



## LJMU Research Online

**Wilkinson, CM, Carter, B, Keating, P and Bray, L**

**Not a nurse but more than a mother: The practices of mothering children with complex health care needs**

<http://researchonline.ljmu.ac.uk/id/eprint/12750/>

### Article

**Citation** (please note it is advisable to refer to the publisher's version if you intend to cite from this work)

**Wilkinson, CM, Carter, B, Keating, P and Bray, L (2020) Not a nurse but more than a mother: The practices of mothering children with complex health care needs. Children's Geographies. ISSN 1473-3277**

LJMU has developed **LJMU Research Online** for users to access the research output of the University more effectively. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LJMU Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain.

The version presented here may differ from the published version or from the version of the record. Please see the repository URL above for details on accessing the published version and note that access may require a subscription.

For more information please contact [researchonline@ljmu.ac.uk](mailto:researchonline@ljmu.ac.uk)

<http://researchonline.ljmu.ac.uk/>

**Not a nurse but more than a mother: The everyday geographies of mothering children with complex health care needs**

Dr Catherine Wilkinson, Liverpool John Moores University, UK, School of Education,  
c.wilkinson@ljmu.ac.uk

Dr Lucy Bray, Edge Hill University, UK, Faculty of Health and Social Care,  
brayl@edgehill.ac.uk

Professor Bernie Carter, Edge Hill University, UK, Faculty of Health and Social Care,  
Bernie.Carter@edgehill.ac.uk

Dr Paula Keating, Edge Hill University, UK, Faculty of Health and Social Care,  
keatingp@edgehill.ac.uk

**Correspondence concerning this article should be addressed to Catherine Wilkinson:**

**c.wilkinson@ljmu.ac.uk**

Acknowledgement of financial and other support:

This study was funded by WellChild and a contribution in kind from the Faculty of Health and Social Care, Edge Hill University.

Declaration of Interest:

The authors report that the study was partially funded by WellChild but that the analysis was undertaken and the paper was written independently of any oversight from WellChild. The authors gained no financial benefit from undertaking the study.

## **Not a nurse but more than a mother: The everyday geographies of mothering children with complex health care needs**

### **Abstract**

This paper reports on the analysis of parent-recorded video diaries from a parent-driven campaign, #notanurse\_but, supported by the charity WellChild. The campaign reveals the challenges that parents (predominantly mothers) face providing high level, ongoing clinical care for a son or daughter who has complex care needs. A team of four researchers analysed 30 videos from the WellChild website, WellChild Facebook page, a dedicated #notanurse\_but campaign Facebook page, YouTube and Twitter. An interpretative, inductive qualitative analytical approach was utilised. This paper reflects on the portrayal of mothering (it was predominantly mothers who produced campaign videos) a child with complex health care needs. In particular, this paper considers the competing identities of mother and nurse that these mothers fulfil as part of their daily regimes in 'being mum'. This paper also contributes to geographical discussions concerning methods and ethics of online data collection and the use of secondary online material.

**Key words: Children; Complex health care; Everyday geographies; Mothering; Video campaign.**

## Introduction

It is part of a mother's relationship to her child to engage with that child's absolute corporeal uniqueness. It cannot be denied or avoided (Rose, 2003, p. 16).

Child-rearing guides of the past have often assumed that mothers, living in heterosexual nuclear families, will have primary responsibility for childcare, and that this entails raising healthy, disciplined, well-balanced children (Marshall, 1991). While Richardson (1993) acknowledges that mothers have acquired additional responsibilities (for instance, for the intellectual development of their children through education and nurturing), what happens, then, if the child has complex health care needs<sup>1</sup>? Carnevale et al. (2008) have described that most parents of a child with complex health care needs, and in particular mothers, experience ongoing strain, chronic fatigue and distress related to concerns about their child's physical, psychological and social wellbeing.

Holloway (1998) suggests that mothers are under-researched because of social sciences' domination by the masculinised subject. More than two decades have passed since this claim, and recent years have seen deserving attention paid to the geographies of mothering. Further, Ekinsmyth's (2011; 2013) considers of the roles of space and place in "mumpreneurship". The author examines the spatialities and practices of UK mumpreneurs, that is female entrepreneurs who operate between paid work and motherhood. Ekinsmyth (2013) finds that spatial factors affect mothers' levels of capability and constraint, and thereby the gender role and entrepreneurial choices that are made. Holloway and Pimlott-Wilson (2014), writing on local

---

<sup>1</sup> Complex health care needs refer to health care needs that are substantial and ongoing. These can be the result of chronic illness, disabilities or following hospital treatment.

mothering cultures, discuss how class matters in attitudes to parents, but it is experienced through local mothering cultures which are established through the diversity of class backgrounds, rather than through the dominance of any one class grouping.

Other literature has considered the spatialities of motherhood via the topics of breastfeeding in public (e.g. Boyer, 2011; Boyer, 2012) and pram mobilities (Clement and Waitt, 2018). Boyer (2011) argues that lactation advocacy is an under-examined form of health activism and that by exploring it geographical knowledge can be enhanced through providing an example of “care-work activism” (Boyer, 2011, p. 431); that is, efforts to challenge existing social norms concerned with where specific kinds of care-work are / are not supposed to take place. Clement and Wait (2018) offer the concept of mother–child–pram assemblage to highlight the corporeal dimensions of everyday pram journeys. Analysing sensory ethnographic materials collected with mothers and young children, the authors highlight how the affective affordances and affective atmospheres of pram mobilities shape urban experience, specifically with reference to how motherhood and childhood are achieved on-the-move.

