a substantive theory.

²⁰⁹ Parsimony also contributes to the rigour of a qualitative study (Gehman et al., 2017). See 4.7 (Quality in qualitative research).

Another strength of the study is the depth and scope of the data. Having spent several months collecting and analysing data, and targeting recruitment activities across a wide range of organisations, the researcher recruited a broad sample of participants with different personal circumstances and across geographical locations. By spreading recruitment activities as widely as possible over this period, the researcher sought to increase variation in the data. The number of participants (32) interviewed to achieve data saturation is a strength of the study.²¹⁰ For example, the mix of participants living in metropolitan, suburban and regional areas of the state of Victoria added to the depth of the data, as the experience of accessing support frequently differed between those living in small regional communities and the city.

The gender mix of participants is also a strength (59% were female and 41% were male). Although it was not the researcher's primary aim, the participant mix broadly reflects the gender distribution of older adults in Australia, with women accounting for 54% of people aged 65 and over, and 65% of people aged 85 and over (Australian Institute of Health and Welfare, 2017c). By comparison, a study by Chambers et al. (2015) into the self-management of longer-term depression reported 71% female participants, while a study into the coping strategies of older adults with depression reported that the depressed group comprised 72% females and the control group 66% females (Helvik et al., 2016).

While recruiting participants who met the selection criteria was, at times, challenging, the process continued until data saturation had been achieved.²¹¹ At this point, the links between categories could be clearly explicated and linked to the overarching core category. Through the process of concurrent data collection and analysis, the researcher ensured that all major categories were fully developed, showed variation and were integrated around a core category. In this way, the researcher could account for the complex processes by which participants self-managed their unique experience of depression. The rigour and validity of the study were also strengthened by data triangulation. Triangulation increases the scope and depth of a study, as different sets of data are used to expand understanding (Morse, 2015). The researcher collected and

²¹⁰ Although qualitative studies do not usually stipulate sample sizes, attempts to operationalise the concept of theoretical saturation have recommended between 20 and 35 participants for grounded theory studies (Guest, Bunce, & Johnson, 2006). See 3.3.2.2 (Theoretical sampling).

²¹¹ The challenge of recruiting participants is presented at 4.5.2.1 (Selection and recruitment of participants).

analysed three different sets of data—interviews, observations and questionnaires—referred to literature to enhance theoretical sensitivity, and participated in regular meetings with research supervisors, which provided the opportunity for discussion, reflection and critique. Thus, another strength of the study is the researcher’s deep understanding of the study context, which resulted in the generation of a plausible and coherent theory in response to the problem of *Struggling to maintain personal identity as an older adult with depression*.

13.2.2 Limitations

This study has four main limitations. As a qualitative study, findings are context-bound to the participants and settings in which recruitment occurred (Green et al., 2007). While generalisability is not a prerequisite of qualitative research (Sandelowski, 1986), the findings of the study can be verified. Thus, the potential exists for the current theory to contribute to the greater body of knowledge on ageing with depression, as its theoretical concepts may be applied to other settings and conditions. In this way, the knowledge obtained through a substantive grounded theory has broad explanatory power. To illustrate, Corbin and Strauss (2015) cite the example of using knowledge from a study conducted in one organisation to improve understanding of another, as the core concept from the study should be broad enough to have application beyond its immediate context.

In line with the grounded theory methodology, purposive and theoretical sampling were used for participant recruitment. However, the fact that they self-selected to be included in the current study constitutes another potential limitation. While an opt-in approach²¹² is considered the gold standard in participant recruitment from an ethical perspective (Michelet et al., 2014), self-selection bias may occur when members of the target population who choose to participate in a study differ in a systematic way from those who do not. In the current study, data were collected from participants who had been sufficiently motivated to access services and support for depression, respond to the researcher’s recruitment efforts and contact the researcher directly to discuss participation. Thus, older adults who were not coping well with depression, for example,

²¹² The opt-in approach requires that potential participants are informed about the study and must then agree to participate (Michelet, Lund, & Sveen, 2014).

may have been precluded. Notwithstanding the unknown effect of self-selection bias, there is still much to learn from those who shared effective strategies for self-managing depression.

Another limitation is the time constraint in conducting a doctoral degree study. Although the different elements of grounded theory research—concurrent data collection and analysis, compilation of field notes and use of memos—were appropriate, the process was time-consuming and resource intensive. For example, the researcher actively recruited participants for nine months, while simultaneously collecting and analysing data. Some interviews and observations required several hours' travel to regional or outer suburban areas. While rich data were obtained through individual interviews, observations and questionnaires, and data saturation was achieved, follow-up interviews may have added additional depth and perspective to the current study. An additional limitation relates to the observations conducted in the study. In qualitative research, observations as fieldwork are used to collect data about the social processes in which participants are engaged. The researcher attended five events in the role of observer-as-participant. These opportunities were identified during recruitment, generally at the suggestion of a person working in a relevant organisation. Thus, while the researcher observed interactions in a naturalistic setting, it may have been more valuable to have attended events at the invitation of participants or at which participants were present.

A final potential limitation concerns the lack of cultural diversity among participants. Only one of the 32 identified as coming from a culturally and linguistically diverse background. More expansive recruitment methods targeting a greater number of multicultural organisations may have presented a more diverse sample.

13.3 Implications of the study findings

Australia has one of the highest life expectancies in the world. In 2014, older adults accounted for 15% of the population (Australian Institute of Health and Welfare, 2017c). Population projections indicate that, by 2064, 23% of Australia's population will be comprised of adults aged 65 and older (Australian Bureau of Statistics, 2012a). In any one year, approximately one million Australian adults experience depression (Australian

Bureau of Statistics, 2008). Depression is now the leading cause of disability worldwide (Malhi et al., 2018; World Health Organization, 2017). As the most common mental disorder in older adults, it is associated with a decline in well-being, daily functioning and independence (World Health Organization, 2015c). It is estimated that up to 15% of older Australian adults living in the community experience depression at any one time (Haralambous et al., 2009). However, it is highly likely that the prevalence of depression in older adults is under-estimated (Arias et al., 2017; Snowden et al., 2016; Tanner et al., 2014). With Australian National Health Survey data identifying the consequences of depression in terms of demands on primary health care, cost and burden of disease (Australian Institute of Health and Welfare, 2015), there is increased pressure on policy makers, service providers, researchers and individuals to understand the experiences, determinants and self-management strategies of older adults with depression (Chambers et al., 2015; Stanhope & Henwood, 2014). Effective self-management may reduce health service utilisation, while improving individual well-being (Chambers et al., 2015; De Silva, 2011).

There are five broad implications of the findings of the current study, relating to policy, professional practice, the portrayal of age and depression, older adults and their significant others, and future research. Although these are discussed separately, they are interconnected and typically influence each other.

13.3.1 Implications for policy

The theory of *Self-empowering to maintain and enhance personal identity as an older adult with depression* reflects the importance of a wellness-oriented model of support for older adults living with depression. The finding that participants were *Struggling to maintain personal identity* highlights the importance that an older adult ascribes to being treated as an individual when seeking a diagnosis and considering treatment options for depression. However, there appear to be gaps between Commonwealth and state government policies, and meeting the needs of the individual in this context. These gaps relate to terminology and the translation of policy into practice.

Generally, health policies propose the value of self-determination and self-management. Despite elucidating participants' commitment to self-managing their depression, based on a sense of self-determination, most did not identify with these terms. They described actions and interactions that align with self-management, using wording such as "looking after myself", but their lack of familiarity with the term indicates that they could be missing out on services or support that could assist them to self-manage an illness. In other words, they may not be seeking or accessing information or support related to the term. At the most fundamental level, there appears to be a lack of a universal definition of self-management. This finding is consistent with an investigation into stakeholder views of self-management for chronic conditions, which found a lack of clarity around the concept of self-management (Ellis et al., 2017). The term was used interchangeably and/or associated with self-efficacy, patient empowerment, activation, care, self-monitoring and self-governance (Ellis et al., 2017). Ellis et al. (2017) postulated that self-management may not be as universally promoted in practice as policy makers might think, perhaps due, in part, to the inconsistent terminology around the concept and components of self-management. It may be appropriate for policy makers to consider the accessibility of the language being used to describe how individuals look after themselves. A clearer understanding of terms and concepts would be helpful to individuals, significant others and service providers (McSharry et al., 2013). It would be appropriate and potentially more useful to individuals to ask key stakeholders to suggest their preferred term. To illustrate, participants indicated that the term "self-care" would resonate more strongly with them than "self-management", although both essentially carried the same meaning. Another reason for the inconsistent promotion of self-management concerns the view by many policy makers and service providers that individuals should take responsibility for their own well-being (Ellis et al., 2017). Fisher et al. (2017) reported GPs' views that public health campaigns should focus more positively on "self-treatment", encouraging patients to take greater responsibility for self-management. However, the finding that GPs have been slow to support self-management (Hibbard et al., 2010) indicates a need to improve education and skills at the professional practice level, and to encourage a broader paradigm shift from the biomedical model of care to one which supports self-management (McEvoy, 2016; Northwood et al., 2018).

From a policy perspective, the potential for self-management to reduce health service utilisation and medical expenditure compared with traditional clinical models is appealing. It is opportune to identify and support self-management strategies that are likely to be helpful to the individual, while providing the best possible outcomes from a health system with limited resources (Cramm & Nieboer, 2015; Morgan et al., 2012). However, cost-effectiveness analyses of self-management are highly complex (Battersby et al., 2010). To illustrate, health service utilisation is a major evaluation indicator for self-management, but the costs associated with health service utilisation only decrease over a long period of time (Battersby et al., 2010; Du & Yuan, 2010). Nonetheless, a study by Washington et al. (2016) into the self-management of chronic kidney disease identified positive outcomes of self-management, including improvements to participants' overall health and quality of life, and a reduction in health care usage. Similar findings were reported in a longitudinal study into the self-management of depression, with participants' development of knowledge, skills and confidence associated with improved quality of life (Turner et al., 2015). Turner et al. (2015) suggested that self-management programs could make a valuable contribution to recovery-based services in mental health. Similarly, Ashman et al. (2017) identified self-management as a central component of the recovery approach to mental health.

Although the recovery approach that underpins mental health service provision aims to build resilience, create hope and promote self-management (Ashman et al., 2017; Coulombe et al., 2016), it is unclear whether policy makers and service providers are focussing on self-management as a way to achieve financial sustainability, rather than sustainable positive health behaviours (Goedendorp, Kuiper, Reijneveld, Sanderman, & Steverink, 2017). Noting a lack of evidence for the sustained effectiveness of empirically supported well-being interventions implemented in practice settings, Goedendorp et al. (2017) call for further studies to determine the extent to which individuals adhere to self-management interventions over the longer term, and whether health professionals perform interventions according to protocol. There is agreement, however, that the effectiveness of self-management depends on a delicate balance in which the individual's needs are met, while health professionals work in a manner which reflects their skills and meets the appropriate standard of care (Archer, 2017; Holm & Severinsson, 2014a).

Cost-related barriers to formal services also require consideration at the policy level (Paul et al., 2016). In Australia, the national Medicare Benefits Schedule offers a “bulk billing” option, whereby the government’s contribution covers the fee allocated to a specific service. The fee is billed directly to Medicare at the time of the appointment, with no payment made by the consumer. Mental health services are included in the Schedule. To illustrate, under the *Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS* [Medicare Benefits Schedule] initiative, a GP may provide a mental health treatment plan that provides access to up to 10 individual and/or 10 group sessions with a registered psychologist, occupational therapist, social worker or GP with mental health skills training, per calendar year (Department of Health, 2017). The take-up of this Medicare-subsidised option is high (Australian Institute of Health and Welfare, 2015).²¹³ However, many mental health professionals, including psychologists and psychiatrists, request a fee that is greater than the amount covered by Medicare. Thus, the individual must choose between a service that bulk bills, but for which there are frequently other barriers to access, such as long waiting times, the requirement to travel or a lack of flexibility with appointment times, or pay an amount over and above what is subsidised by Medicare or reimbursed by a private health insurer. In addition, those who require more than 10 sessions in a calendar year must pay the full fee after the mental health treatment plan has been completed. These issues warrant attention, to ensure that the *Better Access* initiative achieves its purpose of improving treatment and management of mental illness in the community (Department of Health, 2017).

Concerning the translation of policy into practice, the findings of the current study contribute to an improved understanding of the broader components of well-being. This can be considered in the decision-making process around planning, funding and delivering services that support older adults with depression to optimise their well-being. However, the adoption of programs that support self-management requires change at the policy level. For example, individualised self-management education requires a detailed needs assessment for each person (Lorig & Holman, 2003), but current health service

²¹³ In 2013–14, for example, *GP Mental Health Treatment Services*— which includes the development of a mental health treatment plan—was the most frequently provided mental health-related service type subsidised by Medicare (Australian Institute of Health and Welfare, 2015).

models and structures often make collaborative care difficult, as health professionals lack the time and information needed to facilitate knowledge-sharing and decision-making practices associated with effective self-management (Ellis et al., 2017; Lawn, Delany, Sweet, Battersby, & Skinner, 2013). Frequently, GPs only have time to listen to the patient to obtain information that helps them to make a diagnosis (Karp, 2017). Current systems of care also frequently lead to the disempowerment of patients, rather than facilitating better engagement and health outcomes (Lawn et al., 2013).

A practical implication of the current research would be to offer health care planners and providers a better understanding of the broader components of well-being in older adults with depression, including the personal and contextual determinants that affect their well-being and moderate their ability to self-manage their illness. Given that overarching government policy underpins the quality and availability of support for older adults living with depression, this information could be used to inform the planning, funding and delivery of services that support older adults with depression to age well. Policy-level improvements might also consider the role of leadership and advocacy in promoting self-management of depression in older age, and integrative policies that accommodate the needs and preferences of older adults with depression. These improvements should be related directly to making improvements to professional practice.

13.3.2 Implications for professional practice

The findings from this study highlight the need for health professionals²¹⁴ to facilitate the individual's capacity for self-management of depression. This requires that they embrace and advocate self-management practices that are aligned to the needs and preferences of older adults with depression. In so doing, they need to challenge prevailing (mis)preconceptions about age and mental health. Models of care that integrate mental health care into medical care are urgently needed (Coulombe et al., 2016; Fisher et al., 2017; Karel, Gatz, & Smyer, 2012; Katon, 2012). In addition, there should be improved screening for symptoms of depression in older adults (Mitchell et al., 2011; Park, Choi-Kwon, Park, Suh, & Jung, 2017; Sunderland, Carragher, Buchan, Batterham, & Slade,

²¹⁴ Although most received ongoing support for their depression from a local GP, the broader term of health professional is used here to include other support or services.

2014; Xiang et al., 2018), particularly because the process of diagnosing depression in older adults is often confused with symptoms of physical illness (Arias et al., 2017; Kessler et al., 2010). Several reported that it had been difficult to obtain a diagnosis of depression, despite their repeated insistence to their GP that something was wrong.

The common, but erroneous, view of depression as a normal part of ageing serves as an obstacle to effective diagnosis and treatment (Ludvigsson et al., 2015; Xiang et al., 2018), and should be addressed through education and training. At all levels of health care, the ageist attitude²¹⁵ that older adults are less functional or capable of actively participating in optimising their health and quality of life should be addressed (Blancato & Ponder, 2015; Schroyen et al., 2018; Wilson et al., 2017).²¹⁶ It is important that the health care workforce understands the complexities of ageing with depression, and that contextual factors are considered when supporting an older adult with depression (Switzer et al., 2006). This will require that the dominant biomedical view of depression and depression treatment be moderated by improved understanding of the personal, social and environmental factors that impact on individuals (Cruwys et al., 2013; Northwood et al., 2018). However, research in general practice demonstrates that depression is generally diagnosed and managed according to GPs' clinical knowledge, which does not necessarily accommodate the individual's experience of depression (Ridge & Ziebland, 2012; Robinson et al., 2017). A study of individuals with depression who presented to primary care in England, conducted by Robinson et al. (2017), noted the importance of the doctor-patient relationship in enabling "a careful unpacking of patients' symptoms" (p. 8). Similarly, Dowrick et al. (2009) recommended that depression treatment occur within a holistic framework. Thus, the imperative to improve the diagnosis and treatment of depression may require that health professionals change their views and clinical behaviour (Dowrick et al., 2009; Yu et al., 2017).

