

Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study

Siobhan Sharkey BA (Hons) PhD,* Claire Lloyd BSc (Hons) MSc,† Richard Tomlinson BM BS BMedSci MSc MRCP MRCPCH,‡ Eleanor Thomas MB BS BSc (Hons) MRCP,§ Alice Martin BM BS BMedSci MRCPCH,¶ Stuart Logan MB ChB MSc (Epidemiology) MSc (Politics) MRCP FRCPC** and Christopher Morris MSc DPhil††

*PenCLAHRC Lecturer in Qualitative Methods, Primary Care Research Group, University of Plymouth Medical School, University of Plymouth, Plymouth, †Associate Research Fellow in Child Health, **Cerebra Professor of Paediatric Epidemiology, ‡†Senior Research Fellow in Child Health, Peninsula Cerebra Research Unit and PenCLAHRC, University of Exeter Medical School, University of Exeter, Exeter and ‡Consultant Paediatrician, §Consultant Paediatrician, ¶Specialist trainee in Paediatrics Royal Devon & Exeter NHS Foundation Trust, Exeter, UK

Abstract

Correspondence

Chris Morris MSc, DPhil
Senior Research Fellow in Child Health
Child Health Group
University of Exeter Medical School
Veysey Building
Salmon Pool Lane
EX2 4SG
UK
E-mail: Christopher.Morris@exeter.ac.uk

Accepted for publication

31 July 2014

Keywords: communication, disabled children, involvement, parents, professionals, qualitative

Background Communication is a fundamental part of health care, but can be more difficult with disabled children. Disabled children are more frequently admitted to hospital than other children.

Aims To explore experiences of ward staff and families to identify barriers and facilitators to effective communication with disabled children whilst inpatients.

Design This was an exploratory qualitative study.

Methods We consulted 25 staff working on paediatric wards and 15 parents of disabled children recently admitted to those wards. We had difficulty in recruiting children and evaluating their experiences. Data were collected through interviews and focus groups. A thematic analysis of the data supported by the Framework Approach was used to explore experiences and views about communication. Emerging themes were subsequently synthesised to identify barriers and facilitators to good communication.

Results Barriers to communication included time, professionals not prioritising communication in their role and poor information sharing between parents and professionals. Facilitators included professionals building rapport with a child, good relationships between professionals and parents, professionals having a family-centred approach, and the use of communication aids.

Conclusions Communication with disabled children on the ward was perceived as less than optimal. Parents are instrumental in the communication between their children and professionals. Although aware of the importance of communication with disabled children,

staff perceived time pressures and lack of priority given to communicating directly with the child as major barriers.

Introduction

The UN Convention on the Rights of the Child and the Rights of Persons with Disabilities state that disabled children* should be consulted about their care and all decisions that affect them.^{1,2} The United Kingdom is a signatory to both conventions, and UK child health policy states that children have the right to be treated with respect and enabled to make decisions about their health care.³ However, negative experiences of health services for disabled children and their families are reported, particularly regarding how involved they were in decisions.⁴

Disabled children are more often admitted to hospital than typically developing children.^{5,6} A recent review focusing on the experience of disabled children as inpatients suggested that communication mediates many aspects of their experience but is often inadequate.⁷ Communication in hospital can be particularly challenging for children who use augmentative and alternative communication.⁸ It has been reported that parents often feel unable to leave such children because of concerns about communication.^{9–11} If communication is poor, then children and parents may not understand choices and will have inadequate opportunity to engage in making decisions about their care.

This study was part of a programme of research aiming to develop a parent-led intervention to improve communication with disabled children in hospital. A fuller understanding was needed about the concerns, skills and resources influencing communication with disabled children and their families while on hospital wards. This work would help to identify

modifiable environmental and interpersonal factors and practices, to inform ways that communication might be improved.

The aim of this study was to explore experiences of ward staff and families regarding communication with children with 'communication difficulties' while inpatients and to use the information to identify barriers and facilitators to effective communication.

Methods

Ethical approval and considerations

Approval was provided by the South West REC (10/H0206/4) and from the Research and Development committees at the two hospital sites. Informed consent was documented before interviews/focus groups took place. A 'stopping interviews' guide was used, which included stopping if a participant became distressed and only continuing if the participant was happy to proceed.