As well as scholarship noting the public and private practices of mothering in real-world space and place, a related body of literature has documented the presence of mothers on the internet. This literature can be seen to champion the internet, almost paradoxically, as an “intimate mothering public” (Orton-Johnson, 2015, p. 238). For instance, Chan (2008) examines how a group of Hong Kong working mothers use the internet in performing and realising their paid work and domestic role identities. The author finds that the virtual space of the Internet plays a role in the social reproduction of the contemporary dual-earner family by enabling working mothers who use the website to perform roles in production and reproduction respectively. Madge and O’Connor (2005; 2006) investigate the simultaneity of online/onsite experiences

through an exploration of cyberspace as a performative liminal space, one where new mothers experimented by different versions of motherhood. Madge and O'Connor (2005) find that although cyberspace can result in the production of new selves, these selves have attachments to 'real world' experiences and practices. As such, they make a case for cyberspace and geographical space coexisting simultaneously. Madge and O'Connor (2006) find that the internet plays a central role in providing virtual social support and information for new mothers. However, the authors find that the internet was both liberating and constraining for these new mothers: whilst it played an important social role for some women, it encouraged restrictive and unequal gender stereotypes.

Despite a growing body of literature, there is a noted deficit of research examining mothering activities in the home (Holloway, 1998), and while gendered spaces of mothering are now being stretched beyond the home (Longhurst, 2013), the home remains an important site for parents of children with complex health care needs. This is because children with complex health care needs are now increasingly being cared for at home as a result of medical advances and government policies emphasising the community as the arena for care (Woodgate et al. 2015). Further, these families are relatively housebound because transporting their children can be challenging (Nicholl, 2015), their conditions are precarious, specialised care is unavailable in many outdoor spaces and places, and there may be other structural barriers that restrict their inclusion out of the home (Carnevale et al. 2008). As such, the specific contribution of this paper in relation to extant literature is to provide an account of the geographies of mothering, in the home, children with complex health care needs.

This paper achieves this by reporting on the analysis of video diaries recorded by mothers from a parent-driven campaign, #notanurse\_but, supported by WellChild. #notanurse\_but is a

parent-driven campaign that stems from parents of children with complex health care needs self-identifying that they are ‘not a nurse but’ they undertake nursing type roles to care for their child. This paper explores how mothers of children with complex health care needs negotiate specific aspects, not only of their maternal responsibility, but other responsibilities they hold in acting as nurses for their children in their own homes. The definition of nursing we use in this paper is from The Royal College of Nursing (2014, p. 3):

The use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death.

This paper explores how these constructions or identities (principally mother and nurse, but also carer and advocate) are played out in the geographies of everyday life, as captured on film. As such, this paper makes a valuable contribution to the geographical literature on mothering, specifically for children with complex care needs. Further, through the approach to analysing publicly available video content as data, this paper contributes to geographical discussion concerning methods and ethics of using secondary online material (e.g. Madge, 2007; Sparks, Collins & Kearns, 2016; von Benzon, 2018). This paper begins with an overview of research on parenting a child with complex health care needs, with a consideration of home as a both a therapeutic landscape and caringscape. It then reviews different conceptualisations of mothering and moves on to describe the methods used in the study. After presenting and discussing our findings in relation to being *more-than-a-mother*, the paper ends with some concluding comments and suggestions for further research.

## **Parenting children with complex health care needs**

With the added responsibilities and challenges of caring for a child with complex care needs, parents have reported role alternations, most notably the role of the nurse, which requires parents to provide skilled care in order to ensure their child's wellbeing and survival (Kirk, Glendinning and Callery, 2005). This "quasi-nursing role" (Redmond and Richardson, 2003, p. 206) includes administering complex medication and the maintenance of technically sophisticated equipment and procedures and managing caregivers who provide additional support within the home (Keilty, Nicholas and Selkirk, 2018). Woodgate et al. (2015, p. 4) term this "intense parenting", referring to the extra efforts parents contribute in raising their children with complex care needs. Meanwhile, the time demands and relentlessness of parents' caregiving and parenting responsibilities has been described as both 'extraordinary' (Carter and Bray, 2016) and an imposed 'clinical career' (Carter and Bray, 2017).

Caring can be identity-defining in the way that it changes the life of the person who is caring. This has been documented in the work of Holditch-Davis et al. (2011), who discuss the 'attainment' of the maternal role with medically fragile infants. Due to the need to be constantly vigilant, many parents feel like they are 'on duty' all the time (Kvarme et al. 2016), and some parents report losing aspects of their identity (Beresford, Rabiee and Sloper, 2007). Whilst some parents feel they lose aspects of their identity, others bestow on them the identity of 'expert' parents (Kirk and Glendinning, 2002). Research by Kirk, Glendinning and Callery (2005) has revealed that, for parents of children with complex health care needs, their constructions of parenting are shaped by the nature of their role in caring for their child, and also by the transformation of their homes by medical equipment and personnel (Lindahl and Lindblad, 2013). Whilst these parents described having a role that had both parenting and nursing dimensions, they defined their role to be primarily one of parenting, by differentiating



parental care-giving and its underpinning knowledge from that of nursing. McCann et al.'s (2016) work shows that mothers rate health care related activities lower than almost all emotional care activities.

Researchers in this area have predominantly focused on parental stress and the burden of care for parents of children with complex health care needs (Nygård and Clancy, 2018), whilst some have discussed the positive or existential transformation that occurs in parents and their perspectives on life, due to the experience of parenting a child with a disability (see Skinner et al. 1999). Other scholars have discussed the paradox of “joy and sorrow” (Kearney and Griffin, 2001, p. 582), “distress and enrichment” (Carnevale et al. 2006, p. e48) - with enrichment coming emotionally and through acquisition of new knowledge and skills, and the “benefits and burdens” (Green, 2007, p. 150) - with burdens including the isolation of being a parent of a child with complex care needs (Carter et al. 2017). This paper contributes to this body of literature by analysing parent-recorded videos which enable us to ‘see’ the mothers at work in their homes – a place where interviews and other research methods may not have reached.

