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Supporting communication for children with cerebral palsy in hospital: Views of community and hospital staff

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Abstract

Objective: We aimed to investigate the views of allied health and nursing staff on supporting the communication of children with cerebral palsy (CP) and complex communication needs (CCN) in hospital.
Method: We conducted 12 focus groups with 49 community- and hospital-based allied health professionals and hospital nurses.
Results: Participants reported having active roles in supporting children's seating, mobility, equipment, mealtime management and psychosocial needs, but not in supporting the children's communication in hospital. Participants described several environmental barriers to supporting children's augmentative and alternative communication (AAC) in hospital, and suggested a range of strategies to ease communication difficulties at the bedside.
Conclusion: Results indicate a potential new role for community- and hospital-based health professionals in supporting nurses to implement AAC strategies at the bedside. Supporting nursing staff to remove environmental barriers and use communication technologies might create a more communicatively accessible hospital ward for children with CP and CCN.

Keywords: *Children, hospital, cerebral palsy, communication, augmentative and alternative communication, AAC*

Introduction

Children with cerebral palsy (CP) have a wide range of health conditions [1] and utilise health services significantly more frequently than their age peers without disability [2–4]. Indeed, they enter hospital more than twice as often as their peers without disability, and stay for significantly longer periods [3–6]. Up to 80% of children with CP have communication impairments, with as many as 25% of children with CP being non-verbal or having complex communication needs (CCN) [2]. Once in hospital, they encounter difficulties communicating with hospital staff [7–9]. These difficulties impact negatively upon their care and parental satisfaction [9]. Children with CP and CCN and their parents have reported a desire that nurses communicate directly with the children using augmentative and alternative communication (AAC) systems [7, 8].

To some degree, parents mitigate problems related to communication by remaining at the bedside to speak on the child's behalf [9–11]. However, children in hospital also want to be able to communicate directly with hospital staff about their needs [12–14]. Beyond reinforcing continued reliance upon parents to speak on the children's behalf [9, 10, 15], however, there is little information in the literature about ways to enable children with CP and CCN to communicate directly with hospital staff.

In any environment, effective communication for children with CCN is achieved through (a) the engineering of a communicatively accessible environment [16], (b) skilled communication partners applying effective strategies, and (c) implementation of a range of AAC systems such as sign and gesture, communication boards, and speech generating devices [16]. It is important to explore the use of

these strategies for children with CP and CCN in hospital, as effective communication is essential to family-centred care [17] and poor communication is associated with a significantly increased risk for experiencing multiple, preventable, patient safety incidents [18–20]. Indeed, hospital accreditation and healthcare standards in the US now demand a proactive approach by hospital staff towards creating a communicatively accessible environment for all patients [21]. There is growing recognition of this for children with acquired conditions [22, 23] but little information relating to children and adults with lifelong developmental disabilities such as CP. In discussing children with temporary or permanent acquired CCN in the intensive care unit, Costello et al. [22] highlighted the 'paramount importance' (p. 298) of well-informed communication interventions in order to promote better patient outcomes. Indeed, Fager and Spellman [23] recommended that hospitalised children with acquired CCN have increased access to call signals to gain assistance, techniques that help children use eye gaze to indicate simple messages, strategies to establish a consistent yes/no response, communication boards with pictures or words, books that encourage interaction, and electronic speech generating devices with pre-programmed messages. The successful use of such AAC systems and strategies relies on input from multidisciplinary, collaborative teams working closely with the client and the family [16]. Unfortunately, both parents and children with CP and CCN have reported that if they take AAC systems such as communication boards to the hospital, these are rarely used by staff, who seem unfamiliar with AAC [7, 8].

Being in regular contact with clients in the community or patients in hospital and well-attuned to the communicative demands of the hospital setting, allied health professionals and hospital nurses may be key figures in improving communication at the bedside for children with CP and CCN. However, there are no reports in the literature on the roles of either community or hospital-based allied health and nursing staff in: (a) supporting children with CP and CCN and their families through repeated periods of hospitalisation; (b) enabling children with CP and CCN to communicate more effectively with their parents, nurses and medical staff in hospital and/or (c) increasing the communicative accessibility of the hospital ward or support the child's communication, including their use of AAC, in hospital. This represents a significant gap in the literature, as children with CP and CCN might benefit greatly by interventions that enable them to communicate directly with hospital staff and to have a say in their own healthcare [24, 25]. Therefore, the aim of this study was to explore the views of both community- and hospital-based allied health professionals and hospital nurses on: (a) their role in supporting children with CP and CCN to communicate in hospital, (b) the children's communication needs in hospital and (c) barriers to and strategies for better communication with children with CP and CCN in hospital. Information gained will help to develop role clarity between professionals, an essential step in forming collaborative partnerships [26]. Furthermore, the findings can be used to increase the communication accessibility of hospital wards, and to prepare children with CP and CCN and their communication partners for effective communication in hospital.

