Title: The meaning of 'place' in families' lived experiences of paediatric outpatient care in different settings: A descriptive phenomenological study

Short Manuscript Title: The meaning of place in paediatric outpatient care

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Abstract

Health service reforms in the United Kingdom have sought to ensure that children and young people who are ill receive timely, high quality and effective care as close to home as possible. Using phenomenological methods, this study examined the experience and impact of introducing new, community-based paediatric outpatient clinics from the perspective of NHS service-users. Findings reveal that paediatric outpatient 'care closer to home' is experienced in ways that go beyond concerns about location and proximity. For families it means care that 'fits into their lives' spatially, temporally and emotionally; facilitating a sense of 'at-homeness' within the self and within the place, through the creation of a warm and welcoming environment, and by providing timely consultations which attend to aspects of the families' lifeworld.

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Introduction

Part of the vision of the UK National Service Framework for Children and Young People (2004) was to ensure that young people who are ill receive timely, high quality and effective care as close to home as possible. This was presented in policy documents as a way of improving access to specialist healthcare, increasing patient satisfaction and relieving demand on hospital services (DH, 2006). Many evaluations of Care Closer to Home (CCTH) however, focus on adult health services (Bowling et al., 1997, Black et al., 1997, Bond et al., 2000, Bowling and Bond, 2001, Sibbald et al., 2007, 2008) which may not be transferable to the provision of care for children and young people. Studies specifically evaluating the movement of paediatric healthcare into community settings are few, particularly those exploring outpatient clinics from the perspectives of parents and patients.

A mixed method evaluation of service models providing paediatric CCTH focusing on preventing inpatient admission and reducing length of stay in hospital, found that CCTH delivers similar clinical outcomes for children, at no extra cost to families (Parker et al., 2011). Although this research offers a valuable contribution to the under-developed evidence-base for paediatric CCTH, its emphasis on 'inpatient' care delivered at home fails to address gaps in the literature regarding alternative settings for paediatric outpatient care. Moreover, only one child was recruited for the qualitative arm of the study; hence the views and experiences of young people on receiving CCTH remain largely unknown. The paucity of evidence describing or evaluating community-based paediatric outpatient clinics could be explained by the 'low profile' outpatient services have in comparison to other areas of clinical practice (Dodd and Newton, 2001) and the under-representation of children and young people in the literature more generally (La Valle et al., 2012). One study which has

explored the provision of consultant-led paediatric outreach clinics (Spencer, 1993) reported that such models could improve access, while "facilitating effective patient management and clinical decision making particularly in deprived areas where the need is greatest" (p.500).

Despite the spatial nature of UK policy initiatives recommending specialist healthcare be provided closer to patients' homes, reforms have proceeded with little regard for the location of services, or people's experiences of those locations. Moreover, there have been few attempts to systematically investigate those aspects of place which matter most in healthcare (Poland et al., 2005). Subsequently, the notion of 'place' has been neglected in many health service evaluations, which have instead opted to focus on the philosophy of care (Moore et al., 2013). Shifting the place of healthcare delivery from hospital to the community is likely to affect service use, patient experience and professional practice because 'place' is increasingly understood to hold complex, shared and unique meanings (Casey, 2001, Cresswell, 2009). For example, a study of health professionals' views on providing paediatric CCTH found that place and professional identity were intimately related, with implicit assumptions made about where high quality of care and clinical expertise are located (Heath et al., 2012). Understanding the place of care and its ascribed meanings is therefore imperative to understanding the impact of health service de-centralisation on families and staff (Kearns and Joseph, 1993).