### ***Home as a therapeutic landscape and caringscape***

There is a small but emerging body of literature in geography on home as a therapeutic landscape (e.g. Dyck et al. 2005; Martin et al. 2005; Williams, 2002). The topics of these studies are broad, including home births and home as a space for hospice care as people get to the end of life. Alongside the body of literature on therapeutic landscapes is literature on home as a caringscape (e.g. Bowlby, 2012; Evans, 2012; O’Hagan, 2014). A caringscape is the shifting and changing multi-dimensional terrain that comprises people's vision of caring possibilities and obligations: routes that are influenced by everyday scheduling, combining caring work with paid work and the paid work of carers (McKie et al., 2002). Caringscape is

an appropriate lens to use within this paper as, following McKie, Gregory and Bowlby (2004), it enables us to consider the complexity of the range of activities, feelings and reflective positions in people's shaping of care. Our paper builds on this existing body of knowledge by bringing to light use of the home as a caringscape for mothers of complex health care needs. What these bodies of literature on therapeutic landscapes and caringscapes have in common is recognition that the home environment not only designates a dwelling, but also represents a multitude of meanings. Whilst therapeutic landscapes typically refer to places dedicated to or adapted to the healing and recovery of illness (see Williams, 2002), we extend this term to sites of lifetime commitment to dependent children. The specific contribution of this paper is that we position the home as a therapeutic landscape in one sense, through a space of care-giving and consumption, whilst at the same time challenging this idea in the same way as Williams (2002) does. To explain, we show how the therapeutic landscape of home can also be a site of struggle relating to physical and emotional labour.

### **Conceptualisations of mothering**

Over the past forty years, a large body of work pertaining to mothering has been produced across several disciplines and theoretical fields. Despite this, child-rearing has not been a major focus of geographical research, notwithstanding that it is both spatially and temporally variable (Holloway, 1998; Dowling, 2000). Holloway (1998, p. 31) put forward a moral geography of mothering which she describes as "a localised discourse concerned with what is considered right and wrong in the raising of children". Certainly, research in the geographies of care has identified the central role of mothers in caring for children (Barker, 2011).

Recent feminist work in geography has explored the affective force and embodiment of motherhood (Clement and Waitt, 2017), intensive mothering ideologies (Parker and Morrow,

2017), and ‘good motherhood’ (Lane, 2014). There has been a deficit of research into the mothering of children with complex health care needs in the geography literature, though health researchers have extensively studied this area. This area of research is particularly worthy of attention when considering the ‘myth versus reality’ of motherhood (see Choi et al. 2005). Here the framings of intensive mothering and the constructions of a good mother become interesting. According to Hays (1996, p. 122), intensive mothering is a “child-centred, expert-guided, emotionally absorbing, labour intensive, financially expensive” ideology in which mothers are primarily responsible for the nurture and development of the child, and in which children’s needs take precedence over the needs of their mothers. In other words, the mothering practices prioritise the needs of children through women’s self-sacrifice (Baraitser, 2009). This can be seen in women who care for their children with complex health care needs, who often sacrifice self-care practices and socialising, and who give up paid work and the prospect of their own imagined future as a worker.

The traditional mother ideology, written about within sociological western texts, defined a “good mother” as full-time, at-home, White, middle-class and entirely fulfilled through domestic aspiration (Boris, 1994). This no longer reflects contemporary understanding but is more a reflection of the focus of academic research at the time. Further, it is argued that good mothers should facilitate the provision of a good childhood (Burman, 2008). This picture is muddled for women who have children with complex health care needs (and indeed a range of alternative life experiences), with questions of whether a good childhood can be one that is characterised, for instance, by pain and lack of independence. Further, while these mothers undertake domestic tasks such as tidying and cleaning, they have other more pressing duties in the home such as giving medicines, dressing, lifting, and monitoring a potentially fragile child.

Satisfying, though not exceeding, the ideals of motherhood is the ‘good enough’ mother who provides ‘good enough’ care for her child (Winnicott, 1960). Mothers who do not, or are unable to, meet children’s needs are at risk of being labelled as deviant or “bad mothers” (Miller, 2007; Orton-Johnson, 2017); mothers are expected to rise to the additional challenges of meeting their child’s complex clinical needs. The discourses of ‘intense parenting’ and the ‘good mother’, or ‘good enough mother’ are useful for exploring how mothers of children with complex health care needs negotiate the everyday geographies of mothering, as well as the expectations of their role in delivering care for their children. Further, these discourses help to challenge what Douglas and Michaels (2005) refer to as the unrealistic and unattainable idealisation of motherhood presented in mainstream cultural narratives. This paper extends normative ideas of mothering and motherhood, and indeed the ‘good mother’, with a consideration of mothering bound with parenting and nursing dimensions.

### **Overview of the #notanurse\_but Campaign**

WellChild is a national UK charity providing support to children with complex health care needs and their families. #notanurse\_but is a parent-driven campaign that stems from parents of children with complex health care needs self-identifying that they are ‘not a nurse but’ they undertake nursing type roles to care for their child. The campaign was launched with the aim of influencing commissioners of services, professionals and policy makers to improve support of and services for carers (Jones-Berry, 2015).

The home videos / diaries, have an essence of ‘a day in the life of...’, and are created by parents whose children receive support from WellChild. The idea for the videos originated from one mother, Leanne, whose daughter Sophie has cerebral palsy and multiple other complex needs,

who, in collaboration with WellChild, launched the campaign and called for other parents to create videos:

I'm not a nurse but I do medical procedures at home to keep my daughter safe and well. And I'm not alone in that. SO I would encourage all parents, all carers, grandparents, siblings...any of the families out there that are delivering medical procedures, medical care, anything you're doing with your children at home to keep them safe and well that goes above and beyond...Get your cameras out, get your iPhones out, your iPads out. Share your experiences, share your stories

(Leanne, video 2).

Parents use the videos to share (and/or raise awareness of) aspects of their lives with children with complex needs, for instance administering medication, maintaining their child's airway, and undertaking a sleep study. The videos are uploaded and shared on the WellChild website, the WellChild Families Facebook page, a dedicated #notanurse\_but Facebook campaign page, via YouTube, Twitter, and parents' personal Facebook pages. We now turn to outline the methods used in the research project.

### **Materials and methods**

We used an interpretative, inductive qualitative approach for analysing the videos (Derry, 2007) and have been guided by best analytical practices proposed for working with pre-existing video data (Barron & Engle, 2007). For more information about the methodological approach adopted in this research see REMOVED FOR ANONYMITY.