Method

Ethical approval for this study was granted by the University of Queensland ethics committee and the ethics committees of the hospitals and disability organisations assisting with recruitment.

Participants

In total, 49 participants were included in 12 focus groups. We conducted three focus groups with children's hospital allied health ($n = 19$), five focus groups with hospital nursing staff ($n = 14$) and four focus groups with community-based allied health staff ($n = 16$). The five hospital nurse focus groups were small and limited by the number of nurses who could attend at any one time. These groups took place in the nurses' breaks to minimise the impact of the research on the ward. The views of nurses from the recovery ward were gathered in two small group interviews as four nurses volunteering could not leave the recovery ward at the same time. Information on participants' setting, discipline and group composition is presented in Table I.

Procedures

Established focus group research methods were used to capitalise on the group interaction and generate new ideas in answering the research questions [27, 28]. Each focus group was moderated by the first author with assistance from one other author and lasted, in the community, from 45 to 90 minutes and, in the hospital, from 30 to 45 minutes. The key questions were: (a) what is your role in supporting children with CP and CCN in hospital? (b) what do children with CP and CCN need to communicate in hospital? and (c) what are the barriers to and strategies for better communication with children with CP and CCN in hospital? All groups were digitally audio and video recorded. Each recording was transcribed verbatim with identifying information removed or

Table I. Focus group participants.

Focus group	Focus group label	Total number of participants	Setting	Number of participants of each discipline
Hospital allied health	HAH1	8	Hospital	3 Occupational therapists 5 Physiotherapists
Hospital allied health	HAH2	4	Hospital	2 Occupational therapists 1 Physiotherapist 1 Speech pathologist
Hospital allied health	HAH3	7	Hospital	7 Speech pathologists
Hospital nurses	HN1	3	Hospital (surgical ward)	3 Hospital nurses
Hospital nurses	HN2	2	Hospital (surgical ward)	2 Hospital nurses
Hospital nurses	HN3	2	Hospital (recovery ward)	2 Hospital nurses
Hospital nurses	HN4	3	Hospital (medical ward)	3 Hospital nurses
Hospital nurses	HN5	4	Hospital (medical ward)	4 Hospital nurses
Community allied health	CAH1	4	Community	1 Occupational therapist 1 Physiotherapist 1 Social worker 1 Speech pathologist
Community allied health	CAH2	4	Community	4 Speech pathologists
Community allied health	CAH3	5	Community	2 Occupational therapists 1 Physiotherapist 2 Speech pathologists
Community allied health	CAH4	3	Community	1 Occupational therapist 1 Psychologist 1 Speech pathologist

changed to protect the privacy of participants and any person or service referred to in the discussion. De-identified transcripts were read and re-read by all authors and then analysed within and across focus groups for content themes [27, 29]. Categories of meaning emerging from the data and relating to the research questions were identified, coded and collated within and across all of the focus group transcripts. The authors met twice to (a) discuss the coded categories of meaning emerging within and across the focus groups, and (b) reach consensus on the common content themes and sub-themes in the results. A summary of the researchers' interpretations for each focus group was written and sent by email to its participants. Participants were invited to read and amend the summary as desired and return their desired changes by email or in a telephone discussion with the researcher. Overall, 27 of the 33 hospital-based participants and 14 of the 16 community-based participants responded to the invitation. All responding verified that the summaries reflected the views put forward in the focus group they had attended. In this article, raw data in the form of quotes and excerpts from the group discussion are provided to illustrate findings and to increase the confirmability and plausibility of the findings [30]. Quotes are labelled according to each participant's discipline and group. For example, a quote from a speech pathologist in the first community allied health focus group is labelled as [SP, CAH1].

