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Communication needs and support for children and adolescents with complex communication needs requiring hospitalization in Hong Kong: an explorative study

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Communication needs and support for children and adolescents with complex communication needs requiring hospitalization in Hong Kong: an explorative study

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ABSTRACT

Purpose: Children with complex communication needs face particular challenges during hospitalization. This study aimed to understand the situation for hospitalized Hong Kong Chinese children with complex communication needs.

Methods: Six group interviews were conducted with 23 participants, including nurses, doctors, adolescents with acquired brain injury, parents of children with acquired brain injury or cerebral palsy, and community-based therapists.

Results: Parents and children reported unmet physical and emotional needs due to lack of communication. Healthcare providers felt that direct communication with children was not essential, expecting that parents serve as proxy in conveying needs. The passive interaction mode of Chinese parents, and their increased vigilance in protecting their children, further reduced opportunities for direct child-healthcare provider interaction. Limited patient communication protocols were reported, while tight hospital space discouraged bedside communication activities and tools. Community therapists who knew these children were not involved in pre-admission handover.

Conclusion: To address the communication barriers, changes in the healthcare, education, and community systems are proposed. Empowerment of the children and parents to promote direct patient-healthcare provider communication, dissemination of simple protocols and bedside communication tools, time allowance for staff to interact with the children, pre-/in-service staff training, and collaboration with community healthcare providers are recommended.

Communication is a powerful tool for human survival. It enables expression of needs and desires, learning and sharing of information, influencing the environment and social engagement. Severe communication difficulties and the complex communication needs that follow may arise from chronic developmental disabilities such as physical disabilities (PD), autism spectrum disorder (ASD), intellectual disabilities, neurological disorders, acquired neurological impairment from brain injuries, tumours or infections, or from temporary situations resulting from intensive medical intervention. Without the ability to communicate effectively, people are unable to participate in most aspects of living and self-determination.

Complex communication needs of persons with medical conditions or developmental disabilities have gained attention over the past decades from service providers, researchers, parent and patient advocates, and policymakers. Augmentative and alternative communication (AAC) strategies grew with research and technical advances. Increased awareness and acceptance of AAC have resulted in its integration into existing speech and language interventions for groups such as children with ASD, adults with severe aphasia (Light, McNaughton, Beukelman, et al., 2019), children with cerebral palsy and/or intellectual disabilities (Hemsley et al., 2013). The proliferation of technology and especially mobile technologies (Bornman et al., 2016) have resulted in enhanced acceptance, access and efficient utilization of AAC by persons with complex communication needs, while effective service delivery models and further research for enhancing positive outcomes are still needed (McNaughton & Light, 2013). Accessibility to internet and digital platforms facilitates communication and has expanded interaction opportunities for all (Light, McNaughton, Beukelman, et al., 2019). Heightened expectations and advocacy by persons with complex communication needs, the presence of laws that protect the rights of persons with special needs, and established compliance standards to safeguard the quality of care (The Joint Commission, 2010), contributed to the promotion of AAC services.

In terms of the effective use of AAC, from a contextual analysis point of view (Svensson &

Doumas, 2013), while the situation varies between countries with different levels of awareness and resources, several components can be identified from the literature. The first component is the service setting such as schools and hospitals. The sub-components include (i) the wider policy surrounding the service settings (Hemsley & Balandin, 2014), (ii) attitudes, knowledge and practice of service providers such as inadequate knowledgeable service providers dedicated to AAC support (McNaughton et al., 2019), insufficient time devoted to communication (Hemsley et al., 2012), and limited awareness of the need by service providers (e.g., speech therapists, nurses and doctors) (Finke et al., 2008; Hemsley et al., 2001, 2014), and (iii) staffing resources and practices within the setting. Another component is the service recipient and their family members/caregivers. The sub-components include (i) the characteristics of the service recipient and their ability to advocate for themselves; (ii) the attitudes of the service recipient and their family members/caregivers towards communication and AAC such as their limited awareness of such need (Finke et al., 2008; Hemsley et al., 2001, 2014). The last component is the wider cultural context. These components may affect the adequacy of accommodation for individuals with special motor and cognitive needs (Light, McNaughton, & Caron, 2019). The present study focused on the experience of child and adolescent inpatients with complex communication needs and their use of AAC in Hong Kong public hospitals.

Regarding the service setting, among the numerous life situations of individuals with complex communication needs for which communication is essential, hospitalization is one in which access to support for communication is often unavailable. In addition to children with prior disabilities and complex communication needs, children in intensive care may become communication vulnerable because of airway patency, physical weakness, and neurocognitive impairment (Costello et al., 2010). Negative outcomes, including frustration to the patients, adverse medical events (Bartlett et al., 2008), negative patient experience, increased length of stay (David et al., 2013), and poor health outcomes (Hemsley et al., 2014), often result from communication problems between patients and healthcare providers. In a review of the impact of communication problems on the risk of adverse events in acute care settings, 29% were judged to be preventable, and those experiencing adverse events were significantly more likely to have a communication problem than those without adverse events (odds ratio [OR] 3.00; 95% 1.43–6.27) (Bartlett et al., 2008). A study on sentinel events root causes (2004–2014) named communication breakdowns as one of the most frequent causes (The Joint Commission, 2014).

The sub-component of government policy impacts the effective communication and use of AAC in hospital settings. From the policy perspective, The Hong Kong Government Rehabilitation Advisory Council's 2020 policy paper acknowledged the need for supporting "barrier-free access to information and entertainment" and "more knowledge of the spirit and core values of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) among youngsters in primary and secondary schools" in their strategic recommendations, but the document did not include the hospital setting, nor specific mention of accessibility for children and adolescents with complex communication needs (Labour and Welfare Bureau, 2020).

Apart from government policy, the practice and staffing sub-components within the public hospital system play an important part in affecting effective patient-provider communication and the application of AAC in hospital settings. At a practice level, the Hong Kong public hospital system is another factor affecting patient-provider communication practices. In Hong Kong, healthcare expenditure accounts for 6.8% of gross domestic product, which is less than that in South Korea (8%) and Japan (11.1%) (Lam, 2023). The nurse–patient ratio in Hong Kong is 8.2 per 1,000 population in 2020 which exceeds those of Korea, Taiwan and Singapore, but is below those of the USA, Australia and the Organization for Economic Co-operation and Development (OECD) recommendation of nine nurses per 1,000 population (Lam, 2023). There is also a shortage of doctors in Hong Kong public hospitals. The doctor-to-population ratio of 2.1 per 1,000 population in 2021 is below the ratios in neighbouring countries such as Singapore, Japan and South Korea (Legislative Council Secretariat, 2023). The manpower shortage might affect the communication between patients and health professionals, especially in the case of patients with complex communication needs.

The supply of professionals to support the use of AAC is another component. In supporting patients with complex communication needs, speech therapists play an important role. However, like other healthcare professionals, speech therapists are in short supply globally. In Hong Kong, the ratio of speech therapists to population is 1:20,000 as compared with the US ratio of 1:2,290 (Legislative Council Secretariat, 2023). According to the 2019 health manpower survey on healthcare personnel, over 50% of the 835 speech therapists enumerated were employed by the sub-vented sectors, whereas less than 10% worked in public hospitals (Department of Health, 2019). Such shortage might mean that there is inadequate support for patients with complex communication needs in public hospitals.

A large cross-sectional study was conducted to measure general in-patient experience in 25 selected acute and convalescent public hospitals in Hong Kong (Wong et al., 2012). Although paediatric patients were not included in the interviews, results provide an insight into Hong Kong's general hospital situation with its large patient loads, busy healthcare providers and prevailing provider-patient communication practices. Around 20% of respondents reported that healthcare providers did not always provide them with answers that they could comprehend, and a majority did not feel involved in decision-making about their care and discharge. Secure storage space was apparently not available for most of the patients, which would be a problem for those who needed to use personal communication devices. These observations shed light on potential obstacles for children and adolescents with complex communication needs and their parents in Hong Kong's general hospitals.

