

PERSPECTIVE: Focusing on Families' Experiences of Health Care: Choosing a Qualitative Research Design

Abstract

Patient and carer experiences of health care are important for service improvements. However, the literature available often evaluates experiences from a health professional perspective rather than exploring the perspective of patients or families. Health care of children with cerebral palsy directly involves and impacts families. Accordingly, research exploring experiences of health care for this group of patients and carers should adopt a family perspective. This article provides an illustrative example of the decision-making processes that guided selection of social constructivism and grounded theory methodology for a research project aiming to capture family experiences of health care for children with cerebral palsy in a regional area of Australia. Adopting a family approach for the investigation of experiences of health care should be considered for future research in the area of paediatrics, but also for other areas of health in which the family plays a key role.

Understanding patient and carer experiences of health care are important for delivering improvements in quality and outcome of health care services (see Abelson, Miller, & Giacomini, 2009; Chow, Mayer, Darzi, & Athanasiou, 2009; Prakash, 2010; Williams, 1998). Research investigating patient and carer experiences often focuses on evaluation of important aspects of care as understood from the health professional viewpoint, such as access to services, health professional communication styles, unmet needs and satisfaction with care (Brunto & Bartlett, 2013; Garwick, Kohrman, Wolman, & Blum, 1998; Liptak et al., 2006; McKay & Hensey, 1990; Phua, Reid, Walstab, & Reddihough, 2005). However, patients' and carers' understanding of important aspects of health care can differ from that of health professionals (Landsman, 2006).

Cerebral palsy is a complex neuro-developmental disorder and is the most common cause of physical disability in childhood (Australian Cerebral Palsy Register, (n.d.); Rosenbaum, 2003; Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). Health care for children with cerebral palsy and their families is often complex due to the nature of the health condition as well as the nature of the health care interaction. Experiences of health care for this population implicitly involve the child's parents. The importance of the parents to the health care of their child indicates the need to adopt a parent or family perspective, rather than a health professional perspective, for the investigation of health care experiences for this population. In addition, health care service delivery practices for children with or at high risk of cerebral palsy have changed over the past two decades from a child-focused, professionally driven approach towards a family-focused, collaborative approach (Dirks & Hadders-Algra 2011). The

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family-centred approach to care recommends involving families in their child's health care, which includes making decisions about their child's health care needs and participating in the development and evaluation of services for their child (King, Teplicky, King, & Rosenbaum, 2004; Law et al., 2003). However, the current approach to investigating health care experiences from the health professional viewpoint is in contrast with the family-centred approach and limits the exploration of the perspectives of children with cerebral palsy and their families.

Choosing a research approach, viewpoint and methodology that fits the purposes and clinic context of a research study is an important to enhance methodological rigour. Methodological rigour relates to the credibility of a study, and examines how well the chosen methodology fits the aims of the research, as well as how appropriate the methodology is applied (Liamputtong, 2005; Maggs-Rapport, 2001). However, the processes involved in selecting a research design are not well described in the methodological literature. In this article, the authors aim to address this lack of understanding by outlining the purposes and clinical context of their study exploring parents' experiences of health care for their children with cerebral palsy that guided their selection of a research design which comprised a relativist approach, social constructivist viewpoint and grounded theory methodology.

Methods

Exploring the Purpose and Clinical Context of the Study

The purpose for the authors' study developed from the lead author's experiences as an allied health professional as part of a team that aimed to develop a new health care service for children with cerebral palsy and their families in a regional area of Queensland, Australia. The experiences of the health care team were consistent with studies that concluded that parents of children with cerebral palsy are dissatisfied with their child's health care, despite theoretical changes of health care service delivery practices toward a more family-centred approach (Darrah, Magill-Evans, & Adkins, 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011). In addition, the available guidelines and standards of care for this population had been developed