Results

Roles in supporting children with CP and CCN in hospital

Service co-ordination and family support. Across the community-based focus groups, participants reported acting as service co-ordinators for children entering hospital to 'link with that family – they let us know when surgeries actually arise and we liaise with the rest of the team' [SP, CAH4]. They reported that hospital admissions were stressful for children and their families, reflected in an increased demand for services before, during and after hospitalisation. Accordingly, they highlighted the importance of inter-agency communication about the child's hospitalisation in both the preparation for hospital admission and discharge planning phases:

> Planning is the key, honestly. And sorting out whose role is it, whether it's the hospital's role or if we should be taking a greater lead in that process . . . preparing the family for surgery, liaising with the hospital, liaising with the doctors, the other ward physio. [SW, CAH1]

The psychologist in CAH4 helped children to prepare for hospital admission using the talk and draw method: 'We'll just draw a suitcase, and we'll say "what's going to go inside your suitcase?" they always pick good items like "my game-boy and my portable DVD player"'. To prepare children for expected discomforts associated with surgery, the

psychologist asked them about pain ('What do you think the pain might be like? What can you do if you're in pain?'), talked with parent about behaviour management, explored how to express feeling 'cranky', and identified what might make them the child feel better. The social worker if CAH1 reported also visiting the hospital to help families arrange follow-up supports in the home that might help after discharge.

Although describing active roles in supporting the children and families, community-based participants reported being limited in some situations by lack of funding to cross-service boundaries and attend the hospital. They acknowledged that providing a direct service to children in hospital was problematic:

> We're a community organisation…we don't receive health funding, so we do need to be mindful of how many hours are going into supporting that process. Ideally we would like to be more involved in that process but we're not funded to do that, and I guess the hours put there are taken away from school visits, or early intervention. [PT, CAH1]

Making the most of the limited resources available, community staff attended hospital team meetings or case conferences with the family, and visited the hospital to provide adaptive seating, positioning or mobility equipment. The visits to the hospital enabled the staff to plan future services for that child, educate families on what to expect, and support the family to manage at home and in hospital, as noted by the OT in CAH3:

> I would be pre-operatively running meetings and drawing up scenarios for management at home and management in the hospital. I refer to the social worker to do some preparation for going to the hospital with the child and with the surgeons. Post-operatively it's working with the physiotherapist and looking at management at home.

The critical period for providing support was around discharge or return to physical therapy following surgery. However, community-based participants noted that lack of discharge planning impacted negatively upon their work in supporting families:

> We don't receive hospital letters. We can request the families to add us to the letter list but it doesn't always happen, so when we're not getting even basic letters for appointments three months ago, so it's hard to know what is happening and what has happened. There is no clear process, where the lead therapist is - you know, given an email - even if we were the ones to refer them, it doesn't always happen. [OT, CAH4]

Supporting acute physical needs in hospital. Community-based participants described

discipline-specific and overlapping roles in supporting the child with CP and CCN in hospital. Both occupational therapists (OTs) and physiotherapists (PTs) attended to the child's positioning and equipment needs in hospital, by (a) providing adapted seating or mobility equipment to the hospital for use during the child's hospitalisation, and (b) reviewing the child's mobility, seating and equipment needs soon after discharge. Before admission, speech pathologists provided information to hospital staff about the child's nutrition, safety in swallowing, food or mealtime assistance requirements, particularly with the altered postures associated with surgery; and attended the child's specialist appointments and tests (e.g. videoflouroscopy examinations). Speech pathologists informed decisions about (a) surgery (SP3, CAH2: 'does the child have the adequate weight to undergo surgery – the SP with all the team members become quite involved in supporting the family, to address those weight issues'); (b) determining safety in swallowing after surgery and 'liaising with the hospital speech pathologist about whether they need a mealtime assessment while they're at the hospital' [SP1, CAH2] and (c) tube feeding (SP2, CAH2: 'We often take on the role in attending dietician appointments, gastroenterology appointments, we might help families with the decision-making process with regard to looking at alternative means to meet their nutritional needs').

For the most part, hospital-based allied health staff mirrored their community-based colleagues in their respective roles supporting children with CP in hospital. Hospital OTs and PTs advised others on the child's mobility, positioning and adaptive equipment needs, and SPs addressed the child's dysphagia and mealtime management, as SPHAH3 noted: 'Usually, with the CP kids that I've seen, they've been on the wards and usually (seen) just for a feeding assessment in the acute setting'. Hospital allied health professionals also described taking a collaborative team and holistic approach to the child's needs: SP in HAH2 said: 'I guess that's why we work together as well because we try and maximise the function for that child, not just the immediate, acute medical need'.