The staff awareness of services for communication support to children and adolescents with complex communication needs remains limited in Hong Kong. A 2010 survey on AAC service provision, knowledge, use, and attitude in Hong Kong (Siu et al., 2010) showed that, while a higher proportion of school-aged children with PD and complex communication needs had access to AAC support within their special schools, extension of these services into families, the community, and especially into hospital settings, was minimal. Although similar studies have been carried out on in-patients with complex communication needs in other countries (Avis & Reardon, 2008; Finke et al., 2008; Ford & Turner, 2001; Hemsley et al., 2001, 2013, 2014), no studies were conducted on in-patients in Hong Kong.

A case series study of hospitalized patients with complex communication needs (Marshall & Hurtig, 2019a) demonstrated the effectiveness of dynamic assessments by hospital team members to provide ongoing solutions for communication, but that education and combination of training modes were needed for widespread system change. A second case series on institutional factors showed the need for inter-professional collaboration and shared resources (Marshall & Hurtig, 2019b). Both studies pointed to the importance of building a hospital-wide culture of patient-provider communication.

For the characteristics of recipients and their caregivers, children and adolescents with complex communication needs are additionally vulnerable because of their limited ability to advocate for themselves. Their use of AAC is influenced by components including the attitudes and practice of healthcare professionals and their parents/caregivers. Views collected from community and hospital allied health and nursing staff indicated that while they might be involved in supporting children's seating, mobility, equipment, mealtime management and psychosocial needs, they were not participating in supporting these children's communication needs in hospital (Hemsley et al., 2012, 2014). The problems were compounded by a prevailing view of the role of parents during hospitalization. A focus group study on parents, children and adolescents with cerebral palsy and complex communication needs in hospital showed that parents of children of all ages saw it as their roles to "be the child's voice" (Hemsley et al., 2013, p. 367) and to interpret their needs for hospital staff. Parents also perceived that hospital staff were often uncomfortable and unable to communicate with their children and that this impacted upon the care the child received (Avis & Reardon, 2008). Furthermore, staff felt that they did not have enough time to communicate with the children (Ford & Turner, 2001). Nurses caring for children with disabilities appreciated parents who assisted them in providing care, and hospital policies routinely supported parents in their role as care partners (Ygge et al., 2006). In a focus group study of children with cerebral palsy and complex communication needs, participants indicated that preferences for direct communication with staff partly depended on whether communication tools were available to them in the hospital, and whether the children were active participants in social interactions with them in the ward (Hemsley et al., 2013).

For Hong Kong caregivers, it is also important to take into consideration the cultural component. In the case of Hong Kong parents, from a theoretical perspective, parenting styles of Chinese and western cultures are believed to bear differences. Chinese parenting is often characterized by an authoritarian parenting style that emphasizes hierarchical structure (Stockman, 2013), parents' power to control their children, and the expectation that children should obey their parents. In contrast, western cultures often embrace an authoritative parenting style that at the same time encourages children to think independently while respecting parent authority, and where parents are responsive towards their children (Baumrind, 1996). Furthermore, the concept of *guan* is significant in Chinese culture. It endorses the idea that it is the responsibility of parents to govern and train their children through monitoring, providing firm instructions, and making demands on their children. Parents are expected to do as much as possible for their children to enhance their development (Wang & Chang, 2010). As a result, parents of different cultures are likely to show affection to their children with complex communication needs in a stressful situation like hospitalization in different ways. Lee and Lau (2013) found that Chinese mothers were "driven by the overwhelming need to be actively 'doing' something purposeful for their hospitalized sick child" (p. 1812). On the other hand, the western parenting style may encourage communication between the child patient and healthcare staff (Prevoo & Tamis LeMonda, 2017) and parents as partners in their children's care

(Harbaugh et al., 2004). Although both practices aim to protect their children, including those with complex communication needs (Dudley & Carr, 2004), Chinese parents might do things for their children such as making decisions for their children, and taking up the role of communication with healthcare providers on behalf of their children, reducing the opportunity for their children to independently communicate directly with providers. Chinese mothers of hospitalized children in Hong Kong would maintain a vigilant role in hospital settings (Lee & Lau, 2013). Chinese mothers were often passive in seeking help, feeling that they needed to show respect to the hospital staff, and tended to avoid asking questions and filing complaints. Instead, they coped by staying vigilant and sensitive to healthcare providers' interactions to see when they could solicit communication opportunities with them. The parents' strategy of constant vigilance was to be sensitive to healthcare providers' interactions, monitoring and helping with their own children's needs, while being passive in speaking up or seeking help. These in turn could reduce the opportunity for their children to directly communicate with the healthcare providers (Lee & Lau, 2013). This pattern of interaction was different from a US study on child-parent-provider interactions of a child with complex communication needs in hospital, which revealed 49 interactions between the child patient with 26 healthcare staff over 10 days, covering a range of activities and needs (Gormley & Light, 2021). Given the perceived healthcare provider-parent driven interactions in Hong Kong's paediatric wards, such active roles by the child in inpatient interactions as described in the Gormley and Light (2021) study would likely be limited. However, challenges in service delivery and tools raised in the Gormley and Light (2021) study are common to Hong Kong's situation.

The present study constituted one of the limited studies on the experience of child in-patients with complex communication needs in Hong Kong. The objective was to understand the communication experience and the use of (or lack of) AAC among child and adolescent patients with complex communication needs in Hong Kong public hospitals. The setting components (the hospital system and policy, knowledge, skills, attitudes and practice of staff), the recipient/caregiver component (their attitudes and awareness) and the cultural component of Chinese parenting style will be explored.

Method

Research design

This study aimed to adopt a qualitative design using focus groups to capture the experiences and perceptions of the participants simultaneously in an effective manner, where group interactions are used to explore what people thought, and how and why they thought

that way (Kitzinger, 1995). Busetto et al. (2020) described focus groups as group interviews with six to eight people in a group facilitated by a moderator, using an interview or topic guide. However, due to the difficulties in recruiting participants in some groups (see Group Description sub-section below), a group interview approach was used where the facilitator focused more on asking individual participants questions, rather than interaction among participants (Brown & Edmunds, 2011). Participants from different stakeholder groups were recruited for separate groups. An interview guide with key research questions which were applied to all groups was designed. Follow-up questions were adapted according to the respective group's background. All researchers contributed to the development of questions, and to the procedures of the interviews. The first four authors were the group facilitators. A case study approach examines a case in terms of its particularities and complexities, to understand its characteristics and circumstances, incorporating multiple sources (Tomaszewski et al., 2020). Cases studies are useful in the study of a programme or a service such as our present case of use of AAC in hospital settings.

Setting

In the professional interaction of the authors (a speech therapist, three psychologists, a paediatrician) with community groups of patients with complex communication needs, and parent groups, many issues which occurred within public hospitals were raised. This study was thus conducted against the setting of public hospitals in Hong Kong, as experienced by patients with complex communication needs and their families.

Participants

A total of 23 doctors, nurses, parents, adolescents with history of complex communication needs and therapists (see Table I) were recruited for the study and subsequently placed in six groups.

The participants were purposively sampled to include individuals with rich experience as parents or healthcare providers caring for children or adolescents with complex communication needs who had to be hospitalized, or who had personal experience of being a patient. To solicit a variety of perspectives, a balance between homogeneity of participants within groups, while representing different years of experience and settings of professional employment, was considered in recruitment. Each group's composition was intended to capitalize on the mix and exchange between members. Care was taken to secure the best possible variety of perspectives by striking a balance between homogeneity and heterogeneity of subject selection. Each group consisted of

Table I. Participant demographics (N = 23).