Different disciplines have developed different theoretical perspectives on place. One strand of the literature has roots in phenomenological philosophy (Manzo, 2005). Phenomenology is the study of human experience with the aim of examining and describing events, meanings and experiences as they are known in everyday life, but typically unnoticed

beneath the level of conscious awareness (Husserl, 1936/1970, Seamon, 2000). The concept

of a pre-reflective lived world or 'lifeworld' was developed by Husserl, emerging from his

critique of modern science and philosophy. To investigate, analyse, and articulate nuances

of the lifeworld, four dimensions or existential constituents have been emphasised: 'lived

space' (spatiality); 'lived time' (temporality); 'lived body' (embodiment); and 'lived other'

(inter-subjectivity). These dimensions attend to the experiential nature of how time, space,

body and the social world are actively lived and given meaning beyond attempts at

objectification or measurement. For a more detailed explanation of lifeworld theory, see

Merleau-Ponty (1962), Todres et al (2009) and Svenaeus (2000).

It is from this lifeworld perspective that phenomenologists move away from the

objectification of place (i.e. interpreting place as an objective environment outside of

experiencers) (Million, 1996), towards a rich understanding of person-place intimacy that

escapes any subject-object dichotomy. Much of this work builds on Husserl's notion of

intentionality whereby consciousness is always consciousness *of something* and Heidegger's

notion of 'dwelling' as a particular way of being, where people are inseparable from the

world, and thus all knowledge and meaning is embedded and emplaced within it (Seamon,

2000). In the 1970s phenomenological geographers (e.g. Tuan, 1977, Relph, 1976, Seamon,

1979) directed attention towards the everyday, taken-for-granted nature of place and its

significance as a feature of human life (Seamon and Sowers, 2008).

As a result empirical studies have begun to consider healthcare settings as more than their

physical location and material environment. For example, research exploring the provision

of hospital care in patients' homes demonstrates that the experience of 'homeliness' can be

disturbed by medical technologies and healthcare professionals (Angus et al., 2005, Moore

et al., 2010, Lindahl and Lindblad, 2011), and that the meaning of home can change over the course of illness, from a therapeutic to a non-therapeutic place (Donovan and Williams, 2007). The therapeutic nature of an environment is therefore argued to be dependent on a person's "physical, psychological and social meanings of place" (Martin et al., 2005, p.1893). This finding is supported in a study of older people's experiences of hospice day care (Moore et al., 2013), demonstrating that within the context of health and illness, individuals purposefully re-construct places as therapeutic, in order to achieve a sense of 'homelikeness' within themselves (Svenaeus, 2001).

Despite increasing conceptualisations of place as "as an operational 'living' construct" (Kearns and Moon, 2002, p.609), there remains a dearth of knowledge regarding how place contributes to healthcare experience and how healthcare contributes to place experience (Kearns and Joseph, 1993, Williams, 1998). This is particularly the case for paediatrics. Moreover, while patients' direct experiences of care are recognised as a unique and valuable source of information that should be positioned at the heart of service transformations (National Institute for Health and Care Excellence, 2012), evidence for the systematic inclusion of young people's experiences in service improvements is lacking (Hargreaves and Viner, 2012, La Valle et al., 2012). By enhancing understanding of the meanings that places hold for patients and parents, it may be possible to understand why families experience CCTH as they do. This information could be used to develop acceptable and effective CCTH services for children and young people.

As part of a wider programme of research, the aim of this study was to describe paediatric outpatient care as experienced by paediatric patients and parents, focusing on how the place of care delivery impacted on the experience of care. The study was carried out in

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collaboration with a UK specialist children's hospital, and formed part of an evaluation of its consultant-led General Paediatric outpatient clinics delivered in community settings; one in a family doctors' health centre located 5.3 km from the hospital, the second in a 'Sure Start' children's centre providing a range of support services for families (e.g. childcare, early education, financial advice) and located 9.5km from the hospital. Other components of the evaluation included: studies of clinic effectiveness and efficiency; staff views on paediatric CCTH (Heath et al., 2012); an investigation of factors associated with non-attendance at paediatric outpatient appointments (Cameron et al., 2013).

Methodology

The study was underpinned by descriptive phenomenology, which can be defined as both a philosophical approach and range of methods concerned with how things appear to us in our experience, with a focus on the lived world and its meanings (Langdridge, 2007). Following Husserlian philosophy, the aim of descriptive phenomenology as a research methodology is to gain deeper understandings of the meaning of everyday lived experiences, by describing the essential structure of the phenomenon being studied.