Setting and participants

Participants were sampled through paediatric wards in two English district general hospitals and included parents and ward staff. Parents were eligible if their disabled child was aged 5–16 years old, had been admitted to the hospital ward for a stay of more than 24 h for either acute or elective reasons and was perceived (by staff and parents) to have a 'communication difficulty'. Clinical and non-clinical staff were eligible if they worked on the paediatric wards taking part in the study.

Sample and recruitment

Convenience sampling was used to identify participants initially; part-way through the study, it was evident that we had not recruited nurses, so we actively sought them.^{12,13} Recruitment posters were displayed on wards

*We use the term 'disabled children' on purpose. 'Person-first language' is appropriate to describe people who 'have' impairments and health conditions. However, consistent with the WHO ICF, disability is created as a result of an interaction between a person and their environment; therefore, we perceive disability cannot be considered intrinsic to the person.

Table 1 Sample characteristics

Sites	Parent interviews ¹	Professional focus groups and interviews
Site A	<i>N</i> = 9 Mother 8 Both parents 1	<i>N</i> = 17 Focus Group 13 Consultants (6); Middle grade doctors (5) Medical students (2); Interviews 4 Nurses
Site B	<i>N</i> = 6 Mother 4 Father 1 Both parents 1	<i>N</i> = 8 Focus Group 3 Playleader (1); Dietician (1); Teacher (1) Interviews 5 Nurses (4), HCA3 (1)
Total	15	25

¹The children about whom these interviews were focused were both male and female, aged between 5–16 and admitted to hospital for both acute and elective reasons.

and in staff and parent rooms. Ward staff provided information, verbally and using the study leaflets, to eligible families while the child was an inpatient. Posters and information sheets were written in English language, as the region where the study took place is not ethnically diverse. Staff were provided with information about the study at team meetings. Both staff and parents contacted the research team directly if they wanted to volunteer.

Data collection

Views and experiences about communication in hospital were collected via semi-structured

face-to-face interviews with parents and nurses and in focus groups with doctors and allied health professionals (details in Table 1). The use of focus groups or interviews was pragmatically determined; interviews were easiest for parents, focus groups were preferred for professionals, but interviews were used with nurses who we found it difficult to gather in the same place at the same time. Topic guides aided consistency across interviews and focus groups; they contained open questions and prompts relevant to areas of interest (Table 2). Parents and staff gave consent to audio-record focus groups and interviews, which were subsequently transcribed verbatim and anonymized.

Patient and Public Involvement (PPI)

Parents of disabled children from the Peninsula Cerebra Research Unit (PenCRU) Family Faculty participated in a Steering Group with three paediatricians and two paediatric nurses. The group was consulted about the specific research questions, the content and phrasing of the information sheets and interview topic guides, and themes emerging from analyses. Parents participated in meetings and/or by email; unsalaried members of the group were offered financial acknowledgement. They are involved in disseminating the findings through presentations and producing a plain language summary and further stages of the research programme.

Table 2 Issues explored by interviews and focus groups

Professional	Parent
Awareness of and adherence to National Service Framework (NSF) standards about communicating with children, that is giving information and involving them in decision making	Experience of communication in hospital
Finding out about and documenting a child's communication difficulty	Examples of good and poor practice in relation to communication with both parents and children in hospital
Examples of good practice and of things that could be done better/ barriers to good communication	Information needs of child and parent – were they met?
Training and advice about communication with disabled children	Child and parent involvement in decisions
	Recommendations and changes that could be made to improve communication with disabled children in hospital

Analysis

Our analytical approach is guided by 'subtle realism' in which 'real' actions, events and views are studied, while acknowledging inherent participant and researcher perspectives.¹⁴ This allowed us to summarize findings and draw out tangible barriers and facilitators to communication.

We were pragmatic and reflexive in our approach to the analysis. The parent and professional data were initially managed independently and analysed using thematic analysis.¹⁵ The findings were then combined. Data were managed using NVivo software. The Framework Approach was used to aid systematic analysis and increase rigour.¹⁶ Framework Approach incorporates five stages of analysis: familiarization, identifying a thematic framework, indexing, charting and mapping, and interpretation. It was used to look at the data deductively from pre-set aims and objectives.¹⁷ Two researchers (SS and CL) developed the initial coding frames based on research questions and *a priori* issues of interest. SS and CL then independently read and coded the same two transcripts and met to discuss and revise the coding frames for each set of data. Both researchers independently read and indexed remaining transcripts, noting any additional codes. Key themes and subthemes were identified, charted and summarized. Links between these themes were mapped and discussed. Refined framework and summary matrices were developed to aid the focus on barriers and facilitators for both parents and professional data. Researchers met to challenge analytical interpretations and discuss the relevance of the findings, allowing for further synthesis of the data. The 'detection work' confirmed important overarching 'meta-themes'^{16,18} and helped to form conclusions.

