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Introduction

Across the world, the number of children with disabilities and complex health needs is increasing. However, interpretation of the data relating to prevalence and incidence within this population is problematic at an international level, in large part because of major inconsistencies in the way that disability is both defined and measured (Cappa et al., 2015). In the United Kingdom, although there is no robust system for routinely collecting data on this population, it is a widely held view that the numbers of such children continues to increase year-on-year (Children and Young People's Health Outcome Forum, 2012). This includes children who have life-limiting or life-threatening illness (Fraser et al., 2012), children who are technology dependent, for example children who are ventilated at home (Wallis et al., 2011) and children who might be otherwise considered as disabled.

Over the course of the last sixty years, the locus of care for this group of children has shifted significantly from hospital to community. This has been in part as a result social, personal and political imperatives dating back to the publication of the Platt Report (Ministry of Health, 1959), and which continue to the present day (Royal College of Paediatrics and Child Health, 2015). A second major factor is the advancement of medical science as a result of which there is a growing population of children who in previous generations might have died in childhood but are now surviving premature birth, complex congenital abnormality, inherited or acquired disease and major trauma. Many of these children are, however, living with long term conditions and disabilities which place very significant additional care responsibilities upon their parents and families.

In the UK, the move towards community care has been supported in no small part by significant growth in the availability of community children's nursing service provision (Figure 1).

WellChild Nurses

In 2006, the National charity WellChild introduced the first of what has grown to become an established network of 37 WellChild Nurse (WCN) posts located in England, Scotland, Wales and Northern Ireland. The programme works to improve the provision of community nursing care for children, is concerned with the care of children with complex health needs and is focussed upon coordination and planning for discharge of children from hospital and supporting those children and families once at home (Johnson and Coad, 2008; Carter et al. 2010; Coad et al. 2015, Carter et al., 2016)

A number of the established WCN posts are 'stand-alone', for example a hospital-based WCN who provides an outreach role to support children who require invasive ventilation at home. Other posts are 'embedded' within an existing community children's nursing team – with a role for the WCN that is clearly differentiated from those of other members of the team. Whilst it is clear that many of the children upon whom the WCN programme focusses are likely to require care and support throughout the 24 hour day, the WCNs have generally been employed to work on a 9-5, Monday to Friday basis.

Research Approach

This qualitative exploratory study set out to gain insight into the experience of parents of children with complex health needs and disabilities, and was focussed upon aspects of parental decision making when seeking advice and support in relation to their child's care needs throughout the 24 hour day. Data was collected using semi-structured face-to-face interviews with WCNs and parents

In order to inform the development of the content of the interview schedule within the main study, a preliminary scoping exercise was undertaken. This consisted of two sets of exploratory questions which were set out in a short questionnaire sent to two groups of 'experts'. The first Expert Group 1 consisted of the 14 WCNs in post on 31st December 2013; 11 responses were received (response rate = 79%). The second Expert Group was a Parent Reference Group (PRG) consisting of 6 parents drawn from the Hertfordshire Parent Carer Involvement Board (identified as a result of direct involvement of the author with the Board) and 6 parents nominated by WellChild and identified as a result of their previous involvement with the WellChild Parent Network. Five responses were received from the PRG (response rate = 83%) and four responses were received from the parents nominated by WellChild (response rate = 67%). Responses from the scoping exercise were incorporated into the interview schedule for the main study.

Study sample

Interviews were undertaken with two participant groups: group 1 consisted of all WCNs in post in February 2014 (n = 12, two WCN posts became vacant in between the initial scoping study and the date of application for study ethical approval); group 2 was made up of parents who had been nominated to participate in the study by WCNs. The WCNs were asked to identify one parent from their caseload who would be able to provide an 'expertise by experience' perspective to the study based upon their role in caring for one or more children with medically complex health needs throughout the 24 hour day.

WCN interviews were undertaken at the nurses' work bases. Interviews were of between 13 and 27 minutes duration, covered a range of issues related to WCN's and families' experience of care during the 24 hour day but were not specifically focussed upon the care needs of the child whose parents was also to be interviewed at that study site. Parental interviews took place in the family homes, though one was conducted in the local hospital as the subject child was an in-patient at the time of the interview. Interviews were of between 15 and 63 minutes duration and were concerned specifically with the parents' experience as it related to the care of their child.

Ethics approval for the study was provided by the London Central Health Research Authority NRES Committee (REC Reference 14/LO/0449). When securing informed consent to participate in the study parents and WCNs were specifically asked to confirm their consent to digital audio recording of the interviews and also to the subsequent use within study reports or presentations of anonymised verbatim text from the study transcripts.

Data analysis

Each of the digitally recorded interviews was transcribed to provide a verbatim record of the conversation. In order to identify categories and sub-categories from within the data sets, the transcribed interviews were then subjected to a thematic comparative analysis using a step-wise sequential coding approach similar to that described by Glaser and Strauss (1967) and Strauss and Corbin (1998).