What is appealing about descriptive phenomenology for the study of health service improvement is that it provides a means of informing care at practice and policy levels on the basis of concrete descriptions of people's lived experiences (Todres et al., 2007, Dahlberg et al., 2009). Consequently, the approach does not rely on respondents to produce articulated views, but makes use of their complex and multi-layered lived experience as a source of knowledge. Findings of this kind also permit movement from individual experiential accounts to a general, shared structure of the phenomenon, while retaining idiographic variations.

Recruitment and sampling

A favourable opinion from West Midlands NHS Research Ethics Committee was given for the family recruitment strategy, which included approaching families in General Paediatric clinic waiting areas and sending letters to families who had received a General Paediatric appointment. Parents and young people were purposively selected on the basis of their experience of attending General Paediatric outpatient appointments in one of three settings under investigation (hospital, health centre, children's centre). In line with Giorgi's (2009) recommendation of including at least three participants with experience of the phenomenon, we recruited participants who shared experiences of one of the settings, but who varied on a range of demographic characteristics including age, sex and ethnicity, employment status and distance of home from the main hospital. This enabled us to identify differences between participants' accounts, making it easier to distinguish aspects of the experience that were invariant and those which varied (Finlay, 2009). Although there is no official lower age limit at which children can participate in qualitative research (Shaw et al., 2011), the depth and detail of recounted experience needed for descriptive phenomenological analyses would have been difficult to achieve with very young children, and would have required more creative methods of data collection (Shaw et al., 2011). A lower age limit of (approximately) 8 years was therefore set.

Data Collection

Consistent with the philosophical underpinnings of descriptive phenomenology, individual interviews were conducted to elicit concrete, detailed descriptions of participants' experiences of paediatric outpatient care (Giorgi, 2008, Englander, 2012). Each interview started with a 'grand tour question' (Leech, 2002) (e.g. Can you tell me a bit about why

you/your child attended the outpatient clinic?), followed by an invitation to the participant to describe in detail the experience of their/child's last outpatient appointment. Subsequent questions were tailored to participant responses, mainly serving to clarify understanding and prompt for detail.

Interviews were carried out at a time and location that was convenient for the participant (e.g. participant's home, Children's Hospital, a nearby University or community centre). Most participants chose to be interviewed in their homes. This had advantages of being a relaxed and familiar environment, providing context of the participant's lifespace (Sin, 2003) and redistributing power from the researcher to the respondent (Elwood and Martin, 2000). Three interviews took place at the hospital. This environment provided fewer distractions, but felt more impersonal, which may have influenced participants' responses.

Informed consent was obtained from parents who were participating themselves and from the parents of participating young people. Informed assent (agreement to participate) was also obtained from young people participants (Phelan and Kinsella, 2013, Fargas-Malet et al., 2010). Throughout data collection, the researcher aimed to appear friendly and interested, apprehending the phenomenon by reflecting back understandings to check for shared meaning (Taylor, 2005). Participants were also prompted to explain commonly used, descriptive words, thus suspending the researcher's assumptions, in order to reveal the experience as it appeared to the participant (Jasper, 1994).

Data analysis

Data analysis followed the steps set out in Giorgi's (2009) descriptive phenomenological method. This required the researcher to assume the attitude of the 'phenomenological

reduction' throughout the analytic process. The aim of the phenomenological reduction is to retain openness to the phenomenon so as to see it in a new way (Dahlberg et al., 2008). This meant acknowledging existing understandings (developed from theoretical knowledge and personal experiences) and then engaging in a process of both restraining those pre-understandings and using them as a source of insight (Finlay, 2009). Attempts were also made to refrain from making judgments about the importance of different features of the phenomenon by treating them with equal importance (Langdridge, 2007).