The findings of the current study suggest that health care professionals, particularly GPs, would benefit from training and education that supports their understanding of self-management. Clearer specification of the processes of self-management may facilitate

²¹⁵ See 2.2.2.2 (The experience of ageism).

²¹⁶ One way to redress ageism in health care is to engage more older adults in research studies (Blancato & Ponder, 2015), as with the current study.

assessment and planning, leading to improved health outcomes and accurate reporting (Chambers et al., 2015; Mitchell et al., 2011; Raven, 2015). Greater clarity should enable health care professionals to work with the person to target specific interventions aimed at achieving the most relevant goals (Richard & Shea, 2011). The experiences of individuals in seeking a diagnosis, receiving treatment and becoming experts in their own care should be used to inform strategies to support self-management at the practice level. From this perspective, the findings of this study may contribute to the broader discourse of depression in older age. However, depression should be viewed in terms of its changeable nature, and not as a condition that, once diagnosed, can necessarily be treated the same way over time.

A fuller appreciation of an individual's propensity to self-manage their illness and the personal and environmental contexts in which this occurs aligns with the commitment by the Australian Government to embed holistic and person-centred practice as a cornerstone of service development and delivery (Department of Health, 2015). However, participants reported a disconnect between policy and practice, describing how their appointments with health professionals were often conducted in haste, with little opportunity to examine influencing factors in their experience of depression in older age, nor the range of treatment options that may suit their individual needs or preferences. There is a need to review the ways in which shared decision-making and strategies for self-management can be implemented effectively in practice. A study by Harris et al. (2015) highlighted the difficulty of changing practice to support self-management in the mental illness field. The main challenges in this regard include the number of theoretical models that have not been tested empirically, and the uncertain degree to which an intervention could be adapted to meet local needs (Damschroder et al., 2009; Harris et al., 2015).

Access to information, leadership engagement and operational resources—such as education, training, time and money—are essential elements of any efforts to implement change (Damschroder et al., 2009). At the service level interface, Légaré et al. (2008) identified several practical challenges to be overcome in this regard: more time is needed during appointments, to involve patients in making decisions and facilitating self-management practices, and—resonant with the current study—health professionals

should not make assumptions about an individual's capacity for self-management. Rather, they should gain an appreciation of the expertise individuals bring to the self-management of their condition (Ellis et al., 2017; Koch et al., 2004; Taylor et al., 2016).

The extent to which health professionals embrace self-management should also be addressed. Typically, the first point of service access, GPs are strongly placed to educate and support self-management for chronic, long-term health conditions. However, the extent to which their training focuses on identifying opportunities for and supporting self-management is unclear (McEvoy, 2016). The level of GP engagement with or responsibility for self-management is also inconsistent. To illustrate, one study (Shackelford & Bachman, 2009) identified the role of the health professional in determining the patient's type of education for self-management, whereas another (Fisher et al., 2017) found that GPs felt they were not responsible for self-management education. There appears to be consensus, however, on the potential for delegating this task to health educators, allied health professionals, non-clinical staff and community centres (Fisher et al., 2017; Shackelford & Bachman, 2009).

The finding that no participants had received support from mental health nurses in the community indicates that the largest section of the mental health workforce did not contribute to the treatment and support so urgently needed by this sample of older adults with depression. Notwithstanding significant challenges regarding expanding scope of practice, funding and recruitment (Dreizler, Koppitz, Probst, & Mahrer-Imhof, 2014; Heslop, Wynaden, Tohotoa, & Heslop, 2016; Wilberforce et al., 2017), the potential exists for mental health nurses to play a greater role in the treatment and support of older adults living in the community with depression. This is especially important, given that population ageing will require that healthcare systems meet the needs of a growing number of older adults with depression (Day, P., 2017).²¹⁷ It is important that older adults and their families understand the role of mental health nurses in this regard, so that they may actively seek their support, as needed. Thus, consideration should be given to promoting the availability of mental health nurses to provide education and support.

²¹⁷ It is timely that the Australian Government has announced significant funding in its 2018 budget to initiatives aimed at improving the mental health of older adults (www.budget.gov.au). This commitment has been welcomed by organisations such as the Australian College of Mental Health Nurses (www.acmhn.org), the Royal Australian College of General Practitioners (www.racgp.org) and the National Mental Health Commission (www.mentalhealthcommission.gov.au).

Telephone support provided by mental health nurses and other mental health clinicians between face-to-face consultations may also be an effective adjunct to individual self-management. Self-management support provided by telephone by clinicians (Fisher et al., 2017), and even automated depression monitoring (Piette et al., 2013),²¹⁸ are effective in this regard. Thus, an implication for practice may be that additional formal support is provided by mental health nurses or social workers, as a way of addressing the urgent gap between individuals' needs and the restrictions of a constrained health system. There is also strong potential for mental health nurses to provide support and education to older adults with depression and their families (Heslop et al., 2016).

The use of psychotherapy, particularly CBT, to support older adults with depression should also be promoted. There is considerable evidence that older adults respond very positively to CBT (Cuijpers et al., 2014; Jayasekara et al., 2015; Laidlaw et al., 2008). Its use may be particularly appropriate for those who are reluctant to take antidepressant medication. However, GPs appear disinclined to refer older patients for psychotherapy (Prina, Marioni, et al., 2014). As a result, it often remains up to the individual or significant other to negotiate a service pathway to access this form of treatment. Service providers should understand and promote the usefulness of CBT as an intervention for depression in older age.

The shift from broad statements of commitment to actual implementation of self-management support will also require a better understanding of how to operationalise shared decision-making and self-management, as well as outcome measures that are useful to health professionals and individuals (Pincus et al., 2016). To illustrate, it is unclear how health professionals might be able to support individuals who would prefer to access alternative, social interventions. The extent to which they might be able to support or enable patient participation in social clubs, for example, may be influenced by prevailing treatment and funding models (Cruwys et al., 2013). An important role of the health professional could be to assess individuals' informal support networks and

²¹⁸ A study by Piette et al. (2013) demonstrated the effectiveness of interactive voice response calls to reduce barriers to depression care management.

recommend ways for them to maintain or increase social engagement. Supportive social relationships promote positive mental health and identify the importance of meaningful relationships for older adults (Hatfield et al., 2013; Stoeckel & Litwin, 2015; Werner-Seidler et al., 2017). A practical implication of these findings is that health professionals should be more aware of an individual's social networks and access to support from significant others when negotiating treatment options (Stoeckel & Litwin, 2015).

13.3.3 Implications for the portrayal of age and depression

To improve their reach and effectiveness, efforts to support older adults through improved policy and practice should be framed by a clear understanding of how ageing and depression are portrayed in the public realm (Soroka, Maioni, & Martin, 2013). The way older adults and mental illness are portrayed plays an important role in shaping opinion and facilitating change in the broader community. Despite global population ageing, older adults are still frequently portrayed in a negative light in the media and popular culture (Edström, 2018; Malta & Doyle, 2016). These negative stereotypes can contribute to discrimination and ageism (Edström, 2018; Tortajada, Dhaenens, & Willem, 2018). In addition, diversity is often ignored, as older adults are regarded as a homogenous burden on society in general, and health care systems in particular (Edgar & Edgar, 2015).

Concerning the current study, the media's role in reinforcing the problems of old age and stereotypes of mental illness should be challenged by individuals and organisations. Negative perceptions of ageing often result in decreased motivation to engage in healthy behaviour, imposing self-fulfilling limitations on the individual's expectations of well-being (Law et al., 2010; Levy, 2003).²¹⁹ The media also has direct effects on public attitudes towards mental health (Zhang et al., 2016). These attitudes can, in turn, influence health policies and practices in ways that affect resource allocation for preventing, treating and supporting mental health issues (Schomerus et al., 2014; Zhang et al., 2016). Indeed, the media is a powerful influence on the broader political discourse and policy-making process (Soroka et al., 2013). A retiring member of parliament relayed the challenges of ageism in politics, noting that her age (59 years at the time) was used as an argument against her re-election (Day, R., 2017). The low participation by older adults in

²¹⁹ See 2.2.2.2 (The experience of ageism).

the Australian parliament also reflects a culture and structure that values younger adults over those with greater age and experience (Tatz, 2015). A typically negative view of older age is reflected in reports that labour force participation rates for older Australians lag far behind comparable countries (Australian Human Rights Commission, 2016). The portrayal of older adults as a burden on society should also be challenged. For example, seniors' groups have labelled as offensive suggestions that older adults move out of their homes to make way for younger families (Combined Pensioners and Superannuants Association, 2018; Magarey, 2017). The burden conversation has also led to concerns that blaming older adults for major social ills and financial burden could drive a wedge between generations (Edgar & Edgar, 2015).

A more positive portrayal of older adults and those with mental health issues aligns with policies that support the health and human rights of all people (Department of Health, 2016; World Health Organization, 2015b). Portraying older adults and those with depression as individuals with a wealth of experience and potential, and who are experts in their own circumstances and needs, may lead to an improved understanding of the rights and responsibilities of individuals and service providers. This, in turn, may support the implementation of effective self-management approaches that suit the needs and preferences of individuals, and health professionals' models of care. Another strategy to address the portrayal of age and mental illness, including depression, might be for researchers to engage directly with the media, to promote more balanced findings of ageing and mental health research. This approach is supported by an Australian study, which found that researchers' engagement with the media was an essential strategy for influencing public health policy (Chapman et al., 2014). Indeed, policy makers and service providers are more likely to promote change if there is a commensurate change in public opinion or understanding. The media can also be used to educate older adults and those with mental health issues on their rights, and the services and support that are available to them.

The potential for the media to play a role in debunking stereotypes of older age and mental health is supported by a considerable amount of literature (Corrigan et al., 2015; Crowe et al., 2016; Edgar & Edgar, 2015; Edström, 2018; Rozanova, 2010; Zhang et al., 2016).

An analysis of depictions of ageing in Russian and Canadian newspapers, magazine and television content (Rozanova, 2010) confirmed that older adults were under-represented, and that negative portrayals were far more common than positive portrayals. According to the International Council on Active Aging (2015), negative media portrayals of ageing affect the way older adults view themselves, and how they are treated by society. Its efforts to counter ageist stereotypes include campaign toolkits for marketers and the media, which encourage and assist in the integration of positive, realistic images of older adults (International Council on Active Aging, 2015).²²⁰ As the peak national organisation representing the rights and interests of older Australians, COTA (formerly known as the Council on the Ageing) (2018) endeavours to raise the profile of older adults in the media and counter ageist images. Similarly, the work of the National Ageing Research Institute (2017) is aimed at improving the experience of ageing in Australia through research, advocacy and education.

In the mental health sphere, SANE Australia's (2018) StigmaWatch campaign challenges stigmatising portrayals of mental illness or suicide, while promoting responsible reporting. Although more evaluative research is needed to determine the effectiveness of these efforts, public health campaigns appear to have improved the public's understanding of depression (Pilkington et al., 2013; Reavley & Jorm, 2014). To illustrate, improvements in the Australian public's mental health literacy have been associated with the establishment of national initiatives that aim to inform, educate and destigmatise mental illness (Pilkington et al., 2013). However, the findings of the current study indicate that there remains a strong need to present more positive images of older adults and mental health issues in the media. These efforts should aim to reduce ageism and mental health stigma. By challenging stereotypes of age and mental health, individuals will learn about themselves and others, while health planners and providers will broaden their understanding of individual needs. Importantly, efforts should be made to promote the fact that depression is not a normal part of ageing.

²²⁰ The World Health Organization's (2016) #YearsAhead campaign aims to challenge ageism and ageing stereotypes through photography. On a local level, it is encouraging to see initiatives such as the Western Australian *Lights, camera and a focus on positive ageing* short film competition, which seeks to raise awareness and challenge misconceptions about ageing (Revelation Perth International Film Festival, 2017).

13.3.4 Implications for older adults and their significant others

Although the findings from the current study cannot be generalised,²²¹ the data indicate a need for further education for individuals and significant others about the experience of ageing, and ageing with depression. Improved understanding of the ageing process and mental health issues, as well as the services and support that are available in the community, could assist them in determining the most appropriate response to their changing needs. Given that negative stereotypes of ageing have a detrimental effect on mental and physical health outcomes in older age (Coudin & Alexopoulos, 2010; Wurm & Benyamini, 2014), it is important that the experience of ageing is considered in a positive light, rather than as an inevitable process of decline and loss. By approaching ageing as a process of adaptation and change, older adults and their significant others can maximise coping processes that support well-being, foster personal control and increase confidence in self-management (Troutman-Jordan, 2015).

From the older adult's perspective, a long-term commitment to self-management should be adopted. Indeed, ageing well reflects a life-span process of pursuing and maintaining mental and physical well-being (Cramm, Hartgerink, et al., 2012). The individual should begin this process by gaining an in-depth understanding of depression and adopting a healthy lifestyle. With growing access to health information, older adults with depression should increasingly seek to maximise opportunities to identify and embed appropriate self-management strategies, and invest in resources for long-term benefits (Cramm, Hartgerink, et al., 2012; Yeung et al., 2010). This is particularly important for older adults with physical and/or mental multimorbidity (McSharry et al., 2013). Thus, a proactive attitude is integral to effective depression self-management (Van Grieken et al., 2013). The imperative is to start looking after oneself early, to optimise their well-being in the long term.

Given that long-term illnesses typically affect significant others (Boger et al., 2015), their role in providing and/or receiving support for depression should also be considered. This informal support moderates the experience of depression, with higher support associated with improved recovery (Kamen et al., 2011). Lyberg et al. (2013), for example, found

²²¹ See 13.2.2 (Limitations).

that positive family relationships served as a buffer against and improved the experience of depression in older adults. For support to be effective, however, older adults and their significant others need to consider the amount and quality of support they would like to receive or are able to provide. In this light, the discourse around burden should be addressed. Although it is common for older adults with depression to fear being a burden on others (Girling & Morgan, 2014), the absence of support may be a burden to the older adult (Lyberg et al., 2013). This is particularly relevant to the current study, given the changing structure and composition of families (Wilby, 2011). For example, family networks are changing in response to the ageing population (Australian Institute of Health and Welfare, 2017c), a tendency towards smaller families (Aylaz et al., 2012) and/or the effect of migration on family networks (Park & Kim, 2013). The meaning and value of these different relationships should be better understood, as they influence the older adult's experience of ageing and depression.

An additional implication for older adults and their families relates to the increasing reliance on older women to look after family members (Shiba et al., 2016; Victor et al., 2009). A study into gender norms and palliative care in families (Williams, Giddings, Bellamy, & Gott, 2017) confirmed the expectation that older women would provide end-of-life care, even when it exacerbated their experience of burden. Thus, the impact of a diagnosis of depression on the older woman may have wide ramifications for the family, as their capacity to provide support may be limited by their own mental health challenges. If individual expectations and roles can be negotiated appropriately, it is considered ideal for older adults and significant others to work together to create effective strategies to manage and support their depression (Boger et al., 2015). Where possible, health professionals should promote informal support by facilitating open communication, shared decision-making and problem-solving (Grey, Knafl, & McCorkle, 2006). The need for and availability of support from health services should also be considered.

Finally, older adults, including those with depression, and significant others should consider opportunities to participate in research and/or community forums, as a way of contributing to the development of policy and programs that are more likely to reflect their needs (National Ageing Research Institute, 2013). Open discussion between older

adults with depression and significant others about their needs and preferences, as well as their rights and responsibilities, should guide the decision-making process about their formal and/or informal support needs.