Where reference to the individual WCNs and parents is made in the presentation of findings, the alphanumeric codes N1 to N12 (WCNs) and P1 to P12 (parents) are used in order to preserve that anonymity (although only 10 parent interviews were undertaken the numeric element of the codes was retained to support data analysis)

Findings

12 WCNs (nine in England, two in Wales and one in Scotland) and 10 parents participated in the study. Although each of the WCNs nominated a parent to participate in the study, two parents withdrew on the day of the scheduled interview due to personal circumstances.

The findings reported below relate to how parents seek advice and support from professional staff throughout the 24 hour day. Four key questions seemed to guide parents (Figure 2): Why call? When to call? Who to call? How to call?

Why Call?

The reasons why parents might seek advice and support throughout the 24 hour day are illustrated in Figure 2. Parents and WCNs provided many examples of calls made by parents who were seeking professional advice and support when having to deal with or trouble-shoot an evolving clinical care issue such as a rise in the child's temperature or a change in the colour or consistency of airway secretions. In addition, participants in both the parent and nurse study samples highlighted issues related to malfunctioning equipment (such as alarms on medical devices or equipment failure) as a reason for making a call.

During normal service hours (see below), parents reported that they would often seek advice from clinical staff before taking any action themselves. However, in discussing calls that they might make 'out-of-hours', several parents described how they would, in the first instance, take steps to manage the situation themselves - only seeking professional advice if they were unable to resolve a problem themselves or perhaps seeking retrospective assurance from the WCN (or other staff whom they recognised as possessing clinical expertise) that their actions had been appropriate. Sometimes parents made a call out-of-hours because they wanted the nurse to know what they had done – and the nurse would generally call back in order to receive an update and offer reassurance.

'For instance I had a mum phone me at the weekend and leave a message, just to tell me the gastrostomy button had come out and she had managed to put it back in herself, because she had never done it before. She had seen it done, but wanted somebody to know, and she just wanted to make sure.... 'Was that okay?' [N4]

Both parents and WCNs reported that during the period immediately following a child's discharge from hospital the need for both practical advice and emotional support is particularly high though this tends to reduce over time.

'I think it was very helpful when she came home at the beginning.. she had so many problems and really scared me sometimes a lot....I even thought I couldn't save her life sometimes.... My confidence was really low at the beginning...' [P2]

WCNs and parents both described how increasing parental confidence and the development, over time, of knowledge, skills and experience allowed parents to become more empowered, to be able to trouble-shoot problems without the need for recourse to professional advice.

'I know him and I know when he needs to come in (to hospital) so I don't need to ring somebody else to ask them what they think, I know that he needs to be seen and I bring him in' [N7 – quoting directly from a conversation with a parent]

When to Call?

There was variability in the experiences of both parents and WCNs in respect of the availability of staff and services throughout the 24 hour day, 7 day week as illustrated in Figure 2. These findings are consistent with comments made by both parents and WCNs in the scoping exercise undertaken in advance of the main study.

Although WCNs have generally been employed to work on a 9-5, Monday to Friday basis, the individual WCNs described considerable flexibility in their working patterns.

'So, out-of-hours, because I work so late, sometimes I'll pop in and see the child asleep and see how they are working and that they are synchronising with the ventilator.' [N9]

The WCNs described how this flexible working has developed over time, in order to meet the particular need of the children and families within the caseloads. Variability in the WCNs' work patterns also reflected both the differences between the nature of the nursing service within which the individual posts were located and the particular clinical focus of those posts. However, WCNs (and parents) consistently identified significant flexibility in the pattern of working hours for the WCNs.

'One care package, I was going into the home at 7 o'clock in the morning because I had to learn what care Mum was giving, we were going to teach the care staff to take on that care... and the travelling distance from here to down where they lived was an hour and a half, which was a very early start'. [N1].

'You know what, I just ring (WCN) anytime, I mean I would never ring her at midnight, I would never ring her at 9 o'clock, but I ring

her.....' [P9]

The parents and the WCNs were asked specifically whether they felt that there was a need for additional support through the night. In general, parents felt sufficiently well supported and that this was not a priority. One parent whose child had recently

received a course of four-times daily intravenous antibiotics in hospital felt that it would be easier for her to be taught how to administer the antibiotics herself at home than to expect nursing visits during the night. However, not all of the parents felt that they were adequately supported. One mother observed: *“I have not actually got anyone that I can ring out of hours, at all.”* [P6]

Although the WCNs were enthusiastic about the prospect of formally developing the nursing support services during extended day time hours including over weekends, they were largely unsupportive of the suggestion of overnight, ‘24-7’ provision, offering a range of reasons for this including lack of a clinical need for such a development, shortage of nurses with the necessary skills to deal with acutely unwell children overnight, concerns regarding workforce capacity, and financial resourcing.

