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J Child Health Care published online 21 November 2013

DOI: 10.1177/1367493513508233

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Journal of Child Health Care
001-11

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DOI: 10.1177/1367493513508233

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Abstract

In this ethically approved hermeneutic phenomenological study conducted in Ireland, mothers' experiences in caring for children with complex needs were explored. The sample comprised mothers ($n = 17$) at home caring for children with complex needs. Data were analysed from multiple interviews ($n = 48$) and diary records ($n = 11$). Care is provided in a going between world of travel. Providing care when travelling is challenging, and all journeys require careful preparation and pre-emptive care. Few unnecessary journeys are undertaken. Unnecessary travelling could be avoided by careful and coordinated service planning.

Keywords

Caregiving, complex needs, disability, home care, mothers, travel

Advances in technology, medicine and health care have improved the health and well-being of children generally and have also resulted in the increased survival of increasing numbers of children with complex needs (Glendinning et al., 2001; Hewitt-Taylor, 2009). Consequently, national (Department of Health and Children [DOHC], 2005, 2010) and international policy directives (Department of Health, 2008) are focusing on the delivery of care to children with complex needs whose parents are their main carers. The needs of these children and the complex nature of their care as well as the impact on caregiving on the family are reported in the literature (Manhas and Mitchell, 2013; Price and McFarlane, 2009; Raina et al., 2004; Simkiss, 2011).

This article reports the findings from an ethically approved qualitative hermeneutical study that identified the significant preparations that mothers' caring for children with complex needs undertake before and during travelling. This includes significant practical preparation and the implementation of pre-emptive caregiving to ensure that the child travels safely. The difficulties

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that can occur during travel and the consequences for the child and family will be examined in this study.

Background

Increasingly care to children with complex needs, including those referred to as ‘technology dependent’ (Kirk, 2008) or with special needs (Burke and Cigno, 2000) is being provided at home by their families, and considerable evidence exists on the physical, emotional and financial costs of this caring (Carnevale et al., 2006; Kirk, 1998; Strunk, 2010) and on the practical, physical and emotional exhausting realities and impact of this care (Gupta et al., 2001; Hodgkinson and Lester, 2002; Manhas and Mitchell, 2013; Moore et al., 2010). In addition, the mother’s role within home care has been identified as one with absolute involvement (Wilson et al., 2001) and as challenging (Whiting, 2012).

Literature identifies the need for careful planned discharge to home care for children with complex needs (ACT, 2009; Hewitt-Taylor, 2012). However, the literature does not provide evidence regarding the consequences on the child and mother of having to undertake multiple journeys as part of their caring at home responsibilities. There is little discussion on the provision of any service to assist families including mothers to cope with the demands and consequences that travel makes on them and their child.

Methods

Research design

This phenomenological study conducted in Ireland explored mothers’ experiences at home of caring for a child with complex needs. Phenomenology aims “to clarify, illuminate and elucidate meaning of people’s experiences in the context . . . of the lifeworld” (Eatough, 2012: 328). Phenomenological research focuses on the lived experience, and the experience can be generated in various ways including interviews and diaries (texts), which are then examined in various ways to extract the meaning. Further detail about achieving this is reported in Nicholl and Begley (2012).

Sample

Following ethical approval 17 mothers were interviewed on at least one occasion. Of these, 14 mothers had one child with complex needs and 3 had between two and four children needing complex care. The children were between infancy and 19 years of age. All children were identified by their mother, the gatekeepers and the researcher (experienced children’s nurses) as having conditions that meant they needed complex care at home and were at various stages in their illness trajectory. Their diagnoses included rare syndromes, ‘no specific diagnosis’, genetic and chromosomal abnormalities but the inclusion criteria for the children were specific to their needs for care rather than their diagnosis. The children had significant physical and cognitive disabilities and all needed varying levels of assistance with activities of daily living. In addition, all children required care, physical assistance and close supervision because of developmental delay, progressive deterioration and for the management of numerous individualised symptoms. The children all required ongoing medications, treatments, investigations and routine

assessments as well as general practitioner (GP), outpatient clinic visits, hospital admissions for the management of ongoing and new symptoms as well as for emergency treatments and care.

