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Validating older adult patient's Medical Treatment Decision Maker's (MTDM). A retrospective observational study with follow-up phone interview transcript

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ABSTRACT

A Medical Treatment Decision Maker (MTDM), also referred to as surrogate decision maker, by law, is to be appointed to make medical treatment decisions on behalf of a person who cannot make such decisions for themselves. In the Emergency Department (ED) and acute healthcare services, the clinicians' (nurses and doctors) ability to contact MTDMs is essential for patient care, particularly in time-critical situations. Our primary objective was to review the verification process and assess the accuracy of MTDM contact numbers in the Health Information System (HIS) to assess compliance with legislation. We used a quantitative method with retrospective observational study design and follow-up phone interview transcript. One hundred and fifty-nine participants were randomly selected of whom 76 % had MTDM. Patient advancing age had statistically significant association with the number of call attempts made to reach the listed MTDM (P = 0.043; CI, -3.541 to -0.057) and the MTDM's consent to participate (p = 0.023).

Introduction

A Medical Treatment Decision Maker (MTDM), also referred to as surrogate decision maker, is defined as someone appointed to make medical treatment decisions on behalf of a person who cannot make such decisions for themselves, provided they are reasonably available and willing to make such decisions.[1] In the Emergency Department (ED) and acute healthcare services, the clinicians' (nurses and doctors) ability to reach MTDMs is an essential aspect of patient care, even more so in time-critical situations or when end of life discussion is necessary and are therefore by law, expected to undertake all reasonable steps to ensure compliance.[1] It is important for nurses to be able to contact the MTDM to ensure there is informed decision making, consent for treatment, ensure the patient is receiving appropriate emotional support from family members and carers, enable open and transparent communication channels between care givers and the patient, family and carers, provide optimal coordination and transition of care, and be fully cognisant of a patient's end of life preferences.[2] The findings of a recent study at our institution revealed that, very low number (7 %, n = 29) of Emergency Physicians reporting that, they were able to successfully contact MTDMs at time of need.[3]

Our primary objective was to investigate the accuracy of MTDM contact numbers in the Health Information System (HIS) at our institution by conducting a review of the verification process. Specifically, we examined:

I. The verification processes involved when assigning a person an MTDM, before populating them in the HIS.
II. The process involved in recording verified MTDMs' contact details in the HIS.
III. Whether regular follow-up processes (system generated alerts) are in place to ensure validity of MTDM contacts following a period of a patient's record inactivity.

Abbreviations: CI, Confidence Interval; ED, Emergency Department; EMR, Electronic Medical Record; HIS, Health Information System; MTDM, Medical Treatment Decision Maker

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Method

Study design

Quantitative method utilising retrospective observational study design with phone interview transcript to verify the accuracy of MDTM details in the medical record was used. Participants for this study were drawn from persons listed as a selected patient's MTDM contact. The Inclusion Criteria was - Patients aged ≥65 years old; and the presence of an MTDM listed in the ED electronic medical record (EMR) Cerner/Firstnet®. Exclusion criteria included - Patients aged <65 years old; records showed listed person as a contact or next of kin only but not as their MTDM; and selected patient was recorded as deceased in the EMR.

Sample size

The sample size calculation was based on our 2019 study sample.[4] In that study, we had a sample of 300 patients aged ≥65 years. Based on that study and assuming a frequency of 50 % (anticipated call recipients' frequency), power of 80 %, confidence interval of 95 % and design effect of 1, our sample size was 169. We randomly retrieved the study sample from our 2021 ED patient visit records for patients who were ≥65 years (n = 26,025).

Consent

Participation was voluntary. Once the introduction in the transcript (Appendix 1) was read out to the phone call recipient, they were asked whether they were happy to continue participating in the call and if the person consented (by stating "Yes"), the call continued. If they stated "No", the call was terminated. Participants were provided with the caller's name and contact details and were advised that they could withdraw from the study at any time before data was aggregated, as it would be difficult to identify individual data after this.