Six of the ten children whose parents participated in the study were either currently receiving or had previously received overnight care as part of an agreed Continuing Care package. One care package was provided entirely by Registered Nurses and the other five by Health Care Support Workers/Carers. Parental views were generally quite positive about the overnight care provision itself, particularly in terms of the respite from having to provide direct overnight care to the child.

Who to call?

Parents could seek advice and support from a range of clinical staff (and hospital departments) (see Figure 2). This list is very similar to that provided by the Parent Reference Group in the scoping exercise that preceded the main study. Parents reported that they actively try to make contact with somebody who actually knows their child as this meant the clinician would be able to interpret their request for advice within the context of prior knowledge of the child. Parents observed that this helps to avoid the need to provide a very detailed clinical history. In addition, parents explained that professionals who know the child are less likely to suggest hospital attendance or admission. Both the WCNs and parents referred to the importance of parents having trust and faith in the specific clinician from whom they might seek advice – again predicated upon a pre-existing relationship.

Parental expectation of the support which they might receive from the family General Practitioner was quite consistent within the study sample, with parents explaining that they would make contact with the GP for minor childhood ailments, but not usually for more complex or ‘specialist’ issues. However, parents reported that even simple requests to GPs were not always managed effectively.

‘...and the one time we ran out of Co-Amoxiclav, it was a weekend, I rang the out of hours GP ... as soon as he saw she was ventilated he said ‘Take her to A&E’. I could have banged my head against the wall (laughing).’ [P11]

The WCNs reported that they encouraged engagement with the child’s GP although they acknowledged the relationship could be tricky.

‘We try to involve GPs as much as possible, because, you know, they should be involved in their care, but sometimes some of my parents (of children with long-term ventilation) they lack confidence with their GP.’ [N2]

How to call?

The use of modern technology, such as mobile telephones, text messaging and e-mail, allowed parents to access advice both during normal working hours and also when the WCNs were not on duty. Comments from both parents and WCNs were overwhelmingly positive in terms of the value of mobile working technology in allowing them to deal with a range of issues in a timely manner. However, two of the WCNs did comment on the need to establish clear boundaries and appropriate ways of working for out-of-hours calls. The parents indicated that they found the WCNs to be responsive and there was very little evidence that the WCNs considered calls, answerphone messages, text or emails that were made or sent out-of-hours to be inappropriate or intrusive.

When dealing with out-of-hours issues that required an immediate response, parents described the occasional use of emergency ambulance (via '999' calls) and direct land-line calls to Intensive Care/High Dependency Units/Transitional Care Units as well as Accident and Emergency or Children's Assessment Units. A number of parents also described how they used the land-line and mobile telephone numbers to access specific clinicians (including Registrar and Consultant Paediatricians), sometimes in order to request an urgent clinical review.

The possible use of video-conference calls or photographs, for instance using Skype® or Facetime®, was explored with both parents and WCNs. Although experience was limited, there was significant enthusiasm from amongst the WCNs and the parents. The WCNs reported that these methods could save time, allowing them to *"see the child without having to go out, because it is half an hour drive there and half an hour back."* [N7]. Other benefits included the potential for improved respiratory assessments *"If you can actually see them, that would be much better."* [N8]. Photographs of wounds and dressings were thought to improve assessment: *"Being able to take a picture and then perhaps email to the tissue viability nurse."* [N7]. Communication with the child: *"Being able to ask them 'are you okay?'"* [N9] as well as communication with the family were also reported as likely to be improved through these methods:

"To be able to see the family again, see how stressed they look, seeing the body language can tell you far more than what a voice call can do on the phone." [N9]

Parents offered a similar range of positive comments on how video technology might be used. In relation to clinical assessment, the use of photography was identified as a mean of clarifying the situation *"cos if she had a sore stoma or something like that I could video it or take a picture."* [P5]. Video and photography also offered an opportunity to provide a record of clinical events: *"Because obviously if it (seizure activity) happens during the night when the Consultant was not there, at least I can record things."* [P6]. The other key benefit was seen in relation to trouble-shooting:

"You can talk to somebody on the phone, but if you've got somebody on Skype, and you are trying all these different things, to, I don't know, get their saturations up or can't pass the nasogastric tube or they are fitting, the Midazolam hasn't worked and you are still waiting for the ambulance, then if you've got somebody

on Skype, or something like that, then I would imagine that would be quite good really.” [P8]

However, parents and WCNs both sounded notes of caution in relation to the possible use of a video assessment of a child who is acutely unwell at home: *‘But if you are really worried about something, there’s nothing like face-to-face contact.’ [P8].*

Discussion

Caring for a child with complex care needs in out-of-hospital settings presents many challenges for parents (Lewis and Noyes, 2007; Whiting, 2013; Carter et al., 2016). This is clearly different to care provision in hospital settings where professional advice and support is readily available at all times. Parents in this study identified a number of challenges which they faced in providing care to their child 24 hours per day, this experience was related in the context of the multiple roles that they are required to enact particularly where their child’s needs include significant technology dependence. Parents described a range of strategies upon which they are able to draw in order to secure advice and support. This includes support provided by the WCNs, a role which is highly valued.