Findings

Eight key dimensions including caregiving (that comprised normal mothering, technical caregiving, individualised caregiving and pre-emptive caregiving aspects), paperwork and administration, managing constant instability, constant communication and constant observation as well as caring in a 'no choice situation' were identified in the phenomenon of caregiving (Nicholl and Begley, 2012). Additionally knowingness in mothers and unknowingness in others were dimensions identified in the phenomenon. The findings also importantly illuminated three different contexts, or environments, in which mothers are required to provide care when they care for their children at home. The delivery of care to children with complex needs "at" home involves the provision of care in three different environments, in the home (the inside world), outside the home (the outside world) and in travel (the going between worlds).

The focus of this article is on a new and important issue, that is, the need for mother to provide care for her child while travelling (the going between worlds) and the impact of this on the mother and the child. In these findings, mothers identified that a key component of caregiving involves managing many significant practical challenges that occur because of having to travel and also when travelling with their child.

Context

Mothers reported generally that travelling when the child is a baby is not problematic, as the child has less need for equipment, is easier to handle and the complications of the disease process that impact on mobility may not as yet have arisen. In addition, the child's symptoms and care needs may not have developed to the extent where additional emergency equipment is needed during the journey. The younger child also weighs less, is more easily positioned in the car and has less need for space for their mobility equipment. However, over time as the child's needs change and complications or deterioration occurs, mothers are required to include life-sustaining equipment for their journeys. Travelling with a toddler or an older child therefore becomes increasingly difficult over time as increasing levels of dependency or complexity in care needs occur, which entails greater planning. This can impact on the mother's physical and emotional well-being when preparing to travel and during journeys. Brenda explains:

But he's harder to manage now because he's bigger ... and it's more tiring. Whereas when he was small ... he was lighter, easier to manage.

The lack of achievement of continence, as a simple example, results in the continued need to carry nappies and changing equipment which is bulky. Similarly the lack of development of normal head control in infants, or deterioration in an older child, limits the child's sitting ability for prolonged period of time, resulting in the need for seat adaptations or mobility aids for travel. The growth of the child as well as the changing level of need increases the need for a larger vehicle, which can raise financial issues. These difficulties can be compounded when multiple children in the family have complex needs. These practical difficulties raise concerns as travelling and getting outside the home for any reason becomes more difficult over time.

Preparing to travel

The complicated nature of travelling with a child with complex needs demands that care needs are provided in difficult and uncontrolled circumstances. The constant instability in a child's condition had a significant impact on the preparation needed for travel. Mothers had to prepare for every eventuality that could occur as they knew their child's condition was labile and could change within minutes or hours. Significant travel preparations were meticulously planned and every eventuality was thought out. Gretta explains:

Before I go out I have to stand there have I got this, this, this, this for him ... his pyjamas ... medicine crusher ... medicines ... Thick and Easy, ... spoons ... special cups ... everything before I go out the door ... buggies.

Mothers had to simultaneously observe their child while carrying heavy and bulky equipments to the car, which meant moving the child with them, and they were also continually interrupted in their preparations as they needed to meet the child's current needs. For all mothers this was physically and emotionally exhausting as explained by Imelda:

I've a ramp ... the chair ... a ramp out of the house, a ramp into the vehicle ... strapped to the floor. Strap him in, strap to the floor ... That's it, and then go. You are taking a fierce chance.

All mothers had to simultaneously plan to meet the needs of all their children for the journey, and often other children if old enough had to do their own preparation. Mothers with more than one child with complex needs had to manage multiple types of equipment as well as the requirements for their normal children. Every journey, irrespective of its duration, requires this elaborate and time-consuming preparation, including very short journeys, for example, to travel with her other children on the daily 'school run'. Anita explains:

It takes 5 journeys to the car before I can get behind the wheel and drive. I've counted, just out of curiosity ... If I'm planning ... to pick her (sibling) up ... at 10 past two, I will start ... packing the car at maybe half 1 ... He's only 5 minutes away ... With her in my sight at all times ... Then you have to plan ... when the suction machine goes in because the suction machine must always be beside her. Because she'll unexpectedly ... (start seizing).

Travelling for respite care, which for some mothers involved 3- to 4-hour journey, were planned precisely and 'just-in-case' equipment was planned in the preparations. This could often mean moving two sets of equipment; one for use in the car and another for use when they arrived. Imelda reports:

The car was laden because you didn't know what you were going to encounter on the day ... There is an amount of preparation and there's just so much to bring, to physically bring with you.