13.3.5 Implications for research

This study identifies the need to continue improving our understanding of the complexities of self-management of depression in older age. As a starting point—and as mentioned under *Implications for policy*—there is a need to develop a clear definition of self-management. The findings of this study also indicate the need to better understand and contextualise how shared decision-making and self-management support may develop in the health care field. It would be useful to improve understanding of the facilitators and barriers to self-management of depression, particularly in older adults (Holm et al., 2013; Morgan et al., 2012). Evaluations of self-management interventions in different contexts and across health jurisdictions should reflect the experience of self-management from the perspective of the individual and the health professional (Damschroder et al., 2009; Pincus et al., 2016). Future research in this area could help to shape strategies for aged and mental health support, and explain the impact of self-management on health service delivery.

As the experience of ageing and depression differs between and within cultural groups (Haralambous et al., 2016; Ranzijn, 2015), studies that focus specifically on aspects relating to cultural diversity in ageing and mental health are warranted. Additional research might also address assumptions about at-risk groups. For example, many participants expressed that solitude was one of their strategies for looking after themselves, but much of the current research highlights the connection between loneliness and depression. Being alone and loneliness are different concepts worthy of further investigation, particularly in relation to the experience of depression in older age. An improved understanding of the types of social relationships and the meanings given to different social networks of older adults with depression could also inform interventions for this cohort (Volkert et al., 2017; Wilby, 2011). Thus, the broader social implications of self-management also warrant attention, given the predictions of population ageing and depression prevalence (McEvoy, 2016). Another priority should be further research into

the social and contextual determinants that affect the well-being of older adults with depression, with the aim of improving the timeliness of receiving an accurate diagnosis and effective treatment (Ludvigsson et al., 2015).²²² In addition, the findings from the current study suggest the need to improve understanding of the characteristics that determine treatment concordance or preferences of older adults with depression. A study by Zivin and Kales (2008) found that the identification of fundamental personal factors would enable health professionals to modify risk factors and establish effective treatments in this cohort. By tailoring treatment approaches to the individual, concordance with treatment and sustained healthy behaviour is more likely to occur (Aakhus, Flottorp, & Oxman, 2012; Zivin & Kales, 2008). However, the process by which they practice may be embedded requires further research.

Findings from this study, supported by the literature, also indicate a need to broaden understanding of the usefulness of psychotherapy for older adults with depression (Jayasekara et al., 2015; Laidlaw et al., 2008).²²³ Potential barriers to older adults receiving psychotherapy should be examined, and the understanding of the service pathway for older adults with depression improved (Prina, Marioni, et al., 2014; Wuthrich & Frei, 2015). Given that almost all participants used online and electronic tools to communicate and obtain information, the potential for self-guided Internet-delivered support for depression in older adults warrants further investigation.

From a broader perspective, there is a need for future research to address the negative stereotypes that continue to be associated with ageing and mental health. Participants reported a range of strategies for empowering themselves to have a meaningful existence as an older adult with depression. Their reports of their daily activities, interests and future plans contradicted the prevailing negative view of ageing. They were motivated and resourceful, and fully understood their rights and responsibilities in terms of accessing support. However, ageing and mental illness are most commonly presented negatively in the media. These views are reflected in society's generally poor response to these experiences and, in turn, influence policy decisions that often marginalise this cohort

²²² The Australian Government's 2018 budget has committed significant funds for research and services in the mental health and aged care sectors (www.budget.gov.au).

²²³ See 2.3.4.2 (Psychotherapy).

(Malta & Doyle, 2016). Highlighting the positive aspects of ageing and reducing the discourse around the burden of an ageing population on society are important steps in this regard. In this light, Karp describes individuals' "extraordinary capacity for adaptation ... their unique ability to define the meaning of their life constraints and to determine how they will respond to them" (p. 250). Thus, a final implication for research is to identify opportunities to focus on the positive aspects of ageing.

13.4 Concluding statement

Health care policy in developed countries increasingly promotes the benefits of self-management of long-term conditions, including depression. However, much of the current research into depression in older age has focused on issues of prevalence, diagnosis and treatment, with less attention given to the personal experience of living with depression in older age, and the self-management strategies used by older adults with depression. Raising awareness of the constructive strategies used by older adults in order to optimise their well-being and quality of life may serve to broaden the discourse on ageing and depression from one that is often focused on loss to one that offers encouragement and inspiration. The theory of *Self-empowering to maintain and enhance personal identity as an older adult with depression* represents a range of experiences, strategies and preferences for managing depression in older age. Importantly, it reflects a shift from a narrow biomedical discourse of depression in older age to a broader experiential focus on individuals as experts for managing long-term conditions. The motivation and capacity of older adults with depression to manage their illness and create new meaning from a change in their wellness-illness status is evident. Founded on a range of experiences, knowledge and strategies, the theory is presented as a possible guide to facilitating the self-management of depression in older adults. This is done in the hope that a positive shift may occur in how depression in older adults is perceived and managed by individuals, health professionals and the broader community. In addition to further disseminating the findings of this study, its implications suggest important opportunities for further research. This neophyte researcher looks forward to being part of this important work.

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Appendices

Appendix A: Information flyer

CALL FOR STUDY PARTICIPANTS

PhD
study

How do older people with depression take care of themselves to optimise wellbeing?

Through this study, I aim to describe the factors that influence how older people with depression look after themselves. I would like to interview people who:

- Are aged 65 years and over
- Live in their own home (i.e. not in residential care)
- Are no longer in paid employment
- Have a diagnosis of moderate depression, for which they are currently receiving treatment or support.

As part of the study, you will be asked to answer a questionnaire and participate in a one-on-one interview at a place and time of your choice. The information you provide will be confidential and you will not be named in the study.

More details are available on the 'Information for participants' and 'Consent' forms, which will be provided to all participants.

Please contact me if you are interested and eligible to participate in the study, or if you would like more information.

Ms Meg Polacsek
PhD candidate
College of Health and Biomedicine, Victoria University

Tel: 0448 056 591
Email: meg.polacsek@live.vu.edu.au
Website: www.megsresearch.com



Appendix B:

Sample of organisations asked to promote call for participants

- | | |
|---|--|
| 1. 3CR Community Radio | 38. Good Karma Network (online forum) |
| 2. Altona North Senior Citizens Club | 39. Grandparents Victoria |
| 3. Anglo-Indian Australasian Association | 40. Harvest Yoga Studio |
| 4. Annecto – the people network | 41. Healthy Ageing Team, City of Melbourne |
| 5. Anxiety Disorders Association of Victoria | 42. Highett Neighbourhood House |
| 6. Anzano Di Puglia Social Club | 43. Highett Senior Citizens Centre |
| 7. Ardmillan Place Retirement Community | 44. Hobsons Bay City Council, Social Planning and Development Team |
| 8. Association of Independent Retirees | 45. Hobsons Bay Men's Shed, Altona |
| 9. Australasian Hellenic Educational Progressive Association | 46. Just Better Care (Victoria) |
| 10. Bacchus Marsh Community Housing | 47. Kathleen Syme Library and Community Centre |
| 11. Ballarat and District Probus Clubs | 48. Kensington Bowling Club |
| 12. Ballarat South Community Hub | 49. Kensington Community Centre and YMCA |
| 13. Balwyn Evergreen Centre | 50. Kensington Healthcare |
| 14. Bentleigh Bayside Community Health | 51. Kensington Neighbourhood House |
| 15. Bentleigh RSL | 52. KinCare (Victoria) |
| 16. Berwick News | 53. Kyabram Free Press |
| 17. beyondblue | 54. Lalor and District Men's Shed |
| 18. Brimbank Star Weekly | 55. Leader newspapers |
| 19. Carlton Probus Club | 56. Life Activities Club (8 Victorian branches) |
| 20. Castlemaine District Community Health | 57. Lions Senior Citizens Village (Sunbury) |
| 21. City Memorial Bowls Club (Warrnambool) | 58. Lionsville Retirement Community |
| 22. CO.AS.IT organisation for Italians and Australians of Italian descent | 59. Malvern Probus Club |
| 23. Cobaw Community Health | 60. Maribyrnong Council |
| 24. Council on the Ageing (Victoria) | 61. Maribyrnong Council, Aged Services Team |
| 25. Country News | 62. Melton Council |
| 26. Country Women's Association (Altona Branch) | 63. Melton Seniors Community and Learning Centre |
| 27. Cranbourne Community House | 64. Midland Express newspaper |
| 28. Doreen Seniors Club | 65. Moonee Ponds Bowls Club |
| 29. East Coburg Community House | 66. Moonee Valley Men's Shed |
| 30. Elgin Street Community Centre | 67. Moreland City Council |
| 31. Elsternwick Park Sports Club | 68. Multicultural Aged Care Services |
| 32. Evergreen Senior Citizens Club | 69. National Seniors (Victoria) |
| 33. FaceBook (various online forums) | 70. Neal Street Medical Clinic |
| 34. Farnham Street Neighbourhood Learning Centre, Flemington | 71. North Melbourne Probus Club |
| 35. Gateway Community Services | 72. Ocean Grove Voice |
| 36. Geelong City Council | 73. On The Line telephone helpline |
| 37. Gillin Park Retirement Village (Warrnambool) | 74. Over 60 Club |
| | 75. Pakenham Gazette |
| | 76. Princes Park Bowls Club |
| | 77. Probus Club of Ballarat South |

- | | |
|--|---|
| <ul style="list-style-type: none"> 78. Probus Club of Kyneton 79. Rathdowne Place Retirement Community 80. Rotary Clubs (six Victorian branches) 81. South West Do Care (Colac) 82. Sunbury Senior Citizens Club 83. The Ballarat Courier newspaper 84. The Clinic Williamstown 85. The Melbourne Sports Medicine Centre 86. The Senior newspaper 87. Uniting Age Well | <ul style="list-style-type: none"> 88. University of the Third Age (15 Victorian branches) 89. Victorian Primary Health Network Alliance 90. Volunteer Alliance 91. Wantirna Village Retirement Community 92. Waverley Gardens Combined Probus Club 93. Wendouree Senior Citizens Club 94. Wesley Mission Victoria 95. Wintringham Community Housing (Kensington) 96. Wyndham City Council |
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Appendix C:

Participant information document

INFORMATION

FOR PARTICIPANTS INVOLVED IN RESEARCH

You are invited to participate

You are invited to participate in a research project entitled:

How older people with depression self-manage their illness in order to optimise well-being.

This project is being conducted by Meg Polacsek, as part of her PhD study, under the supervision of Professor Terence McCann and Dr Gayelene Boardman from the College of Health and Biomedicine at Victoria University.

Project explanation

In this study, we want to understand how older people with depression take care of themselves to maintain their quality of life. It will examine the actions you take to meet your social, emotional and psychological needs (i.e. to self-manage your illness). By improving our understanding of how older people with depression take care of themselves, the findings from this study can be used to inform and guide improvements to policies or services related to the support of older people with depression.

What will I be asked to do?

Participation in the study will involve answering a questionnaire and participating in a one-on-one interview at a time and place of your choice. The interview will take about 60 minutes and will be audio-recorded. Questions will relate to your experience of ageing and depression, and how you take care of yourself (i.e. self-management). The student investigator may also conduct observations in a social setting, at which you may be present (e.g. at a club or community centre). All the information we collect will be confidential and you will not be named in the study.

Participation in this study is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage. If you decide to take part, you will be given this participant information and asked to sign a consent form. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the treatment and/or support you currently receive.

What will I gain from participating?

Your participation in this study will contribute to a greater understanding of how older people with depression self-manage their illness to optimise well-being. It is an opportunity for you to share your experiences and tell us about how you take care of yourself to maintain your quality of life. In this way, you will help us to understand ways that services or support might be improved for older people with depression.

How will the information I give be used?

The information we get from questionnaires and interviews will form the basis of the student investigator's PhD thesis. Information from all participants will be combined and analysed to identify any patterns or themes. All information will be treated as confidential and individual participants will not be identified in the findings or in any publications or presentations relating to the research.

What are the potential risks of participating in this project?

We do not anticipate any risks to participants in this project. However, you may feel a range of emotions when sharing your experiences of ageing and depression. You can take a break or stop the interview at any time. In the unlikely event that you become upset, the student investigator will offer basic emotional support. If needed, the student investigator can arrange for you to access professional support through the university.

How will this project be conducted?

For this study, you must be aged 65 or over and be receiving formal support and/or treatment for moderate depression. You must no longer be in paid employment, and must still be living in your own home. You must also be able to communicate in conversational English. Before confirming your participation, the student investigator will ask you a set of 10 questions about how you have been feeling over the past 30 days. These questions will help to confirm your suitability to be part of the study. As part of the study, you will be asked to answer a questionnaire and participate in a one-on-one

interview at a place and time of your choice. The student investigator may also observe activities in social settings, at which you may be present (e.g. at a club or community centre). The student investigator may also contact you after the interview, most probably by telephone, to clarify any questions from the interview or observations. All information you provide will be confidential.

Who is conducting the study?

Chief investigator

Professor Terence McCann

Tel: (03) 9919 2325; Email: terence.mccann@vu.edu.au

Associate investigator

Dr Gayelene Boardman

Tel: (03) 9919 2396; Email: gayelene.boardman@vu.edu.au

Student investigator

Ms Meg Polacsek

Tel: 0448 056 591; Email: meg.polacsek@live.vu.edu.au

Any queries about your participation in this project may be directed to the chief or associate investigator listed above. If you have any queries or complaints about the way you have been treated, you may contact the Ethics Secretary, Victoria University Human Research Ethics Committee, Office for Research, Victoria University, PO Box 14428, Melbourne, VIC, 8001, email researchethics@vu.edu.au or phone (03) 9919 4781 or 4461.

Appendix D: Participant consent form

CONSENT FORM

FOR PARTICIPANTS INVOLVED IN RESEARCH

INFORMATION TO PARTICIPANTS

We would like to invite you to take part in a study entitled *How older people with depression self-manage their illness in order to optimise well-being*. Through this study, we want to understand how you take care of yourself to maintain your quality of life. It will examine the actions you take to meet your social, emotional and psychological needs (i.e. to self-manage your illness). By improving our understanding of how older people with depression take care of themselves, the findings from this study can be used to inform and guide improvements to policies and services. Your participation in the study will involve answering a questionnaire and participating in a one-on-one interview at a time and place of your choice. The interview will take about 60 minutes and will be audio-recorded. Questions will relate to your experience of ageing and depression, and how you take care of yourself. The student investigator may also conduct observations in a social setting, at which you may be present (e.g. at a club or community centre). All information will be treated as confidential and individual participants will not be identified in the findings or in any publications.

CERTIFICATION BY SUBJECT

I,
of

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study *How older people with depression self-manage their illness in order to optimise well-being*, which is being conducted at Victoria University by Professor Terence McCann and Dr Gayelene Boardman. I certify that the objectives of the study, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by the student investigator, Meg Polacsek, and that I freely consent to participation involving the below mentioned procedures:

- Completing a questionnaire
- Participating in a one-on-one interview
- Being present during observations in a group setting.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way. I have been informed that the information I provide will be kept confidential.

Signed: Date:

Any queries about your participation in this project may be directed to:
The student investigator, Ms Meg Polacsek, on 0448 056 591
The associate investigator, Dr Gayelene Boardman, on (03) 9919 2396
The chief investigator, Professor Terence McCann, on (03) 9919 2325

If you have any queries or complaints about the way you have been treated, you may contact the Ethics Secretary, Victoria University Human Research Ethics Committee, Office for Research, Victoria University, PO Box 14428, Melbourne, VIC, 8001, email Researchethics@vu.edu.au or phone (03) 9919 4781 or 4461.