The fly on the wall nature of the home videos (for the research team) enabled us to explore the everyday geographies and experiences of embodiment for the mothers as they care for their

children both in the maternal sense (McKeever and Miller, 2004) and the professional (nursing) sense (Kirk, Glendinning and Callery, 2005). It is important to critically reflect on how the videos are made by parents for the purpose of the campaign, and as such convey a series of pre-determined points about the challenges they face, which may contain elements of performance.

Performance, for Goffman (1959), is characterised by a series of dramaturgical metaphors, including the world as stage; stage management; front and back regions; guises; and stage props. Goffman (1959) considers the ways in which individuals, in ordinary work situations, present themselves and their activity to others. He presents two regions 'front stage' and 'back stage' which complexifies the notion of performance. For Goffman (1959:109;114) "front region" describes the place in which the performance is delivered, and "backstage" describes where the performer drops his/her front and offers a more authentic act. The back region is not typically accessible to audience members. As we are analysing video content, it may be assumed that we are concerned with the front stage performances only, since we did not have access the 'back stage'; that is those times where performers 'drop their act'. However, in the videos that formed our dataset, this distinction between front and back stage is not clear cut. To explain; the videos show us the 'back stage' lives of these mothers; that is life behind closed doors. However, through filming and sharing these videos, we must also acknowledge that these are front stage performances, and as such the mothers may be careful to "put their best foot forward"; their performances may be wary and self-conscious (Goffman, 1981, 198).

### ***Method for sampling videos***

The dataset consisted of 47 videos which made up the campaign in October 2016; some parents contributed one video, others contributed several; one mother contributed twelve. We

purposively selected a subset of 30 videos to analyse. This selection was undertaken to ensure representation of all parents who had posted videos, the range and nature/content of videos (based on the titles of the videos and on an initial viewing of content) and the platforms the videos were posted on. The videos ranged from 8 seconds and 9 minutes 52 seconds (average 2 minutes), and were either self-filmed or filmed by another individual in the house (this person was not always identified).

### ***The Ethics of Using Publicly-available Content***

As a research platform, online sites have been celebrated as providing a point of access for naturalistic data, which has the ability to accurately depict the lived realities of a range of individuals (Rokka, 2010). Online data can provide a rich source of data that has not been produced with an attempt to please a researcher or to fit into certain themes pre-determined by the researcher (von Benzon, 2018). Whilst having many benefits and opening up new opportunities for geographers undertaking research, there has also been much debate regarding the ethical codes of conduct for online studies (Rokka, 2010). For instance, there is an issue of consent, and indeed informed consent, in research that uses publicly available personal content. Whilst the online content is, arguably, already public (Zimmer, 2010), consideration needs to be given to whether, or not, the creators of online content should be protected (von Benzon, 2018).

There has been little attention paid to the implication of parents sharing personal information about their children online (Ammari et al. 2015). The consent of parents and children's assent was something we considered carefully before we undertook the research. WellChild, who endorsed our use of the videos, has a robust process for ensuring that parents know that the video will be in the public domain; all the videos we used in the study had been screened by WellChild as ones which had full permission. WellChild maintains that personal data will only

be collected from children with the explicit and verifiable consent of the person who has parental responsibility (e.g. child's parent/guardian/representative) unless that child is aged 13 years or over, in which case consent will be sought from them where they are able to provide it. WellChild maintains that each circumstance should be considered on a case by case basis and the following should be taken into account:

- The best interests of the child
- All necessary steps are taken in relation to the protection and care necessary for the well-being of the child
- Respecting a child's right to privacy
- Capability of the child to provide consent
- Representation of the child – a child's representative can give consent but the position should be reviewed when the child reaches the age of 13. Data protection rights are those of the child and not their representative
- The language of the explanation should be clear and appropriate to the age group. If the child does not understand what they are consenting to then the consent is not informed so is, therefore, invalid

Regarding the videos that have formed part of our research, the only child that was aged 13 or over did not have capacity to consent (as judged by the parent), and consent was instead given by her mother. In the case of another parent, she used eye gaze to consent (even though her daughter was under 13). In the consent process, there is reference to information in the 'public domain': WellChild will only ever use the material in a sensitive and appropriate manner and will not make it available to third parties who request it without prior consent. WellChild gives parents an opportunity to discontinue permission for their video to be used. However,



WellChild offer a warning that if permission is withdrawn they will use best endeavours to remove the material from the public domain, whilst making it clear that this may not always be possible. We refer the reader to REMOVED FOR ANONYMITY for more information about the ethical approach to using online secondary data adopted in this research.

### *Data Analysis*

We developed a data extraction sheet which helped us to maintain focus, whilst also helping to ensure consistency between researchers in our analysis. We initially used this data extraction sheet to extract data from four videos. All four researchers were informally trained in using the data extraction sheet to record observational data. The first version of this sheet presented some challenges, as it did not accommodate all the comments we wanted to make, and in certain categories it encouraged duplication. Following a group discussion about the strengths and weaknesses of the data extraction sheet, we collapsed some fields, clarified working terms/definitions to help define the focus of what data should be recorded, and added some new fields. For instance, one researcher suggested that we include a section on clinical language to capture the terminology used by subjects. The final data extraction sheet (see figure 1) supports Barron and Engle's (2007) best analytical practices for working with pre-existing video data, allowing us to map (identify what is happening and who it is happening to), explore the 'sense of being there' (affect), macro-code (generate a timeline for key events in the video) and produce a narrative summary of key selected moments.

[Insert figure 1 here]

To increase the reliability and validity of the analysis, each video was reviewed by at least two researchers (see also Cahill and Papageorgiou, 2007). Where there were discrepancies, the video was shared with other members of the research team as a means to guard against inherent bias and to become reflexively more aware of any assumptions. The discussions over

discrepancies were useful in surfacing salient dimensions for analysis, and to highlight potential issues to investigate further. We analysed the videos separately and came back together to discuss our analysis. This reduced the likelihood of the selective subjectivity of the observer (Caldwell and Atwal, 2005). There was a high degree of consistency between the researchers' observations.