Preparations were often made the night before travel and mothers reported dressing their child on the previous night as there was so little time available in the morning, especially for early appointments. Plans to travel were frequently changed at short notice if the child was unwell, including cancelling travel. However, mothers were determined to attend all medical appointments, irrespective of the consequences for them.

Pre-emptive caregiving

Mothers were acutely aware of the risks and the child's sensitivity to changes in routines, medications or care practices that travelling caused. Mothers used their 'knowingness' of what worked for their child, and what did not, when preparing to travel. Pre-emptive caregiving was evoked when mothers implemented care to prevent things happening or 'just in case'. This strategy was used to prevent or minimise disruption to the child's routines and to maintain their safety during travel. Despite mothers' understanding of the importance of adhering to strict regular routines for their child's well-being, however before leaving home they frequently changed their child's medications or feeding routines in an attempt to prevent any complication or deterioration arising during travel. This included altering drug dosages to ensure that the child would, for example, be seizure free or have reduced pain or respiratory difficulties. Feeding volumes and times were similarly altered.

The journey

Caregiving during every journey that involved mothers' driving includes the management of the constant instability in the child's (health) condition, monitoring for changes that can emerge while providing constant observation to maintain the child physical safety. Dara's child had a shunt inserted for hydrocephalus, which blocked suddenly. She explains:

It was just horrendous ... going out to a party and half way there in the car, in the back seat ... she just screamed and grabbed her temples and threw up ... you know so there's just no kind of warning to it.

Mothers frequently reported that they had to do the best they could alone in a 'no choice' situation. Relatives, neighbours and family friends were generally unaware and unavailable to help and even in situations where a home help was available to the family they often could not help with travel because of practical issues including role conflict and insurance indemnity. Only on very rare occasions, and for specific visits, was a taxi service offered by the health board for a hospital visit. Emer explains one such occasion:

This was the worse day of my life (laughter) ... so I asked the (health service) for a taxi to go up to hospital ... We couldn't get the buggy into the taxi ... we juggled the buggy, got in and me and her got into the back ... I hadn't time to eat breakfast between packing and getting her dressed ... I was getting sick ... I looked and she had poohed all over ... her clothes and everything ... The taxi driver was going to kick us all out ... Oh, it was the worst experience I ever went through in my life. I had to just literally change her and put as many poohy clothes into bags and wash my trousers because I was going into a consultant in the hospital with trousers ... dreadful experience ... and I say never ever again am I leaving this house without breakfast with her ... when I go anywhere I have to bring a spare trousers ... just to be sure you know.

While driving, mothers were constantly observing their child and this was particularly difficult and added to the concern for safety and time pressure. Children with the potential for sudden onset seizures required to be in their mothers' sight at all times to ensure physical safety. In addition, mothers were concerned about the child's temperature and pressure areas as well as boredom and physical safety as many of these children exhibit self-harming behaviours. This meant that journeys were often interrupted or performed at high speed. Two mothers reported

on journeys where they were being stopped by the police who were very understanding of the mother's situation. These difficult and unstable situations had to be managed single-handedly, often while caring for other siblings in the car. Mothers concerns during travel were also compounded by the need to find a parking space or assistance when they arrived at their destination. In her bad day diary, Dara explains her experience of a hospital appointment and the emotional and practical issues a mother face:

The new tramline had messed up my usual road . . . re-rerouting me into a completely unrecognizable part of town . . . no signposts, heavy traffic and very late. I was however only twenty minutes late when I parked up. It took a further 10 minutes to load (child) into his undersized buggy, and the baby (sibling infant) . . . strapped to my front. Bags went on my back . . . [She goes on] . . . Before long I am back in the car . . . It was rush hour by this time the traffic was bedlam . . . (child) started crying again because of his cramped position and lack of movement in the car. This got louder for the remaining journey.

Consequently mothers were under real-time pressure to get where they were going or back to their home as quickly as possible. Having unlimited time outside home for any reason was often not feasible for these children, causing mothers to reduce all travelling when possible. Orla explains:

She can hack the car for a wee while . . . I would need to be going at say 9 o'clock in the morning when things are quiet when she'd be like that . . . but it's really not worth the hassle.

In addition, journeys had a negative emotional impact on siblings. Mothers knew this and it concerned them but they often had no choice but to take siblings on difficult journeys. The child with complex needs, as well as their siblings, often reacted badly physically and emotionally to travelling. Consequently, siblings were included only when no alternative existed or when the journey was very short. Emer records in her bad day diary, 'They * (siblings) start. They don't want to go to Dublin. It's too long. It makes me feel sick'.