Lacking roles in supporting communication. Despite having a leading role in supporting communication in children with CP and CCN at home, community-based speech pathologists described having no input into supporting the child's communication in hospital. They also noted having received 'no specific request in regards to communication in hospital…I've never taken a phone call about

speech or communication' [SP, CAH4]. CAH3 discussed possible reasons for this lack of demand:

> SP (CAH3): I think that has been due to gaps in our service due to staffing. Because I think that's obviously been a priority as a speech pathologist, what do you think?
> OT (CAH3): Yes it has been a priority but out of all the children who have been hospitalised, those that are nonverbal don't always take their devices to hospital with them. It's that 'we're here for a medical thing, and that is that therapy thing'. It's for use in therapy and it's for use in school ... it's not a holistic part of the child, often.

Hospital-based speech pathologists explained that no previous requests for communication interventions had been made in relation to children with CP and CCN. They hypothesised that even if requests to support communication were to be made, there was not enough time in the child's hospital stay to assess the child's communication or to design or implement AAC interventions (HAH3): 'As ward acute therapists, we wouldn't have time to devise a system to explain something when maybe we'd see them once or twice and then they'll be going home'. Hospital nurses acknowledged having an important role in communicating directly with the child, and valued the presence of parents on the ward to share everyday care and support their child's communication, as N2 HN2 said:

> It [communicating with a child with CP and CCN] is challenging but it's made a lot easier when we have the families with us to assist with cares and interpret some of the communication - which is hard for us to understand. Parents, especially, are a great resource for learning how the child communicates and also some of the different things that are unique to that child, and how they use them to communicate.

The dominant theme across focus groups of nurses was that parents were the primary source for support in communicating with the children. Nurses commonly described using unaided communication strategies and interpreting the children's non-verbal responses, particularly in relation to pain. In contrast, nurses in FG5 were familiar with a range of AAC practices that supported communication. They described enabling children to use communication aids just as they enabled other children access to laptops or portable gaming devices – by propping up children in bed with pillows to use technologies resting on the meal trolley. This group of nurses also described making communication boards by finding pictures on the internet, inserting these into Word^{TM} documents, before printing and laminating these for use at the bedside. They explained that they had used similar strategies in caring for children with acquired brain injury on the ward.

Views on children's communication needs in hospital

Participants agreed upon the child's need to gain the attention of nursing staff; however, three hospital-based groups noted that children with CP and CCN had little or no access to the hospital call system. Adapted call bell switches, designed by the hospital's rehabilitation engineer, were available on request but not stored on the ward and rarely used by children with CP. As SP2 explained: 'The children that I know ... can't move any arms and they only have eye gaze as a way of communicating, and sometimes they can vocalise. I don't think they have a way of getting attention'. Participants across all groups agreed that children with CP and CCN would need to communicate pain, positioning, toileting and nausea/vomiting. HAH2 highlighted that if the child seemed uncomfortable, and unable to convey this, nurses would probably check through a list of basic needs until arriving at the specific problem: 'I don't know what's wrong with this child – fed, watered, toileted, those sorts of things'. Participants in HN2 agreed that this included regularly checking on the following: 'Is the child wet? Have they had a wash? Is their mouth care done? Has their medication been administered? Are they in pain? Are they comfortable?' (N1, HN2). However, HAH1 participants suggested that often communicating toilet is difficult, even to those who are familiar, as PT5 reported: 'I thought a child was trying to spell to me, name things, but he was just trying to tell me toilet over and over, and that was actually a child I knew quite well'.

The ability to convey levels of pain was described as the primary communication need of children with CP and CCN in hospital. Although nurses had access to various pain picture scales for children to indicate the site and severity of pain, it was not always easy for the child to convey messages about pain: 'One child ... was able to eye gaze to say she was in pain; and she had a broken bone. And that took a long time before anyone actually paid attention to the fact that she was grimacing and she was really tense'. One PT reported: 'I had just made this assumption that it wasn't hurting because they couldn't tell me'. Participants agreed that difficulty establishing direct communication with children with CP and CCN impacted upon care. As the PT in HAH1 explained, 'If they're lying there passively not saying anything and they should be awake and talking, you'd be going you know: "Have we over medicated them? Is their shunt working?"'. Furthermore, nurses' inability to comprehend communication attempts made by the child, often resulted in frustration for both the child and nurse alike, as described by NI, HN1:

> It can be frustrating for them and for us. I can relate to boy on a ward that I actually looked after.