Appendix E:

Interview schedule

INTERVIEW SCHEDULE: QUESTIONS AND PROMPTS

1. I'd like to start by asking you to tell me a bit about yourself.

- Prompt: Current living arrangements, significant relationships
- Prompt: Example of a typical day

2. Getting a bit more specific now, can you tell me about your experience of being an older adult?

- What is it like, for you, being an older person here and now?
 - Prompt: Physical, psychological or social changes
 - Prompt: Type of previous work (if any), time since/experience of retirement
 - Prompt: Financial status
 - Prompt: Capacity/interest in taking care of self at home, e.g. cooking, cleaning
- In general, do people treat you differently now compared to when you were, say, in your 50s?
 - Prompt: Sense of value or burden, ageism
- If you have any medical or mental health issue, do you find that people treat you differently now compared to when you were younger?
- Can you tell me what effect, if any, this has on the way you look after yourself or get help for medical or mental health issues?
 - Prompt: Noticed any difference in accessing or receiving services?

3. Can you tell me what it's like, in general, to live with depression?

- How long have you lived with depression?
 - Prompt: The experience of first getting the diagnosis and initial treatment/support, if any
- What effect, if any, has depression had on your daily life?
 - Prompt: Physical health, personal relationships, overall quality of life
 - Prompt: Do you keep yourself busy? (hobbies, interests)
- What effect, if any, has depression had on how you view yourself?
 - Prompt: Stigma, sense of value or burden

4. I'd now like to ask you about your understanding of self-management, or self-help, in the context of living with depression.

- Can you give me an idea of what self-management (or self-help) means to you?
- Can you tell me the things you do, if any, that improve your quality of life?
 - Prompt: How you "self-manage" your illness
 - Prompt: Type of action/activity, how it was discovered, the effect it has had on physical, social or emotional health
 - Prompt: What helped you (i.e. enabled) to take these actions?
 - Prompt: Anything that makes/made it difficult to take these actions (i.e. barriers)?
- Can you tell me how you generally go about getting information about your health, or about

ways to look after yourself?

- Prompt: Type or amount of information needed in order to be able to take care of self
- Prompt: Sourcing, accessing and using information
- Is there anything you might want to do differently to look after yourself?
 - Prompt: Why do you (enablers) / do you not (barriers) do this?
- What effect, if any, do your financial circumstances have on the way you look after yourself?
 - Prompt: Whether finances influence help-seeking behavior, e.g. Medicare or private insurance

5. Can you tell me what professional treatment or support, if any, you get for your depression?

- Prompt: GP, other health worker, medications, therapy, counselling
- Do you use any other types of support?
 - Prompt: e.g. support groups, telephone helplines, online support
- To what extent, if any, do you participate in making decisions about how to take care of your health?
 - Prompt: Sharing decisions with GP or health worker
- What effect, if any, do you think a GP or health worker's perception of your age might have on their beliefs about your ability or capacity to manage your depression?
 - Prompt: Perception of compliance with medication or attending appointments
 - Prompt: Has this changed over the years?
 - Prompt: Whether the perception of ageism influences your decision to seek help for depression
- What things, if any, do they do that help you to look after yourself, as an older person living with depression?
- What things, if any, could they do, to help you look after yourself, as an older person living with depression?

6. What assistance/support, if any, do you get from others, like family members, friends or neighbours to assist your with your depression

- Prompt: Type and frequency of support, if any, from family, friends or other networks
- Prompt: Community activities (e.g. church, lawn bowls or neighbourhood house)
- Prompt: Loneliness
- Prompt: Personal sense of value or burden
- What things, if any, do they do that help you to look after yourself?
- What things, if any, could they do to help you look after yourself?

7. What advice, if any, would you give someone else if they were in your situation?

- Prompt: Any advice you wish you had been given

8. What made you agree to participate in this study?

9. Is there anything else you think I should be asking in these interviews?

Appendix F: Kessler Psychological Distress Scale

These questions concern how you have been feeling over the past 30 days. Tick a box below each question that best represents how you have been.

	None of the time (1)	A little of the time (2)	Some of the time (3)	Most of the time (4)	All of the time (5)
1. During the last 30 days, about how often did you feel tired out for no good reason?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. During the last 30 days, about how often did you feel nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. During the last 30 days, about how often did you feel so nervous that nothing could calm you down?*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. During the last 30 days, about how often did you feel hopeless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. During the last 30 days, about how often did you feel restless or fidgety?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. During the last 30 days, about how often did you feel so restless you could not sit still?*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. During the last 30 days, about how often did you feel depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. During the last 30 days, about how often did you feel that everything was an effort?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. During the last 30 days, about how often did you feel so sad that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. During the last 30 days, about how often did you feel worthless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Notes:

- The K10 uses a five-value response option for each question
- The maximum score is 50 (indicating severe distress); the minimum score is 10 (indicating no distress); moderate depression is indicated by a score of at least 25
- If a person's score is high, their participation will be checked against the exclusion criteria for the research study, i.e. if they are currently receiving inpatient treatment or experienced suicide intent/attempt within the past week.

* Questions 3 and 6 are not asked if the preceding question was 'none of the time', in which case questions 3 and 6 would automatically receive a score of one.

Appendix G: Participant data and Self-Management Ability Scale

Demographic data		
Date of interview:	Name of participant:	Study ID:
DEMOGRAPHICS		
1.	Age:	
2.	Gender:	Male Female
3.	Marital status:	Single In a relationship Separated / divorced Widowed
4.	Highest level of education:	Primary school Secondary school Vocational education University
5.	Work history:	Type of work (detail): Time since retirement Never worked
6.	Living arrangements:	Live alone With someone else (detail):
7.	Approx year of depression diagnosis:	

Self-Management Ability Scale²²⁴

Date of SMAS completion:	Name of participant:	Study ID:
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The following 30 questions are about all sorts of things in your daily life, including activities that you do, your hobbies, contact with other people, family, and so on. Think about your situation in general over the last three months when answering the questions.

The first five questions ask how often you begin activities of your own accord or take the initiative to go and do something. Each question is about a particular activity. Circle the number that best answers how often you do these activities.

	Never	Hardly ever	Sometimes	Often	Very often	Always
1. How often do you take the initiative to get in touch with people who are dear to you?	1	2	3	4	5	6
2. How often do you make an effort to have friendly contacts with other people?	1	2	3	4	5	6
3. How often do you take the initiative to keep yourself busy?	1	2	3	4	5	6
4. How often are you engaged in making your home or room as comfortable as possible (for example, by tidying your room or making it more inviting)?	1	2	3	4	5	6
5. How often do you try to be good at something?	1	2	3	4	5	6

²²⁴ Schuurmans et al. (2005)

Now a few questions about the confidence you have in your own abilities. Each question asks how sure you are you can do a particular activity. Circle the number that best answers how sure you are you can do these activities.

	I can not	Don't think I can	Sometimes can / sometimes not	Think I can	Usually can	Always can
6. Are you able to do something well?	1	2	3	4	5	6
7. Are you able to find enjoyable activities?	1	2	3	4	5	6
8. Are you able to let others know you care about them?	1	2	3	4	5	6
9. Are you capable of taking good care of yourself?	1	2	3	4	5	6
10. Are you able to have friendly contact with others?	1	2	3	4	5	6

The next questions are about things you do to get benefit from them in the long term. An example is eating healthily now so you stay healthy for longer. These questions ask about specific activities. Thinking about the last few months, indicate how often you do each activity for the long term benefits.

	Never	Hardly ever	Sometimes	Often	Very often	Always
11. How often do you do something to maintain your acquaintance-type social contacts? (speaking in the street or at the library, at the supermarket, greeting neighbours, etc)	1	2	3	4	5	6
12. Do you ensure that you have enough interests to keep you active?	1	2	3	4	5	6
13. How often do you do something to maintain your close social contacts?	1	2	3	4	5	6
14. Do you keep busy with things you are good at so you stay good at them?	1	2	3	4	5	6
15. How often do you do physical exercise to keep fit?	1	2	3	4	5	6

The next five questions are about your expectations for the future in regard to health, social contact, enjoyable activities, etc. Circle the number of the answer that best applies to you.

	No!	No	More or less	Yes	Yes!
16. Do you expect that in the future you will be able to care for yourself?	1	2	3	4	5
17. Do you expect that in the future you will have enjoyable pasttimes?	1	2	3	4	5
18. Do you expect that in the future you will have friends and family around you?	1	2	3	4	5
19. Do you expect that in the future you will be important to others?	1	2	3	4	5
20. Do you expect that in the future you will have sufficient friendly interactions with others?	1	2	3	4	5

The next five questions are about the different ways in which you combine activities. Circle the number for the answer that applies to you for each situation.

	Never	Almost never	Once in a while / sometimes	Usually	Often	Very often
21. The activities I enjoy are activities I do with others.	1	2	3	4	5	6
22. Others benefit from the things I do for pleasure.	1	2	3	4	5	6
23. I participate in my hobbies with others.	1	2	3	4	5	6
24. I do enjoyable things with people who live nearby.	1	2	3	4	5	6
25. I sometimes help people.	1	2	3	4	5	6

The final questions are about the number of different activities you do, or the number of people you usually see. Circle the number for the answer that applies to you the most.

	None	One	Two	Three or four	Five or six	More than six
26. How many hobbies or activities do you currently participate in?	1	2	3	4	5	6
27. How many different ways do you relax?	1	2	3	4	5	6
28. How many things are you good at?	1	2	3	4	5	6
29. How many people do you have confidential relationships with?	1	2	3	4	5	6
30. How many different occasions per week do you have friendly contact with others (for example, when shopping or at a meeting)?	1	2	3	4	5	6

Appendix H: Audit trail for the study

Element	Action taken
Ethical considerations	<p>Ethical approval received prior to commencement of the study</p> <p>Participant information and consent forms included as appendices</p> <p>All participant data de-identified and anonymised</p>
Review of literature	<p>Initial cursory literature review (approx. 80 references): required for study proposal, ethics application; contributed to theoretical sensitivity</p> <p>Detailed review of literature (approx. 1,300 references in total): undertaken after data collection and analysis, to aid theoretical integration and provide broader context</p>
Data collection	<p>Interviews: in-depth, semi-structured interviews</p> <p>Observations: following Gold (1958), Spradley (1980) and Corbin and Strauss' (2015) guidelines</p> <p>Questionnaires: validated instruments (K10, SMAS-30)</p> <p>Raw data: audio recordings, completed questionnaires, field notes, interview transcriptions</p>
Participant selection	<p>Six inclusion criteria and two exclusion criteria</p> <p>Initial purposive sampling followed by theoretical sampling</p>
Coding	<p>Coding steps explained fully (open, axial and selective)</p> <p>Manual and electronic coding</p> <p>82 initial codes distilled into categories</p>
Trustworthiness techniques	<p>Triangulation of data sources and methods (interviews, observations and questionnaires)</p> <p>Asking Corbin and Strauss' (2015) four sets of questions of the data</p> <p>Interview guide adapted to reflect participant responses and suggestions (e.g., loneliness, receiving a diagnosis)</p> <p>Diagrams developed to illustrate theory generation</p> <p>Memos used to document the data collection and analysis process, development of concepts and reflections on analysis</p> <p>Use of thick description and <i>in vivo</i> codes (participants' exact words) to provide an accurate representation of participants' meanings</p> <p>Feedback from supervisors</p>
Final thesis	<p>Context, methodology and method of the study presented</p> <p>Data collection and analysis described, with results presented in categories and sub-categories, including participant exemplars</p> <p>Tables and diagrams used to support data analysis and theoretical integration</p> <p>Implications and limitations presented</p> <p>Supporting documents attached as appendices, including ethics approval, participant information and consent forms, interview schedule and questionnaires</p> <p>Papers published during the course of study validated through blind peer review</p>


Appendix I: Published papers

JAN

Informing Practice and Policy Worldwide through Research and Scholarship

DISCUSSION PAPER

Paying patient and caregiver research participants: putting theory into practice

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Abstract

Aim. To review and discuss the ethical and practical considerations about paying patient and caregiver participants in nursing research and, based on this review, to develop a set of guiding principles about payment of participants.

Background. To increase recruitment and retention, it is becoming increasingly common in nursing research to provide some form of payment to participants. The risk is that the promise of a payment may influence a patient or caregiver's decision to participate in research. However, research ethics protocols seldom provide explicit guidance about paying participants. Even where formal policies or fee schedules exist, there is little consistency in determining how payments should be calculated or administered. This has resulted in highly variable payment practices between locations, disciplines and institutions.

Design. Discussion paper.

Data sources. PubMed, MEDLINE with Full Text, CINAHL and Health Source (Nursing/Academic Edition) were searched for terms related to paying research participants published between 2000 – August 2016.

Implications for nursing. Nurse researchers must comply with international, national and institutional ethical standards. Important ethical and practical considerations should guide the decision-making process about whether to pay research participants and how to determine the nature or value of the payment. Guiding principles can support researchers by highlighting key factors that may direct their decision-making in this regard.

Conclusion. A deeper understanding of the fundamental ethical and practical considerations is needed to support researchers in their deliberations about paying participants in nursing research.

Keywords: ethics, inducement, informed consent, nursing, nursing research payment, reimbursement, research participants

Why is this research or review needed?

- Payment practices in nursing research are highly variable, posing practical, methodological and ethical questions.
- There are few specific instructions on when and how to pay participants in nursing research and most existing guidelines for biomedical research cannot easily be applied to broader nursing research involving patients and caregivers.
- Outlining the key factors associated with paying research participants may assist nurse researchers in the decision-making process.

What are the key findings?

- It is common for researchers to offer payments to increase participant recruitment and retention, but few guidelines exist to inform the practice.
- Important ethical issues should be considered when deciding whether or how much to pay patient or caregiver research participants.
- Payments must be reasonable and fair, appropriate to the study design and population and should not present an excessive inducement to participants.

How should the findings be used to influence policy/practice/research/education?

- A deeper understanding and contextualisation of the key considerations regarding paying patient and caregiver participants is required.
- Clearly defined terms and concepts should underpin discussions of the ethical and practical issues associated with paying participants.
- Guiding principles can assist researchers to make more consistent decisions that are appropriate to their research purpose, design and target group.

Introduction

Good quality research depends, in part, on successful recruitment and retention of participants (Draper *et al.* 2009). In recent decades, there has been a gradual decline in research participation and recruitment of participants in nursing research has become increasingly challenging (Permuth-Wey & Borenstein 2009, Chowdhury *et al.* 2014). Time demands, absences from work, medical problems, travelling to appointments and concerns about confidentiality are frequently cited as personal factors that influence prospective participants' willingness to participate in research (Garney & Axinn 2012, Chowdhury *et al.* 2014, Normansell *et al.* 2016). Other reasons given by those who are unwilling to participate include a perceived risk of

harm, a reluctance to be the subject of an experiment (not being a 'guinea pig') and the expectation that the research would not personally benefit them (Geppert *et al.* 2014, Bouida *et al.* 2016). A lack of understanding about the research aims and methodology and concerns about the study length, are other influencing factors (Geppert *et al.* 2014, Shah *et al.* 2014), while research fatigue is also increasingly reported (Cleary *et al.* 2016). To facilitate recruitment and retention, researchers frequently offer some form of payment to participants (Permuth-Wey & Borenstein 2009, Roche *et al.* 2013). However, paying research participants gives rise to several ethical and practical considerations.

The premise of this paper arose from a current study on older people with depression. The researchers' decision about whether and how much to pay participants for completing a questionnaire and participating in a semi-structured interview had to be made in the absence of clear ethical guidelines on payment. To inform their decision, the researchers referred to comparable nursing studies where participant payment occurred (Draper *et al.* 2009, Geppert *et al.* 2014, Hampton *et al.* 2016). The research proposal was approved by the institution's human research ethics committee. While responsibility for governing research activities usually lies with individual ethics committees, however, they too often lack policies or protocols to inform their decisions about payment (Largent *et al.* 2012, Roche *et al.* 2013). The aim of this article is to explicate and contextualize the ethical and practical considerations related to paying participants in nursing research. A set of guiding principles is presented to support nurse researchers and human research ethics committees in their deliberations in this regard.