Lack of understanding by health providers

Mothers reported unnecessary journeys resulted from a lack of coordinated service planning amongst service providers. Mothers were required to attend multiple appointments with their children, sometimes 2–5 per week at different venues. Some children, for example, with neurological disorders were seen at a single site for their seizure management but for feeding management they had to travel extensively to meet the multidisciplinary team and to collect equipment or medications. Others had to attend both local and national centres to meet their child's needs and mothers considered attending these appointments as essential. Mothers reported that others lacked any appreciation of how they and their child had journeyed. Health professionals and clinic administrators appeared to lack an understanding of the impact of this uncoordinated approach on mothers, the numerous visits mothers undertook and the no choice situations they faced when attending clinics to meet their child's numerous health-care needs. Few mothers reported on any attempt to coordinate services to prevent multiple visits, the provision of alternative home visits or coordination of the resupply of equipment to the home. For some mothers their child or siblings also required visits to hospitals and centres in the United Kingdom because of the complexity of the disorder and its rareness. These journeys, though problematic, were managed.

Mothers perceived that no one in the care services really understood their situation or what caring for their children really entailed when travelling. Imelda described the need to leave home for a “2-minute” interview, a no choice situation for her, to be assessed for financial benefits. The practical difficulties and emotional responses are evident. Imelda states:

To bring him for an assessment ... 4 years on ... the greatest insult. The health board# sent me this letter to appear at 9 o'clock ... in their offices in the middle of the city with him ... and I thought how am I going to do this? ... which I don't like to do. It's like going to the hospital with no medication ... They wanted ... a doctor to interview me because they were going to refuse giving me domiciliary care of 150 hours a month ... I thought Jesus ... what do they think has changed? ... It was so maddening to have to go ... I showed the letter to (his dad) and ... he says to me 'well you better go in ... you know it all helps, it pays.' ... I don't know what time I got up that morning ... but I went without the ramps for his chair ... so much to bring now, couldn't get a park anywhere near ... It was pouring rain ... I wrote a letter, put it up on the dash along with his wheelchair sign ... How was I going to get him out of the car on my own because I couldn't lift the chair down ... so I saw a man coming out ... and I went up to him as near as I could ... Would you mind helping me? ... and he gave me a hand lifting it out ... The minute the doctor inside saw him she said to me, 'I don't believe ... we called you in ... The minute she saw him ... she said 'how did we bring you in here?' ... 2 minutes, literally 5 minutes later I was back in the car and I couldn't get him back into the car. It took me a half an hour to get someone to carry the seat back in. So I spent longer getting parked and getting him in and out than I did with the doctor.

In many visits, mothers' concerns were unrecognised or dismissed and there was little understanding of an increasing difficulty with travel. In addition, mothers had the responsibility for collecting equipment, medications and essential supplies. Limited opening hours of suppliers and services often meant that mothers had to travel during the working day and at times when no one else was available to help them. There was little understanding of the difficulty encountered by mothers of having to travel to collect equipment for their children.

Consequences

The challenges of travelling with a child with complex needs have an impact on the normal family functioning and limit travelling. When there are other preschool children in the family, travel is often impossible for daytime journeys with all the children together unless help is available, which is rare. As a consequence, only essential visits are made and social isolation for the mother and child can occur as social outings are seen as non-essential, and they become less of a priority than attending medical appointments and clinics.

The need to travel for social events for other children including school functions also creates difficulties. Often if mothers had already in a day undertaken a difficult journey, they would not travel again. On some occasions, mothers did opt to go out with siblings without the child with complex needs if someone was available to care for the child at home. This required organisation, scheduling around the available help and because of this, these were rare journeys. Occasionally, the child was left with the father, but this too had to be accommodated within work schedules and availability. School holiday times were particularly problematic for travel when preschool or school services for the affected child, which may have provided some free daytime for mothers, were not available. Journeys during school holidays and over the summer break with the child with complex needs were not easy unless the siblings could be cared for by neighbours or family, which

was infrequent. Care services were not available at short notice or when emergencies arose which were frequent occurrences in these mothers' experiences.