Data extraction

To meet the study's first objective the following variables were captured from the EMR: patient demographics; whether MTDM contact person was listed; source of information if index patient had since deceased. The following variables were captured from the phone call to the MTDM: number of call attempts made to reach the listed MTDM; whether successfully reached; verbal consent to participate; MTDM as a source of information if patient since deceased (but not reflected in the hospital record); person listed aware they are the MTDM; whether they have recently changed their contact details and any other remarks. In addition, formal inquiry was undertaken on the process of registering and validating a person as a MTDM in the EMR, whether any existing contact update alert systems existed and what process was in place to ensure validity of listed MTDM contact details.

Data analysis

Data was entered into a Microsoft Office Excel Spreadsheet and imported to SPSS™ 27 for analysis. Numerical data were presented in counts and percentages. Categorical data were analysed using Chi-square tests or Fisher's exact tests as appropriate, ordinal and interval data with Kruskal-Wallis test, bivariate correlation and simple linear regression tests. Statistical significance was indicated by a two-sided P value <0.05 and Confidence Interval (CI) range that did not cross unity.

Ethics

The study received institutional ethics approval from the institutions Health Human Research Ethics Committee reference HREC/69,061/Austin-2020.

Result

The process of registering and validating a person as a MTDM in the EMR was found to be compliant with legal requirements.[5] There were no existing contact update alert process or prompt in the EMR. The process of ensuring validity of listed MTDM contact details relied on patients representing to the health services where administrative staff of the specific services they are attending updates the information. In cases where patients lacked cognitive or verbal capacity, their existing contact details would remain unchanged unless an accountable family member, carer or guardian was in attendance.

One hundred and sixty-nine patients were included in the data collection following random sample selection from the EMR of which 57 % were female, 43 % male with ages ranging from 65 to 97 years (mean age=79.13 years). Seventy six percent had a person identified as a MTDM listed, 9 % had no MTDM contact listed and 15 % were listed as deceased in the EMR.

One hundred and twenty-eight (76 %) patients who had a MTDM listed were selected for contact. Seventy-five (59 %) responded when called; 84 % responded on the first attempt and the remainder responded on the second attempt after couple of hours. No call backs to our voice messages were received on that day. Consent for participation was obtained from sixty-seven respondents, the remainder (in equal numbers) either declined consent (n = 4) or the related patient had since deceased (n = 4).

Those who provided consent to participate and who did not have a deceased family member (n = 67) were aware of being the patient's MTDM. Those who declined consent stated hesitance in answering a call from a private number or no caller identification being the reason. Sixty-four respondents reported to have not made any changes to their contact details over the past year, while three reported changing their home phone contact numbers but not their mobile phone number.

Patient's advancing age had statistically significant association with the number of call attempts made to reach the listed MTDM (P = 0.043; CI, −3.541 to −0.057) and MTDM's consent to participate (p = 0.023) However, Patient advancing age was not associated with having a MTDM contact person listed (P = 0.131; CI, −0.397 to 3.044) or successfully contacting the listed MTDM (p = 0.314; CI, −4.297 to 1.393) based on the distribution of those whom we could successfully reach.

Patient gender had statistically significant association with successfully contacting the listed MTDM (p = 0.036; CI, 0.012 to 0.355) and the number of call attempts made to reach the listed MTDM (P = 0.039; CI, 0.006 to 0.218) as MTDM's of female older adult patients were responding to the calls quicker or during first attempt but was not associated with having a MTDM contact person listed (P = 0.072; CI, −0.197 to 0.008) or MTDMs consent to participate (p = 0.348).