Characteristics	Group 1: Pediatric neurologists (n = 4)	Group 2: Pediatric nurses (n = 6)	Group 3: Parents of children with PD (n = 5)	Group 4: Parents of children with ABI (n = 2)	Group 5: Children/ adolescents with ABI (n = 3)	Group 6: Special schools therapists (n = 3)
Sex						
Male	2		1		1	
Female	2	6	4	2	2	3
Place of employment						
Public hospital	2	6				
Private practice	2					
Special school						3
Years of related employment						
<10 years		1				
10–20 years	1	1				1
21 years or over	3	4				2
Age of child at first hospital admission						
0–10			5	2	2	
11–20					1	
Nature of child's disability (may be > 1)						
Physical disability			5			
Intellectual disability			4	2	3	
Acquired brain injury						

Note. PD = Physical Disability; ABI = Acquired Brain Injury.

a homogenous group of participants who shared similar backgrounds and characteristics. Healthcare providers working in different hospital settings, with different gender, expertise, and years of experience were included. Different stakeholders were represented in different groups. Invitations were sent through phone calls or emails. Doctors were selected through authors' knowledge of their work in different settings. Nurses in representative settings were recruited through the nomination of a senior nurse in the field. Parents of children with PD were recruited through a self-help group for parents of persons with PD, while their children were not recruited because of their severe multiple disabilities rendering reliable group interview not viable without extensive resources. Parents and their adolescent children with acquired brain injury (ABI) were recruited through a mutual support organization for children with brain tumours and their parents. Adolescents with ABI were specifically included as a group as they represented patients with short-term complex communication needs incurred by acquired medical conditions and hospital interventions, with adequate verbal ability to participate in group discussion without communication aids. Therapists working in special schools for children with PD were recruited through the AAC Working Group of the HK Society of Child Neurology and Developmental Pediatrics.

Group description

The first group comprised four paediatric neurologists with 10–30 years' experience, from acute paediatric neurology practice in public hospitals. Their patients included children with temporary and chronic communication difficulties during hospital stay. The second group was comprised of six nurses from paediatric departments in administration, intensive care, palliative care, general acute paediatrics, and chronic disabilities with ventilator dependency. One nurse was from infirmary services for individuals with mental and intellectual disabilities who have transitioned from paediatric rehabilitation wards. The third group consisted of five parents of young persons with severe PD and complex communication needs. Their children all had one or more hospital admissions for elective surgery or acute medical care (aged 10 years or younger at the time of hospitalization). The fourth group consisted of two parents of children and adolescents with brain tumours. Three parents were recruited but one parent opted out on the day of the group interview due to her reluctance to revisit the emotional trauma. The fifth group comprised three adolescents who were the children of the fourth parent group. They were hospitalized for brain tumour treatment. Two adolescents were diagnosed with germinoma and had brain surgery conducted when they were aged 7 and 9. The third adolescent had right cerebellar medulloblastoma, and tumour resection was performed in his adolescent year. These adolescents experienced transient loss of speech and communication abilities as a result of the medical problems and procedures. Their premorbid and post-morbid intellectual functioning were within average range. Their spoken language abilities before and after hospital stay were satisfactory such that the group interviews could be conducted verbally. The sixth group was comprised of two speech therapists and one occupational

therapist who worked at special schools for students with PD. They each had over 10 years' experience supporting communication for students with complex communication needs, including regular use of AAC.

Data collection

Three key questions were developed, based on literature review on overseas services, research status and respective gaps. These key questions focused on three aspects: (a) What is the observation or experience on communication support for children with complex communication needs who needed hospitalization in Hong Kong? (b) What are the current communication practices for children with complex communication needs for pre-admission preparation, in-patient support and discharge coordination with family and rehabilitation services? and (c) What are the suggestions to improve the effectiveness of communication for children with complex communication needs in the hospitals in Hong Kong? Follow-up probes were developed with adjustment to suit each group's specific backgrounds.

The first four authors acted as group moderators or assistant moderators, while the fifth author provided advice on data analysis and writing up. Each group was held in a quiet clinic room at a Child Assessment Centre of the Department of Health of Hong Kong SAR and lasted from 90 to 120 min depending on the size of the groups. Each group had a main and one to two assistant moderators. All group discussions were digitally audio recorded.

Data analysis

After conducting the six groups, the moderators met together to share their observations, and decided as a group that data saturation was achieved. Three post-graduate students supported verbatim transcriptions of the audio recordings, which were reviewed by the authors for accuracy. The analysis was conducted based on the original Cantonese transcriptions. For the current paper, the transcribed data was translated from Cantonese to English text through joint work and consensus of the authors. Any information that might identify a participant was removed to preserve anonymity.

The responses in the data set were analysed using the inductive thematic analysis procedure (Braun & Clarke, 2006). The transcribed data set was examined first by three of the authors to identify units of information relevant to the research topic. Based on the data set of one group and guided by the fifth author who was experienced in qualitative research, coding guidelines and procedures were established. An initial set of categories was generated. After familiarization with the coding procedure, the three authors coded the data of the remaining five groups independently. The categories generated for all six groups were then counterchecked by all group members again. Categories were modified and agreed upon consensus to maximize inter-coder consistency. Initial themes were generated by grouping similar categories across the entire data set. The themes were checked for their cohesiveness and organized into the smallest number of groups with maximum information and minimal overlap by group members together. Repeated analysis and further discussion among the authors were conducted to refine the themes. Operational definitions of finalized themes and subthemes were produced. The entire process of identification and grouping of themes and subthemes was achieved through consensus (Balandin & Goldbart, 2011; Caron & Light, 2016; Gormley & Light, 2019).

Reliability and integrity

For reflexivity, at the end of each group interview, the moderators and assistant moderators held an evaluation meeting to identify areas of improvement in the facilitation process, and to identify issues that might need further elaboration or probes in future groups.

Crystallization was achieved through a series of steps (Gormley & Light, 2019). The main and assistant moderators for each group counterchecked the transcripts to ensure they were correctly transcribed. Transcripts were read repeatedly by the moderators to familiarize themselves with the data and to systematically identify participants' unitized input and to arrive at operational definitions of codes used for documentation.

The research member of this study who did not take part in the facilitation of group interviews is an experienced qualitative researcher. This member reviewed and questioned all the steps of the analysis after the first set of themes and subthemes were developed by the moderators. Measures to ensure the satisfactory rigour of this research were implemented (Balandin & Goldbart, 2011; Caron & Light, 2016; Gormley & Light, 2019).

Ethical considerations

Formal approval was obtained from the Ethics Committee of the first author's affiliated institution (Reference Number: (19) in L/M 399/2019 in DHHQ/1055/15/1/2). Study information was sent to all participants; all of whom provided written voluntary consent, including the adolescent participants who provided written assent in the presence of their

parents. There was no conflict of interests between the researchers and participants.

Results

The analysis revealed three core themes and several subthemes which were presented in the visual model (see Figure 1). The core theme of unaddressed physical, somatic and emotional needs emerged, which seemed to be underlined by two other core themes of beliefs and practices, and system issues. Table II presents the representative quotes generated across subthemes and group participants.

Theme 1: unaddressed needs of children with complex communication needs in hospital

Participants reported numerous physical, somatic and emotional needs of children staying in hospital, during acute and post-acute stage, or those of transient or permanent nature. Their needs were not effectively communicated resulting in many of them being unaddressed.