Rigour and trustworthiness

A number of approaches were used to enhance rigour during textual analysis including purposive sampling to increase representation and transferability, checks for thematic saturation and consistency, multiple researchers, use of

framework and audit trail of analysis decision, which reduced bias and tracked variability between researchers, and peer debriefing which allowed for discussion and identification of themes and concepts to increase representation.¹⁹ Memos were kept by researchers and used to undertake deviant case analysis.²⁰ Trustworthiness was enhanced through feedback of initial themes to the steering group, who commented on the consistency of the themes and the significance of the findings.

Results

Findings are presented from parents and professionals. Where extracts of representative quotes are used, identification codes are the following: PI = parent interview, NI = nurse interview, FG AHP = focus group of allied health professionals and FG Dr = focus group of doctors. Square brackets containing three dots [...] indicate short sections of omitted speech. All names are aliases.

Initial analysis: key themes and subthemes

Table 3 contains key themes and subthemes from the initial analysis. Data were coded to key themes of *knowing the child*, *prioritizing communication*, *parent-professional relationships* and *not enough time* from parent and professional data. The key themes *professional world* (professionals only) and *child-eye view* (parents only) reflect exclusive experiences and perspectives.

Focus on barriers and facilitators

Table 4 includes extracts from the summary matrix 'knowing the child' to illustrate our focus on barriers and facilitators; the same process was followed for each of the key themes. Barriers and facilitators were identified as overarching themes (Table 5).

Time

Time seemed to weigh heavily on professionals, affecting time to 'do' communication, how they

Table 3 Initial analysis: key themes and subthemes for parents and/or children

Key themes	Knowing (shared)	Prioritising communication (Shared)	Parent–professional relationship (shared)	Not enough time (shared)	Professional world (Prof. Only)	Child's eye view (parent only)
Subthemes	We know it's not easy See the child/know the child Making contact Experienced practitioner Rapport Seeking knowledge <i>Who knows?</i> <i>Building relationships</i> <i>Experience beyond ward</i>	Dignity and respect Positioning Utilising the child's capabilities Involvement in decision making Verbal skills – right level, detail and pace Non-verbal skills – using the body Quiet place/space The right tools <i>Personal skills</i> <i>Using communication tools</i> <i>Cross-professional</i> <i>Over reliance on parent</i> <i>Duplication of documentation</i> <i>Nurses as mediators</i>	Checking under-standing (with parent and child) Parents expertise <i>Empathy for parents</i> <i>Parents as the experts</i> <i>Can't live with, can't live without</i> <i>Parental concerns about leaving child</i> <i>Professional view of parental beliefs and perspectives</i> <i>Mediators /interpreters</i>	No time to communicate <i>Lack of time</i> <i>Time for acute care needs</i> <i>Lack of staff</i>	<i>Professional focus</i> <i>Impossible situation</i> <i>Whatever it takes</i> <i>Not doing enough /regret</i>	Not just a medical interaction Lasting memories Emotions of the child I want my mum Distraction Choices

Italic script indicates professional themes; normal script indicates parent categories.

Table 4 Barriers and facilitators to communication with children: extracted matrix synthesising themes from parents and professionals in initial analyses

key theme	Barriers parents	Barriers professionals	Facilitators parents	Facilitators professionals
Knowing the child	Not enough time Seeing the diagnosis not the child Shifts = staff don't know history of admission	Acute environment means that no feedback is received Time ...linked to individuality of child Taking the position that it is someone else's job to get to know the child Organisational context, e.g. shifts	Need for a 'communication passport' Professional taking an interest in child Chatting and rapport building Experienced staff = relaxed attitude Being allocated staff who know child from previous admissions/other environments Ask the parents	Parents as interpreters or sources of info Initial assessments – info from parents Knowing a child over a period of time, that is repeat admissions or from a different environment Specialist members of staff, that is play specialists Nurses/HCA's