by medical and health care professionals, with limited or no consultation or collaboration with parents of children with cerebral palsy (Bakheit et al., 2001; Berker & Yalçın, 2010; Koops, Burd-Hartman, & Dodge, 2008; Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000). This professional-centred approach contradicted the principles of family-centred care. If the guidelines and standards did not reflect the needs of children with cerebral palsy and their families due to the lack of parental input, this may have been part of the reason why parents continued to be dissatisfied with their child's health care. Although parents' experiences of care for their children with cerebral palsy had previously been investigated from a health professional perspective (Baird, McConachie, & Scrutton, 2000; Darrah et al., 2002; Irochu-Omare, 2004; Reid et al., 2011), no researchers had explored this from the parents' perspectives. Therefore the authors identified the need to address this gap in knowledge by conducting a study that aimed to explore how parents living in their service area experienced health care for their children with cerebral palsy from the parents' perspective. From this exploration, the authors wanted to develop a conceptual model of parents' experiences that would complement the existing guidelines and standards of care and could be incorporated into clinical practice. By doing so, the health care team aimed to potentially contribute to improved health care service delivery and satisfaction with care for families of children with cerebral palsy in the regional area.

The author's choice of research design for their study needed to match the key theoretical aspects of the study, which are outlined below:

Complexity and Variability of the Experiences of Health Care for Children with Cerebral Palsy and Their Families

The process of delivering health care to children with cerebral palsy and their families involves a complex and variable interactive process between the child, the parent, the family and the health care providers. Parents' experiences of health care for their children with cerebral palsy in the study area will vary due to the variability of the nature and severity of the child's cerebral palsy,

but also due to the variability in the type and amount of services available in different parts of the regional area. In addition, cerebral palsy is a lifelong condition and the focus of health care and the relative importance of different aspects of health care can change over time. The heterogeneity of needs and parents' subsequent experiences of health care, both between cases and within cases across childhood and across the regional area, indicated that the study design needed to be able to capture and explore these variations in parents' experiences.

The Lead Researcher's Dual Role as Clinician and Researcher

The lead researcher's previous experience and continuing role as an allied health professional providing clinical care for children with cerebral palsy and their families required the selection of a study design that suited this dual role. The lead researcher's experiences as a health practitioner have contributed to her developing both personal and professional viewpoints about health care services for children with cerebral palsy and their families, which could be considered both a strength and a liability for the quality of the research conduct and study outcomes. While the lead researcher's professional experience has provided unique access, insights and sensitivity to underlying issues for families of children with cerebral palsy, they also had the potential to unduly influence the interpretations made during the course of data analysis. Of key importance to the authors' study was the aim to capture parents' perspectives of their experiences of health care for their children with cerebral palsy, not health professional perspectives. Therefore, the choice of research approach, viewpoint and methodology needed to manage the lead researcher's preconceptions about the study topic and to enable her to take a fresh look at the issues from the vantage point of parents of children with cerebral palsy.

Cross-Disciplinary Study Purpose

The purpose of the study was to explore parents' experiences of health care for their children with cerebral palsy. This required a holistic, cross-disciplinary research approach, rather than following the approach of any specific discipline or type of health service. In addition, the choice of methodology needed to ensure

parents of children with cerebral palsy were able to openly discuss their experiences without influence of any current approach or principles of care. By adopting an open-ended approach to the exploration of parents' experiences, the study outcomes would therefore be widely applicable across different disciplines and health services within the regional area.

Limited Availability of Previous Research and Need to Generate New Information and Understanding

The topic of enquiry for the authors' study had limited previous research available to guide the study design. As a result, the choice of research design needed to fit the purpose of the study to generate new information in order to address the gap in the literature regarding parents' experiences of health care for their children with cerebral palsy. This purpose guided the selection of an inductive qualitative research methodology.

Outcomes of the Research Needed to Have Potential to Affect Quality Improvement in Health Care

The purpose for the author's study developed from a clinical context which aimed to improve service delivery and care for children with cerebral palsy and their families. As a result, the outcomes of the study needed to be useful in this clinical context and needed to be able to inform improvements in health care service delivery practices. The authors had identified that the development of an explanatory model would complement the existing guidelines and standards of care and could be incorporated into the clinical practices. As a result, the authors needed to choose a research methodology that could facilitate the development of an explanatory model and, therefore, affect improvements in health care for this population (Becker, 1993).