Within the phenomenological attitude, audio-recorded interviews were transcribed verbatim. Transcripts were read to obtain a sense of the data as a whole. Each transcript was then re-read with a focus on discriminating units of meaning within the description. This was carried out by marking with a slash in the text every time a significant change of meaning was observed. At the end of this process, transcripts were divided into a series of meaning units guided by the data itself. Following the identification of meaning units, raw data were transformed from the participant's 'natural attitude' into more phenomenologically sensitive and meaningful expressions. The aim here was to reveal meanings that were lived but not necessarily explicitly articulated, and to move from specific descriptions of concrete situations to more general expressions (Giorgi and Giorgi, 2003). Following transformations, meaning units that seemed to belong to together were 'clustered' into groups, before clusters were rearranged to create a preliminary pattern of understanding (Dahlberg et al., 2008).

The text was then treated as a whole once again. Individual structures of the outpatient experience were synthesised into a general structure for families' experiences of paediatric

outpatient care received in the hospital and in 'closer to home' community settings. These structures presented a statement of the invariant themes that ran through each participant's experience of that phenomenon, thus determining those parts which were typically essential. The two structures were then compared and variations highlighted.

Findings and discussion

Participants

Seven parents and eight young people provided descriptions of their experiences of receiving outpatient care at the hospital, and six parents and six young people did the same for their experiences of receiving outpatient care at one of the two community-based clinics. Parent participants were not related to the young people participants, thereby providing a wider range of experiences. There was also variation in participants' ethnicity, age and how close in proximity they lived to the Children's Hospital. All parent participants were mothers, which reflected the gender of the majority of parents accompanying their child to outpatient appointments.

Findings

Essential structures for General Paediatric outpatient care in hospital and community settings are described followed by a discussion of the main constituents: *time wasted, time saved; therapeutic environment; interpersonal interactions; adolescent needs – all is forgotten; my community, not the community.*

General Paediatric outpatient care at the Children's Hospital

Attending a hospital outpatient appointment requires considerable mental and physical preparation. The unpredictable nature of the appointment means that allocation of time is difficult to estimate. This causes disruption to the family routine, with activities of daily life requiring re-construction around the child's appointment. Hospital outpatient care is experienced as more than just the appointment. It is an event which governs the family's life for that entire day and those leading up to it. When appointments are impending, families feel torn between a desire to access specialist paediatric healthcare and the dread of enduring the whole procedure. After a hectic journey, hampered by heavy traffic and lack of time, families arrive at the outpatient department. Leaving behind their sense of identity and autonomy, they step into a vast, self-governing and all-embracing space, bursting with people, noise and colour. Giving themselves over to a time and activity schedule not of their making, families are guided through various administration checks and processes, before being instructed to find a seat amongst the chaos of people and toys. Waiting is briefly relieved by a nurse calling for routine measurements to be taken, before the family is escorted to another, calmer area to resume waiting. When it eventually comes, the care provided by a Specialist Paediatrician is succinct, but does provide the kind of compassionate reassurance that families crave. After the appointment families seek out pleasurable activities to restore equilibrium, always striving towards the point at which medical intervention is no longer required.

General Paediatric outpatient care in community settings

Attending a community-based outpatient clinic is a fairly insignificant activity within the family's hectic life. As time allocated for the appointment is contained to a manageable amount, families feel able to balance attending their child's appointment alongside other

activities of daily living. An existing, trusted relationship with the Consultant Paediatrician helps to alleviate anxieties about the quality of care provided at an alternative location. As clinics are embedded within the community, they are experienced as a familiar part of the family's everyday surroundings. Comfortable and convenient travel and parking also help to ease the burden of attending appointments. On arrival, the process is relaxed, but efficient. A pleasant, uncluttered and informal environment contributes to a calm atmosphere in which families feel 'at home' and 'at ease'. Waiting areas are small and intimate, but adequately sized for the amount of people. Being seen promptly at their allotted time leads to families feeling that they are respected and their time is valued. Unhurried and unpressured by time and space, the clinician and family engage in meaningful dialogue, working towards a shared understanding of the child's health condition, within the context of the families' unique and subjective world. Such an empathic approach supports families on their journey towards wellbeing. After the consultation, families return to their everyday activities with minimal disruption to their usual routine.