The four key questions identified above, which seemed to be important determinants of how parents sought advice from professionals, were underpinned and informed by parental skills, knowledge and experience. Parents provided examples of how they had been supported in developing this expertise by a number of professionals. When questioned specifically about their experience of out-of-hours care parents described how the WCNs, acting as ‘informed guides’ (Carter et al., 2016) had helped them to develop a range of clinical skills alongside enhanced decision making and trouble-shooting strategies which allowed them to confidently meet their child’s needs.

Previous studies have highlighted the multiple roles taken on by parents in caring for children with complex health needs (Carnevale et al., 2006; Lewis and Noyes, 2007; Whiting, 2013). Many of the parents in this study are clearly taking on roles which are significantly beyond those which they might reasonably have expected to take on in parenting their child. This challenge for parents is reflected in a major campaign “#NotANurse...but” which was launched by WellChild in 2015.

(https://www.wellchild.org.uk/news_item/wellchild-parents-launch-campaign-notanurse-but/).

This parent-led initiative sets out to highlight the complex and multiple roles which parents take on when caring for their child throughout the 24 hour day. A series of video diaries provided by parents dramatically illustrate how the four key questions identified in this study reflect the lived experiences and complex decision making required of parents caring for children with complex needs at home.

Conclusion

The findings of this study provide valuable insights into the perspectives of both parents and WCNs in respect of care provision throughout the 24 hour day. The four key questions which emerged from the analysis of the interview data from both

parents and WCNs may be a useful tool in establishing a more structured approach to help parents and WCNs in developing the necessary strategies when they need to access help and advice, particularly 'out-of-hours'.

References

- Cappa C, Petrowksi N & Njelesani J 2015 Navigating the landscape of child disability measurement: A review of available data collection instruments. ALTER European Journal of Disability Research. 9, 317-330.
- Carnevale FA, Alexander E, Davis M, Renick J and Trioni R 2006 Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. Pediatrics. 117 e48-60.
- Carter B, Bray L, Sanders C, Van Miert, C & Hunt A 2010 An evaluation of the WellChild children's nurse programme. University of Central Lancashire.
- Carter B, Bray L, Sanders C, van Miert C, Hunt A and Moore A 2016 "Knowing the places of care": How nurses facilitate transition for children with complex health care needs from hospital to home. Comprehensive Child and Adolescent Nursing. 39, 2, 139-153.
- Children and Young People's Health Outcome Forum 2012 Report of the children and young people's health outcomes forum long term conditions, disability and palliative care subgroup. (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216856/CYP-Long-Term-Conditions.pdf Accessed 22.12.2017)
- Coad J, Ashley N, Clowes C, Kelly J, Whiting M, Graham S, Pengelly T and Widdas D 2015 Through the eyes of children, young people and their families. Coventry University.
- Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA & Parslow RC 2012 Rising national prevalence of life-limiting conditions in children in England. Pediatrics. 129 e923, originally published online March 12, 2012.
- Glaser BG & Strauss A L 1967 The discovery of grounded theory: strategies for qualitative research. New York. Aldine de Gruyter.
- Johnson D & Coad J 2008 Audit report of the first four nurse posts. Cheltenham. WellChild.
- Lewis M & Noyes J 2007 Discharge Management for children with complex needs. Paediatric Nursing. 19, 4, 26-30.
- Ministry of Health 1959 The welfare of children in hospital. (Report of the Committee – Chairman Sir H. Platt). London. HMSO.

Royal College of Paediatrics and Child Health 2015 Facing the future: together for child health. London. Royal College of Paediatrics and Child Health.

Strauss AL & Corbin J 1998 Basics of qualitative research: techniques and procedures for developing grounded theory (2nd edn). London. Sage Publications.

Wallis C, Paton J, Beaton S & Jardine E 2011 Children on long-term ventilatory support: 10 years of progress. Archives of disease in childhood. 96, 11, 998-1002.

Whiting M, Myers J and Widdas D 2009 Community children's nursing. In Sines D, Saunders M and Forbes-Burford J (eds) Community health care nursing. (4th edn.) Chichester. Blackwell Publishers Ltd.

Whiting M 2013 Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life-limiting/life-threatening illness or technology dependence. Journal of Child Health Care. 17, 1, 92-108.