Table 5 Overarching themes influencing communication with disabled children during a hospital stay integrating professionals' and parents' views

Barriers	Facilitators
Time	Learning about the child
Professionals not prioritising communication in their role	Facilitating trusting relations between parents and professionals
Poor information sharing	Building rapport with the child Using communication aids Having a family centred approach

managed their time and also how they felt about their work. Nurses in particular felt that they just did not have enough time to communicate or indeed to undertake care properly. This was also recognized as a problem by parents who linked 'not making time' with poor communication experiences of their children.

for whatever reason, time has not been taken to explain to A, win her trust and get her to understand why it needs to happen and then get her to be compliant (PI E8)

Parents also identified when staff gave up or ran out of time:

Health care professionals are often busy, well always busy and they run out of time, and they will have a go, and then sorry we can't hear, and then straight to the mum and dad. (PI B6)

Parents were aware of the negative impacts of staff being busy; the following extract suggests that a 'non-demanding' disabled child might not be able to make its needs known in a busy setting:

I know that they are really difficult as they are busy, but if B was, and I hate using this word, but if B was a 'normal 14 year old' child then he would be demanding the Xbox or his food and wanting this and that and they would have to spend their time getting it for him [...] He is not getting their time [...] (PI B2)

The busy environment caused other issues as well;

If it is a busy time, if you have a special needs child that is mobile, you know it can be quite

hard, especially if they don't understand that they have to sit and wait. (PI E5)

Several professionals commented on the additional time that caring for a child with a disability takes; nurses particularly highlighted this:

you have to give them that much more time. You know everything is slower (NI9)

I feel that the special needs child is probably the work of two patients with no special needs. (NI2)

Professionals linked lack of time with feeling unable to match parental expectations and working under increased pressure:

you get quite high expectations from the parents that we can follow what they do and we can't. We nowhere near can. We do our best and always try and achieve the best but it's we're always like we're always worried that we're not going to do it well enough and always striving for time and it's, do you know what I mean it's, it does put quite a lot of pressure on you when you've got a special needs child in. (NI9)

While doctors, AHPs and nurses often attributed unsatisfactory communication to lack of time or to having to prioritize medical care, they differed in perceptions about the impact it has on practice or how they manage time. Whereas most nurses expressed regret and a desire to have more time available to talk to children,

I sit in the car on the drive home and I think I really wish I'd had more time to do that and more time to do this or whatever (NI5)

In contrast, doctors appeared to take a pragmatic approach about trying to prioritize their work tasks in the time available to them.

we have to pick up ways of going about things, of getting a certain number of questions across in a certain amount of time (FG Dr)

Professionals not prioritizing communication in their role

Professionals demonstrated awareness of the importance of communication, but failed to convert this into their communication with dis-

abled children. Some doctors attributed the role of communicator to others. As highlighted in the previous barrier, the lack of time meant they felt expected to prioritize making diagnostic and treatment decisions over communication.

Well they may not have been satisfied with communication but just from my goal-orientated, how am I going to make this patient better, get medicine into them. Communication with them came less down on the list (FG Dr)

...using a nurse or health care assistant often and I can think of a few HCAs that are fantastic and they are fantastic, as they [have] longer than anyone else know a lot of these patients very well (FG Dr)

Nurses acknowledged specialist members of staff or parents better placed to communicate with a disabled child,

our play leader who often knows them better [...]. she often sort of, well she knows them so they like such and such, or they can understand this (NI8)

We would be completely scuppered if parents weren't with them. [...] On a paediatric ward if you don't have the parents or carer or big brother or someone that knows that child with them you just haven't got the resources to do quality care. (NI1)

Parents also commented on professionals not prioritizing communication. They were aware of reliance on them to enable interaction between their children and the professional, for some this made them reluctant to leave the ward.

it felt like we were, we had our camp there and they would come in to do what they had to do with the medication but otherwise left us to it, and that made me feel uncomfortable as because I had a younger son I could not be there all the time. (PI E2)

Interestingly, one nurse felt that she had much more opportunity to communicate with a child when the parent had to go home:

I'd never learnt to communicate with that child the way I did those few days when we had her here on her own and I am really, it was lovely

because I really built up a rapport with her.
(NI8)