Constituents

Time wasted, Time Saved

Fitting appointments into families' hectic lives, together with the hassle of difficult to find parking spaces and unreliable public transport contributes to feelings of stress for parents attending the hospital for their child's outpatient appointment. The highly unpredictable nature of hospital-based care means that a whole day is allocated to the appointment, as families feel unable to plan for or do anything else that day.

> *"I know it's going to be hours and even if the others are at school I still need to organise child care because you just can't guarantee what time you're going to be back." (Parent 6)*

The hospital outpatient department is anticipated to be extremely busy with long waiting times. To prepare, parents try to equip themselves with enough refreshments and entertainment to keep their children satisfied. The aim is to complete the appointment as quickly and as smoothly as possible:

> *"I just want to get in and out and not have the whole drama of going to the hospital and then trying to find parking and paying umpteen pounds and waiting for hours." (Parent 5)*

Preparation is less cumbersome for young people, who often view their appointment as an opportunity to avoid school; relying on long waiting times to capitalise on the amount of school missed. Nevertheless, multiple appointments during school time can severely disrupt learning. Community-based clinics in contrast, allow families to attend appointments without experiencing significant disruption to their usual routine. In this way, care closer to home is more convenient; it facilitates the careful balancing of work, school and other child-care commitments, alongside paediatric outpatient appointment attendance.

Time spent waiting is experienced as unproductive, 'wasted' time, leading parents and older children to feel consumed by feelings of irritation and boredom. Little indication of how long the waiting will last further contributes to the experience of time passing slowly.

> *"We had to wait quite a long time, and that is my experience of the outpatients, I have had to wait a long time, the clinics are usually running late... I felt restless, I felt like I just wanted to go up and say how much longer am I going to have to wait?" (Parent 4)*

> *"I was sitting there thinking how bored and what a waste of time it was just sitting there for ages but, like, I didn't really have anything to do so I just sat there and waited." (YP 1, age 14)*

Time is 'saved' at community-based clinics, as they provide easier and more convenient access to specialist care during the allocated time slot.

A therapeutic environment

At community-based clinics, families are struck by the absence of a large and chaotic waiting area which characterises the hospital outpatient department. For young children, this vibrant environment constitutes an exciting space in which to play; for parents and older children it makes for uncomfortable waiting. In contrast, the calmer atmosphere, domestic-like rooms and soft furnishings of 'closer to home' clinics help to create a sense of homeliness, leading to families feeling 'at-ease' in their surroundings. This helps to restore coherence at a time when uncertainty often surrounds the child's health status.

> *"It was friendly, really bright, well it wasn't scary. The hospital I find can be quite daunting especially for (daughter); it's very noisy and echoey, lots going on. It's quite calm at the children's centre, even though there are people doing different things, you know everyone smiles and says hello and it's just a welcoming atmosphere, which I think puts (daughter) at ease definitely." (Parent 9)*

> *"Even though (community clinic) is small, it's big in a way because there's loads of room to move around in like, so I feel more comfortable and less claustrophobic there." (YP 9, age 11)*

The CCTH environment thus enables families to feel comfortable and relaxed, particularly during the clinical interaction. Not only then are the mechanical processes of outpatient care improved in community settings, but the relational aspects are too.

> *"It's just nice and relaxing when you go in there, you know it doesn't feel like you're going in to see a Consultant, you're, it's just like you're going in to see your own GP.*

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It's less pressure, it makes you feel more relaxed... If you're up tight then you don't get to the problems and sorting things out because you feel nervous and everything. If you feel relaxed you're like, you're more prone to open up about things and relax in a situation and say what you feel." (Parent 8)

For families with small children however, community clinics fail to deliver the excitement and exclusivity that the Children's Hospital provides. For parents with much younger children, this can mean a trade-off between convenience and experience. For some, the absence of medical technologies also serves to undermine community settings as legitimate places for paediatric outpatient appointments; leading to decreased confidence in the quality of care provided.

