



# The embodied spaces of children with complex care needs: Effects on the social realities and power negotiations of families



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## ARTICLE INFO

### Keywords:

Complex care needs  
Embodied space  
Families  
Health geography  
Social realities

## ABSTRACT

This paper presents research findings that advance knowledge around the power and agency families with children with complex care needs (CCN). Our conceptual framework uses concepts from geography towards situating the experiences and social realities of family carers within the 'embodied space of care'. The data originate from a longitudinal qualitative study of Canadian families with children with CCN. Findings reveal that interactions and decision-making processes relating to health and everyday life were complex and socially interconnected, and emphasize the need for provisions for family-based decision-making and enhanced social inclusion of families and the importance of the renegotiation of power.

## 1. Introduction

People living with complex care needs (CCN) struggle with chronic illness and/or disability(ies) that require intensive care and support. The CCN of children can often create contentious spaces where multiple actors (i.e., the child, family, doctors, nurses, and other care providers) become engaged in decision-making processes ultimately affecting the child's and whole family's short- and long-term well-being (Twiggs, 2006). Further, the day-to-day negotiation of care for a child with CCN can deeply affect the lived experiences of children and their family members (Muenchberger et al., 2011; Woodgate et al., 2012, 2016). As systems of care are transitioning in many locations from government-supported institutions to various forms of homecare, negotiations around caregiving have intensified as families of children with CCN are increasingly taking on roles related to primary care (Woodgate et al., 2012, 2015, 2016).

This transition has the potential to shift the social realities of families who play a central role in caregiving and also has the potential to impact how power is negotiated between the different agents of care (Woodgate et al., 2012, 2015). This paper presents research findings that advance knowledge around the embodied spaces of care of family carers (i.e., parents and siblings) of children with CCN with a special focus on power and agency and attention to how different kinds of institutions (e.g., social, health, familial, cultural) shape the geography

of care of children with CCN. The findings originate from a longitudinal qualitative study that examined how the changing geographies of care influence the ways that Canadian families with children with CCN participate in everyday life (Woodgate et al., 2012).

## 2. Conceptual framework: space, place, body, and power

Our conceptual framework is built towards our understanding of how embodied space and place affect the social realities of children with CCN and their families. 'Space' and 'place' have been continuously evolving as concepts in human geography. 'Space' was originally described as a location devoid of social connections until critical and feminist geographers deconstructed its meaning and connected it strongly to time (i.e., 'space-time'). The connection to time also enabled geographers to describe how 'space' has an effect on 'place' (Duncan, 1996; Massey, 1994, 2005; Rose, 1993; Valentine, 1989). Massey's (1994, 2005) expansions of geographic concepts provided more progressive and fluid understandings of 'space' and 'place' as being dynamic and connected to simultaneous occurrences, resulting in multiple meanings and socially constructed boundaries. Massey's (1994) definition of place includes four main characteristics: 1) places are not static and are built around social interactions, which are processes and are not bound by time; 2) places are not naturally bounded or subdivided, meaning that 'outside' and 'inside' are human

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<http://dx.doi.org/10.1016/j.healthplace.2017.04.001>

Received 15 August 2016; Received in revised form 23 January 2017; Accepted 5 April 2017  
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constructs; 3) places have multiple identities and are fraught with internal conflicts; and 4) all places are unique, important, and based on continuously changing social relations. Massey (1994, p. 152) also described the connections between places and our experiences of them as “linking that place to place beyond”.

Newer ways of thinking about the body in health geography have continued to emerge in relation to place as socially constructed, and are grounded in Foucault (1974) who contended that discourse ‘makes up’ the body. This shift away from considering the body as purely physical and towards understanding ‘embodied space’ has been developed by geographers (Giesbrecht and Crooks, 2016; Hall and Wilton, 2016; Holt, 2008, 2016; Laurier and Parr, 2000; Milligan et al., 2007; Milligan and Wiles, 2010; Power, 2016; Stephens et al., 2015). Several of these scholars ground their work in non-representational theory, which emphasized the relational connections towards making sense of lived experiences of people with disabilities (Hall and Wilton, 2016; Power, 2016; Stephens et al., 2015). Other scholars have grounded embodied space in feminist geographies stressing the importance of considering inequities and intersectionality (Giesbrecht and Crooks, 2016).

Laurier and Parr (2000) explored embodied space through the intersubjectivity of emotions and relational space created through interviewing people with disability, and highlighted the importance of new (relational) ethical considerations in research. Stephens et al. (2015) added nuance to the discussion on embodied spaces of care by exploring how embodiment responds to ‘assemblages of contexts’ beyond those that are purely social or biological. Other scholars have framed the discussion on embodied spaces of care as ‘landscapes’ in which relationships are spatially created and navigated towards holistically understanding a person’s experience of care (Milligan et al., 2007; Milligan and Wiles, 2010; Woodgate et al., 2012). Relating to such relationships around care, Holt (2008, 2016) argued for the need to prioritize social capital and the voices of disabled young people and expand the focus of care beyond the institutional space.