Discussion

Medical Treatment Decision Maker, also known as surrogate decision maker processes, are usually complex, including the process of identifying or selecting the MTDM.[6,7] Family members are usually patient's preferred MTDMs[8] even though their decision making may not always align with patient wishes[7,9] and in a majority of the cases, discussions related to choosing an MTDM arise during difficult moments and can affect the surrogates' wellbeing.[10] Where no

MTDM records exists, the clinicians can make decisions for the best interest of the patient in emergency situations or make contact with a guardian appointed by the Victorian Civil and Administrative Tribunal (VCAT) or may seek consultation with a family member or carer according to the hierarchical order determined by the Office of Public Advocate in Victoria.[1] Other jurisdictions will have specific processes outlined in jurisdictional legislation requirements.

Identifying and documenting a person in the EMR as a MTDM requires fulfilment of formal requirements in the State of Victoria, Australia,[5] and health institutions documentation of MTDMs in the EMR are expected to comply with these legal requirements. A patient who has an MTDM, can have more than one MTDM listed (could be their spouse, parents, children, other relatives, friends, or trustees) if they wish, and if the MTDM nominee fulfils the requirements.[1] In this situation, the MTDMs are hierarchically listed in the EMR as per the order they are appointed by the patient or their delegate, such as the VCAT.[5]

Contacting the listed MTDM, especially during emergencies where timely treatment or end of life decisions are required, is essential and this requires maintenance of accurate and accessible contact records. In this study, MTDMs of patients with advancing age and female gender were easier to reach, based on the number of calls required to establish contact.

There was dearth of literature on routine contact update alerts in hospitals or electronic systems. The MTDMs preparedness for the role plays a vital part in engaging them and ensuring timely access to them when required.[11,12] Vital to this also, is a reliable contact mechanism, which was found to be lacking during our study and is further complicated by ED structural designs where there are many calling points and peripatetic clinical personnel within the vast department where call backs may not be easily tracked to the original caller. Some EMR systems have patient portals allowing consumers more control and ability to communicate changes to circumstances. Unfortunately, in our institution a patient portal has not been developed.

If institutional outgoing calls are de-identified or set as private (displayed as “No Caller ID” on smart phones), it raises suspicion among call recipients in an era of increasing call spammers and cybersecurity threat.[13-15] The impact of unlisted or unknown number in attempting to contact MTDMs, was unanticipated outcome of our study and one that we are keen to explore further. Our respondents identified that this was a barrier to initially accepting the call and for some, hindered consent, as the MTDM remained suspicious as to the true identity of the caller, even after explanation. As this impedes the ability of clinicians to reach MTDMs at times of needs for critical treatment decisions, institutional communication and information services departments need to ensure that trustworthy, user-friendly systems are in place.

The study has important implications for nursing practice given the vital role nurses play in providing person centred care especially in relation to end of life care.[2] There is clear benefit in having up to date MTDM contact numbers to achieve best nursing practice and fulfill legislative requirements. Current alert systems are not robust, and the inadequacy of documentation has been highlighted during the Covid-19 pandemic period when patient visitor access was restricted.[16-18] The study also highlights the need for health facilities to review their telecommunications policies to address the public’s suspicion regarding non-identifiable numbers.

Limitations

This study has important limitations and needs to be interpreted with caution as it was a single site study and throughout Australia, and globally, variations exist in Advance Care Planning legislation which may produce different results. The study was also based on convenient sampling with contact occurring on weekdays during normal business hours, which will not be wholly representative of the usual ED to MTDM contact hours. The lack of capturing MTDM’s demographic data is also an important limitation as our focus was patient’s demographics only.

Conclusion

Identification and electronic documentation of MTDMs for older adult patients needs to improve, as our study found only 76 % had MTDMs listed. Despite our calling time being during business hours, we managed to reach only 59 % of the identified MTDMs. Index patients increasing age was found to be a factor in obtaining MTDMs consent to participate and index patients advancing age and gender were associated with the number of call attempts made to reach the listed MTDM. Neither age nor gender were found to be a factor in having a MTDM contact person listed in the EMR. “No Caller ID” displays may be a significant barrier to successful contact with a MTDM and should be explored further. We support the development of patient portals that provide consumers with more control and ability to communicate changes to circumstances. While the MDTM details are within the EMR, we recommend that they be visible in the patient banner. We also recommend a process for periodic MTDM contact review to maintain accurate MTDM details. This would be best as an active alert trigger when details change or a periodic prompt to administrative and/or clinical staff to seek verification that existing information is current. As a result of this study, we propose to undertake a multi-centre, cross jurisdictional study to understand communication methods used by healthcare facilities and identify best practice.