Communicating was very, very hard and he got very, very frustrated . . . He did a lot of signing and we couldn't understand the signs, and then when he tried to speak to us he just got more frustrated and started raising his voice because we couldn't understand.

Only two of the three hospital allied health focus groups and one of the five hospital nurse focus groups identified the need for children with CP and CCN to communicate for understanding information, answering questions, or making decisions about their care. HAH1 agreed that it was important for older children to take part in meaningful healthcare discussions, particularly if the child was opposed to an intervention: 'If the kids are really saying a downright "no" then that's a big concern for us, and we really try and explore that (with the child)'. HAH3 outlined the importance of conversational topics in AAC that might also reflect the child's other interests or personality and that this might support interaction and conversation: 'Just nice things in the communication book . . . family members or pets, or you know, just general topical information'. Nurses in FGN2 agreed that hospitalisation significantly disrupted a child's routine and that children were more likely to feel isolated, restless and bored whilst confined to bed in an unfamiliar setting. N1, HN2 described a child with CP and CCN who often called the ward nurse 'just for a chat', stating: '[Name] loves interaction. That's what he wants. He calls out pretty much every half an hour – every ten minutes sometimes – not because he's in pain or anything but because he wants someone to talk to'. However, social communication and the need to express feelings and emotion were not mentioned as an important communication need by any of the focus groups.

Barriers to effective communication in hospital

Hospital nurses reported lacking information at admission relating to the children's communication, and that this affected their ability to communicate successfully with them at the bedside. Supporting the views of hospital-based allied health staff, they also did not seek or obtain assistance from hospital speech pathologists on communicating with children with CP and CCN. Discussion across focus groups of allied health professionals and nurses reflected that they tended to rely upon parents being present to assist them in communicating with the child. However, participants also agreed that staff were more likely to explain procedures to the parent and 'neglect [talking to] the child' (HAH1). Such a dynamic was also attributed to parents preferring to speak for the child, as PT1 in HAH2 said: 'You actually make a big effort to get your information from the child, but the parent keeps answering you'.

In contrast to the allied health professionals' assertions that parents usually spoke on behalf of children, nurses reported that parents were frequently not present at the bedside owing to other family responsibilities. Some nurses voiced the opinion that parents of children with special needs viewed their child's hospitalisation as respite from daily care responsibilities. Nurses agreed that parents needing to take a break from daily care routines was 'unsurprising' (N1, HN1) and 'well deserved' (N2, HN4).

> When you've cared for a child with complex needs you realise it's little wonder that parents need a break sometimes. I think having them [children] in hospital just gives the parents some time to attend to other matters - like household chores and other things that would usually be secondary to their role as a carer. (N2, HN1)

Indeed, recovery ward nurses expressed a preference *not* to have parents present unless absolutely necessary, as the children were 'not always conscious or co-operative at this stage' (N1, HN3). N2 (HN3) stated: 'You wouldn't have a mother in theatre while they actually operate. I don't think people understand that recovery is still at that acute phase, so it [parental involvement] is not always appropriate just yet'. However, nurses on medical and surgical wards described the negative impact of parents not being present to support children with CP and CCN in hospital:

> Probably the most stressful time is when we don't have a parent with us, especially when we know that they [children with CP and CCN] understand us but they can't articulate their needs to us. That's distressing for them and for us. (N2, HN2)

Nurses also reported that children with CP and CCN often attempted to communicate, particularly when parents were not present. When this occurred, nurses attended to all possible care needs until the child had settled: 'You just have to go through the whole list until you can figure it out' (N3, HN4). In addition, nurses discussed being uncertain as to whether they had provided enough care, as N1, HN1 reported:

> It almost feels like you can't do your job properly without, you know [communicating]. You just don't feel like you've fulfilled what their needs are. You walk away from the shift with someone who you've not been able to communicate very well with and think 'hopefully I've done everything' . . . It's that doubt that you've truly done everything you could have.