Results

Choosing a Relativist Approach, Social Constructivist Viewpoint and Grounded Theory Methodology

The authors' choice of research design, including the theoretical approach, viewpoint and methodology, were guided by the key

theoretical aspects of the study described above. Relativism is a research approach that considers that individuals have different views and perspectives of reality and truth which is created through their individual experiences (Annells, 1996; Corbin & Strauss, 2008; Guba & Lincoln, 1994). The aim of the study was to explore parents' experiences in all their variations, which therefore suited a relativist approach. Complementary to this approach was a social constructivist viewpoint, which considers that each individual's understandings of their reality are constructed through social interactions and social experiences (Charmaz, 2006; Creswell, 2009; Liamputtong, 2005). In addition, researchers using a social constructivist viewpoint consider themselves as active participants in the research process; the outcomes of their research are constructed from participants' perspectives as shared and interpreted with the researcher during the research process (Birks & Mills, 2011; Charmaz, 2006). This viewpoint, therefore, suited the dual role of the lead researcher as both a health professional and researcher. Finally, grounded theory is a qualitative research methodology that has been used to investigate patients' experiences of health and health care (Artinian, 1998; McCann & Clark, 2003; Mullen, 2006). Grounded theory had three key methodological principles that suited the purposes and clinical context of the authors' study, which are explained in detail below:

1. Grounded theory methodology is exploratory and facilitates discovery of new understandings of social phenomena or experiences.

Grounded theory methodology suits research that aims to develop new knowledge and understanding of poorly understood social phenomena (Cutcliffe, 2000). In the field of health care, grounded theory is particularly suited to research that aims to explore complex and socially interactive aspects of health care (McCaffery, 2003). This principle of grounded theory methodology fit two important purposes of the authors' study. First, the authors' had identified a lack of research into parents' experiences of health care for their children with cerebral palsy which required discovery of new information. Second, the process of health care for children with cerebral palsy and their families can be considered a complex sociological interaction that

occurs between the child, the parent, the health care professional, the health care service and the larger governing health care organization. Consequently, grounded theory suited the purpose of the study to explore the parents' experiences of health care for their child.

2. Grounded theory aims to develop explanatory theories or models.

Researchers using grounded theory methodology aim to develop theories or models that explain how the social situation they are studying occurs in a variety of situations. One type of theory, a substantive theory – which can also be described as an “everyday” explanatory model – provides understanding of a specific social experience in a specific area or context and is particularly useful for health care research that aims to deliver practical outcomes such as improvement in experiences of or satisfaction with care (Becker, 1993; Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008). Grounded theory, therefore, provided the authors with a methodology that could develop an explanatory model that would meet their purposes of a practically useful study outcome that could potentially contribute to improved quality of and satisfaction with care for children with cerebral palsy and their families.

3. The outcomes of research using grounded theory methodology are “grounded” in the data and attempt to reflect the participants' viewpoints as closely as possible.

Capturing parents' viewpoints of their experiences of health care for their children with cerebral palsy was an essential purpose of the authors' study. Grounded theory methodology achieves this through grounding of the research outcomes in the “raw” data using the key method of constant comparative analysis. Using this method, data collection and analysis occurs concurrently. New data is analysed, checked and compared with old data, as well as the codes, categories and theories that are developing through ongoing analysis, which facilitates a continuous cycle of adaptation of the emerging analysis according to the participants' raw data (Birks & Mills, 2011; Glaser & Strauss, 1967; Mills, Bonner, & Francis, 2006).

This process would help the authors to ensure that the study outcomes closely reflected parents' viewpoints.

A review of recently published literature demonstrates that there has been a shift

towards exploring the health care experiences of children with cerebral palsy and their families from their own perspectives (see Björquist, Nordmark & Hallström, 2015; Iversen, Graue & Råheim, 2013; Myrhaug & Østensjø, 2014; Kruijsen-Terpstra et al, 2014;

Table 1. *Methodological Congruence of Grounded Theory with the Author's Research*