We deemed each video to be a unit of analysis and analysable events (Gibson, 2005), with the start and end points being defined by the start and end of the video. The mothers' names and the names of their children are presented in the findings as they are attached to the campaign videos within the public domain.

## **Findings and discussion**

### ***More-than-a mother***

Discourses of the "good" mother were apparent in the campaign videos as the mothers positioned themselves as meeting the needs of their children, often at the expense of self-sacrifice (Baraitser, 2009; Johnston and Swanson, 2006). However, beyond being a "good" mother, when reviewing the videos we noted a blurring of roles between parent and carer. For instance, in video 11, the professional carer is doing Sophie's [daughter] hair and 'getting her ready', whilst Leanne [mum] is making sure Sophie has all of her medical supplies and equipment to take with her to school. Reviewer 2 of video 11 reflected that the carer is doing "some mum-type elements and mum-doing some of the medical-type elements". The conflation of these roles was also tied up with some more high-level care, comparable to nursing.

Using the definition of nursing presented earlier in this paper, it is easy to see why parents of children with complex health care needs can be considered to fulfil the role of a nurse. If we

break this down further to look at the specific duties that nurses undertake, such as hands-on care (i.e. administering medications); monitoring patients' conditions; maintaining records; and delivering technical interventions, the nursing role of mothers in the #notanurse\_but campaign becomes more apparent still. Within the overarching theme of '*more-than-a-mother*', on which this paper is based, we found three sub-themes: Administering medication; mastering medical equipment; and exercising clinical judgment. We now discuss each of these sub-themes in turn.

### ***Administering medication***

Mothers in the campaign videos described the extent of their daily care of their child, which revealed that many had acquired sophisticated nursing skills. As can be seen from the quotations from mothers Sian and Faith, administering medication is an important component of care.

12 hours apart, morning evenings; daily. It's not like paracetamol or antibiotics where if you miss one it doesn't matter, because Olly's have a cumulative benefit and they build up resistance and cause stability for epilepsy...So any slip in the routine when administering the drugs or even if he spits out or refuses to take it from the syringe one day or vomits or has an upset stomach can have a major consequence on his stability and start off a whole pattern of increased seizure activity.

(Sian, video 46)

[Discussing medications] this one here is more muscle spasms; this one is to keep her gut working, this one's an anticonvulsant...this one's for muscle spasms; this one's for reflux...that one's for pain relief and that one's to keep her gut working too

(Faith, video 13)

Sian delivers a time-sensitive regime of administering medication. This level of responsibility undertaken by a nurse would usually only occur in intensive and high dependency settings by

nurses with additional specific experience and education. Looking at the second quotation, what is clear from Faith is a blurring of maternal and professional knowledge as she demonstrates a clear familiarity with medical and nursing language. Faith discusses her responsibility of ensuring her daughter adheres to her medication regimen. Medicines and their administration is a key aspect of nursing that requires professional regulation, and so the extent of Faith's knowledge and ability to administer a complex cocktail of medicines is meaningful. This knowledge appears to become embodied and intuitive (see MacAllister 2016 on the relational co-construction of parenting knowledges). Here then, the idea of a "naturally good mother" (Hrdy, 1999, p. 26) appears to give way to the 'naturally good nurse'. However, it is worth noting that a nurse would care and adapt their knowledge and expertise to care for different children with different conditions – these mothers are experts on their child. Parents have a very specific albeit deep and detailed informal ad hoc curriculum, whereas nurses have a formal structured, supported and much broader curriculum (Carter et al. 2017).

### ***Mastering medical equipment***

Our analysis of the videos revealed that the amount of medical equipment (machinery and consumables) either discussed in the videos or 'on show' in the background was "quite startling", including sats machines, ventilator, oxygen/cylinders, cough assist machines and drip stands. At times, for us as reviewers, it was difficult to distinguish between a hospital and home setting. This is also reflected in the quotation from one of the mothers, Leanne:

At one point Sophie had only just come home from hospital and in effect we had our own HD [High Dependency] Unit set up in the living room because Sophie was requiring so much medical care. She was ventilated 24/7 with her oxygen and numerous other things going on

(Leanne, video 2)

This relates to how the presence of medical equipment and supplies can change the use, organisation and feeling of home.

We observed that such modifications changed the aesthetics of the living environment, also considering the potential increased independence, functionality, practicality and decreased physical strain that such adaptations may bring to the children and their families. Indeed, it could be argued that by promoting and maintaining the use of these technologies, the mothers fulfil practices of being a good mother, if we accept the definition that good mothers should facilitate the provision of a good childhood, or actually the best possible childhood. Essentially, it is these technologies that enable the child to be cared for at home, and this is the ambition for all of the parents as their children often spend prolonged periods of time out of the home (in hospital or hospice). However, these discussions of good motherhood need to be tempered against discourses of a ‘bad mother’ (e.g. Miller, 2007; Orton-Johnson, 2017) that came through in some of the videos. To explain, the cost of being a good mother to the sick child (in terms of time, energy and finances) was sometimes at the expense of time and attention to well siblings. Further, the dominance of medical equipment in the household was positioned as ‘taking over’ the house, for instance the children’s playroom and communal living spaces.

Surprisingly, and unlike medicine as previously discussed, a number of mothers did not discuss the technology they were using in the videos. That is, we as the research team could see the technologies either in shot or being used, but they were often not pointed out unless they were the specific focus of the video. Arguably, this could be because the technology has become an extension of the child, and indeed the home, and it is a taken-for-granted part of daily life (see also Dyck et al.’s discussion of home as a place of care), perhaps in a way that medicine is not (it could be argued that some technology, that is continually present, is more embodied than medicine that is administered at regular intervals).

### *Exercising clinical judgment*

The third sub-theme to emerge is that of exercising clinical judgment. This needs to be seen in the context of the mothers having to acquire clinical skills to care for their children, rather than nurses having chosen to acquire such skills:

I'm not a nurse, I didn't go to University, didn't study to be a nurse but I find myself more and more often delivering complex medical procedures at home.