Lack of access to the child's own AAC system. Participants noted that children with CP

and CCN rarely brought their own speech generating devices to the hospital. They recited a litany of common environmental barriers to the use of AAC. They surmised that families did not realise the importance of using the systems across all settings: 'It's something that they learn at school and it has nothing to do with home. And it's too complicated...it's too bulky. It's not how they communicate. I understand what they need anyway – so why should they need this?' (HAH3). In HAH1, PT5 said: 'I think fairly consistently parents forget to bring devices or communication systems to the hospital so even if they do use a system it's somewhere else it's often not brought here which makes it difficult to ask questions of the child'. Participants also identified a wide range of environmental barriers that prevented children's access to their own AAC systems in hospital. The hospital environment did not support functional use or safe storage of the AAC system, as SP1 HAH2 stated: 'Space is an issue in here as well, by the bedside. Plus the electronic things, they need to be tag [safety] tested'. The barrier to technology did not apply equally to all devices, however, with nurses reporting that children often brought costly electronic equipment such as mobile phones, laptops, and tablet touch screen devices to hospital.

Lack of time to communicate. The majority of nurses ($n = 10$) reported that time constraints on the ward prevented them from being able to allocate the extra time needed to interact with children with CP and CCN. N3, HN3 said: 'It's all very task orientated on the ward...It's not that you don't mean to [communicate], it's just that you haven't got the time'. Constrained time often prevented nurses from reading information supplied by parents on ways to interact with their child, especially if this information was 'extensive and lengthy' (N2, HN4). However, participants agreed that concise information regarding ways to communicate with children with CP and CCN was useful and could prevent frustration. HAH3 suggested that even if allied health professionals received education about speech generating devices, using the systems would be too time-consuming: 'They're less likely to engage or get it out for the child because they're in a hurry, and it takes time to work all of it out'. As SP1 in HAH2 stated: 'People will not necessarily have the time or the inclination to go through and take the opportunity to communicate with a child with increased communication needs – because it's time consuming, it's labour intensive, you get things wrong, it's frustrating'. Community-based staff suggested that hospital staff needed (CAH1)

'not to make assumptions', to ask the parent how the child communicates, and 'to give them (the child) more time, to move, to think, to speak'.

Lack of knowledge and experience in the use of AAC. Participants' discussions reflected minimal experience with using high technology AAC to support communication. Speech generating devices were described as being 'really hard to use' especially when children were ill. N3, HN1, who had recently worked with a child who used a SGD to communicate, reported: 'It (SGD) took quite a while to set up and wasn't very straight forward. I really couldn't do it by myself. I would have to get the parent to set it up'. As nurses often still relied upon parents to use the device, four of the five focus groups believed that high technology systems did not necessarily help direct communication with the child in the absence of parents. However, nurses in FGN5 described several experiences of caring for children who used high technology AAC systems to communicate, and were in favour of such systems being used in hospital. However, their discussions reflected lack of knowledge about AAC. An example of this was the view that use of the system might impede the child's oral communication:

> N3, HN1: I just think if they can talk they should talk...I mean we want them to be able to communicate but at the same time, you don't want to hinder their language just because we want them to get their message across.
> N1, HN4: If it was something specific that he wanted, like a [name of computer game] then maybe it would help, but we like to get them to talk instead of just making it easy for them with the [communication] board.
> N3, HN4: Definitely. That might close them up...-make them go back in their shell type of thing.

However, perceptions that AAC might hinder language development or result in the child communicating less did not prevent its use on the ward. Nurses also described striving to be 'child-centred' and follow the child's own preferences. HN2 and HN5 viewed that the majority of nurses generally used 'whatever works best for the individual' (N1, HN5). N2, HN2 reported: 'We usually try to keep what's normal for the child [group agreement]. I mean, it's not about suiting us, it's really about what he or she wants. We communicate how they want to communicate'.

Strategies to help children prepare for communication in hospital

Talking directly to the children. Participants across all groups suggested a range of strategies that might

help hospital staff determine a child's views. Speech pathologists in FG2 and FG3 reported talking directly to children with CP and CCN, as opposed to their parents, as a strategy to improve communication. In FGHAH2, SP1 explained that they aim to talk to both the child and the parent: 'Regardless of their communication capacity...talk to the kids'. The SP in HAH3 said: 'They (parents) will answer the questions and the way of getting around that is to keep eye contact with the child and ask them (the child) the questions directly'. However, HAH2 and HAH3 also agreed that they took cues from the parents: 'We'll look at the level of language the parents are using and whether they're signing or anything, and you just sort of go with it, and get the parents to help as much as possible'. Many of the strategies suggested involved the use of non-verbal unaided communication. Recovery ward nurses reported becoming particularly skilled at interpreting non-verbal cues (such as body posturing, facial expression and gestures), as they frequently encountered patients who were unable to speak due to their medical status, and needed to quickly determine their recovery by responses gained. Allied health professionals also explained the importance of being attuned to the child's non-verbal communication: 'It's about the education to the medical staff to take more time to invest in finding out, if they don't have their AAC system, what is their yes/no response and reading their non-verbal intentional communication, and then responding to those strategies – to respond to those non-symbolic forms of communication' (SP, CAH2). In concern with these reports, nurses' discussions reflected a strong awareness of children's non-verbal and unaided communication, albeit an ad hoc approach to the introduction or use of visual supports to communication on the ward (e.g. using pain scales, printing pictures to help basic needs communication).