Background

There is a long history of giving monetary payments to participants in research and this is now considered a routine component of nursing research (Bernstein & Feldman 2015, Devine *et al.* 2015). Payment for participation can be presented as a reimbursement, incentive, inducement, compensation, reward, gift or token of appreciation (Bernstein & Feldman 2015). These terms are often used interchangeably and without clear definitions and conceptual boundaries are often blurred (Grant & Sugarman 2004). Indeed, key terms regarding payment, coercion and excessive inducement are more often invoked than defined (Largent *et al.* 2012). For the purposes of this discussion, the United Kingdom Health Research Authority's (2014) definition of 'payment' has been adopted (Table 1). Brief examples and explanatory

Table 1 Definitions of key terms relating to payment of research participants.

Term (listed alphabetically)	Definition	Assessment of payment practice
Coercion	<ul style="list-style-type: none"> The intentional imposition of one person's will on another, often through an overt threat of harm, to obtain compliance. For example, prospective participants on low incomes might feel coerced to participate if the level of payment is too high to refuse. 	Unacceptable
Excessive inducement	<ul style="list-style-type: none"> An offer of excessive, inappropriate or improper reward that leads people to do something they would normally object to, based on their assessment of risk or other fundamental values. In some cases, it may be more appropriate to offer non-monetary forms of payment, to ensure that participants' consideration of the risks associated with the research are not distorted by a cash payment offer. 	Unacceptable
Incentive	<ul style="list-style-type: none"> Generally constitutes an offer over and above the reimbursement of actual costs to the participant. May be used to encourage participation, but should not constitute an excessive inducement. May take the form of money or other goods. 	Acceptable
Payment	<ul style="list-style-type: none"> Generic term that covers any transactions involving money or goods with a monetary value, such as a gift voucher or actual gift. May be understood as a reward for participation. 	Acceptable
Reimbursement	<ul style="list-style-type: none"> Monetary payment that covers any losses incurred by the participant, such as train fares, car parking, accommodation, or lost earnings. May be considered as compensation, where participants are reimbursed for direct expenses (e.g. train fares) or for non-financial losses (e.g. time or inconvenience). 	Acceptable

statements are drawn from Head (2009) and Wertheimer and Miller (2008).

A common objection to paying research participants relates to the issue of informed consent (Stones & McMillan 2010, Largent *et al.* 2012), specifically the risk that payment may influence a participant's decision to join a study (Wertheimer & Miller 2008, Schrems 2014). Grounded in the notions of autonomy and respect for human beings, the key components of informed consent are disclosure (the adequacy of the information provided to the prospective participant), comprehension (the extent to which that information is understood), competence (the person's capacity to give consent), and voluntariness (making the decision to participate in the absence of coercion or inducement) (Sim 2010).

Historically, efforts to establish international rules for ethical conduct in research stem from the time after the Second World War, when abuses under the banner of research were made public in the Doctors' Trial in Nuremberg in 1946–1947 (Nuremberg Military Tribunals 1946). The disregard for human dignity that occurred in German concentration camps during the war included assigning 'patients' to clinical interventions without their knowledge or consent (Kaufman 1997). Other reports of unethical conduct that took place during the Second World War included medical researchers

in the United States injecting hospital patients with radioactive plutonium to learn its effects on the human body (Kaufman 1997). Shaping the subsequent research ethics process, the Doctors' Trial verdict adopted 10 points, known as the Nuremberg Code, to define and govern legitimate medical research (Nuremberg Military Tribunals 1946). The guiding principles of the Nuremberg Code were subsequently enshrined in the Declaration of Helsinki, which has directed research on human subjects since 1964 (World Medical Association 2013). The Declaration asserts that research should never take precedence over the rights and interests of participants and that all medical research should follow ethical rules of practice that promote and ensure respect for participants, while protecting their health and rights (World Medical Association 2013). The Declaration of Helsinki explicitly states that incentives for research subjects should be included in research protocols (World Medical Association 2013), while the International Ethical Guidelines for Biomedical Research involving Human Subjects articulates broad requirements in this regard (Council for International Organizations of Medical Sciences 2002). In the absence of clear local guidelines, researchers and ethics committees are frequently left to refer to these broad international statements when considering issues about paying participants (Table 2).

Table 2 Examples of international statements about paying participants.

Source	Clause/item	Statement
<i>International</i> 2000 Declaration of Helsinki (World Medical Association 2013)	22	Each research protocol should include information regarding incentives for subjects.
<i>International</i> Council for International Organizations of Medical Sciences International Ethical Guidelines for Biomedical Research involving Human Subjects (2002)	7	Participants may be reimbursed for inconvenience and time spent, lost earnings, travel costs, and other expenses incurred in taking part in a study. They may also receive free medical services. Prospective participants should not be presented with excessive inducements to participate in the research against their better judgment.
<i>Australia</i> National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015), (National Health and Medical Research Council 2015)	2-2-10	It is generally appropriate to reimburse the costs to participants of taking part in research, including travel, accommodation and parking. Sometimes participants may also be paid for time involved. However, payment that is disproportionate to the time involved, or any other inducement that is likely to encourage participants to take risks, is ethically unacceptable.
<i>Canada</i> Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans, Canada (Government of Canada 2010)	3-1	Incentives are anything offered to participants, monetary or otherwise, for participation in research. They should not be so large or attractive as to encourage reckless disregard of risks.
<i>United Kingdom</i> UK Health Research Authority (Ethics guidance: Payments and incentives in research) (2014)	3-9	Payments should never be related to risk, and financial or other incentives should not present an excessive inducement to participate.
<i>United States</i> Office for Human Research Protections (U.S. Department of Health and Human Services 2009)	–	Paying research participants is a common and, in general, acceptable practice, but the payment must be just and fair.

Even where local guidelines exist, it may be challenging for institutional ethics committees to reach agreement on a complex issue such as participant payment, given the diversity of their composition (Ripley *et al.* 2006). In Australia, for example, human research ethics committees are required to include scientists, non-scientists, institutional representatives, lay people who do not engage in medical, scientific, legal or academic work and a person who performs a community pastoral care role (National Health and Medical Research Council 2015). Lacking clear guidelines about paying participants, it is largely left up to individual committee members to interpret issues around consent, coercion, and payment (Ripley *et al.* 2006, Largent *et al.* 2012, Roche *et al.* 2013). A review by Ripley *et al.* (2006) into the perspectives of research ethics committee members regarding paying research participants revealed that monetary amounts varied widely without explanation in research studies and even across sites in the same multi-site study. In an effort to streamline and standardise ethical processes across local, national and international jurisdictions, countries such as Australia, Canada, the United Kingdom and the United States are now adopting mutual acceptance principles (Rahimzadeh & Knoppers 2016, National Health

and Medical Research Council n.d.). However, while these principles remain to be further simplified and homogenised (De Smit *et al.* 2016), they do not provide guidance on the payment of participants. Guiding principles can facilitate more consistent practices in relation to paying research participants (Singer & Couper 2008, Largent *et al.* 2012, Li *et al.* 2016), while arrangements for collaborative research projects involving payment should be addressed with partnering organisations or researchers before a study begins.

Typically, payments in research serve to acknowledge participants' time and inconvenience (Head 2009). They are also frequently presented as reimbursement for lost earnings, travel costs or other expenses. An unexpectedly or disproportionately high payment may be considered an excessive inducement, which may compromise a person's ability to give informed consent (U.S. Department of Health and Human Services 2009, Devine *et al.* 2015). In the event that a person ignores potential risks or moral concerns to participate in research (in other words, their participation may be harmful to themselves), they are deemed to have acceded to excessive inducement (Largent *et al.* 2012). However, whether a payment is considered an incentive or inducement to participate in research does not necessarily

make it unethical. Wertheimer and Miller (2008) assert that offers of benefit cannot constitute coercion, as a payment is an offer and not a threat. An inducement is only excessive if it triggers irrational decision-making that compromises the person's usual values or risk-taking behaviour (Wertheimer & Miller 2008). Largent *et al.* (2012) offer another perspective, postulating that researchers may, in fact, find it difficult to recruit participants if payment is not offered. The decision about payment is also dependent on the level of funding available to the researcher, giving rise to the risk that better-funded studies may attract more participants by offering a payment (Grady 2005, Ripley 2006, Jennings *et al.* 2015).

The researcher should ensure that participants understand whether or how they may benefit from the research (Townsend & Cox 2013). Payments are ethically contentious only when an individual agrees to do something to which they are, in fact, averse (Grant & Sugarman 2004). To mitigate this risk, participants should understand the extent of participation required to receive a payment, with a clear distinction made between paying participants for reasonable expenses and using payment as an incentive to participate (Jennings *et al.* 2015). They should also be informed of the amount and timing of the payment. For example, the institution may have stringent protocols for managing cash payments, while lotteries or wage payments may have tax implications (Grady 2005). Where participants are given a choice of the method of payment, efforts should be made to ensure equitable pay for their participation (Ripley *et al.* 2006). When conducting research with vulnerable populations, in particular, it is advisable to seek advice from the local community to establish the most appropriate form of payment based on a sound understanding of the importance of money or material possessions (Ensign 2003, Hammett & Sporton 2012, LeBaron *et al.* 2015).

When it comes to considering whether or how much to pay research participants, vulnerable individuals may be particularly at risk (Schrems 2014), as the promise of a payment may cause the person to feel that they have no reasonable alternative to participating, when they would otherwise not have done so (Cleary *et al.* 2008, Largent *et al.* 2012). Vulnerable participants include those who are socially or economically disadvantaged, people with a cognitive or mental disorder, hospital patients and their caregivers, people with a chronic or terminal illness, or are homeless (Sim 2010). An additional consideration is that attitudes about whether to pay participants vary between countries and cultures (Jennings *et al.* 2015, LeBaron *et al.* 2015). In the United Kingdom, healthy volunteers are typically paid for participating in research, while patient

participants generally receive reimbursement for health care (Jennings *et al.* 2015). In the United States, higher payments have been identified as a key motivation for participation in biomedical research (Singer & Couper 2008). Conversely, a study in Tunisia (Boudia *et al.* 2016) found that most participants in medical research were motivated by altruism. In Russia, a study (Zvonareva *et al.* 2015) into the risks and benefits of trial participation found that those with higher healthcare needs were more willing to participate in studies that provide some form of free treatment, such as regular check-ups, individual test results or access to a physician (Zvonareva *et al.* 2015). Gatny and Axinn (2012) reported that pregnant women in the United States were more likely to participate in research if they expected to learn more about pregnancy health and get a free medical test, than if they were to receive a monetary payment.

Noting the lack of consensus about due and undue incentives, researchers working with vulnerable populations highlight the importance of ensuring that participants are paid for their time and inconvenience and that the payment is not based on the level of risk of the research (Ensign 2003, Cleary *et al.* 2008, Hammett & Sporton 2012). Nor should the payment be so high as to be coercive (Grant & Sugarman 2004). This risk was evident in a study by Goodman *et al.* (2004), who found that even a relatively small cash payment for participation may be too substantial for some participants on low-incomes to refuse. Subsequently, those who are on low incomes may feel unable to refuse a payment of any amount (Draper *et al.* 2009, Head 2009). Similarly, nurse researchers in low- and middle-income countries such as Argentina, India, South Africa and Tanzania found that a promise of payment was likely to be considered coercive to communities in impoverished areas (LeBaron *et al.* 2015). In these cases, it may be appropriate to consult local collaborators about the most culturally proper way to acknowledge participants' contribution (LeBaron *et al.* 2015). Gift cards, vouchers, and non-monetary gifts such as t-shirts or mugs have been found to have a lower influence than money on the decision-making process of prospective participants (Largent *et al.* 2012). However, a person's motivation to participate in research is not always about remuneration. A study by Jennings *et al.* (2015) into the under-representation of research participants who are older, socially deprived or living with multiple comorbidities found that a cash payment did not improve recruitment rates in the target group. Seeking to understand the motivations of patients with diabetes to participate in research, Geppert *et al.* (2014) reported that 75% of study participants cited reasons related to treatment and no participants mentioned money as a reason for

participating. An exploratory study by Townsend and Cox (2013) found that only a minority of participants were motivated by payment, while others considered payment insignificant in their decision to participate. Rather, most people participated in research for altruistic reasons, to contribute to knowledge or to 'be a good citizen' (Townsend & Cox 2013, Bouida *et al.* 2016). Altruism has been strongly associated with research participation and money alone is often just one factor that is taken into account when a decision is made about whether or not to participate in research (Grady 2001). While some researchers raise concerns that paying participants wrongly commodifies a practice that should be based on altruism, others consider making payments as a mark of ethically sound research (Wertheimer & Miller 2008). In their view, the practice could be seen as a demonstration of respect and serve as a way of equalising the uneven power relationship between researcher and participant (Grady 2001, Head 2009), with participants viewing participation as an opportunity and not a burden (Grady 2005).

Payment of patients and caregivers in nursing research is frequently contentious, particularly if the form of payment includes free treatment or access to services (Cleary *et al.* 2008, Largent *et al.* 2012, Devine *et al.* 2015, Zvonareva *et al.* 2015). Without established principles in this regard, it remains incumbent on the individual researcher to follow local institutional and study-specific protocols to ensure that the requirement for voluntary participation is met and that consent is obtained without coercion (Ripley 2006, Wertheimer & Miller 2008). In this article, important ethical and practical considerations are described that should be taken into account when deciding whether to pay participants and how to determine the value or nature of payment. A set of guiding principles is presented to support nurse researchers in this regard.

Data sources

A search was conducted of four major health-related databases: PubMed, MEDLINE with Full Text, CINAHL and Health Source (Nursing/Academic Edition). Inclusion criteria were: publication in the period 2000–2016; publication in books, journals or web pages; English language; and field of health and nursing. Exclusion criteria were: conference papers or presentations; and non-nursing related studies or publications. Search terms included combinations of the following keywords: 'remunerat*', 'incentive', 'pay*', 'reimburs*', 'compensat*', 'research', 'participa*', 'recruit*', 'ethic*', 'induce*' and 'nurs*'. To illustrate, a PubMed search for 'pay for participation' yielded 820 publications

or webpages, which was reduced to 472 when the search term 'research' was added. Filtering these results with 'nursing' reduced this number to 47. Several publications were identified by reviewing the reference lists of the literature identified through the search. An internet-based search of English-language government and agency reports and professional guidelines relating to the topic was also conducted.

Discussion

By their very nature, deliberations relating to research ethics and integrity are often complex (Speer & Stokoe 2014). One of the issues attracting attention concerns payment to research participants. Despite its widespread use, the practice of paying participants in research remains controversial (Jennings *et al.* 2015, Cantinotti *et al.* 2016). For researchers, the requirement to comply with international and national ethical statements is fundamental to any decision about paying participants (Grady 2005, Largent *et al.* 2012). However, even where formal policies or research participant fee schedules exist, there appears to be little consistency in determining how payments should be calculated or administered (Czarny *et al.* 2010). Furthermore, while ever more nursing studies report paying participants (Chen *et al.* 2015, Cantinotti *et al.* 2016, Hampton *et al.* 2016), few published studies detail the decision-making process around payment. This has resulted in highly variable payment practices between disciplines, institutions and individual researchers (Head 2009, Roche *et al.* 2013).

Regardless of the nature of the payment, the expectation that paying research participants to increase recruitment and retention will remain a common practice reinforces the need for practical guidelines to inform decision-making in this area (Grant & Sugarman 2004, Permuth-Wey & Borenstein 2009). The guiding principles suggested in this paper summarise important considerations that should be taken into account in the development or review of a research proposal where researchers seek to pay participants (Table 3).

Participants may – by chance or random assignment into different experimental conditions – be required to provide different time commitments, effort or performance. Although money is generally considered more effective than non-cash payments for recruiting and retaining participants, it is not a unique influence on a research participant's decision-making process (Singer & Couper 2008). Higher payments are usually associated with more invasive procedures, while completion bonuses may be offered in studies where participants are asked to attend multiple visits

Table 3 Key considerations and guiding principles for paying research participants.