In some videos, the mothers emphasised how important it is to be vigilant and attentive to their child's needs so that they could either prevent or deal with crises. In this sense, the mothers are 'on duty' all of the time. A 'good' mother for these mothers is being able to clinically care for their child. Yet, beyond the role of good mother, there is a feeling upon viewing these videos that the mothers are 'supermums' (Choi et al., 2005).

Parents talked about the need to listen to their child's breathing to determine if they were "bubbly" or "rattly" as well as to check whether the child's "sats (oxygen levels) were dropping" or if they had a "temperature". Jill talked in detail about the skilled attention to detail and vigilance required when settling her son down for the night and attaching him to his ventilator (life support machine):

This is a video of what happens when I attach Noah to the ventilator at night. I was trying to show the decisions that we have to make despite not being a nurse. Whether to add oxygen or a nebulizer for example. Being in charge of someone's breathing when they are on life support is actually quite technical but it's something that me and lots of other parents do daily. There is no room for error when it's someone's life

(Jill, text accompanying video 18 on Facebook page)

Parents were aware that vigilance was coupled with a need to be able to take action based on good and timely decisions. The absolute importance of this is emphasised by Jill when she states “there is no room for error when it’s someone’s life’. Here, intensive mothering of the kind discussed by Hays (1996): child-centred, expert-guided, emotionally absorbing, labour intensive, and financially expensive, can be seen as a necessity to sustain the life of the child.

Through discussing intensive mothering (Hays, 1996; Parker and Morrow, 2017) and the construction of the good mother (Baraitser, 2009; Johnston and Swanson, 2006), we have problematised the typical application of these terms for mothers of children with complex care needs, arguing that they bear little relation to the realities of the everyday lives for the mothers whose videos we analysed. We believe the videos forming the WellChild campaign can challenge mainstream representations of motherhood in the same way as mummy blogs (see Friedman, 2013; Orton-Johnson, 2017), providing us with new ways of thinking about the construction of the identity of mother.

## **Conclusion**

Through the specific example of mothers of children with complex health care needs, this study explores how their responsibilities are changing in the home. We found that mothering a child who has complex health care needs extends normative ideas of mothering and motherhood, and indeed the ‘good mother’, whereby mothering is bound with parenting and nursing dimensions.

Little is known about the impact of providing home-based care on the mother’s construction of her role(s) and negotiations of everyday life. As such, this paper makes a case for the importance of the space of the home when researching into the geographies of mothering. Further, whilst therapeutic landscapes typically refer to places dedicated to or adapted to the

healing and recovery of illness (see Williams, 2002), we extended this term in this paper to sites of lifetime commitment to dependent children. With this paper we positioned the home as a therapeutic landscape in one sense, through a space of care giving and consumption, whilst at the same time challenging this idea in the same way as Williams (2002) does. To explain, we have shown how the therapeutic landscape of home can also be a site of struggle relating to physical and emotional labour.

While a key message running through many of the videos in the #notanurse\_but campaign is that care at home is important to these families, the campaign videos also highlight new levels of responsibility that care at home brings. Mothering a child with complex needs was described by May (1997, p. 18) as mothering “plus extras”. It is likely that in 1997 children would not have been at home with such complicated technology. From our research these extras include administering complex cocktails of medication, mastering medical equipment, and exercising clinical judgment. In particular, the medium of videos enabled us to ‘see’ the mothers at work in their homes – a place where interviews and other research methods may not have reached. As such, this paper has highlighted the complexity and time demands of caregiving tasks that mothers in the campaign undertake daily, revealing how they negotiate this within the home and alongside other mothering duties.

The role of the campaign can be seen to be structuring what the mothers said, alongside the fact that mothers were in their home space and creating a representation (or performance, Goffman, 1959) of their lives for public consumption. Research has found that mothers feel pressure to present themselves online in a way that maintains an ideal image of motherhood (Jang and Dworkin, 2014). Further, the online sites on which the videos are shared can be considered performative arena in which mothers are able to experiment with different identities



(see Madge and O'Connor, 2006). As such we can consider online (re)presentations of motherhood to be somewhat curated (see also Orton-Johnson's 2017 discussion of 'mummy blogs'). Thus, while we advocate the usefulness of video analysis of pre-recorded videos to analyse data that has not been produced with an attempt to please a researcher or to fit into certain themes pre-determined by the researcher (von Benzon, 2018), we acknowledge that the videos were still created with a particular audience in mind and therefore are not completely naturalistic. Indeed, other methods encounter similar problems – for instance in participant observation, participants may 'perform' to the researcher. As such, we recommend the triangulation of video analysis with other methods (such as participant observation or interviews) to continue to unpack the geographies of mothering children with complex health care needs at home.

#### **Declaration of interest statement**

Anonymised for review.

## References

- Ammari, T., Kumar, P., Lampe, C., & Schoenebeck, S. (2015). Managing children's online identities: How parents decide what to disclose about their children online. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. pp. 1895-1904.
- Baraitser, L. (2009). *Maternal Encounters: The ethics of Interruption*. London: UK
- Barker, J. (2011). 'Manic mums' and 'distant dads'? Gendered geographies of care and the journey to school. *Health & Place*, 17, 413-421.
- Barron, Brigid & Engle, Randi. A. (2007). Analysing data derived from video records. In Sharon .J. Derr (Ed.), *Guidelines for video research in education: Recommendations from an expert panel*. Chicago, IL: Data research and Development Center Chicago.
- Beresford, B., Rabiee, P., & Sloper, P. (2007). Outcomes for parents with disabled children. Research Works, 2007-03, Social Policy Research Unit. York: University of York.
- Boris, E. (1994). Mothers are not workers: Homework regulation and the construction of motherhood, 1948-1953. In Glenn, E. N., Chang, G. and Forcey, L. (Eds.). *Mothering: Ideology, Experience and Agency*. New York: Routledge. pp. 161-180.
- Boyer, K. (2011). The way to break the taboo is to do the taboo thing”: Breastfeeding in public and citizen-activism in the UK. *Health and Place*, 17(2), 430-437.
- Boyer, K. (2012). Affect, corporeality and the limits of belonging: Breastfeeding in public in the contemporary UK. *Health and Place*, 18(3), 552-560.
- Bowlby, S. (2012). Recognising the time-space dimensions of care: Caringscapes and carescapes. *Environment and Planning A*. 44(9), 2101-2118.
- Cahill, P. & Papageorgiou, A. (2007). Video analysis of communication in paediatric consultations in primary care. *British Journal of General Practice*, 57(544), 866-871.
- Caldwell, K. & Atwal, A. (2005) Non-participant observation: Using video tapes to collect data in nursing research. *Nurse Researcher*, 13(2), 42-54.