Poor information sharing

Parents and nurses identified the importance of sharing techniques for communicating with a child. Parents felt that they were not always asked for advice and that their views are not always sought,

Just sit with us first, just sit and talk to us and explain [...] How does she show pain? Is this normal? How does she communicate? All those, and just sit down with us (PI E3)

Whereas nurses expressed frustration that parents withheld information about their child, though they acknowledged that parental stress and anxiety about hospital admittance can prevent information sharing.

the main problem I would say that we find is the parents' reluctance to actually give us the full story (NI6)

when they come in they are just focused on you know they are anxious and they're stressed and they are focused on the medical problem or whatever, but in order for us to assess them it's we need a bigger overall picture of what their normal, what they are normally like (N6)

Shift work appeared to compound the issues around information sharing. Different staff care for a child each day which made it hard to build relationships and meant that staff did not always know the child's history.

It is really hard as they did not know what had gone on and so it was hard for them to communicate with me (PI E7)

Reflecting on the impact of shifts, nurses highlighted the importance of handovers to inform colleagues.

[...] from one nurse to another nurse and it will be documented in the care plan and in the notes as well (NI7)

Doctors barely mention communication between themselves and parents.

Learning about the child

Nurses and parents viewed getting to know the child as aiding communication, including already remembering them from previous episodes of care.

I have seen some children who I remember being born, no diagnosis, no this and now we are at a point where they are 15 years old and we have been through a lot and there is history there.
(FG AHP)

Parents stressed the importance of recognizing and utilizing their knowledge about their child, and nurses acknowledged that they learned a lot from asking parents and taking their advice.

If you get on with the parents and respect what they say, because they've been with that child 24/7 and it's no good a nurse going in and saying 'well actually I don't want to do it that way', it doesn't work (NI2)

Facilitating trusting relations between parents and professionals

Parents rather than professionals identified the need for a good rapport between them, which they suggested helps with trust and a child's confidence, in turn facilitating good communication.

[...] the child will pick up very quickly the communication that the staff have with the parents, and if that is a good rapport, with the parents, it gives the child more confidence in the whole set up. (PI E1)

Nurses also recognized trust between staff and parents as important:

you know at the end of the day they're, they [parents] look after them 24/7 it's hard work...they've got to trust us so you've got to gain their trust first really. (NI2)

Doctors did not specifically talk about building relationships with families. Nurses mentioned one of their roles as facilitating the relationship between the doctor and parents, for instance interpreting medical jargon.

it's really important [...] that things are going the way the parents want them to go and that they don't get bogged down with the fact that you know this professional is saying this and this but that they are able to actually say 'no that's not what I want' (NI5)

going behind the doctors really and explaining again when they're using medical jargon for them well for the child and for the parents and kind of saying you know 'what they are meaning is [...]' just, just normal kind of things like you know 'have you had your bowels open?' you know a five year old hasn't got a clue even if they haven't got communication problems you know but you know sometimes people feel embarrassed to say you know 'have you had a poo?' (NI9)

While not specifically about disabled children, these extracts may point to underlying issues in doctors' communication with families.

Building rapport with the child

The relationship between a child and the professionals was also seen to aid communication. Focusing on the child, using quiet moments and being experienced in working with children are indicated as influential. Parents articulated that awareness and empathy for the 'child's eye view' of being in hospital as important. Parents and AHPs highlighted building a rapport with the child as part of good communication and how focusing on the individual is valuable in initiating communication.

he came and sat down next to C on the bed [...] some informal chatting, where do you go to school? [...] And so you get a rapport going with the child (PI E1)

so I generally always try to know their name, you never quite know how old they are, and talk about something that is on their person, whether it be you know a ribbon, or a Barbie, or their school badge, something you can see, and you can usually engage in conversation quite quickly that way. It also stops some of the parents answering questions. Because the child actually thinks you are interested in me know, and so I will talk to you. (FG AHP)

Parents shared experiences of how 'quiet time talk' can increase a child's engagement.

Because those quiet moments, just a general chit chat of when she might just open up a little bit. (PI B6)

To use those quiet times to actually gently probe and ask her [...] got information that when asked directly on a hospital round that they would not have got. (PI E8)

Parents also suggested that experienced staff have a more relaxed attitude towards communicating and are better able to respond.