Physical needs

Physical needs included the desire for water and food, to get changed, to go to washroom, to change their resting/seating posture, etc. Given the children's difficulties in verbal communication, medical staff were not able to understand their communication, and their needs were not addressed in a timely way, causing embarrassment such as wetting of pants and beds. A parent of a child with PD said, "No one gave him water to drink nor food to eat. He could not tell others. Even (if) he, he wanted to express, people could not understand" (Participant 4 – parent of

a child with PD). Another parent of a child with PD pointed out, "He could not express, so there were chances he might wet the bed" (Participant 1 – parent of a child with PD).

Somatic needs

Somatic problems such as pain, itchiness, numbness, nausea, dizziness, fever, headache, and digestive problems were frequently experienced, particularly after surgery, when children were intubated, or during chemotherapy; however, the children were not able to communicate their somatic symptoms. A parent of a child with PD stated that, "The first day after the operation, he was admitted to ICU. We saw that he was in great pain through his facial expression. He wanted to talk but was intubated so he could not talk" (Participant 1 – parent of a child with PD).

Emotional needs

Emotional problems were reported by parents of children with ABI and PD. These included sadness, unhappiness, anxiety, frustration, fear of the medical procedures (surgery, injection, etc.), crying and angry outbursts, elated and labile mood. These were exacerbated by the children's difficulties in verbal expression, which caused communication breakdown. A parent of a child with ABI said, "Medicine indeed triggered her nightmare, anxiety, crying as well, constant fear; there is much anxious feeling. (She) cried every now and then, almost cried from dawn till dust, cried whenever you asked her" (Participant 2 – parent of a child with ABI). A parent of a child with PD pointed out, "He could partly understand, but when he wanted to speak, wanted to express, he could not express but resorted to throwing tantrums, temper tantrums" (Participant 5 – parent of a child with PD).
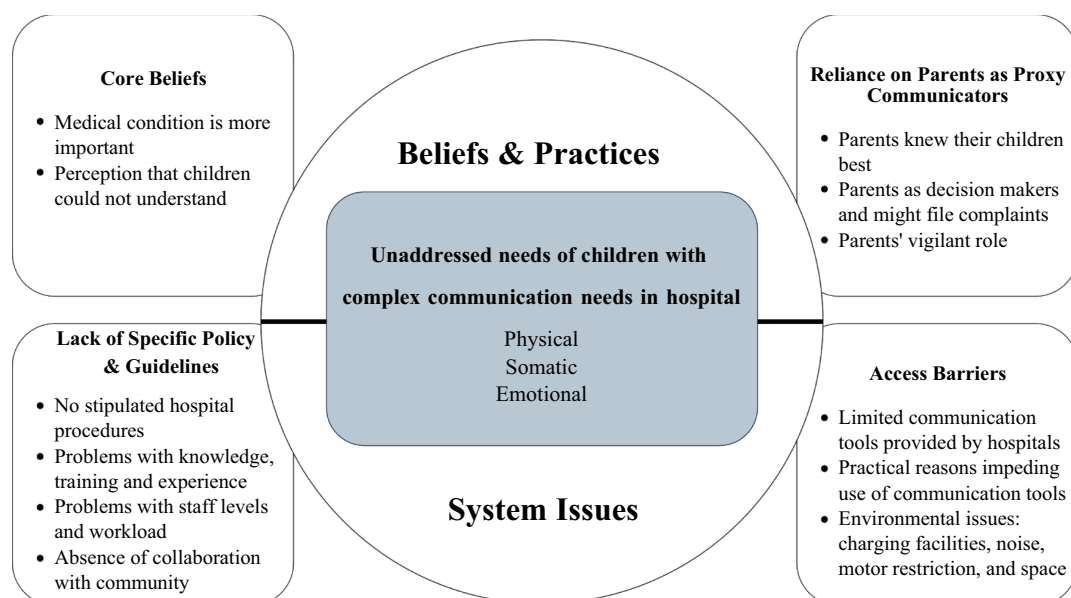

Figure 1. Visual model of themes and subthemes.

Table II. Themes, subthemes with operational definition, examples of quotations by each group.

Themes and Subthemes	Example quote
1 Unaddressed needs of children with CCN in hospital	
Physical needs	"No one gave him water to drink nor food to eat. He could not tell others. Even (if) he, he wanted to express, people could not understand." (Participant 4, parent of a child with PD)
Basic needs such as quest for water, food, toilet or diaper change, etc. to fulfill daily basic desires.	
Somatic needs	"The first day after the operation, he was admitted to ICU. We saw that he was in great pain through his facial expression. He wanted to talk but was intubated so he could not talk." (Participant 1, parent of a child with PD)
Needs related to discomfort such as pain, itchiness, numbness, nausea, dizziness, etc.	
Emotional needs	"Medicine indeed triggered her nightmare, anxiety, crying as well, constant fear, there is much anxious feeling. (She) cried every now and then, almost cried from dawn till dust, cried whenever you asked her." (Participant 2, parent of a child with ABI)
Psychological needs such as fear, frustration, sadness, tantrums, crying episodes, etc.	
2 Beliefs & Practices	
Core beliefs	
Medical condition is more important	"Since for hospitalization, in fact this is a clinical admission, there's bound to be clinical condition driven. Of course, the clinical condition is most important." (Participant 2, doctor)
The belief that medical condition comes first, which outweighs the other needs.	
Perception that children could not understand	"Talking about psychological preparation for children who required AAC, since they could not express, (they) usually will be underestimated. That is, they (medical team) think that you don't understand, they therefore will not spend time to talk to you that much." (Participant 3, special school therapist)
The belief that children have problem comprehending the content pertaining to the medical condition, procedures, etc.	
Reliance on parents as proxy communicators	
Parents knew their children best	"The mother accompanies the child round the clock. It is her who knows eye blinking refers to 'like' and tongue flicking refers to 'dislike'." (Participant 5, nurse)
The belief that parents knew their children thoroughly and are the best informant.	
Parents as decision makers and might file complaints	"(We) usually communicate with parents. Since the mother is the decision maker, obviously (we) will talk to the decision-maker." (Participant 2, doctor)
The belief that parents were the ones who made decision and they were the complainants whenever complaints were filed.	"But I think the current practice, basically (we) do not explain to the child, will only explain to the parent, since only the parent but not the child will file a complaint." (Participant 3, special school therapist)
Parents' vigilant role	"So far, all the time I was in hospital for 24 hours to accompany him, only except when the domestic helper would come to take shift for 2 to 3 hours. Almost always, I stay as long as he is in hospital. Since they do not know what he expresses, and I have to tell them. (Participant 2, parent of a child with PD)
The practice that parents assumed a vigilant role during the children's hospitalization through their active involvement in direct communication with healthcare professionals and this was made possible by their physical presence at the hospital round the clock.	"My mother helped to respond to the doctor cause I wanted to rest (Participant 1, adolescent of ABI)
3 System Issues	
Lack of specific policy and guidelines	
No Stipulated hospital procedures	"There are ones (protocols) specified during pre-admission and discharge, but for AAC purpose, there are none." (Participant 1, doctor)
Lack of standardized protocols and procedure for child patients with CCN	
Problems with knowledge, training, and experience	"If you talk about AAC, I think it refers to those I-Pads." (Participant 4, doctor)
Refers to the problem of inadequate knowledge, insufficient training and lack of experience of healthcare professionals in regard to communication with children with CCN	"Training is meagre, (training on) special tools for frontline nurse is meagre." (Participant 5, nurse)
	"I think at PICU, apart from time issues, experience is a problem, specifically, nurses' experience. Young and junior nurses are assigned to learn at PICU. They are relatively young. It takes time to train the communication skills. In fact, 30% of the nurses are with less than 3 years' experience." (Participant 5, nurse)
Problems with staff levels and workload	"One time I pressed the call button, she (the nurse) was aware. She switched off the call button but did not come over to me" (Participant 3, adolescent of ABI)
The problem with manpower and heavy workload which impeded communication	"Generally, medical team, as said earlier, of course, they will attend to you when they are free. If they are not free, they will not attend to you" (Participant 1, parent of a child with PD)
Absence of collaboration with community	Moderate grade intellectual disability … non-verbal, that time when she was hospitalized in general ward, the child was considered having no ability to communicate. Then I clipped a "Yes" and "No" card on the bedside, and a "Not clear" card as well so that the child could use eye-pointing. Then the nurse realized, "Oh! She has the ability to communicate" and this method was then used. (Participant 1, special school therapist)
The absence of collaboration with community special school therapists, for example, in soliciting information such as the children's premorbid functioning, preferred mode of communication, AAC tools, etc.	
Access Barriers	
Limited communication tools provided by hospitals	"Sometimes I have to repeat two or three times before others can hear clearly what I want. In fact, I think if there is something like a computer or button, it can help express my needs, such as going to toilet or to ask for nurse's help." (Participant 1, adolescent of ABI)
Limited AAC communication tools, both low and high-tech provided by the hospitals	
Practical reasons impeding use of communication tools	"Will not bring stuff that is not required for medical purpose. It may get lost." (Participant 1, special school therapist)
Security and storage issues, which might give room for theft or loss of AAC tools	