- Carnevale, F. A., Alexander, E., Davis, M., Rennick, J. E., & Troini, R. (2006). Daily Living with Distress and Enrichment: the Moral Experience of Families with Ventilator Assisted Children at Home, *Pediatrics*, *117*(1), e48–60.
- Carnevale, F. A., Rehm, R. S., Kirk, S., & McKeever, P. (2008). What we know (and do not know) about raising children with complex continuing care needs. *Journal of Child Health Care*, *12*(1), 4-6.
- Carter, B., Arnott, J., Simons, J. & Bray, L. (2017). Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives. *Pain Research and Management*.
- Carter, B. & Bray, L. 2016. How caring for a child with complex health needs can be both isolating and extraordinary. Available at: <https://theconversation.com/how-caring-for-a-child-with-complex-health-needs-can-be-both-isolating-and-extraordinary-66651>. [Accessed 01/02/2018].
- Carter, B.. & Bray, L.. (2017) Parenting a Child With Complex Health Care Needs: A Stressful and Imposed “Clinical Career”. *Comprehensive Child and Adolescent Nursing*, *40*(4), 219-222.
- Chan, A. (2008). ‘Life in Happy Land’: Using virtual space and doing motherhood in Hong Kong. *Gender, Place and Culture*, *15*(2), 169-188.
- Clement, S. & Waitt, G. (2017). Walking, mothering and care: a sensory ethnography of journeying on-foot with children in Wollongong, Australia. *Gender, Place & Culture*, *24*(8), 1185-1203.
- Clement, S., & Waitt, G. (2018). Pram mobilities: affordances and atmospheres that assemble childhood and motherhood on-the-move. *Children's Geographies*, *16*(3), 252-265.
- Choi, P., Henshaw, C., Baker, S., & Tree, J. (2005). Supermum, superwife, supereverything: performing femininity in the transition to motherhood. *Journal of Reproductive and Infant Psychology*, *23*(2), 167-180.

- Derry, S.J. (2007). Guidelines for video research in education. Recommendations from an expert panel. Chicago, IL: Data Research and Development Center Chicago. Retrieved from: <https://drdc.uchicago.edu/what/video-research-guidelines.pdf>
- Douglas, S. and Michaels, M. (2005). *The mommy myth: The Idealization of Motherhood and how it has Undermined all Women*. New York, NY: Simon & Schuster.
- Dowling, R. (2000). Cultures of mothering and car use in suburban Sydney: a preliminary investigation. *Geoforum*, 31(3), 345-353.
- Dyck, I., Kontos, P., Angus, J. and McKeever, P. (2005). The home as a site for long-term care: Meanings and management of bodies and spaces. *Health & Place*. 11(2), 173-185.
- Friedman, M. (2013). *Mommyblogs and the Changing Face of Motherhood*. Toronto: University of Toronto Press.
- Evans, R. (2012). Sibling caringscapes: Time–space practices of caring within youth-headed households in Tanzania and Uganda. *Geoforum*, 43(4), 824-835.
- Gibson, B. (2005). Co-producing video diaries: The presence of the “absent” researcher. *International Journal of Qualitative Methods*, 4(4), 34-43.
- Goffman, E. (1959). *The Presentation of Self in Everyday Life*. London: Penguin Books.
- Goffman, E. (1981). *Forms of Talk*. Pennsylvania, University of Pennsylvania Press.
- Green, S. E. (2007). “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64(1), 150-163.
- Ekinsmyth, C. (2011). Challenging the boundaries of entrepreneurship: The spatialities and practices of UK ‘Mumpreneurs’. *Geoforum*. 42. (1). pp. 104-114.

- Ekinsmyth, C. (2013). Managing the business of everyday life: The roles of space and place in “mumpreneurship”. *International Journal of Entrepreneurial Behaviour & Research*. 19. (5). pp. 525-546.
- Hrdy, S. B. (1999). *Mother Nature*. Cambridge: Harvard University Press.
- Hays, S. (1996). *The Cultural Contradictions of Motherhood*. New Haven, CT: Yale University Press.
- Holditch-Davis, D., Miles, M. S., Burchinal, M. R., & Goldman, B. D. (2011). Maternal role attainment with medically fragile infants: Part 2. relationship to the quality of parenting. *Research in Nursing & Health*, 34(1), 35-48.
- Holloway, S. L. (1998). Local childcare cultures: Moral geographies of mothering and the social organisation of pre-school education. *Gender, Place and Culture: A Journal of Feminist Geography*. 5(1), 29-53.
- Holloway, S. L. and Pimlott-Wilson, H. (2014). “Any advice is welcome isn’t it?”: Neoliberal parenting education, local mothering cultures, and social class. *Environment and Planning A*. 46(1), 94-111.
- Jang, J. and Dworkin, J. (2014). Does social network site use matter for mothers? Implications for bonding and bridging capital. *Computers in Human Behavior*. 35, 489-495.
- Jones-Berry, S. (2015). Social media campaign highlights lack of expert care provision for parents. *Nursing Children and Young people*, 27(10), 7.
- Kearney, P. M. & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582-592.
- Keilty, K., Nicholas, D., & Selkirk, E. (2018). Experiences with unregulated respite care among family caregivers of children dependent on respiratory technologies. *Journal of Child Health Care*, 22(1), 46-56.