I think they just work with children all the time and they know exactly. They know what makes them tick and she was just fantastic with C and C just completely responded to her, and was relaxed. (PI E1)

Using communication aids

Professionals were asked about their approach when caring for a disabled child; some identified communication aids, but indicated that they did not use them much. Nurses referred to other tools that are used on wards to facilitate communication, but there was lack of clarity about what was available and keeping them up to date.

I'm sure in our office we have got resources we can go to [...] I think we have a folder of various signs, Makaton and things like that I'm not entirely certain of everything we've got in there (NI3)

Some parents referred to communication passports, such as 'All About Me' booklets, which hold information about how a child communicates, and some highlighted the use of photos of the hospital environment and 'yes/no' cards as potentially useful.

they could have done the yes/no cards. Anybody can do yes/no cards (PI E2)

Having a family centred approach

Nurses identified a family centred approach as important to good communication, mitigating

some of the time and resource barriers discussed earlier.

I think we are all very family orientated and we consider the whole family and the child I think that they are at the forefront of everything we do [...] we will do everything to keep their best interests at the highest place (NI4)

Nurses described doing 'whatever it takes' to make a child feel comfortable in hospital as intrinsic to their role.

I think children are children aren't they and you can communicate in any way through drawing, through playing with toys [...] you know we've got that challenge every day with the babies, with special needs adolescents (NI4)

One divergent view included professionals talking about pre-existing negative parental outlooks on hospital care, in that parents of disabled children may come into hospital with an aggressive manner and expecting mistakes:

they are ready for a fight and they are ready for a battle so they are there waiting which makes it harder as well (NI7)

Discussion

We were successful in capturing the views and experiences of parents and professionals; however, the conclusions would be strengthened by establishing the views of children. We experienced difficulty in recruiting children and evaluating their experiences, despite considerable efforts. Our difficulties mirror some of the same contextual difficulties faced by health professionals in their everyday work.

From our parent and professional data making time, rapport with a child, previous experience of working with children and a family centred outlook are identified as positive influences on communication, while lack of time and low priority given to communication were negative influences. The professional participants in our study clearly expressed awareness of poor communication behaviours and personal frustration with failing to meet children's communication needs.

Time was often cited as a barrier to communication. However, literature suggests that just giving professionals more time would not, on its own, improve communication and that other elements are needed in order for communication to be effective.²¹ Gravel *et al.*²² suggest that it may not take more time to engage in shared decision making and that using appropriate body language and 'attending behaviours' will help to achieve this.²³ Parent participants in our study suggested that using 'quiet moments' and increased use of communication aids might improve communication.

As in previous studies, the priority given to communication varied between different professional groups. Nurses often recognized communication as central to their role, although they acknowledged the need to rely on parents.^{24,25} Doctors in our study suggested that time pressures meant they had to prioritize their attention on diagnosis rather than communication. It is possible that this perception may itself be a barrier to effective communication. Hemsley,²¹ for instance, has argued that professionals who do not value communication may avoid it and might not see the benefit of investing time in becoming familiar with the patient. These differences in priorities between professional groups may be shared by parents who have been reported to view communication as a nurse's domain while evaluating doctors more by their clinical competence than by their ability to communicate.²⁶

As has been reported in other studies,^{9,27-29} parents report feeling the weight of responsibility for communication rested on them, and they were reluctant to go home because they felt that no one would be able to communicate effectively with their child in their absence.

This study highlights on-going issues with trust and information sharing between parents and professionals. Parents feel their knowledge about their child is not always considered or valued, which has been highlighted in previous studies,²⁹ while professionals suggest parents do not always share necessary information. This may be explained by a parent's desire to remain in control.⁹ Some nurses in our study

suggested that parents may simply be too anxious at the point of admission or may not think that certain information is relevant to share.

All groups in this study recognized that effective communication is linked to the relationship between parents and professionals. Parents need to trust nurses, both to care for their child and to recognize parental needs.⁹ Nurses in our study saw mediating between parents and doctors as part of their role, and this has been reported elsewhere.²⁵ It has been suggested that nurses may take on the role invisibly and that parents may be unaware of this mediation.²⁶ Parents in our study did not make reference to nurses mediating their relationship with doctors, but do report relying more on nurses than doctors for communication.