Using low-technology communication aids. There were also a few suggestions made by participants on the use of picture boards as visual supports to (i) support the child's understanding (e.g. a 'book about me', including 'photos of positioning, medications, diagnoses, things they're being investigated for'), and the nurse's ability to understand the child: (e.g. 'what some of their gestures and vocalisations might mean, how to tell if they're in pain or upset or angry, just the basic feelings'); (ii) let the nurses know how to communicate with them (e.g. 'some general ways of ''it take me time to tell you what I want to say...this is how I'll attempt to tell you'''') and (iii) provide topic supports for initiating conversation (e.g. 'maybe some of the things they're interested in,

so if the nurses have some time, and they want to just come and sit with them').

Using high technology AAC systems. As noted previously, community-based participants felt powerless in addressing numerous barriers to the use of AAC in hospital. Hospital staff confirmed that children, for the most part, do not take their own communication aids to hospital. Participants outlined several reasons for this that echo reasons previously cited for adults with CP and CCN (e.g. high personal and financial value of the device, lack of space, difficulty accessing the device in bed). However, they also noted that children in a developmental phase were still learning to use their communication systems and that, when ill, would rely upon their non-verbal communication skills. Also, even out of hospital, families often needed encouragement and multiple supports in place to use AAC systems outside the therapy setting. However, nurses in FG5 said they had cared for a number of children with CP and CCN using high technology AAC systems, recalling both speech generating devices and hand held touch screen devices as being used effectively:

> They [children with CP and CCN] can just tell us what they need...For example, if they need the toilet they just press a button and let us know. It's also good for us as nurses to learn how to think outside of the box. I find it really fascinating. (N2, FGN5)

Nurses had also cared for children using switch access to activate messages: N3FG5: 'With [name], he brought in this pointer that he wore on his head and he just moved his head and sort of used it as a mouse on his device. It was great'. As previously outlined, nurses set up systems on meal trays and used pillows to support the child in a sitting position in order to enable better access to the device. Thus, adaptations to the environment made by staff with little or no training in AAC might go some way to improving communication in hospital by children with CP and CCN.

Discussion

The results of this research confirm earlier reports of children with CP and CCN and their parents about their difficulties communicating in the hospital setting. Indeed, many of the barriers and facilitators to effective communication and communication needs (i.e. pain, basic needs, information, social closeness) are also reported by adults with CP and CCN, their family and paid carers, and nursing staff [31–33]. Despite calls for an increased involvement of speech pathologists in addressing communication access on hospital wards [34, 35] the results of this

study suggest that neither community- nor hospital-based allied health professionals take an active role in enabling the child's access to communication, or removing barriers to communication in the hospital environment. Nonetheless, participants' awareness of children's basic communication needs, barriers, and strategies for communication indicate that health professionals may indeed be ideally suited to a potential future role in increasing the communicative accessibility of hospital settings. The active involvement of community-based allied health staff in liaising with hospital-based counterparts and parents to support children's nutritional, mobility and equipment needs – and in relation to dysphagia management and treatment decisions – is an encouraging indicator of inter-agency collaboration across service boundaries [36]. Hospital-based allied health staff also emphasised the importance of a holistic approach to children's social, and not only medical, needs in hospital. It is possible that existing collaborative multidisciplinary links within and across service agencies could be put to good effect in implementing communication strategies to help children to communicate in hospital.