Declaration of competing interest

The authors declare that they have no competing interests

CRediT authorship contribution statement

Lisa Smithies: Writing – review & editing, Methodology, Conceptualization. **Daryl Jones:** Writing – review & editing, Methodology, Conceptualization. **Jocelyn Howell:** Writing – review & editing, Validation, Resources, Methodology, Investigation, Conceptualization. **George Braitberg:** Writing – review & editing, Supervision, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Ethics approval and consent to participate

The study protocol was approved by the Austin Hospital Human Ethics and Research Committee. HREC/69061/Austin-2020. Approval date June 24, 2022.

Informed consent was obtained from all participants/subjects/legal guardians who were given an option to opt out at any stage of the study.

Declaration of Generative AI and AI-assisted technologies in the writing process - None

Declarations

Ethics approval and Consent to participate

The study received institutional ethics approval from the hospital’s Human Research Ethics Committee (Austin HREC reference HREC/69061/Austin-2020). Participation was voluntary and participant had to agree to proceed once the content in appendix 1 was read out to them.

Consent for publication

Not applicable

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
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Generative AI was not used in this study
Authors' contributions

All authors contributed as follows

Conceptualization: AO, LS, DJ, JH and GB
Data curation: AO and GB
Formal Analysis: AO
Funding acquisition: N/A
Investigation: AO, JH and GB
Methodology: AO, LS, DJ, JH and GB
Project administration: AO
Resources: JH, GB
Software: N/A
Supervision: GB
Validation: JH
Visualization: N/A
Writing – original draft: AO
Writing – review & editing: AO, LS, DJ, JH and GB

Appendix 1. Ethics approved MTDM phone Transcript

Medical Treatment Decision Makers Registered Contacts in Cerner/FirstNet Confirmation Audit Phone Transcript

If Cerner/Firstnet reflects patient is deceased, no call will be placed.

Hello, my name is [caller's name]. I'm a [designation in the organisation] from the Austin Health Emergency Department. Would it be possible for me to speak to (contact's full given name and surname)?

[If not at home] Is there a time that I could call back to speak with (contact's name)?

[If contact is busy] Is there another time that I could call back that would be convenient?

The reason that I am calling is that you are listed as the medical decision maker for (patient's name). We are doing a study to understand whether the contacts for medical treatment decisions are correct within our records. The purpose of this call today will help our aim to improve processes at Austin Health and won't take >5 min of your time.

Your answers obtained today will be recorded in a way that will not identify you and kept for 7 years for auditing purposes before being destroyed. Taking part in this study is voluntary and will not affect your current or future care at Austin Health.

Are you happy to continue with this call?

- **Yes**- Call progresses to next stage.
- **No**- Participant is thanked for their time and the call is terminated.

[If patient is deceased] I am sorry for your loss. Please accept my condolences. I will make sure our records are updated.

Before we proceed can I please confirm your, relationship, and phone/mobile number with our listed details?

If the correct information is listed

Have the contact details been updated within the last year?

[Yes] When were the details updated? Continue to next question.

[No] Continue to next question.

Were you aware that you were the listed medical treatment decision maker?

[Yes] Continue to next response.

[No] Continue to next response.

If the correct information is not listed

Please visit the Austin Health patient service desk during working hours next time you are in the hospital with appropriate documents and update the details.

Please be aware that you can withdraw from this study up until the data is combined with the responses from the other participants. If you have any questions about this study, please don't hesitate to call me on [caller's phone number]. Thank you for taking the time to speak with me today.

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