<i>Aspects of Grounded Theory</i>	<i>Congruence with Background and Clinical Context of Research</i>	<i>Application of Grounded Theory to Meet Aims of Research</i>
Aims to discover new information and understandings	Parents' experiences of health care for their children with CP are not well understood.	Grounded theory allows discovery of new information regarding parents' experiences of health care for their child with CP. The new information adds the experiences of parents to the evidence base for clinical practices for children with CP.
Explores social phenomenon and experiences	Children with CP and their families often require complex multidisciplinary care. The process of health care for children with CP is a complex multi-directional interaction between the child, parent, health care provider, and health care organization.	Grounded theory using a social constructivist viewpoint facilitates exploration of the complex interactive and inter-related processes of health care for children with CP and their families. Grounded theory allows exploration and mapping out of the variations of parents' experiences of health care for their children with CP.
Develop explanatory theories or models	Current guidelines and standards of care for children with CP lack parental input. Previous research has identified and parental dissatisfaction with their child's health care.	Grounded theory facilitates development of an explanatory model of the health care needs of children with CP based on parents' experiences. This explanatory model can be used to inform improvements in health care service delivery for children with CP and their families.
Research conducted from the viewpoint of the participants'	Previous research into health care experiences has primarily explored only the health professional perspective. Parents' experiences of health care for their child with CP might differ from that of health care professionals.	Grounded theory using a social constructivist viewpoint allows a shift in focus from a health professional perspective to that of the parents and family. Methodological process of constant comparative analysis ensures that research outcomes remain "grounded" in the data and closely reflect parents' experiences of health care. Grounded theory allows exploration and mapping of the variety of parents' experiences of health care for their children with CP

Note: CP = Cerebral Palsy

Whittingham et al, 2013). These articles contribute to health professionals understanding of parents' and children's experiences of particular aspects of health care, such as therapy (Myrhaug & Østensjø, 2014; Kruijsen-Terpstra et al, 2014), going through surgery (Iversen, Graue & Råheim, 2013) and transition to adulthood (Björquist, Nordmark & Hallström, 2015). However, grounded theory methodology has not been used in any of these studies.

Discussion

It is important for researchers aiming to explore patients' and families' experiences of health care to match the purposes of their study to their choice of research approach and methodology. Although there is an emerging trend in health research to use qualitative methodologies to investigate patients' experiences of health care (see Banner, 2010; Harvey, 2010; Shaw, Brittain, Tansey, & Williams, 2008; Shikako-Thomas et al., 2009), the reasons for these methodological choices are not always transparent in qualitative research literature. In addition, although there is a substantial body of literature discussing the various approaches to grounded theory, there is limited discussion outlining the justification for the use of grounded theory in health care research. By providing an example of a research study, and describing in detail the key theoretical aspects of the study, the authors have demonstrated the potential reasons for researchers to select grounded theory methodology to explore patients and carers experiences of health care.

Moving from a health professional perspective to a patient or carer perspective for the investigation of experiences of health care for children with cerebral palsy and their families has important implications for the usefulness of research outcomes in clinical practice. The adoption of a patient or carer perspective enables the researcher to deliver research outcomes that are more likely to accurately reflect what contributes to patients' or carers' experiences, and therefore what changes may be useful to improve the health care experience for that chosen population. In addition, adopting a patient or carer perspective for the exploration of experiences of health care for children with cerebral palsy and their families is congruent with the principles of family-centred care, and reflects the same attitude toward the impor-

tance of parents and families in the health care of children as is promoted in clinical practices. It is through this delivery of research outcomes that are congruent with the principles of clinical practice that research into families' experiences of health care for children with cerebral palsy can contribute to improving satisfaction with care for this population.

The authors acknowledge that to fully understand experiences of health care for children with cerebral palsy and their families, future research will need to extend beyond the parents' experiences explored in this study to include exploration of the experiences of children with cerebral palsy, their siblings and other members of the family who are involved in the child's care. However, the authors' study provides the first methodological step toward developing an understanding of experiences and important aspects of health care for children with cerebral palsy and their families.

As demonstrated in this article, a social constructivist approach to grounded theory methodology is suited to the discovery of new understandings of health care from the viewpoint of patients and carers, and can deliver clinically useful research outcomes. This approach and methodology should be considered for future research in the area of paediatrics and cerebral palsy, but could also be considered for research in other areas of health in which the family plays a key role, such as geriatric, palliative and maternity health care. Without the adoption of research approaches and methodologies that can capture patients, carers and families experiences of health care from their own viewpoint, these understandings will remain undiscovered, and dissatisfaction with care will continue.

Key Messages From This Article

People with disabilities: Your experiences of health care, and the experiences of your carers, are important to enable improvements to health care service delivery and your satisfaction with care.

Professionals: Without an understanding of patients' and carers' experiences of care, it is difficult to know how to change clinical practices in order to improve patients' and carers' satisfaction with care.

Polymakers: Research that explores patients' and carers' experiences of health care is important to deliver improvements in satisfaction with care, but requires the use of a methodology that is congruent with the purposes and clinical context of the research.

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