Key consideration	Guiding principles
National and institutional guidelines	<ul style="list-style-type: none"> • Ensure the research complies with national ethics guidelines on paying participants. • Check whether the local ethics committee offers guidelines regarding payment. • Each research context should guide the decision on whether the method and value of a payment is advisable, acceptable, or unacceptable.
Key terms	<ul style="list-style-type: none"> • Define the key terms used to describe how participants will be paid (e.g., payment, reimbursement, reward or gift). • Explain the key terms to the ethics committee, fellow researchers and participants.
Participant characteristics and motivation	<ul style="list-style-type: none"> • Ensure the nature of the payment is appropriate to participant characteristics (e.g., age, gender, location, socio-economic, or health status). • Address any concerns that payment may distort participants' judgements of risk and benefit. • Consider whether or how gatekeepers involved in identifying or recruiting participants may be influenced by the promise of a payment to participants. • Consider whether it is appropriate to conduct a pre-consent assessment of vulnerable participants, to ensure they understand the implications of participating and can give informed consent. • Ensure that colleagues or gatekeepers do not allow their own views on payment to influence their decisions about identifying or recruiting participants.
Participant information and consent	<ul style="list-style-type: none"> • Include information about the nature, amount and timing of the payment on participant information and consent documents. • Ensure that participant consent is given without coercion and that the proposed payment does not constitute an excessive inducement.
Method of payment	<ul style="list-style-type: none"> • Determine the most appropriate payment for each specific research study.
Cash or vouchers	<ul style="list-style-type: none"> • Consider how cash payments will be managed (e.g., obtaining cash from the institution, how and when the cash will be given to participants, and keeping records or evidence of cash payments). • Identify an alternative to monetary payments (e.g., meal or gift vouchers, prepaid telephone cards, public transport vouchers or electronic gift vouchers). • Use gift vouchers from retailers that are commonly available and affordable. • Ensure all participants can access the retailer to redeem the voucher, or use vouchers that can also be redeemed online.
Reimbursement for costs	<ul style="list-style-type: none"> • If participants are reimbursed for expenses incurred (e.g., parking, travel costs), consider issues relating to the perception of equitable pay for participation.
'In-kind' payments	<ul style="list-style-type: none"> • Consider whether participants should be given a choice of cash or in-kind payment (e.g., meals, transport or cheaper/earlier access to a treatment). • Confirm that in-kind payments take into account the customs and values of the community in which the research takes place.
Lotteries, prize draws, or raffles	<ul style="list-style-type: none"> • Establish that participants understand the nature of the prize and the probability of winning. • Consider whether a cash alternative may be substituted for a prize. • Determine whether there are any legal implications of conducting a lottery or prize draw.
Paying wages	<ul style="list-style-type: none"> • If a participant has prolonged involvement in a study, consider whether a minimum wage payment model may be appropriate. • Identify legal implications of paying wages to participants (e.g., payments of tax and implications for participants' benefits, such as pension or allowances).
Timing of payment	<ul style="list-style-type: none"> • Specify the extent of participation required to receive payment (e.g., level of participation, involvement in different stages of a study, or series of payments). • Establish whether participants will be paid before or after each session, or at the end of a series of sessions. • Consider whether participants will be paid if they withdraw, or if a completion bonus will be offered.

(Permuth-Wey & Borenstein 2009). To be deemed acceptable, the method of payment should be appropriate to the research design, aims and population (Largent *et al.* 2012, Bernstein & Feldman 2015). To illustrate, it was considered appropriate for participants in an Australian study on help-seeking barriers and facilitators in young sub-Saharan African migrant communities to receive vouchers redeemable at

a major supermarket chain (McCann *et al.* 2016), while free health checks were offered to participants in a study in Taiwan on social cohesion and health in old age (Chen *et al.* 2015).

Researchers should also consider whether a promise of payment to patients or caregivers for participating in research may influence gatekeepers in identifying potential

participants (Head 2009). Nurse researchers frequently seek to collaborate with colleagues who provide direct care to patients or caregivers, to identify and recruit research participants (Holloway & Wheeler 2010). Discussions with gatekeepers should be aimed at detailing the purpose and design of the research, to ensure that gatekeepers support the research and do not allow their own views on payment to influence their decisions about participants (Clark 2011, Singh & Wassenar 2016).

Implications for nursing

There are four main implications for paying patients and caregivers in nursing research, relating to policies, ethics committees, researchers and patients and caregivers. From a policy perspective, guidance about payment of participants should be incorporated within an overarching research framework that governs the conduct of ethically sound human research. At the very least, research should comply with the Declaration of Helsinki (World Medical Association 2013) and the International Ethical Guidelines for Biomedical Research involving Human Subjects (Council for International Organizations of Medical Sciences 2002), both of which offer broad guidance on incentives in research. By clearly defining terms and expectations of participant payment, local institutional research ethics policies should inform consistent practices that can be applied across research designs and participant groups. These policies must align with relevant legislation, regulations and codes. Furthermore, to make reasonable judgements about the nature of the payment and whether it may influence a person's decision to participate, ethics committees should consider the design and context of the study, and the particulars of the research population (Ripley 2006, Roche et al. 2013).

From a researcher perspective, the chief investigator has primary responsibility for ensuring that payment is appropriate to the research aims and population. Careful consideration of participant characteristics and what a payment may mean to them contributes to the veracity of the research and reduces the risk of consent being obtained through coercion or excessive inducement (Orb et al. 2001). Finally, from a patient and caregiver participant perspective, the decision about participating in research rests on a combination of personal and practical motivations, such as wanting to contribute to knowledge, anticipating a health benefit or the promise of a payment (Townsend & Cox 2013). Participants should know what their participation involves and whether they will receive a payment, and the method and timing of the payment, before they agree to participate.

Conclusion

Paying participants in nursing research is increasingly common, but payment practices are highly variable, posing practical, methodological and ethical questions that merit attention. It is important to consider the context of research when determining payment. Although guiding principles cannot ensure ethical conduct in nursing research, they can guide the decision-making process about paying participants. The ethical issues associated with paying research participants invite further critical exploration, as nurse researchers seek to determine the most appropriate approach for paying participants in different studies.

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Author contributions

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- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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Understanding, choosing and applying grounded theory: Part 1

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Understanding, choosing and applying grounded theory: Part 1 Nurse Researcher

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Keywords

Constant comparative analysis, constant comparison, core category, grounded theory, qualitative research, theoretical integration

Abstract

Aim To provide a critical overview of grounded theory, to support neophyte researchers' understanding of a methodology for systematically generating theory from data.

Background Grounded theory is one of the most widely used qualitative research methodologies. However, it is a complex methodology that is frequently misinterpreted and misapplied. This paper presents the underlying assumptions and characteristics of grounded theory. In Part 2, an explanation of the choice and application of a grounded theory methodology is provided.

Discussion The uniqueness of grounded theory is evident in the way researchers explicate concepts from the data during the research process, rather than entering the field with a

list of pre-defined concepts. Adherence to its rigorous standards enables researchers to contribute to knowledge and practice.

Conclusion Grounded theory is particularly useful in nursing and midwifery research, where it can be applied to a broad range of topics. Neophyte researchers should not be deterred by its rigorous standards, although time and effort are required to appreciate the similarities and differences between grounded theory approaches.

Implications for practice A clear understanding of its philosophical foundations and attention to its main features should underpin researchers' efforts to conduct a high quality grounded theory study.

Introduction

Qualitative research encompasses a diverse collection of approaches, each of which seeks to generate knowledge of human experience. Grounded theory is an effective methodology for investigating individuals' experiences and actions, and their perceptions and thoughts about them. It is unique among qualitative approaches in that researchers do not begin with preconceived assumptions, but seek to systematically generate theory from the data (Corbin and Strauss 2015). The focus in grounded theory on interaction, communication and active engagement facilitates understanding of the process under study (Watling and Lingard 2012). An example of a process is the way in which individuals respond to and manage a change in their wellness-illness status (Ashman et al. 2017).

Grounded theory gets its name from the way in which a theory is constructed from data collected during the research process (Corbin and Strauss 2015). The methodology differs from descriptive qualitative research in that it provides an overarching framework that explains why things happen. Researchers achieve this by collecting data for comparative analysis, developing conceptual categories and properties from the data, and then generating a theory.

Grounded theory was developed in the 1960s by Barney Glaser and Anselm Strauss to improve social scientists' capacities for generating theory from data. They proposed that qualitative enquiry could move beyond pure description, and be used to develop

theoretical explanations of human behaviour (Hall et al. 2013). Grounded theory has its roots in interpretivism, which focuses on the way human beings make sense of their reality. One branch of interpretivism is symbolic interactionism, which explains how people act, interact and adapt in their daily lives (Holloway and Galvin 2017). It is a fundamental feature of symbolic interactionism that individuals cannot be separated from the contexts in which they exist (Handberg et al. 2015).

Since Glaser and Strauss (1967) first presented their new methodology, a series of academic debates around the core tenets of grounded theory has resulted in three main approaches, often referred to by the names of their originators. Glaser has continued to follow the original model of grounded theory, while Strauss—with Corbin—introduced a coding matrix to support data analysis. They also provided additional guidance on theoretical sampling (Corbin and Strauss 2015). Charmaz, a former student of Glaser and Strauss, presented a third adaptation of grounded theory, characterised by a constructivist philosophy. Using a more interpretative and intuitive coding procedure, Charmaz emphasises in-depth, intensive interviewing to explore the meanings participants attribute to their experiences (Charmaz 2008). Although she adopts Glaser and Strauss' original inductive, emergent approach, Charmaz (2017) highlights the role of the researcher in interpreting data and co-constructing understanding with study participants. Despite their divergences, all three approaches acknowledge the same origin and embrace several of the original methodological techniques of grounded theory, including researchers' fundamental aim of developing an integrated theory that explains a process associated with a specific phenomenon (Morse 2001).

Two types of theories can be generated using grounded theory: formal or substantive. In each study, the researcher should focus on generating only one or the other (Glaser and Strauss 1967). Formal theories are more general than substantive theories, and are not specific to a group or place, but may apply across location and time (Kearney 2001, McCann and Clark 2003). An example of formal theory is Elisabeth Kübler-Ross' (1973) theory of the stages of dying, which has wide application beyond its original scope (Birks and Mills 2011). Substantive theories are topic-specific and are developed for a narrow area of study within a clearly defined context. An example is how older adults self-manage depression to optimise wellbeing (see Part 2 of this two-part paper). Most

grounded theory studies result in the development of substantive theories, perhaps because most health researchers who use this approach seek to develop this type of theory (Birks and Mills 2015). Substantive theories are useful as they have specificity for a particular context, such as a certain patient group or care setting (Holloway and Wheeler 2010). However, through expanded analysis, substantive theories can be used to generate new or modify existing formal theories (Glaser and Strauss 1967, Birks and Mills 2015).

Although grounded theory is increasingly popular in nursing and midwifery, it is a complex methodology that is often misinterpreted or not used to its fullest capacity. Even the term *grounded theory* may cause confusion (Charmaz 2017), as contemporary use of the term refers to methodology (the underlying principles of enquiry) and method (as a tool to assist with conducting research). Thus, the term may explain researchers' reasoning behind a particular approach (the focus of this paper), and/or the tools and techniques used in the research process (the focus of Part 2 in this two-part series). Mixing grounded theory methods in a single study is also common. Evans (2013) describes researchers who “skip and dip” between different methods, giving the impression of identical approaches to data analysis (p. 38). The aim of this paper is to provide a critical overview of grounded theory, to support neophyte researchers' understanding of a methodology for systematically generating theory from data.

Features of grounded theory

Seven criteria are considered integral to grounded theory: (i) theoretical sensitivity, (ii) theoretical sampling, (iii) constant comparison, (iv) coding and categorising data, (v) theoretical memos and diagrams, (vi) referral to existing literature, and (vii) integration of theory (Glaser and Strauss 1967, McCann and Clark 2003). These main elements are used in a systematic, yet flexible, manner to collect and analyse data, in order to construct a theory. However, the three main approaches to grounded theory differ in the degree to which these elements are applied (Table 1). Practical strategies and examples of these elements are provided in Part 2 of this two-part paper.

TABLE 1. Main elements of the three main approaches to grounded theory

	Glaser (1998)	Strauss & Corbin (2015)	Charmaz (2014)
Epistemology	Critical realist ontology Postpositivist paradigm More positivistic	Social constructivist and poststructuralist, or postmodern paradigm Less positivistic	Relativist ontology Pragmatist philosophy Constructivist
Researcher's role	Independent	Dialectic and active	Active
Theory	Emphasis on theory generation	Emphasis on verification and validation of theory and hypotheses	Emphasis on co-construction of a theory
Focus in the field	Main emphasis on symbols, interactions and context Emphasis on socially constructed world of participants (micro)	Emphasis on structural, contextual, symbolic and interactional influences Emphasis on describing cultural scene (macro) and socially constructed world of participants (micro)	Emphasis on constructing a conceptual interpretation of the phenomenon
Referral to existing literature	Main review to support emerging theory	Preliminary review to enhance theoretical sensitivity Main review to support emerging theory	Preliminary review to enhance theoretical sensitivity Main review to support emerging theory
Research problem	Emerges in study	Personal experience Suggestion by others Literature Emerges from the data	Personal experience Suggestion by others Literature Emerges from the data
Data collection and analysis	Principles and practices of qualitative research Guided by participants and socially constructed reality	Rules and procedures Rigorous coding framework	Flexible coding guidelines Less structured, impressionistic coding
Evaluation	Fit, work, relevance and modifiability	Deference to canons of qualitative research outlined by other qualitative researchers	Credibility, originality, resonance and usefulness

Theoretical sensitivity

Theoretical sensitivity relates to researchers' ability to have insight, understand and give meaning to the data, and to detach the relevant from the irrelevant (Corbin and Strauss 1990). It allows researchers to enter the field with an awareness of the subtleties of the data (Glaser 1978). Researchers' different backgrounds, knowledge and experiences allow them to develop and increase their sensitivity to concepts in the data, and enable

them to identify connections between concepts (Corbin and Strauss 2015). Thus, researchers demonstrate sensitivity in how they interact with participants, ask questions and respond to the data.

Theoretical sampling

Two types of sampling are used in a grounded theory study. Recruitment of participants commences through purposive sampling using predetermined criteria. Theoretical sampling commences as soon as the first set of data have been analysed and is used to collect new data to compare emerging categories related to the evolving theory (Birks and Mills 2015). This is an iterative approach whereby decisions regarding the number and attributes of participants are based on categories that are developed from the data (McCrae and Purssell 2016). In other words, researchers use the emerging theory to guide further decisions about participants, sample size, settings and the type of data to be collected (McCann and Clark 2003). This category-driven approach to sampling is particularly important when studying an area where little prior research has been undertaken, as it allows researchers to explore issues from different angles (Corbin and Strauss 2015). The circular process of data collection, data analysis and development of categories continues until the point of theoretical saturation, when all major categories have been fully developed, show variation and are integrated (Figure 1).