(*Continued*)

Table II. (Continued).

Themes and Subthemes	Example quote
Environmental Issues: charging facilities, noise, motor restriction and space Prohibition of charging of electronic devices, noise issues when speech-generating devices were used, problems with motor restriction due to intravenous infusion, and space issues where there was no room for mounting necessary equipment, etc.	"I have to bring the backup battery to the ward, but no recharge is allowed in the ward." (Participant 1 and 2, adolescents of ABI) "For those sound generating device, I believe once it is brought out, someone will take it away." (Participant 1, special school therapist) "(From) their position, (they) could not reach the call button." (Participant 5, parent of a child with PD).

Note. CCN = Complex Communication Needs; PD = Physical Disability; ABI = Acquired Brain Injury; AAC = Augmentative and Alternative Communication; PICU= Pediatric Intensive Care Unit.

Therapist participants also noted that the emotional needs were largely unaddressed given the busy workload of medical staff. A therapist stated, "I think the emotional aspect is ignored. Who (child-patient) can I talk to? Everyone is so busy." (Participant 2 – special school therapist). Without suitable communication equipment, children with complex communication needs could not express their physical, somatic and emotional needs. In the following sections, the views of stakeholders about communication with children with complex communication needs are explored.

Theme 2: beliefs and practices

Core beliefs

Participants from different groups revealed the following core beliefs, which impacted on patient-provider communication.

Medical condition is more important. There was the belief that the medical condition always came as first priority and therefore the communication needs of children were downplayed. A doctor stated, "I personally feel that, in fact, we do not take communication as very important, truly" (Participant 3 – doctor). Another doctor mentioned, "Since for hospitalization, in fact this is a clinical admission. It's bound to be clinical condition driven. Of course, the clinical condition is most important" (Participant 2 – doctor). With this belief, the opportunity for patients sharing information, asking questions, indicating preferences from routine activities to serious decisions might not be accommodated.

Perception that children could not understand. Some medical staff held the view that children could not understand and so there was no need to communicate. Consequently, they spent little time on direct communication with the children. Here is a quote from a therapist:

> Talking about psychological preparation for children who required AAC, since they could not express, (they) usually will be underestimated. That is, they (medical team) think that you don't understand;

they therefore will not spend time to talk to you much.
> (Participant 3 – special school therapist)

These attitudes and views resulted in a situation where children were not talked to directly. These children might not be given the opportunities to effectively exchange information and actively participate in health care interactions. However, adolescent patients themselves would like to be personally involved in the decision-making process. An adolescent patient of ABI conveyed that he would feel better if he was involved in the process of decision-making while he was in hospital as a child. He said, "I feel if the doctor can tell me clearly what is going to be done, I will be more at ease" (Participant 3 – adolescent with ABI).

Reliance on parents as proxy communicators

Apart from beliefs held by the healthcare professionals which might impede communication, the practice that they heavily relied on parents as proxy communicators during hospitalization constituted as obstacle in patient-provider communication. Nurses, doctors, and therapists reported that they relied heavily on parents to communicate on their children's behalf. Instead of adopting patient-provider communication, the healthcare professionals engaged with the parents in communication, due to several reasons.

Parents knew their children best

Doctor, nurse and therapist participants believed that the parents knew their children best, and the communication was directed towards the parents, rather than encouraging the children to report their condition, or to communicate their preferences. Here is a quote from a doctor, "(We) generally almost always rely on the parents' report, reflect to us what they have observed or what the child says, or what he is saying" (Participant 3 – doctor). A nurse maintained, "In fact, we emphasize communication, most importantly with family members. We always, not only always, in fact we believe 100% what the family members tell us since the family members know

their child best" (Participant 1 –nurse). One therapist said, "In fact, the problem is, the parent is always there; basically. (We) will tell the mother everything. In fact, there is no need to attend to the child" (Participant 3 –therapist). Another nurse pointed out, "The mother accompanies the child round the clock. It is her who knows eye blinking refers to "like" and tongue flicking refers to "dislike" (Participant 5 – nurse).

Parents as decision makers and might file complaints

Apart from the beliefs that parents knew their children best, the healthcare professionals conveyed the beliefs that children were considered as minors while parents were the decision-makers and they were the ones who might file complaints. Therefore, their views must be heard, and the medical decision had to be discussed with the parents and not the children. A doctor mentioned, "About the child's need, do we classify him/er as a minor? Doesn't mean s/he has no say, but even s/he hears the decision, it is still the mother who has the say", and he supplemented, "(We) usually communicate with parents. Since the mother is the decision-maker, obviously (we) will talk to the decision-maker" (Participant 2 – doctor).

Healthcare professionals conceived that it was the parents who might file complaints, not the child patients. As such, it was important for them to explain to the parents. A therapist mentioned, "But I think the current practice, basically (we) do not explain to the child, will only explain to the parent, since only the parent but not the child will file a complaint" (Participant 3 – special school therapist).

Parents' vigilant role

The reliance on parents as proxy communicators was made possible as the parents assumed a vigilant role during the children's hospitalization. In response to the tight manpower and busy workload of healthcare providers, parents believed that they had to stay with their children with complex communication needs all the time, so they could monitor and report their children's health conditions. The current policy permitted the parents' 24-h presence. A nurse said, "The hospital allows one parent to stay for 24 h to accompany the child, therefore most of the time, we communicate with the parents. When the child is uncomfortable, it is the parent who instantly sees this and tells us" (Participant 3 – nurse). A doctor participant said, "Generally the parents were almost always there 24 hours" (Participant 3 – doctor).

While healthcare professionals assumed that parents could take the role as "spokesperson" for their

children and they were expected to be at the hospital ward round the clock, the parents themselves also believed that they knew their children best and feared that the medical professionals would not be able to comprehend what their children wanted to express. They made themselves available all the time at the bedside. A parent of a child with PD said, "Our children in fact must have to be with us face to face, before s/he knows how to express where s/he feels uncomfortable" (Participant 3 – parent of a child with PD). Another parent maintained:

> So far, all the time I was in hospital for 24 hours to accompany him, except when the domestic helper would come to take shift for 2 to 3 hours. Almost always, I stay as long as he is in hospital. Since they do not know what he expresses, and I have to tell them. (Participant 2 – parent of a child with PD)

A similar view was conveyed by a therapist, "A student with moderate ID, in fact, most of the time the parent stands by (in the hospital); thinks that she (parent) understands everything; the student does not need to express at all" (Participant 3 – special school therapist). Parents also stayed constantly vigilant during their children's hospitalization. They used different means to get themselves prepared to post questions to the doctors, thus leaving no room for communication they considered as not useful. Here is the quote from a parent of a child with ABI, "Every time, shortly before the ward round, I will jot down what to ask" (Participant 2 – parent of a child with ABI). Another parent of a child with ABI concurred, "Indeed! (Parents) do jot down, they jot down in a detailed manner" (Participant 1 – parent of a child with ABI). While the parents were keen to be involved in the communication with healthcare providers, the child patient welcomed the parent's active role. A patient of ABI mentioned, "My mother helped to respond to the doctor because I wanted to rest (Participant 1 – child patient with ABI). With the parents' burning questions and seemingly endorsed by their children, little time will be left for the children to communicate directly with the healthcare providers. Instead of a patient-provider communication, it became a patient's parent-provider communication.