Mothers knew that taking the child away from home where they had little control over most situations was a difficult, emotional and practical decision to make in all situations. This results in the development of an ongoing tension between the need for the child to be taken out for social and emotional reasons and the practical realities of doing so. As such journeying, for any reason created dilemmas. Imelda explains:

And I wonder will your report make that clear, that like it's just such a difficult journey that you don't want to bring him places, which is wrong, isn't it?

Journeys that always involve difficult choices and visits are avoided. Gretta explains:

We wouldn't go shopping or anything because it's just too awkward.

Tensions resulted between the need to normalize and socialize the child and siblings in the outside world. This had significant impact on normal social activities for everyone in the family. The concept of 'turn taking' was identified as a strategy implemented to manage these difficulties. 'Turn taking' was implemented when the child was cared for by the father while the mother and other siblings went out to social events. Siblings in these families consequently often missed out with social, school or play activities with both parents and their brother or sister because of travel difficulties. Ciara explains a social outing for her family in which more than one child has complex needs:

They did get out but there was huge planning went into doing that. You know a trip to the (local) park ... was a big ... a big outing ... Like you didn't just decide in 5 minutes, oh well here, get into the car and we'll go ... It wasn't like that.

Visits involving both parents were equally problematic, these were rare and when they did occur they began late and finished early.

Discussion

The findings from this study indicate how mothers manage caregiving while travelling and the implications of this on the child, mother and family. In addition, the challenges of normalizing the family need when travelling were identified and how transport is problematic for them as supported by Clark and McArthur (2008). The needs of children who require complex care during travel and the demands placed on a child with complex needs and his or her mother and family before and during travel require further consideration. This includes the impact and consequences of travel of children with complex needs, which are not recognised or identified by community services and in the organisation and coordination of services. Children with complex rare conditions are becoming significant users of community services as care at home becomes the norm for many (Hewitt-Taylor, 2012). Raymond (2009) indicates the need to assess a child's social needs when a child is being discharged to home care and how this should be included in the assessment of support needs. The need for mothers to travel to collect or restock equipment should be reviewed. This should be the service provider's responsibility and could be achieved by better organization.

Appointments for children with complex needs should be structured to ensure a coherent approach is provided to children and alternative arrangements should be considered and unnecessary travel avoided. Developing a 'one-stop multi-professional shop service' where children's needs could be met at a single visit should be considered and telemedicine may provide an alternative option. Where necessary, funding for escort services should form part of the child's care plan, as in school services. Finally the challenges and barriers to inclusion that emerged for these mothers and their children require further investigation. The findings from this study indicate the reasons for exclusion and restriction in normal family activities in these families similar to those recently reported by Woodgate et al. (2012). However, the demands that travel places on mothers when they travel with their children are significant and unrecognised.

Conclusion

The reality that home care may place on parents who deliver highly complex care during travel has been highlighted in this study. The findings provide valuable in-depth insights and indicate that caring *at* home for a child with complex needs is more than caring *in* the home, and the study identifies a new context of caregiving for these children and their mothers. This study found that mothers had to manage travel often on their own, which sometimes placed them, and the child, at physical risk. Social travel for the child and mother was avoided. Contact with family and friends by mothers, and vice versa, are consequently reduced, adding to the isolation of mothers.

The needs of children with complex needs and the complex nature of their care, as well as the impact on caregiving on the family, are reported in the literature. What are not apparent are the issues that can concern mothers when they have to travel with their children for multiple appointments, respite care or other health reasons. Isolation is also recognised as a psychosocial impact on the child with complex needs, their mother, their family and siblings but the reasons for this are not evident, nor are how these impacts can be minimized or avoided.

Careful discharge planning and coordination of service provision can help avoid the need for multiple journeys, including those required to obtain supplies that can cause mothers real difficulties and danger. Nurses should have an enhanced understanding of the steps mothers take to avoid travelling, the care that they provide to maintain their child's wellness before and during travel and the actual circumstances under which mothers travel as part of their care responsibilities. Such an improved understanding would enable providers to better understand the issues that can emerge for mothers of children with complex needs when they have to attend a 9am clinic appointment. Additionally, the provision of travel escorts to help mothers travelling with their child, though potentially costly, should also be considered. The content of this article would also promote nurses to consider a more coordinated approach to medical appointments and the resupply of equipment in the home. Finally, the content will also alert nurses to the 'real lived experiences' reported by mothers on the impact of travel on them personally, on the child and on normal family life, which is little recognised.

Declaration of Conflicting Interests

The authors declared no conflicts of interest.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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