- Kirk, S. & Glendinning, C. (2002). Supporting 'expert' parents – professional support and families caring for a child with complex health care needs in the community. *International Journal of Nursing Studies*, 39, 625-635.
- Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or Nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing*, 51(5), 456-464.
- Kvarme, G. L., Albertini-Früh, E., Brekke, I., Gardsjord, R., Halvorsrud, L., & Liden H. (2016). On duty all the time: Health and quality of life among immigrant parents caring for a child with complex health needs. *Journal of Clinical Nursing*, 25(3-4), 362-371.
- Lane, R. (2014). Healthy discretion? Breastfeeding and the mutual maintenance of motherhood and public space. *Gender, Place & Culture*, 21(2), 195-210.
- Lindahl, B., Lindblad, B., Institutionen för Vårdvetenskap, & Högskolan i Borås. (2013). Being the parent of a ventilator-assisted child: Perceptions of the Family–Health care provider relationship when care is offered in the family home. *Journal of Family Nursing*, 19(4), 489-508.
- Longhurst, R. (2013). Stretching mothering: Gender, space and information communication technologies. *Hagar*, 11(1), 121-138.
- MacAllister, L. (2016). Feeling, caring, measuring, knowing: The relational co-construction of parenting knowledges. *Children's Geographies*, 14(5), 590-602.
- Madge, C. (2007). Developing a geographers' agenda for online research ethics. *Progress in Human Geography*, 31(5), 654-674.
- Madge, C. and O'Connor, H. (2005). Mothers in the making?: exploring liminality in cyber/space. *Transactions for the Institute of British Geographers*, 30(1), 83-97.
- Madge, C. and O'Connor, H. (2006). Parenting gone wired: Empowerment of new mothers on the internet? *Social and Cultural Geography*. 7(2). pp. 199-220.

- Marshall, H. (1991). The social construction of motherhood: An analysis of childcare and parenting manuals, in: Ann Phoenix, Anne Woollett & Eva Lloyd (Eds). *Motherhood: Meanings, Practices and Ideologies*. London: Sage. pp. 66-85.
- Martin, G.P., Nancarrow, S.A., Parker, H. et al. Place, police and practitioners: On rehabilitation, independence and the therapeutic landscape in the changing geography of care provision to older people in the UK. *Social Science & Medicine*. 61. (9). 1893-1904.
- May, K.M. (1997). Searching for normalcy: Mothers' caregiving for low birth weight infants. *Pediatric Nursing*, 23(1), 17-25.
- McCann, D., Bull, R., & Winzenberg, T. (2016). Brief report: Competence, value and enjoyment of childcare activities undertaken by parents of children with complex needs. *Journal of Pediatric Nursing*, 31(2), e127-e132.
- McKeever, P. & Miller, K. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science & Medicine*, 59(6), 1177-91.
- McKie, L., Gregory, S. and Bowlby, S. (2002) Shadow times: The temporal and spatial frameworks and experiences of caring and working. *Sociology*, 36(4), 897-924.
- McKie, L., Gregory, S., & Bowlby, S. (2004). Caringscapes: experiences of caring and working [online]. Available at: <https://era.ed.ac.uk/handle/1842/2807> [accessed 31/12/2019].
- Miller, T. (2007). "Is this what motherhood is all about?": Weaving experiences and discourse through transition to first-time motherhood. *Gender and Society*, 21(3), 337-356.
- Nicholl, H. (2015) 'Going between worlds': Travelling with children with complex needs. *Journal of Child Health Care*. 19(3): 293-303.
- Nygård, C., & Clancy, A. (2018). Unsung heroes, flying blind—A metasynthesis of parents' experiences of caring for children with special health-care needs at home. *Journal of Clinical Nursing*, 27(15-16), 3179-3196.

- O'Hagan, C. (2014). Working and mothering: interlocking locations in the caringscape. *Families, Relationships and Societies*, 3(2), 201-217.
- Orton-Johnson, S.A. (2015). 'Intimate mothering publics': Comparing face-to-face support groups and Internet use for women seeking information and advice in the transition to first-time motherhood. *Culture, Health and Sexuality*. 17(2), 237-251.
- Orton-Johnson, K. (2017). Mummy blogs and representations of motherhood: "Bad mummies" and their readers. *Social Media + Society*, 3(2), 1-10.
- Parker, B. & Morrow, O. (2017). Urban homesteading and intensive mothering: (Re) gendering care and environmental responsibility in Boston and Chicago. *Gender, Place & Culture*, 24(2), 247-259.
- Pederson, S. (2016). The good, the bad and the 'good enough' mother on the UK parenting forum mumsnet. *Women's Studies International Forum*, 59: 32-38.
- Redmond, B. & Richardson, V. 2003. Just getting on with it: Exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16(3), 2015-218.
- Richardson, D. 1993. *Women, Motherhood and Childrearing*. London: Macmillan.
- Rokka, J. (2010). Netnographic inquiry and new translocal sites of the social. *International Journal of Consumer Studies*, 34(4), 381-387.
- Rose, G. 2003. Family photographs and domestic spacings: A case study. *Transactions of the Institute of British Geographers*, 28(1), 5-18.
- Royal College of Nursing. 2014. Defining Nursing 2014. Available at: <https://www.rcn.org.uk/professional-development/publications/pub-004768>. [Accessed 30/07/2019].
- Skinner, D., Bailey Jr, D. B., Correa, V, & Rodriguez, P. (1999). Narrating self and disability: Latino mothers' construction of identities vis-à-vis their child with special needs. *Exceptional Children*, 65(4), 481-495.



Sparks, H., Collins, F.L. and Kearns, R. (2016). Reflecting on the risks and ethical dilemmas of digital research. *Geoforum*, 77, 40-46.

von Benzon, N. (2018). Informed consent and secondary data: Reflections on the use of mothers' blogs in social media research. *Area*, 1-8.

Williams, A. (2002). Changing geographies of care: Employing in the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine*. 55(1), 141-154.

Winnicott, D. W. (1960). The theory of the parent-infant relationship. *International Journal of Psychoanalysis*. 41(6), 585-595.

Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B. B & Rempel, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, 15(1), 197.

Zimmer, M. (2010). "But the data is already public": On the ethics of research in Facebook. *Ethics and Information Technology*, 12(4), 313-325.