However, the parents had to make guesses sometimes. It is possible that the children's needs may have been mis-interpreted by their parents. A parent of a child with ABI said, "Must have to make guesses all along" (Participant 2 – parent of a child with ABI). A therapist maintained, "I am thinking of those with lower functioning. These children usually express their emotions through crying. And their parents will then react by asking, are you afraid? Are you afraid?" (Participant 2 – special school therapist).

Theme 3: system issues

Lack of specific policy and guidelines and access barriers were mentioned by the participants which were System Issues that undermined patient-provider communication.

Lack of specific policy and guidelines

Specific policy and guidelines for children with complex communication needs were lacking. The healthcare professionals believed that they did not need to communicate with the children, and this was also reflected in the absence of formal guidelines and protocols.

No stipulated hospital procedure

According to the doctor and nurse participants, in the current practice, there was no stipulated pre-admission procedure on children's cognitive function and communication needs. The pre-admission information covered physical examination, sensory (vision and hearing) functions, the need for hearing or visual aids, and language use. They admitted that during clinical admission intake, there was no cognitive assessment to gauge the patients' cognitive functions or communication aspects, which meant that the prescription of AAC tools and access to equipment essential for communication in hospital for children with complex communication needs was not considered or available. A doctor pointed out, "There are ones (protocols) specified during pre-admission and discharge, but for AAC purpose, there are none" (Participant 1 – doctor). Furthermore, the nurses did not have the readily available tools to gauge the children's cognitive functions and had to rely on their interaction with the children to gain an impression of their cognitive functioning. A nurse mentioned, "Cognitive aspect is not asked; (we) only ask for the language used in communication, Cantonese or English? Any hearing aids" (Participant 4 – nurse).

Problems with knowledge, training, and experience

The absence of policy, guidelines, and work protocol was further exacerbated by the additional barriers identified: problem with lack of knowledge of assistive communication tools, lack of training on communication, and lack of experience of staff.

One of the doctor participants conceived that AAC referred to tablets only, instead of both low and high-tech communication devices as well as respective access requirements. A doctor said, "If you talk about AAC, I think it refers to those I-Pads" (Participant 4 – doctor).

Lack of training in communication was also identified. Doctor participants expressed that they relied on the nurses to "handle" the child patients. While the nurses were expected to do the communication work, nurse participants pointed out there was little training as well as limited refreshing of knowledge or special tools provided to the frontline staff in a periodic manner. The curriculum in nursing school covered communication but training pertaining to children with special needs was meagre. A nurse mentioned, "Training is meagre, (training on) special tools for frontline nurse is meagre", and she also stated, "I do not know whether the curriculum in university includes these now. Obviously, communication is included, but for children with special needs, in fact, there is very little" (Participant 5 – nurse).

Apart from limited training, inadequate experience and high turnover rate also posed additional barriers. Nurses, particularly those with lesser experience, were less competent to engage in specialized communication with the patients. Nurses with less experience were posted to work at Pediatric Intensive Care Unit (PICU). They were young and junior. It took time for them to strengthen their communication skills. Here is a quote from a nurse:

> I think at PICU, apart from time issues, experience is a problem, specifically, nurses' experience. Young and junior nurses are assigned to learn at PICU. They are relatively young. It takes time to train their communication skills. In fact, 30% of the nurses have less than 3 years' experience. (Participant 5 – nurse)

Moreover, the problem with high turnover rate was also mentioned. A nurse mentioned, "Because we do have a very high turnover rate" (Participant 3 – nurse).

Problems with staff levels and workload

Problems with staff levels and heavy workload further strained communication. Participants echoed that with the time constraint and tight manpower of the medical and allied health professionals, they did not necessarily have enough time to understand the needs of the patients with complex communication needs given their very busy schedule. A nurse mentioned, "In fact at the ward, overly busy, that is, there is no time to let (child) slowly point or locate (the apps)" (Participant 4 – nurse). A doctor said, "And (we) actually have to balance nurses' workload, and to facilitate work, and want to improve service but at the same time must not make nurses overloaded" (Participant 3 – doctor). A parent of a child with PD mentioned, "Generally, medical team, as said earlier, of course, they will attend to you when they are free. If they are not free, they will not attend to you" (Participant 1 – parent of a child with PD). An adolescent patient of ABI mentioned, "One time (when) I pressed the call button, she (the nurse) was aware. She switched off the call button but

did not come over to me" (Participant 3 – adolescent patient with ABI).

Therapist participants pointed out that communication with child patients with complex communication needs and lower cognitive functions demanded more time given their unique characteristics, which was difficult in the current practice. A therapist said, "When you undergo an operation, naturally you are scared. There is no one who will talk to you, and it is even more time-consuming when compared with a normal patient" (Participant 2 – special school therapist).

Absence of collaboration with community

Children with complex communication needs are known to assessment centres. Their cognitive ability is documented, as are AAC needs recommended by therapists to be used at home and at school. But given the missing communication linkage between hospital and services that provide AAC assessments such as special schools, and rehabilitation organizations, therapist participants commented that hospital staff did not know the unique characteristics and communication needs of these children, which hindered both the provision of suitable tools and modality in communication. A therapist said,

> Moderate grade intellectual disability … non-verbal, at the time when she was hospitalized in general ward, the child was considered having no ability to communicate. Then I clipped a "Yes" and "No" card on the bedside, and a "Not clear" card as well so that the child could use eye-pointing. Then the nurse realized, 'Oh! She has the ability to communicate, and this method was then used. (Participant 1 – special school therapist)

Access barriers
Apart from attitudes and practices, hospital protocols, staff manpower, and training, access barriers were identified as additional barriers.

Limited communication tools provided by hospitals

The hospital provides no or limited communication tools for patient use, which makes communication difficult. A nurse said, "You mentioned there is Communication Book, in fact, there isn't any" (Participant 3 – nurse). Another nurse pointed out, "For those who cannot talk? No, there is indeed no tool that can help him/her to express" (Participant 4 – nurse). An adolescent patient with ABI also pointed out, "Sometimes I have to repeat two or three times before others can hear clearly what I want. In fact, I think if there is something like a computer or button, it can help express my needs, such as going to toilet

or to ask for nurse's help" (Participant 1 – adolescent patient with ABI).

Medical vocabulary to request assistance, making age-appropriate choices, and asking questions were not provided at the hospital setting. The Communication Book used at home and at school might not include icons/messages for the hospital context. If the children were admitted to hospital on ad-hoc basis, no earlier preparation or modification of the AAC tools could be done. A therapist said, "If (one) gets admitted (to hospital) due to sudden dizziness or fever, then it is difficult to prepare and if the context is changed, it is questionable whether (the tool) can still be used" (Participant 3 – special school therapist).