Low (2003) describes the position of body in ‘embodied space’ as a person’s “centre of agency, a location for speaking and acting on the world” (p. 10). Further, Acarón (2016) describes the body as “both a receiver and actor, producing and being produced by spatial relations” (p. 139), and describes ‘embodied space’ as having four main characteristics: 1) ‘portability’, which relates to our sense of space and the ability to carry it with us; 2) ‘extensibility’, which is the ability to reach beyond the limitations of the physical body; 3) ‘social flexibility’, which describes the changes that occur to a space in reaction to social stimuli, and 4) ‘transversality’, which describes the potential for deconstructing “boundaries between intrapersonal dimensions of the self, self and the other, self and the environment, self and world” (p.142).

Medical geographers have accounted for the socially constructed aspects of illness and disability, and have questioned issues of power related to fixed concepts around ‘space’ and ‘place’ (Dyck, 2003; Grosz, 1994). Kearns (1993) invited medical geographers to reconsider ‘place’ and its role in structure/agency debates. Dorn and Laws (1994) accepted Kearns’ invitation with a request for a greater infusion of social theory and described “the body as a site of struggle” based on the “entwining of opportunity and constraint” (p. 107). Hall (2000) continued the discussion around the geography of health and impairment, stating that “the body has been conspicuous in its absence” and “that a central part of any reform of health geography must be a critical assessment of [the position that the body is simply a site that can be invaded by disease], accompanied by a rethinking of the body as a focus of representations, identity and politics” (p. 21). In this sense the body can be considered to be existentially tangible and a part of the contingencies of the social world (James and Hockey, 2007; Monaghan and Gabe, 2016).

Rose’s (1993) contemplations on time and space contributed to understanding how viewing the body as a container is based on limited assumptions that people (inclusive of the body) are defined by distinct ‘insides’ and ‘outsides’. Conrad (2005) further described the connec-

tion between ‘inside’ and ‘outside’ as ‘the relational self, which is continuously shaped by ‘significant others’ through different kinds of (i.e., physical, psychological) encounters despite its location. This explains how people (e.g., children with CCN and their families) can be affected by events and interactions (e.g., decision-making with regards to their health) occurring at a distance from them. Additionally, bodies can be understood as defining the relational space between personal and ‘other’ (Smith, 1993), and can be viewed differently by ‘others’ depending on the place in which they are found (McDowell, 1999). Furthermore, acknowledging that embodied and relational spaces are socially constructed and are located in place (i.e., have space-time and location connections) can significantly change how power is viewed and negotiated within public and private places. Families of children with CCN may be socially limited due to structures and processes of society that restrict how families move within and across different spaces (Hall, 2000).

By acknowledging that embodied and relational spaces are socially constructed and are located in place, we can consider how different kinds of institutions affect the circles of care for children with CCN and contribute to developing a better understanding of the social dynamics (i.e., between child, family, paid and professional carers, health care professionals) shaping the geography of care of children with CCN (Milligan et al., 2007). Our conceptual framework contributes to previous work though focusing on the boundaries and power negotiations around embodied spaces of care, and how interactions around such boundaries affects the structure of care and the agency of families of children with CCN.

### 3. Research methods

#### 3.1. Data collection

Families of children with CCN are capable of expressing what is most meaningful for them in terms of their health aimed towards being empowered in decision-making processes affecting their everyday lives (Woodgate et al., 2015, 2017). To uncover some of the deeper meanings for families of children with CCN about their roles as carers and members of families of children with CCN, an ethnographic qualitative research design was used in which interviewers spent extended amounts of time with families in their own settings. An ethnographic approach made it possible to explore the emic descriptions of participants within their own cultures and life situations. The research took place in Winnipeg, an urban centre with a steadily rising population over 700,000 in central Canada. Families of children with CCN were recruited from a primary integrated health and social services community program. In addition to providing a single service coordinator, services offered at the time of the study included respite, preschool therapy for children, child development services, behavior psychology services, recreation services, and assistance with some of the extraordinary costs of caring for a child with CCN.

Data collection with families took place over three years. In addition to involving parents in the data collection process, siblings and children with CCN when possible, were also invited to participate in the study. In-depth, open-ended interviews were the main sources of data. Interview questions included those about experiences with day-to-day caregiving responsibilities and sense of place (e.g., “Please describe your sense of place as a family member of a child with CCN”). Participants were also asked to reflect on their experiences within different ‘therapeutic landscapes’, the relational spaces that are associated with processes of healing (Gesler, 1992; Williams, 1999; Woodgate et al., 2012). Separate interview guides were developed and used for the different type of participant (i.e., parents, siblings, and children with CCN) with attention to adapting the interview guides to be understandable and age appropriate.

Photovoice was also used as a means of empowering the participants to reflexively explore their personal realities through taking photographs and describing them during interviews (Wang and Burris, 1997; Wang and Redwood-Jones, 2001; Woodgate et al., 2017).

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