Constant comparative analysis

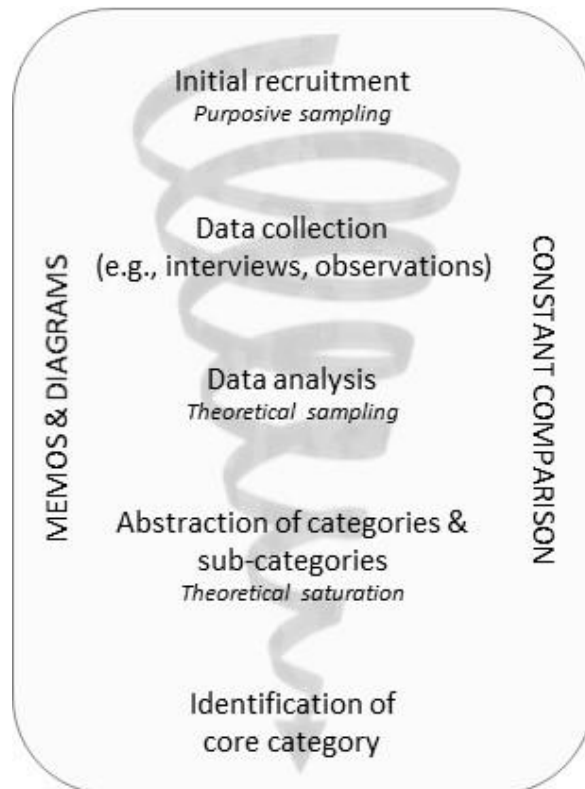
Constant comparison is the main approach to data analysis in grounded theory (McCann and Clark 2003). Data collection and analysis are linked from the outset of the research, proceed in parallel and interact continuously (Holloway and Galvin 2017). Data collection and analysis take place simultaneously, and all data are analysed through constant comparative analysis. Each unit of data is compared to all preceding units, to determine if they are similar or different in meaning (Glaser 2005, Achora and Matua 2016). The four stages of constant comparative analysis require researchers to (i) compare incidents that apply to each category, (ii) integrate categories and their properties, (iii) delimit the theory, and (iv) write the theory (McCann and Clark 2003). In practice, this means that data are broken down into manageable parts, before being compared for similarities and differences. As analysis continues, concepts are grouped and labelled to

form categories. Thus, constant comparative analysis drives theoretical sampling and the ongoing collection of data (Birks and Mills 2015). Approaching the data from different vantage points, asking questions, making comparisons, following leads and building on ideas also support sensitivity, one of the essential elements of grounded theory (Charmaz 2014).

FIGURE 1. Diagrammatic representation of conducting grounded theory

Coding and categorising data

It is through coding that the process of theory development is initiated. However, different coding procedures are apparent across the main approaches to grounded theory. Glaser (2013) describes substantive and theoretical coding, while Corbin and Strauss (Corbin and Strauss 2015) use open, axial and selective coding. Charmaz (2008) advocates the use of highly adaptable coding guidelines which



enable “imaginative engagement with data” (p. 168). Regardless of the approach, this is the fundamental analytic process used by researchers to identify and name concepts, before they are reduced to develop categories (Holloway and Galvin 2017). Initial codes may be provisional, and later modified or transformed as data analysis progresses. Once patterns in the data have been coded, conceptual labels are assigned to individual incidents that are related to a phenomenon (McCann and Clark 2003). In this way, conceptually similar incidents are grouped together to form categories and sub-categories. This process of conceptualisation of data is the foundation of a grounded theory and stops only when researchers are unable to find new information on a specific category, can comprehensively describe the properties of each category, and can establish firm links between categories (Glaser and Strauss 1967).

Theoretical memos and diagrams

Memoing is fundamental to the development of grounded theory (Birks and Mills 2015). Memos are notes made by researchers to record and explicate the theory as it is developed (Charmaz 2014). They vary in style, length and complexity, but typically begin as basic representations of researchers' thoughts and then grow in complexity, density and accuracy as the research progresses (Corbin and Strauss 2015). This pivotal intermediate step between data collection and writing drafts of papers facilitates the process by which data are raised to a conceptual level and categories are developed, which, in turn, supports the formulation of the theory (Holton 2007, Charmaz 2014). Although diagramming is typically done less frequently than memo writing, diagrams may be used to conceptually map analysis throughout the research process and to visually represent the conceptual relationships that develop between categories (Corbin and Strauss 2015). They include maps, charts and figures. Through the process of drawing and redrawing diagrams, researchers can stand back and conceptualise the full theory, which can then be checked against the data (Schreiber 2001).

Literature

Differing views on the role and timing of the literature review in grounded theory are well documented (Cutcliffe 2000, Birks and Mills 2011, Corbin and Strauss 2015). While Glaser and Strauss (1967) originally argued against engaging with literature before data collection, Corbin and Strauss (2015) advocated a brief review at the outset. There is consensus, however, between the different approaches that a review of literature be undertaken at some point, and that it should neither limit creativity, nor allow researchers to impose existing ideas on the data (Corbin and Strauss 2015). A cursory review of literature undertaken prior to data collection and analysis can help justify the need for the study, provide background to the study and enhance theoretical sensitivity (McCann and Clark 2003, Charmaz 2014). The aim of the second, and main, literature review is to help researchers clarify ideas, make comparisons and identify connections between the new and existing research (Holloway and Galvin 2017). Overall, we agree with Dunne (2011), of the need to reach a practical middle-ground in this regard. Regardless of the grounded theory approach adopted, researchers should explain the role and timing of the literature review (Dunne 2011).

Integration of theory

As the theory and its categories and sub-categories are developed, more data are collected to support the development of hypotheses. Categories are then linked around a core or overarching category. As the major category which links all others, the core category should be sufficiently broad and abstract to summarise the main ideas identified in the study (Corbin and Strauss 2015). It must appear frequently in the data and link easily with all other categories (Corbin and Strauss 2015). In this final step of analysis, researchers shift their focus from exploring to summarising. This involves reviewing the theory for internal consistency and logic, filling in any gaps, removing extraneous categories and accounting for variation in the data (Corbin and Strauss 2015). If the theory is grounded in the data, it will be integrated, or fit, and explain the substantive area in which the study took place. At this point, the theory should be discussed critically in relation to the wider literature (Noerager Stern 2007). The final version of the literature review should be tailored to fit the specific purpose and findings of the research (Charmaz 2014). Thus, the literature is not used to verify the new theory, but to enrich the research and demonstrate how it adds a new dimension to existing knowledge (Noerager Stern 2007).

Critique of grounded theory

The main criticism of grounded theory concerns the lack of clarity around beliefs about the nature of knowledge and assumptions about how knowledge can be acquired (that is, its epistemology) (McCann and Clark 2003). The jargon on methodology and procedures can also be particularly mystifying for outsiders (MacDonald and Schreiber 2001). This has left room for confusion among neophyte grounded theory researchers. For example, the researcher is assumed to be simultaneously objective and subjective, and is expected to use inductive and deductive thinking (McCann and Clark 2003). There is similar uncertainty around the position of symbolic interactionism in grounded theory. Symbolic interactionism is almost universally cited as the theoretical foundation for grounded theory (Handberg et al. 2015). However, its actual position in grounded theory is unclear. Glaser (2005) has dismissed the applicability of any specific philosophical position, including symbolic interactionism, believing it would reduce the potential of grounded theory. In contrast, Corbin and Strauss (1990, 2015) maintain that symbolic

interactionism underpins grounded theory, although they explain that researchers do not necessarily have to subscribe to these philosophical and sociological orientations to use grounded theory. Charmaz (2014) suggests that the theoretical perspective of symbolic interactionism gives researchers a way of knowing that broadens their views of meanings, actions and events in the phenomenon under study. Others consider symbolic interactionism to be inherent in grounded theory research, whether or not researchers are aware of it (Milliken and Schreiber 2001).

Remaining true to the original version of grounded theory, Glaser (2013) continues to focus on methods rather than any particular theoretical position, although his views are underpinned by critical realism, post-positivism and objectivity. This paradigm asserts that an objective, external reality exists, and that researchers are independent from those being researched (Kenny and Fourie 2015). Alternatively, Strauss was influenced by the more pragmatic philosophy of symbolic interactionism (MacDonald and Schreiber 2001, Hall et al. 2013). Corbin and Strauss (1990) assumed that people were active agents whose realities were influenced by social interactions. For them, the initial research question identifies the particular phenomenon to be investigated, while research questions are open and focused on social processes (Corbin and Strauss 2015). Although Glaser (2013) criticised their model as too prescriptive, Corbin and Strauss offer clear guidelines and techniques for data collection and analysis, which are useful to neophyte grounded theory researchers (Higginbottom and Lauridsen 2014). However, they also warn against taking a rigid approach, reminding readers that the qualitative researcher should be interpretive and dynamic (Corbin and Strauss 2015). Stressing the principle of flexibility, Charmaz (2014) resists a prescriptive approach to coding, which carries the risk of stifling and suppressing the researcher's creativity. Despite some areas of tension between the different approaches, grounded theory is an appropriate and effective methodology for understanding individuals' experiences, actions and interactions, and their perceptions and thoughts about them.

Conclusion

Grounded theory continues to mature and branch as its appeal as a qualitative research methodology grows. Diversification of the use of grounded theory by researchers and

theorists, and its rigorous standards should not deter neophyte researchers. However, considerable time and effort are required to appreciate the similarities and differences between approaches before making a decision on which one to follow. In Part 2 of this two-part paper, the choice and application of the methodology are explained.

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Understanding, choosing and applying grounded theory: Part 2

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Understanding, choosing and applying grounded theory: Part 2 Nurse Researcher

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Keywords

Coding, constant comparative analysis, core category, grounded theory, nursing research, qualitative research

Abstract

Aim To enable nursing and midwifery researchers to choose and apply a grounded theory methodology, using a worked example to illustrate the main elements and considerations.

Background A fundamental decision when planning a study concerns the selection of the most appropriate research approach. Researchers choosing grounded theory must also consider which approach is best suited to inform their data collection and analysis. Part 1 of this two-part paper presents a critical overview of grounded theory. In Part 2, the choice and application of the methodology are explained.

Discussion Grounded theory provides a helpful framework to guide data collection and analysis, and generate theory from the data. It can also be used to modify or advance

existing theories. The seven key elements of grounded theory are used in a systematic, yet flexible manner to collect and analyse data.

Conclusion To be used to its capacity, neophyte researchers need to understand the jargon, technical language and specific requirements of grounded theory. This understanding supports the correct application of the researcher's preferred approach to grounded theory, and continuity between the research question, aims and methods of a study.

Implications for practice It takes time and effort to understand the different grounded theory approaches, and to learn its rigorous standards. This paper offers guidance to nursing and midwifery researchers by explaining fundamental decisions to be made when choosing and adopting a grounded theory methodology for a study.

Introduction

Qualitative research is a form of social enquiry which is used to understand, describe and interpret people's behaviour, feelings and experiences. This research approach is considered particularly important and appropriate in health professions, which focus on caring, communication and interaction (Holloway and Galvin 2017). Researchers' decision to use a particular qualitative research methodology should be underpinned by a sound understanding of its guiding principles and main features, which can be particularly challenging to neophyte qualitative researchers. The aim of this paper is to enable nursing and midwifery researchers to choose and apply a grounded theory methodology. A current PhD study, which adopted Corbin and Strauss' (2015) approach to grounded theory, is used to illustrate the main elements and considerations to be addressed when planning and conducting a grounded theory study. These include the decision to use grounded theory, the choice of approach and the systematic use of its key elements.

Choosing an appropriate qualitative approach

Broadly, qualitative researchers seek to understand multiple constructed realities that generate different meaning for different individuals, while quantitative researchers believe in a single reality that can be measured using scientific principles (Onwuegbuzie and Leech 2005). Thus, qualitative researchers collect, analyse and interpret data that are

not easily reduced to numbers. These data relate to the social world and the concepts and behaviours of people within a specific context (Anderson 2010). This approach allows participants' experiences to be understood in context and in greater depth than is possible with quantitative study (Denzin and Lincoln 2013).

In the exemplar study, the decision to use a qualitative methodology reflected the researcher's skills and experience, and the research question: "What self-management strategies do older adults diagnosed with moderate depression use to optimise their wellbeing?" The specific aims of the study were to identify their self-management strategies, understand the contextual determinants that moderate their ability to self-manage, and explain how they self-manage their depression to optimise their wellbeing. Consideration was given to several popular approaches to qualitative research, including ethnography, narrative enquiry, phenomenology, action research and grounded theory (Holloway and Galvin 2017). While each serves a specific purpose in qualitative research, grounded theory was selected as the most suitable approach for the study, because the researcher sought to go beyond simple description and exploration, to develop a theory that explained the social processes, structures and/or interactions that influenced older adults' experience of depression.

Choosing a grounded theory approach

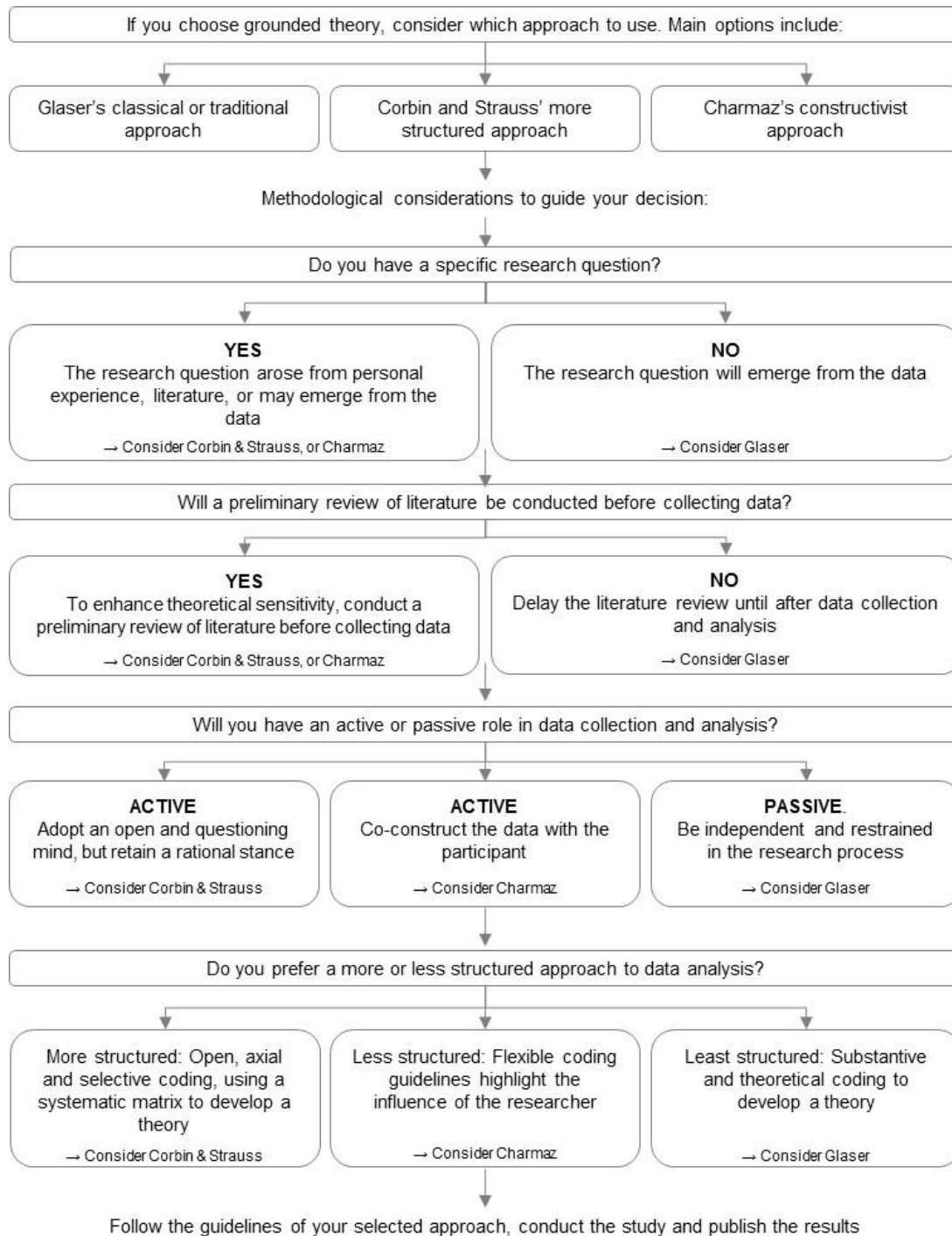
Although it is used widely across a range of disciplines and subject areas, grounded theory is considered particularly useful in health research, where social structure and environment influence health and wellbeing (Holloway and Galvin 2017). However, it takes time and effort for neophyte qualitative researchers to understand the different grounded theory approaches. Jargon and technical language must be understood, before essential methodological decisions can be made and rigorous standards adopted. At the outset, researchers must consider which version of grounded theory—Glaser's classical or traditional approach, Corbin and Strauss' more structured approach, or Charmaz's constructivist approach—will be used to inform data collection and analysis (Figure 1).