Practical reasons impeding use of communication tools

Even when tools were available and these were allowed, as pointed out by the parent participants and echoed by the therapist participants, parents might not bring the available Communication Book to the hospital for practicality reasons. First, there were already too many things to bring along. Second, there was a lack of locked storage facilities in hospital wards, and there were security concerns. A parent of a child with PD said, "It is very clumsy if I have to set up a lot of stuff" (Participant 5 – parent of a child with PD). A therapist maintained, "Will not bring stuff that is not required for medical purpose. It may get lost". The therapist continued further:

> If their ability is weak, that is, the cognitive level is lower, say for example low-tech AAC is used at school, for these children, parents usually might not bring the AAC device to hospital, just as Participant 3 Therapist said. (Participant 1 – special school therapist)

Environmental issues: charging facilities, noise, motor restriction, and space

Another obstacle is that high-technology AAC requires charging and charging of these electronic devices was not always allowed by hospital policy. Two adolescents with ABI both voiced out that "I have to bring the backup battery to the ward, but no recharge is allowed in the ward" (Participant 1 – adolescent with ABI) and concurred by Participant 2 (adolescent with ABI). A therapist pointed out, "And what Participant 1, what therapist said was true, that is, it is difficult if charging is not allowed … that is no matter what level of technology, the fundamental thing (charging) is not available" (Participant 2 – special school therapist).

Speech-generating devices were not welcomed because of concerns that the sounds might cause a fuss. A therapist mentioned, "For those sound

generating devices, I believe once it is brought out, someone will take it away" (Participant 1 – special school therapist).

For children who relied on motor manipulation of communication devices, communication was restricted by continuous intravenous infusion that hindered motor movement. A therapist said, "His/er hands were all tubed, and could not write, therefore s/he had no ways to communicate with people" (Participant 1 – special school therapist). A parent of a child with PD mentioned, "(From) their position, (they) could not reach the call button" (Participant 5 – parent of a child with PD).

As previously discussed, the unavailability of suitable mode of communication and tools resulted in both nurses and parents making guesses about children's needs, which might cause more communication problems. A nurse mentioned, "In fact, we have to make guesses, but sometimes (we) guess wrongly. In fact (we) really don't know if (they) cannot communicate" (Participant 1 - nurse). A parent of child with ABI said:

> I recall one time, my daughter wanted to wash her legs. She pointed to her leg. Her father looked after her on that day, and her father did not understand. (He) thought she had pain in her legs. In fact, it was very simple; she just wanted to have her legs washed. (Participant 1 – parent of a child with ABI)

Space is limited in Hong Kong, and the hospital environment is no exception. This creates problems for the instalment of AAC materials such as headset, mounting, proper placement of AAC devices, etc. This issue was mentioned a few times by parents of children with PD and therapists. The child was deprived of the usual AAC materials which bogged down communication. A parent of a child with PD said, "He previously used head to control. You have to fix the seating so that he can sit up to use the device" (Participant 5 – parent of a child with PD). A therapist maintained,

> Firstly, for example, the device is to be put on tabletop for eye tracking. Basically s/he does not have a tabletop in hospital. In fact, you cannot set this up. Secondly, mother is basically always sleeping next to the bed, therefore, mother thinks there is no need. If there are so many things to bring, might as well keep it simple, have already so many things to bring along. (Participant 1 – special school therapist)

Discussion

The group participants of this study included hospital- and community-based healthcare providers, patients with complex communication needs and their parents. The range of abilities of child patients comprised adolescents with average intellectual functioning to children with more severe cognitive impairment who were represented by their parents. Their need for AAC varied from transient to permanent due to their different aetiologies.

Results were analysed, taking into consideration the three components, the setting, the recipient/caregiver, and culture. The findings are also discussed in the context of the healthcare system and the family system.

Beliefs and practices of providers in the healthcare system

On the setting component, the results in this study would need to be explained in the context of the current healthcare system in Hong Kong with severe manpower shortage and lack of specific protocols and training on AAC. With the high workload and manpower shortage, most of the healthcare provider groups interviewed believed that medical care was the priority and there were concerns whether the children could understand them. There was limited focus on direct child-healthcare provider communication and its potential impact on medical outcomes. Healthcare providers' and parents' experiences were mostly related to task-focused and nurse-controlled care for the children. The concerns shown in this study by nurses were similar to those previously reported, such as inadequate time (Hemsley et al., 2012), inadequate tools and skills (Finke et al., 2008) and limited communication strategies and skills of frontline healthcare providers (Downey & Happ, 2013), as well as inadequate knowledgeable service providers dedicated to AAC support (McNaughton et al., 2019), which severely limit effective communication with children with complex communication needs. Like in other studies (Hemsley & Balandin, 2014), we found barriers due to healthcare policy, practice and attitude.

Lack of policies and protocols to support communication in hospitals in the healthcare system

Regarding the policy sub-component, there is little or no mention of the importance of communication with children or patients with communication difficulties in policy documents, and there is little support from the senior level. In the context of pre-service and in-service training, there is limited input on the importance of AAC or practice guidelines. Within the healthcare system, recurrent themes from parents and healthcare providers indicated that there were few practice guidelines on addressing communication needs of hospitalized children with complex communication needs. There were limited specific skills among the staff and availability of communication aids in hospital wards. As a result, direct communication with the children was time-consuming and ineffective. These are likely due to an overall lack of

awareness of the importance of direct communication with child patients and the need to address the situation. These findings are again consistent with research showing a lack of awareness of the communication needs of child patients by health professionals, as well as patients and parents themselves (Finke et al., 2008; Hemsley et al., 2001, 2014). Reforms within the healthcare system are needed to address the issues of healthcare practices. Reforms in the education system such as tertiary institutions are needed to train healthcare professionals on communication skills with children, and to train speech therapists on AAC.

Availability and access of communication tools in the healthcare system

The limited physical space in Hong Kong is another factor under the setting component. Physical space in public hospitals is generally very limited for each patient (Wong et al., 2012). This posed a barrier for using any AAC device, especially for ones requiring simple mounting, patient seating arrangements and power access. Adolescent patients of ABI spelled out explicitly the need for a computer, press button, and charging facilities so that their needs could be adequately and clearly expressed through these electronic devices. Lacking secure storage space for communication tools further deterred parents from bringing communication tools to the hospital, and indeed it was hospital policy that these should not be left behind when parents left. This is consistent with other studies on inadequate accommodation for individuals with special motor and cognitive needs (Light, McNaughton, & Caron, 2019). In a study on speech therapists' experiences in providing services to individuals with complex communication needs, all participants reported the use of a variety of low- or high-tech tools with their patients, while a majority reported a primary use of low-tech tools which could be easily accessible to caregivers and to be left at the bedside (Gormley & Light, 2019). In the current study, there was minimal mention of accessible no-/low-tech methods among parents or health care providers in the hospitals. From a technological perspective, development and provision of simple and generic communication boards available in each hospital ward, together with basic AAC strategies and skills, could support basic communication needs between the children and the persons they might interact with.

Reliance on parents as a proxy in the healthcare system and the family

For the caregiver component, the culture component will need to be considered together. In the context of the family system in Hong Kong, parents are expected to take responsibility for their children and to act on behalf of their children. Hospital healthcare provider participants demonstrated a heavy reliance on parents to interpret for their children, as "family members know their child best". From the family perspective, parents agreed that they felt duty bound to assist in interpreting the children's needs to hospital staff, although at times they had difficulty detecting their children's needs. This is consistent with literature on parents of children and adolescents with cerebral palsy and complex communication needs who saw it as their roles to "be the child's voice" (Hemsley et al., 2013, p. 367) and to interpret their needs for hospital staff. Many were exhausted and helpless but were reluctant to delegate these to healthcare providers for fear of affecting the relationship with them, which is commonly seen among Chinese parents (Lee & Lau, 2013).

The voice of the recipients

About the recipient component, while the healthcare providers were concerned whether the children could understand them, adolescent patients of ABI with transient communication needs were eager to be involved in the process during their hospital stay. They looked forward to having direct communication with the staff so that they could be better at ease with the forthcoming procedures they had to undergo. Thunberg et al. (2022) pointed out that there might be discrepancies between adults' observation and children's views, and they argued for a person-centred care where the child's experience and the expertise of health professionals and parents could be combined.