"It's ok, don't get me wrong but like it's not, it's not a place where I would say I would see a Consultant if you know what I mean. It's not like a very doctorly environment sort of thing... it's just a room basically with a doctors bed, like thing in and then a computer and chairs and toys and that is about it and it's not like a hospital or a doctor's place." (Parent 10)

Variations regarding the appropriateness of place are also experienced in relation to health status. For example patients who feel unwell or symptomatic of illness desire the kinds of reassurance that being in a medical environment with immediate access to investigations provides. Asymptomatic patients are less concerned about their consultation being carried out in a non-medical setting. Continuity of healthcare professional however is important and significantly contributes to decisions regarding where outpatient appointments are accessed.

Interpersonal interactions

As time with the Consultant is less restricted in community clinics and the environment less frantic, families feel able to discuss their child's condition in a more meaningful way.

> *"When you've waited a long time (at the hospital) and you're aware of all the other people waiting, it's very difficult because you then try and rush everything through because you're aware there's everybody else sitting outside waiting… you don't do it justice if you know what I mean, you don't feel that you can spend the time you want to." (Parent 5)*

Delivery of healthcare is experienced as satisfactory by families when the Consultant presents as welcoming and respectful of families' views and beliefs. Some excellent practitioners also demonstrate intrinsic qualities that make them special, including the ability to intuitively understand families' needs and concerns.

> *"(Consultant) has got that magic touch… I was happy that my child is open for the first time in her life talking to a doctor about inside her what her feelings were." (Parent 7)*

> *"She (Consultant) was kind, it was like a, do you know it was like a one-to-one, like when you have a conversation with your friends, it's nice, it was good, I felt like I could talk to her openly." (YP 14, age 15)*

Parents and patients experience dissatisfaction with healthcare when the clinician's medical understanding conflicts with the parent's intuitive understanding. Interactions with other staff members are considered just as important by families to the overall healthcare encounter and are experienced as positive when reception and support staff are polite and cheerful.

Adolescents' needs - all is forgotten

Adolescents' accounts of their experiences of receiving outpatient care were saturated with feelings of neglect and exclusion, regardless of setting, suggesting that their needs are unaccounted for both in the Children's Hospital which focuses on young children and in community-clinics that are more appropriate for adults.

"There's only stuff there (hospital outpatients) for toddlers, there's nothing there for my age or people older than me, there's nothing there for people like us, there's only toddlers and children's areas, that's it, there's nothing much else there to be honest." (YP 8, age 15)

"When it comes to like my age, there's nothing for us to really do, I just end up sitting there" (YP 9, age 11)

Young people desired adolescent-focused outpatient clinics that did not interfere with their education and that provided the opportunity to be with people who were similar in age and illness experience.

My community, not the community

Participants expressed the importance of local clinics being in their own community and not just in *the* community. This was not only because of the convenience of travel and time, but for those who experienced them, community-based clinics presented families with an opportunity to develop relationships with the people and places of their communities.

"My son was playing and she started talking to my son and I feel ok she is from my community and I can talk to her." (Parent 12)

"It's part of my community. It's just around the corner and like when you go to school or something you go past it, you see it and I'm used to it being there." (YP 14, age 15)

Moreover a physical repositioning of the consultant outside of the hospital was regarded as an effort to connect with the family in their lifeworld context. Extending into the clinic consultation room, this means that consultations which take place in community-based clinics are experienced as more empathetic towards the family perspective.

Discussion

Findings reveal that paediatric outpatient CCTH is experienced in ways that go beyond concerns about location and proximity. For the families interviewed, it means care that 'fits into their lives' spatially, temporally and emotionally; facilitating a sense of 'at-homeness' within the self and within the place, through the creation of a welcoming environment, and by providing timely consultations which attend to aspects of the families' lifeworld.