Four factors influenced the decision to use Corbin and Strauss' (2015) approach in the exemplar study. This justification should not be interpreted as a criticism of other versions

of grounded theory, but as an explanation of the suitability of the chosen approach to the researcher's aims and views. First, their more structured approach to data collection and analysis was considered useful for this neophyte researcher (MP). Compared with Glaser's (1992) preference for the researcher to allow the emergent nature of the analysis to dictate the study's direction and Charmaz's (2014) flexible engagement with the data, the step-by-step guidelines and techniques offered by Corbin and Strauss were particularly helpful. Second, their approach emphasises context in locating and explaining action-interaction. Context includes events, the circumstances that make up a situation, the meanings given to these, the action or interaction that people take to manage or achieve the desired outcome, and the actual consequences that result from their action (Corbin and Strauss 2015). Third, adding to its suitability, Corbin and Strauss (2015) allow for a preliminary review of literature that allows researchers to enter the field with an awareness of the subtleties of the data (i.e., develop theoretical sensitivity). While boundaries are established around what is to be studied, a preliminary review also allows researchers to consider the broader contextual issues influencing the phenomenon being studied (Cooney 2010). Thus, the issue lies not in whether previous knowledge should be used, but in how to make proper use of that knowledge (Strübing 2007). Researchers should enter the field with as few preconceptions as possible and avoid viewing the data from a particular theoretical perspective, which can constrain the process of data collection and analysis (Birks and Mills 2015, Reay et al. 2016). This draws on the researcher's reflexivity: a process of active, conscious self-awareness that guides the researcher's actions and interpretations (Birks and Mills 2015).

The final consideration in deciding to use Corbin and Strauss' approach related to its potential for research translation. Its emphasis on explaining process appealed to the researcher, as theories developed from data offer insight, enhance understanding and provide a meaningful guide to action in the form of policy change, practice change and/or knowledge development (Birks and Mills 2015, Corbin and Strauss 2015). Regardless of the approach chosen for a study, the researcher should be guided by the main elements of grounded theory (Paper 1 in this two-part series provides a more detailed explanation of each element).

Figure 1. Flow chart to guide the choice of grounded theory approach



Data collection and analysis

The process of simultaneous data collection and analysis is fundamental to grounded theory (Birks and Mills 2015). Both are linked from the outset of the research, proceed in parallel and interact continuously (Holloway and Wheeler 2010). Part of this process is constant comparative analysis, which drives theoretical sampling and ongoing data

collection. Approaching the data from different vantage points, asking questions, making comparisons, following leads and building on ideas also support theoretical sensitivity, one of the essential elements of grounded theory (Charmaz 2014).

Theoretical sensitivity

Theoretical sensitivity refers to researchers' ability to have insight in discerning participants' words and actions (Corbin and Strauss 2015). By entering the field with an awareness of the subtleties of the data, researchers should be able to recognise and extract elements that are relevant to the emerging theory. Theoretical sensitivity develops over the course of the research. In the exemplar study, a preliminary review of literature, complemented MP's clinical experience in residential and community aged care, provided sensitising cues about the subject area. Background, knowledge and experience allowed her to develop and increase her sensitivity to concepts in the data, and enabled her to identify connections between concepts (Corbin and Strauss 2015). Approaching the data from different vantage points, asking questions, making comparisons, following leads and building on ideas also support sensitivity (Charmaz 2014).

Theoretical sampling

Theoretical sampling refers to the process of collecting data for comparative analysis in order to generate a substantive theory (Glaser and Strauss 1967). However, in grounded theory, participant recruitment commences through purposive, criterion-based sampling from an identified population and setting, as indicated by the research question (Corbin and Strauss 2015). Inclusion criteria for the exemplar study were: (i) men and women, aged 65 years and over; (ii) living in their own home; (iii) not in full-time paid employment; (iv) self-reported diagnosis of moderate depression for which treatment and/or support was being received; (v) a score of at least 25 (indicating moderate psychological distress) on the Kessler Psychological Distress Scale K10 (Kessler et al. 2002); and (vi) ability to communicate in conversational English. Exclusion criteria were: (i) currently receiving inpatient treatment for an acute episode of depression; and (ii) suicide intent or attempt within the past week.

As data collection and analysis progressed, theoretical sampling was used to collect new data to compare emerging categories. This approach to sampling is based on the emerging theory and continues until saturation is reached, that is, until no new categories are identified (Corbin and Strauss 2015). Sampling becomes more focused as data collection and analysis progress. It is through theoretical sampling that researchers achieve representativeness of concepts and consistency of data (Corbin and Strauss 1990). To achieve this, researchers should ask questions that aim to identify people who have not yet been represented by a tentative category, or who may contribute to further development of a category. In the exemplar study, it became apparent during the process of constant comparative analysis (where data collection and analysis occur simultaneously) that participants had found it particularly challenging to receive an initial diagnosis of depression. Up to that point, the focus of the interviews had been on the type of support they were receiving for their depression, not the process of receiving a diagnosis. In this way, the emerging theory was used to guide further decisions about participants, sample size, settings and the type of data to be collected (McCann and Clark 2003). Although qualitative studies do not usually stipulate sample sizes *a priori*, a sample of between 20 and 35 participants in a grounded theory study is a useful guide (Guest et al. 2006). In the exemplar study, 32 participants were required to achieve theoretical saturation. At that point, no new categories were identified, and the links between categories were explicated and validated.

Data collection

Grounded theory methodology allows for many different sources of data (Corbin and Strauss 2015), with Glaser and Strauss (1967) dismissing the need to distinguish between qualitative and quantitative data. In the exemplar study, data were collected through interviewing participants, observations and questionnaires. This mixed approach to data collection also served as a form of data triangulation, in which researchers use different data sources to enhance the depth, rigour and validity of studies (Holloway and Galvin 2017). This combination of data contributed to the development of a detailed, nuanced grounded theory.

Participant interviews are the most common source of data in grounded theory studies, as researchers seek to explain the world of individuals from their particular perspective (Holloway and Wheeler 2010). However, they should not be considered the only source of data in grounded theory research, but should reflect the nature of the research question and study aims (Birks and Mills 2015). The use of interviews as the main source of data was considered appropriate, as the researcher sought to understand process and change in situations where a problem is new, under-researched and complicated. As a method of data collection in which one person (the researcher) asks questions of another person (the participant), interviews offer an inside view of the phenomenon under study (Holloway and Galvin 2017). All interviews were conducted on a one-to-one basis between the researcher and participant. In an individual in-depth interview, the researcher can delve deeply into social, emotional and personal matters. The open-ended nature of questions in one-on-one interviews encourages depth and vitality, while allowing new concepts to arise in discussions (Misoch 2015). Following a flexible interview guide (Table 1), questions moved from the general to the particular, commencing with broad, open-ended questions before focusing on more specific questions.

TABLE 1. Selected sample of interview questions

- I'd like to start by asking you to tell me a bit about yourself.
- Getting a bit more specific now, can you tell me about your experience of being an older adult?
- Can you tell me what it's like, in general, to live with depression?
- Can you tell me what professional treatment or support, if any, you get for your depression?
- What assistance/support, if any, do you get from others, like family members, friends or neighbours to assist you with your depression
- I'd now like to ask you about your understanding of self-management, or self-help, in the context of living with depression.

In addition to interviews, the use of field observations and questionnaires gave the researcher an insider's view of the field of study, thereby enhancing the rigour of the study. While several observational typologies are used in qualitative research, Corbin and Strauss (2015) recommend letting the scene unfold, taking discreet notes that describe the setting, participants, routine activities, interactions and so on, and asking questions about specific incidents. In the exemplar study, the researcher adopted Gold's (1958) role as observer-as-participant, during which Spradley's (1980) mode of moderate participation

was most frequently used (Table 2). Observations occurred in open settings such as community centres, neighbourhood houses or social activity groups that provide services or support to older adults, and which were identified during the research process.

TABLE 2. Observational typologies	
Typology	Level of participation
Role of the observer in the field (Gold 1958)	<ul style="list-style-type: none"> • Complete participant • Participant-as-observer • Observer-as-participant • Complete observer
Modes of participant observation (Spradley 1980)	<ul style="list-style-type: none"> • Non-participation (e.g., acquiring cultural knowledge by watching television or reading diaries) • Passive participation (e.g., as a bystander) • Moderate participation (maintaining a balance between experiences as the observer or the subject) • Active participation (gaining acceptance in the setting and learning appropriate behaviour) • Complete participation (becoming a member of the group)

The use of questionnaires to obtain additional data facilitated the research process by corroborating (or not) data obtained from interviews and observations. At interview, participants were asked to complete the Self-Management Ability Scale (SMAS-30), developed to measure unique features involved in the self-regulation of wellbeing in older adults (Schuurmans et al. 2005). This data enhanced the depth and rigour of the study, as many of the questions in the interview schedule allowed the researcher to probe relevant items of interest that arose from participants’ responses to the questionnaire. Theoretical sensitivity was enhanced by the researcher reviewing the completed questionnaires before interviews commenced. By identifying high- or low-scoring items, the researcher then used sensitising questions to understand and give meaning to the questionnaire data.

Data preparation and analysis

In the exemplar study, open coding was initially done by hand, during which the researcher highlighted text while reading and listening to participant interviews, taking notes of tentative themes and phenomena in the margins. During this line-by-line analysis, data were carefully examined and questioned, before being broken down into discrete parts. The researcher chose to code the data manually in this initial stage, as computer

programs could assign hundreds of codes to full interviews, making data analysis mechanistic to the detriment of intuition and creativity (Saldaña 2013). Initial codes were then entered into QSR NVivo (Version 11) (2015). While qualitative data analysis software programmes can enhance the organisation, management and analysis of data, they do not replace the role of the researcher in developing ideas that lead to the generation of theory (Hutchison et al. 2010). Many researchers find a combination of manual and computerised coding helpful (Bazeley and Jackson 2013).

Coding and categorising data

Coding is a cyclical process during which researchers move back and forth between different phases of coding throughout data collection and analysis (Kenny and Fourie 2015). This means that the researcher might be simultaneously coding at several levels. The coding process begins with open coding, the interpretive process by which raw data are broken down into discrete parts and concepts identified (Birks and Mills 2015). This concentrated approach requires that the researcher examines the data in minute detail, while asking questions of the data (Corbin and Strauss 2015). In this first step, data are coded, or given conceptual labels (Table 3).

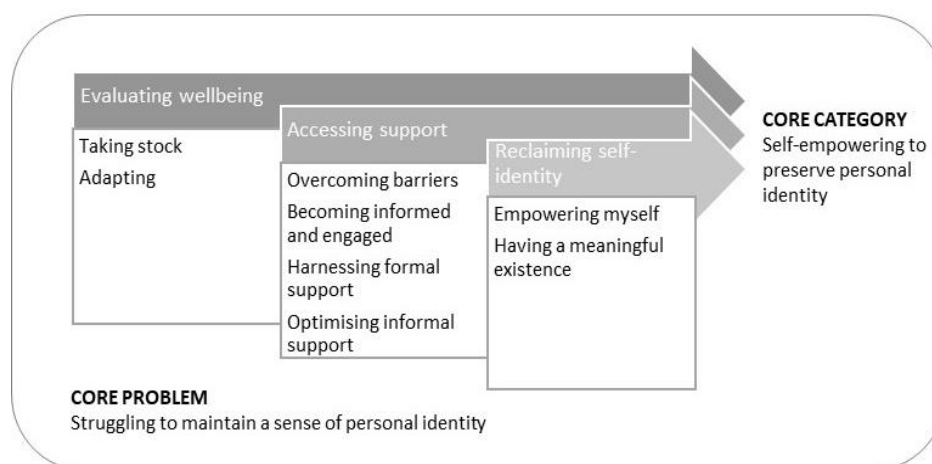
As the raw data were being broken into manageable parts, the researcher used memos to make comparisons, identify possible categories, and ask generative questions. Axial coding took place at the same time as open coding. In this process, the fragmented data were synthesised and brought back into a coherent whole. Links were made between categories and sub-categories, with the category serving as an axis. During selective coding, the third part of the coding process, major categories were developed. Relationships between categories were identified, refined and linked. Through this advanced coding process, a core or overarching category was identified that unified all categories and accounted for variation in the data. The researcher then focused on modifying categories, and integrating the theory with categories and sub-categories. Theoretical memos and diagrams were particularly useful at this stage of analysis. As the different threads of the research were drawn together to construct an explanatory framework, the data ultimately became a theory (see, for example, Cooney 2012).

TABLE 3. Fragmentation of data and conceptual labelling		
Data	Memo extract	Conceptual label
I think I can put on a face that I'm quite all right. I've got a mate that doesn't believe there's a thing wrong with me (Roger, 82 years)	Most participants to date are discerning about whether to disclose their diagnosis, and to whom There is not necessarily a strong sense of shame or stigma about depression, but rather taking control of what they share with others	Putting on a happy face
I'm the sort of person who tries to get the best that I possibly can out of my life ... I'm very determined to do the best I can for me (Rita, 67 years)	Strong sense of being an individual, going against generalisations, seeking my own meaning, doing what works for me in terms of age and depression	Doing my best

Integration of theory

In this final stage, researchers use a more abstract level of thinking, as they shift their focus from exploring to summarising. The goal is to articulate a substantive theory that is grounded in the data and integrated around a core category (see, for example, Kneafsey et al. 2013). Thus, the quality of the research findings depend on the researcher's ability to elevate concepts to the level of an integrated grounded theory (Morse 2001). In the exemplar study, the substantive theory of *Self-empowering to preserve personal identity* represented participants' efforts to respond to the core problem of *Struggling to maintain a sense of identity as an older adult with depression* (Figure 2). This theory fits the phenomenon that it attempts to explain, can be used to predict and explain events concerning depression in older age, and can be easily modified or further developed.

Figure 2.
Graphical
representation of
the theory



Conclusion

Grounded theory is a popular methodology in nursing and midwifery research. To be used to its capacity, researchers should ensure continuity between the research question, aims and methods of study. Neophyte researchers need to first decipher the jargon, technical language and specific requirements of grounded theory. This understanding should underpin decisions about the preferred approach and ensure correct application of the key characteristics of the methodology.

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Help-seeking experiences of older adults with a diagnosis of moderate depression

Polacsek, M., Boardman, G., McCann, T.V. (2018). *Help-seeking experiences of older adults with a diagnosis of moderate depression*. Manuscript submitted for publication.

ABSTRACT: Depression is the most prevalent mental disorder among older adults. However, help-seeking by older adults is frequently delayed, resulting in longer duration of untreated symptoms, poorer health outcomes and consequent higher healthcare use. Early help-seeking and access to appropriate support benefits individuals, while providing better outcomes from health systems constrained by limited resources. The aim of this paper, which is abstracted from a larger study, was to identify the factors that inhibited and enabled formal help-seeking in older adults with a diagnosis of moderate depression. Corbin and Strauss' approach to grounded theory informed data collection and analysis. Two themes and related sub-themes concerning help-seeking barriers and facilitators were abstracted from the data. Help-seeking barriers were attributable to stigma, self-motivation, accessing formal support, ageism and difficulty obtaining an initial diagnosis. Help-seeking facilitators were accepting personal responsibility, mental health literacy, therapeutic alliances, and informal support. Findings have implications for the role of mental health nurses, who are well placed to provide support to community-based older adults with depression. More broadly, mental health nurses and other clinicians should seek to reduce help-seeking barriers and implement ways to facilitate help-seeking in this cohort.