Parents felt that it was important for staff to get to know their child, adding weight to the claim that knowing the child is 'a pre-condition of individualized care'.²⁶ Relationships between disabled children and professionals were thought to be improved by professionals taking the time to build rapport with a child, although parents acknowledged that this could be difficult. Similarly, where the professional had known their child over a period of time, communication was easier. Other studies have reported similar findings.^{9,30} Although nurses are often assumed to be the communicators, they have been reported to find this 'social aspect' of communication difficult. Some express frustration with the complexity of social chat and favour communication about basic needs, which is easier to achieve.³¹ In our study, some nurses reported being unconfident about their capabilities, which may lead to them being less effective communicators, particularly in the light of the time pressures they identify.

Participants in this study suggested that a positive approach by all those involved could facilitate effective communication, and building constructive relationships seems to be influenced by previous experiences. Nurses described some parents as being defensive and 'ready for a fight', which made communication more diffi-

cult. Coyne has suggested that questioning by parents can cause disruption and make professionals feel that their role is subject to scrutiny and surveillance, hindering successful relationships.³² It is important that professionals recognize that previous negative experiences may have led parents to seem negative, defensive or combative and that this does not lead professionals to be avoidant of communication, which may reinforce negative parental expectations and impact on effective delivery of care to children.

There is a real tension between the perceived need for professionals to prioritize 'clinical care' and their role in providing respectful and holistic care by establishing relationships with children and parents that enable effective communication. In order to do this effectively, professionals need sufficient time, but also need knowledge, skills and appropriate attitudes.³³ Staff in acute care settings inevitably juggle competing demands and are often under considerable pressure. This may be compounded by a lack of confidence or failure to recognize the centrality of communication to health care, leading to a failure to make the most effective use of the opportunities that do exist.

We did seek to consult children directly. Our initial strategy was to ask parents who were interviewed whether it would be appropriate to consult their child; however, this proved unsuccessful. Following a protocol amendment and ethics approval, we asked nurses in special schools to identify children who had recently spent time in hospital. Subsequently, we interviewed four children with support from a familiar communicator. The nature of these data was substantively different, and it was not feasible to integrate these data into our synthesis of professional and parent views. Clearly, children's own views should not be overlooked; nevertheless, it is the adults responsible for their care on the ward that control how communication happens.

The findings of our study have implications for the development of training for health professionals, as recently mandated in the UK

National Health Service.³³ Currently, we are using the key messages from our research, and other resources,³⁴ to develop and evaluate a training package for hospital staff. This work is being carried out in partnership with the parents who were involved with this study as our experience, like Goldbart and Caton,³⁴ is that parents are keen to be involved in such initiatives. Core elements of the training include encouraging empathy and a caring approach alongside key practical tips, with the incentive that improving communication can save time in the long run, are. In tandem, there is a need to review routine policies and practices on the ward, to create an environment that values communication and encourages child-centred care by all staff. Training should supplement awareness, implementation and audit of adherence to relevant hospital policies for care of patients with learning disabilities or other additional needs.^{4,35} Such approaches will encourage those responsible for children's health care to fulfil their obligation to uphold the rights of children and those with disabilities.^{1,2}

Acknowledgements

The authors would like to thank Mrs Vanessa Edwards for her involvement in this study, specifically carrying out the parent interviews and professional focus groups. The Peninsula Cerebra Research Unit (PenCRU) receives financial support from the charity Cerebra and The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC). The views expressed in this publication are those of the authors and do not necessarily represent the views of Cerebra, the NHS, the NIHR or the Department of Health.