Although existing theories relating to the phenomenon were set aside during data analysis (Ahern, 1999), existential constituents of lived 'time' (temporality), 'space' (spatiality) and 'other' (inter-subjectivity) became increasingly apparent. Interrogating findings in light of these philosophical notions of the lifeworld was therefore productive for facilitating understanding of the phenomenon as it emerged (Rich et al., 2013).

Temporality

Time was an important feature for families attending paediatric outpatient appointments. Time was discussed in terms of appointment scheduling, journey, waiting, consultation and time spent away from family, work or school. Essentially, community-based clinics allowed time to be 'saved', whereas long journey and waiting times at the hospital meant that time was often 'wasted'. It is possible to understand this concept of 'time wasted, time saved' by looking more closely at time perception. Husserl (1917/1991) for instance, distinguished between objective, shared time as measured by clocks and calendars, and subjective time as a personal or inner experience.

Within the context of families' busy lives, where the planning and allocation of time for activities is crucial for managing various commitments, hospital-based appointments were experienced as difficult and disruptive, because of their unpredictable travel and waiting

times. This finding is consistent with other empirical studies of outpatient care for adults (Mitchell, 2011, Moran et al., 2009) and adolescents (Tivorsak et al., 2004, van Staa et al., 2011). Community-based clinics however, provided healthcare which 'fitted' into families' daily lives with little conscious awareness. *How* participants experienced their appointment time was also related to the setting they were in. For example, while waiting for their consultation, participants' perceptions of time appeared to slow down or speed up depending on how that time was spent (e.g. being bored or occupied), the quality of the waiting environment, the emotional state of the person waiting, and their feelings of control.

Spatiality

By retaining a closeness to families' homes in terms of proximity and through the provision of familiar, warm and welcoming surroundings, CCTH enabled families to experience a sense of comfort, security and unreflective ease (Todres et al., 2009). This was in stark contrast to the sense of alienation and 'dis-ease' parents and adolescents felt within the hospital setting. According to Seamon (1979), feelings of 'at-easeness' constitutes one of the five essential aspects of the experience of 'at-homeness'. Homeness in this sense is not necessarily a house or a shelter, but a distinct way of being (Moore et al., 2013).

Being 'at-ease' also refers to the freedom to be oneself without fear of repercussion and without having to display a particular public image (Seamon, 1979). While many parents found this freedom in CCTH clinics, and younger children in the hospital, adolescents felt un-easy about being themselves, regardless of the setting they were in. Nevertheless, consistent with other studies of young people's clinic preferences (Miller, 1995, Jacobson et al., 2001, Tivorsak et al., 2004, van Staa et al., 2011), adolescents generally favoured the

calmer, more 'home-like' surroundings that CCTH provided. Moreover, the meaning of the environing world was shown to vary according to age and health status. This was made clear by one of the adolescent participants who attended a new community-based clinic while feeling unwell. For her, a new and unfamiliar place led to a deep sense of vulnerability and 'unhomelikeness' (Svenaeus, 2001) both within the place and within herself (Moore et al., 2013).

According to Seamon (1979), appropriation involves a sense of emotional attachment, possession and control over places. In terms of outpatient CCTH, families demonstrated an appropriation of community-based clinics by emphasising the importance of clinics being in their own community. This was not only due to ease of accessibility, but because they provided an opportunity for people to meet in ways that enhanced their sense of community (Curtis, 2004). Moreover, the physical repositioning of the consultant outside of a medical institution was seen as a welcome awareness and responsiveness to the families' lifeworld context, thus bridging the gap between hospital and home.