Adolescent participants expressed their wish to ask questions about their medical condition and to actively participate in their own care, which is consistent with Hemsley et al. (2013) where children with cerebral palsy and complex communication needs indicated their preferences for direct communication with staff. To address these issues, a family-centred approach is proposed, where parents, and children as appropriate, are empowered with adequate information and opportunity to communicate with healthcare providers (Lee & Lau, 2013). In doing so, parents could become partners in this team, rather than simply serving as their children's proxies.

Clinical implications

Measures to be considered in the healthcare system

In the Strategic Plan 2022–2027 laid down by the Hong Kong Hospital Authority, the value of People-centred Care is spelled out as the core value, "to provide service with a caring heart, even when we are busy or a patient is demanding, remembering that

a good two-way communication is indispensable (Hospital Authority, 2021). This concurs with the purpose of the present study in examining and highlighting the importance of patient-provider communication.

To address the previously noted challenges, a series of simple yet effective steps could be considered. Basic information on patients' communication status could be included in admission interviews. The need for attention to communication ability could be flagged in the patients' charts, with referrals for communication support by relevant professionals if indicated. Simple and handy AAC tools such as generic hospital relevant communication boards and charts could be made available in each hospital ward. Signage on the patient's communication modality can be put up on the bedside. Hospital management's explicit recognition of the need for effective patient-provider communication for positive healthcare and patient experience is crucial, supported by polices and resources to enable implementation. Practical guidelines may be developed to cover the hospital admission to discharge journey. For this, a case nurse can be assigned during the pre-admission stage for liaising with parents and the children's community-based carers or therapists, and to prepare for communication measures as far as possible. These findings and needs echo the recommendations of Hemsley and Balandin (2014) for hospital policies to support communication, adequate time and tools and competence and collaborative work. For patients with communication difficulties acutely acquired such as from brain injury, consideration of the readiness, perception and preference of the individuals is key to the introduction of AAC (Mackey et al., 2023). The importance of effective patient-provider communication and a well-coordinated transition plan of care, including communication, is emphasized (Blackstone & Pressman, 2016). Healthcare provider communication partners training is recommended for healthcare providers to understand and empathize with the difficulties faced by patients with complex communication needs. Simple identification instruments for complex communication needs would need to be developed, together with the introduction of a range of communication strategies ranging from no-/low-tech to mobile app devices that will support workplace application.

In supporting the patient-providers communication, tackling the current shortage of healthcare professionals by increasing related education capacity, improving workplace environment, and developing comprehensive workforce planning, with effective recruitment and retention strategies in public hospitals have to be investigated.

Measures to be considered in the education system

Modules on AAC are to be included in the University Speech-Language Pathology Programs so that student clinicians will be equipped with the essential knowledge and skills to apply in future work settings. Universities can be encouraged to set up an online planform to pool and house the e-resources such as video clips and learning materials to optimize resources utilization among universities in Hong Kong that have equivalent programmes.

Equipping the next generation of nursing professionals via nursing programmes in universities and in-service training can empower nurses to be able to communicate effectively with child patients with complex communication needs (Woodring & Harmon, 2022). Nurses being one of the key communication partners at the hospital setting can enhance fruitful interactions to reduce communication breakdown.

Measures to be considered in the community

Community speech therapists are encouraged to incorporate the generic hospital communication toolkit for students' communication board/word bank, etc., so that these children can be familiarized with the common vocabularies and procedures prior to hospitalization. The therapists who conduct day-to-day training to these children are to be connected with the universities so that centre visits, case sharing, and practicums can be offered such that student clinicians can get in-vivo experience in applying AAC and try out their skills.

Parents and family members are important stakeholders and key communication partners. Apart from being their children's advocates, parents are encouraged to refrain from eclectic means but to resort to using AAC system as prescribed by the therapists to unify communication mode and substantiate functional use of the AAC system across settings.

Limitations and future directions

Although patients, caregivers, community therapists, nurses and doctors were recruited, other key stakeholders, including in-hospital therapists and management staff, were not included. Specific disability populations of children with complex communication needs such as ASD and intellectual disabilities have not been included in this study given their relatively small numbers with acute hospital admissions. Children with PD were not included despite higher hospital admission due to their multiple severe disabilities which limited communication in qualitative interviews. Some of these children's challenges were shared by nurse and doctor participants whose work included chronic disabilities or cases from

rehabilitation wards from the groups. Only adolescents with complex communication needs who were verbal were included as it was felt that they would be more able to articulate their experiences and feelings. Recruitment of parents and children with complex communication needs, cerebral palsy, ASD, intellectual disabilities or other specific disabilities should be considered in future studies.

Second, the group sizes in three of the groups (parents and their adolescent children with ABI, special school therapists) were small, being two and three, respectively. This was in part because of the small number of such patients in the registry who were reaching adolescence and able to express themselves clearly in the group. Germinoma is a rare condition (Yeo et al., 2023) with an incidence rate of 0.10 per 100,000 person-years (Osorio & Allen, 2015). The incidence rate of blastoma among adolescents is also low (Yan et al., 2020). Though the sample size of the adolescent group was small, they were included because they represent a group of patients who can articulate their experiences in hospital. Future larger scale studies of this group should be considered, for example through survey and questionnaire. As an initial encounter, however, the small group sizes allowed more in-depth discussion among highly involved participants, and group members felt more at ease in disclosing personal experience.

Third, measures to improve reliability or reduce bias, external audit of the crystallization process and reliability by participants/member check had not been conducted, and we were not able to collect other forms of data, such as observation, for triangulation. Though inter-rater reliability was not conducted, there was extensive discussion among research team members, and final decisions on coding were achieved through consensus. Other processes were done according to recognized procedures to ensure rigour in qualitative research (Balandin & Goldbart, 2011). Reflexive processes were adopted, and the coding procedures were arrived at by repeated reviews and consensus. Thick description in terms of verbatim quotes of participants was provided so that readers could understand and develop their own interpretations.

Fourth, the researchers were the moderators, and this might be less desirable as this might have introduced bias. Future research should try to use moderators independent of the researchers to enhance impartiality.

Future training and research could include pilot implementation studies, to trial some of the recommendations proposed in hospitals which receive more of these patients, and where healthcare and administrative staff were more ready to address the subject. The ecological validity of newly designed communication strategies and AAC tools, particularly in the Chinese culture, may also be examined. The aim of these studies will be to develop family-centred and cost-effective practices, to foster wider awareness of the practical, medical and psychological needs of children and adolescents with complex communication needs and their families.

Conclusion

Subsumed under WHO's assistive technology 5P's model of policy, people, provision, products and personnel for enabling inclusion and participation (World Health Organization, 2022; World Health Organization/UNICEF, 2022), AAC capacity for hospitalized children and adolescents with complex communication needs was examined in this study. The range of challenges shown covered human and system factors. Healthcare providers and parents alike expressed a belief that communicating directly with children with complex communication needs was of lower priority or generally unnecessary and that parents would understand and convey their children's needs. Parents, however, also expressed difficulties and tended to adopt a passive role in interacting with healthcare providers. Staff awareness, knowledge and skills readiness were limited. System measures to address hospital protocols, physical settings, manpower, staff training programmes, availability of communication tools and collaboration with community stakeholders are needed to address these challenges. Overall professional and public awareness of the importance of effective communication in hospitals, for medical safety and the physical and emotional wellbeing of patients with complex communication needs, cannot be overstated.

There are no relevant financial or non-financial competing interests to report.

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includes development of normed assessment instrument for Hong Kong children on early literacy skills.

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