References

- 1 United Nations. Convention on the Rights of the Child, 1989.
- 2 United Nations. Convention on the Rights of Persons with Disabilities, 2006.
- 3 Department of Health. Getting the right start: National Service Framework for children. Standard for hospital services. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199953/Getting_the_right_start_National_Service_Framework_for_Children_Standard_for_Hospital_Services.pdf, accessed 13 August 2014.
- 4 Care Quality Commission. Health care for disabled children and young people. Available at: http://www.cqc.org.uk/sites/default/files/documents/health_care_for_disabled_children.pdf, accessed 13 August 2014.
- 5 Mahon M, Kibirige MS. Patterns of admission for children with special needs to the paediatric assessment unit. *Archives of Disease in Childhood*, 2004; **89**: 165–169.
- 6 Spencer NJ, Lewis MA, Logan S. Diagnostic and socio-demographic changes in multiple hospital admission in children under two over a five-year period. *Journal of Public Health Medicine*, 1993; **15**: 332–336.
- 7 Shilling V, Edwards V, Rogers M, Morris C. The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals. *Child: Care, Health and Development*, 2012; **38**: 778–788.
- 8 Phua V, Reid SM, Walstab JE, Reddihough DS. Inpatient care of children with cerebral palsy as perceived by their parents. *Journal of Paediatrics and Child Health*, 2005; **41**: 432–436.
- 9 Avis M, Reardon R. Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study. *Journal of Child Health Care*, 2008; **12**: 7–17.
- 10 Finke EH, Light J, Kitko L. A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *Journal of Clinical Nursing*, 2008; **17**: 2102–2115.
- 11 Coyne I. Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing*, 2006; **15**: 61–71.
- 12 Huberman AM, Miles MB. *The Qualitative Researcher's Companion*. London: Sage, 2002.
- 13 Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 2006; **18**: 59–82.
- 14 Hammersley M. Ethnography and realism. In: Huberman AM, Miles MB (eds) *The Qualitative Researcher's Companion*. London: Sage, 2002: 65–80.
- 15 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 2006; **3**: 77–101.

- 16 Richie J, Lewis J (eds). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage, 2008.
- 17 Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *British Medical Journal*, 2000; **320**: 114–116.
- 18 Ryan GW, Bernard HR. Techniques to identify themes. *Field Methods*, 2003; **15**: 85–109.
- 19 Padgett DK. *Qualitative Methods in Social Work Research*, 2nd edn. Los Angeles, CA: Sage, 2008.
- 20 Silverman D. *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. London: Sage, 1993.
- 21 Hemsley B, Balandin S, Worrall L. Nursing the patient with complex communication needs: time as a barrier and a facilitator to successful communication in hospital. *Journal of Advanced Nursing*, 2012; **68**: 116–126.
- 22 Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Science*, 2006; **1**: 16.
- 23 McCabe C. Nurse-patient communication: an exploration of patients' experiences. *Journal of Clinical Nursing*, 2004; **13**: 41–49.
- 24 Crawford P, Brown B, Nolan P. *Communicating Care: The Language of Nursing*. Cheltenham: TJ International, 1998.
- 25 Moret L, Rochedreux A, Chevalier S, Lombrail P, Gasquet I. Medical information delivered to patients: discrepancies concerning roles as perceived by physicians and nurses set against patient satisfaction. *Patient Education and Counseling*, 2008; **70**: 94–101.
- 26 Espezel HJ, Canam CJ. Parent-nurse interactions: care of hospitalized children. *Journal of Advanced Nursing*, 2003; **44**: 34–41.
- 27 Coyne I. Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health Expectations*, 2013; doi: 10.1111/hex.12104.
- 28 Reeves E, Timmons S, Dampier S. Parents' experiences of negotiating care for their technology-dependent child. *Journal of Child Health Care*, 2006; **10**: 228–239.
- 29 Hewitt-Taylor J. Parents whose children have complex needs: experiences of hospitalization. *Journal of Children's and Young People's Nursing*, 2008; **2**: 13–19.
- 30 Garth B, Aroni R. 'I value what you have to say'. Seeking the perspective of children with a disability, not just their parents. *Disability & Society*, 2003; **18**: 561–576.
- 31 Hemsley B, Balandin S, Worrall L. The, "Big 5" and beyond: nurses, paid carers, and adults with developmental disability discuss communication needs in hospital. *Applied Nursing Research*, 2011; **24**: e51–e58.
- 32 Coyne I. Disruption of parent participation: nurses' strategies to manage parents on children's wards. *Journal of Clinical Nursing*, 2008; **17**: 3150–3158.
- 33 Department of Health. The Education Outcomes Framework. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/175546/Education_outcomes_framework.pdf, accessed 13 August 2014.
- 34 Goldbart J, Catons S. *Communication and People With the Most Complex Needs: What Works and why This is Essential*. London: Mencap, 2010. http://www.mencap.org.uk/sites/default/files/documents/2010-12/Comms_guide_dec_10.pdf.
- 35 Care Quality Commission. Guidance about compliance Essential standards of quality and safety, 2010. Available at: <http://www.cqc.org.uk/content/guidance-meeting-standards>, accessed 13 August 2014.

Copyright of Health Expectations is the property of Wiley-Blackwell and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.