Inter-subjectivity

Less restricted time, a more therapeutic environment, and being positioned closer to home, enabled families to discuss their child's condition in a more present and meaningful way. CCTH was thus shown to facilitate a model of care in which clinicians could be "open to the lifeworlds of their patients" (Dahlberg et al., 2009, p. 269). Applying Habermas's theory of communicative action to the patient-practitioner interaction, Mishler (1984 p.104) distinguishes between the "contextually-grounded" voice of the lifeworld and the distorted, impersonal voice of medicine, which he suggests are incompatible. Consistent with other observations of healthcare interactions (Coyle, 1999, Barry et al., 2001, Berglund et al.,

2012), families in this study experienced the ignoring or blocking of their voice in consultations as dehumanising and disempowering. In cases where the voice of the lifeworld was used by both doctors and families, consultations were shown to be more relaxed and grounded in everyday events, with a clear emphasis on working together to reach a common understanding. This facilitated a sense of equality and co-operation within the consultation. Such findings support and extend those of Shields et al (2006) who suggest that negotiation is central to achieving effective family-centred care.

Some practitioners in this study were described by participants as having intrinsic qualities that made them special, including an ability to intuitively understand families' concerns. It may be that these individuals had the capacity to operate in both the voice of medicine and that of the lifeworld, demonstrating an ability to oscillate between the two according to perceptions of patient preference. Further understanding might relate to clinicians operating within different organisational systems, given that delivering care outside of the hospital is subject to fewer constraints, professionals may have felt able to trial new ways of working (Heath et al., 2012) .

Implications for practice

Findings of this study hold implications for improvements to service design and delivery. From a family perspective, developing effective and acceptable community-based paediatric outpatient services will require consideration of place, space and time as lived constructs which impact on the experience of service-users. Attention should be directed to ensuring the clinic is responsive to the needs of the community in which it is located, that the clinic environment is comfortably furnished, and that it addresses the needs of both adolescents and younger children; that appointments are scheduled in such a way that they allow time

for dialogue and so can run to time; and that clinical interactions are empathic and attentive to the families' lifeworld perspective. These considerations developed through phenomenological enquiry which privileges the lifeworld are more than 'window dressing', detracting from the real business of delivering healthcare in times of financial constraint. Rather, they are intimately connected with professional healthcare practice and the meaningful-and possibly efficient- use of scarce healthcare resources through ensuring engagement and dialogue.

Methodological considerations

Trustworthiness was maintained through various strategies: keeping a clear and transparent audit trail, maintaining a reflexive diary, discussing emerging understandings within a team, and demonstrating a clear logic of enquiry (Dahlberg et al, 2008). In addition, a conscious decision was made not to engage deeply with previous research until after data analysis, with a view to remaining open to unexpected discoveries (Charmaz, 2006). Dahlberg et al (2008) argue that for qualitative research to be of use, findings must be generalisable to people outside of that study. Generalisability in qualitative research can be conceived of as the extent to which the concepts developed within one study may be exported to provide explanation for the "experiences of other individuals who are in comparable situations" (Horsburg, 2003, p.311). The findings of this study may be applicable to similar settings such as paediatric outpatient care provided by other healthcare organisations or parents and young people accessing services other than General Paediatrics. Findings may also transcend the healthcare context, to be applicable in any situation where place is ascribed meaning through human experience, and where experiences and interactions are shaped by the environment in which they are lived.

Concluding remarks

The findings of this study contribute to the under-developed evidence-base for paediatric CCTH. They demonstrate that from a child and parent perspective, the rationale underlying the policy is well-founded in its assumptions that families prefer CCTH, for reasons of improved access, convenience and overall experience. The findings support those of existing research on paediatric CCTH (Parker et al., 2011), but also extend them to include a community-based outpatient model of care, and add theoretical depth through the lens of 'place'. This has enabled previously taken-for-granted nuances of place and time to be highlighted in the experience of receiving paediatric healthcare. Findings further demonstrate how lifeworld theory and in particular, the existential constituents of temporality, spatiality, embodiment and inter-subjectivity can be used to deepen understanding of service-users' experiences. Such understandings can facilitate more meaningful and experientially grounded patient-led service improvements, in this case, providing consultations which care for the human order and 'therapeutic environments' (Gelser, 1991) which value the place of health service delivery as a social and symbolic landscape.

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