The results of this research reflect a heavy reliance upon parents for understanding and communicating with children with CP and CCN [7–10]. The combination of a clear focus upon basic needs communication and reliance upon parents to interpret communication rests upon the assumptions that: (i) the parent will always be able to be at the bedside, which parents, children and nurses in this study have reported is not always the case, (ii) the parent will always know or understand the child's communicative need without access to their usual AAC systems and (iii) that the child has little need or desire to communicate anything other than pain and basic needs directly with hospital staff. Indeed, older children have reported wanting to be able to speak for themselves in hospital and ask questions about their care [7, 8]. Continued reliance upon parents to meet all of the child's communication needs and speak on their behalf may support children with CP and CCN in the 'passive' role but prevent their being an active participant in discussions about their health [37] and gaining access to their communication rights [38, 39].

The results across focus groups in the hospital also yielded diversity of opinion. Recovery ward nurses described preferring not to involve parents in care and saw the recovery ward as being more aligned with the hospital theatre than with practices on general wards. However, children with CP and CCN have reported distress at not being able to communicate in recovery wards when parents were not present [8]. One group of nurses on a medical ward reported taking steps to develop communication boards using pictures obtained from the internet. These nurses also expressed comfort and familiarity with setting up high technology AAC systems for use by the children, even if in a rudimentary fashion. This finding is promising for future interventions involving AAC in hospital, particularly as it emerged in the context of discussions about children's use of other electronic equipment on the ward (e.g. laptops, mobile devices). Generic computer devices (e.g. smart phones, ipod touch, ipads and other touch screen devices) can now serve as communication aids with the addition of appropriate software applications to assist many children in communicating [40]. Computer technologies already used on the ward might serve to prime staff towards the use of assistive technologies and ultimately benefit children who want to take and use their own AAC systems in hospital [41]. If hospital wards can be made accessible for computer equipment such as laptops and mobile devices, similar procedures and practices might be used to enable children with CP and CCN access to their assistive technology for communication. Increasing the communicative accessibility of the hospital ward might not only enable children with CP and CCN to convey their basic needs, exchange information and participate in healthcare decisions, but also afford them more opportunities for enjoyable chat with hospital staff [8].

Limitations and directions for future research

The focus groups in this study were conducted at one hospital and four sites of one community disability organisation. As such, the results might not apply to all hospital allied health and nursing staff caring for children with CP and CCN. Despite the inclusion of participants across a variety of disciplines and ward settings, this study was limited by (a) its relatively low participation by social workers and psychologists, who might have provided further insights, (b) five of the twelve focus groups being at or below the minimum recommended size [28] and (c) not including participants from intensive care and emergency wards.

Further research is needed to determine the effectiveness of the communication strategies proposed in this study (e.g. providing generic communication boards or personalised information books) to test their ecological validity in relation to improving communication in hospital and hospital care for children with CP and CCN. Investigating the hospital environment as being accessible to any form of technology, including both generic mobile technologies and speech generating devices, would seem to be an important first step in increasing

children's access to their communication rights in hospital. An examination of hospital services and policies towards innovations in the use of technology by staff, patients and visitors might also reveal important factors for audit as hospitals seek to meet accreditation standards for creating communicatively accessible environments [21].

Conclusions

Community-based professionals fulfil a range of roles in supporting children with CP and CCN and their families through periods of hospitalisation. Collaboration across services in meeting children's needs in hospital occurs but might be improved by better inter-agency communication prior to hospital admission and around discharge. Allied health professionals and nurses' suggestions for preparing children with CP and CCN and their families for better communication in hospital (i.e. asking families for information about how children communicate), and modifying the environment for better communication with these children (i.e. allowing more time to communicate, providing generic communication boards, setting up communication technologies for the children to use in bed) have merit and if adopted might help to raise awareness of the child's need to communicate and take an active role in interactions with healthcare providers.

The results of this study provide new insight into the views of hospital-based allied health professionals on their roles in working with and communicating with children with CP and CCN. Communication in hospital for children with CP and CCN might be improved by expanding the roles of hospital-based speech pathologists and occupational therapists in particular to include (a) communicating with colleagues in community-based services to ask for support in relation to the child's communication, (b) conducting a short functional assessment of children with CP and CCN's communicative means to gain attention, convey basic physical needs, indicate choices about enjoyable activities and engage in 'chat' with hospital staff, (c) assisting nurses and parents in the removal of environmental barriers to children's use of their own AAC systems on the ward and (d) supporting nurses and parents to use of simple, functional AAC interventions that include generic or off-the-shelf resources (e.g. communication boards available on internet websites that can be printed and used on the ward). Findings of this study provide limited but promising evidence that despite difficulties commonly encountered, barriers to the use of AAC by children with CP and CCN in hospital can be overcome.

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