

'It doesn't feel like our house anymore': The impact of medical technology upon life at home for families with a medically complex, technology-dependent child.

## Abstract

The study aimed to identify how medical technology impacts upon the home and life at home. Inductive auto-driven photo-elicitation or semi-structured interviews were conducted with technology-dependent children/young people (n=2) and their family members (n=15) from 10 families. Thematic analysis generated three themes: Altered physicality and look of the home; Altered sounds in the home; and 'It's worth it! Technology enables us to stay as a family'. Fundamentally, the detrimental impacts of living with medical technology were perceived as worth it as these enabled their child to be at home. Home was not home, and families were incomplete without their child at home.

## Keywords

Child; Adolescent; Young Adult; Biomedical Technology; Medical Home; Photo-elicitation.

## 1. Introduction

Children who are technology-dependent are a small but growing subset of children with complex health care needs, also termed as medically complex (Barone *et al.*, 2020) or medically fragile children (Curran, Breneol and Vine, 2020). This population has almost trebled in England between 2001/02 and 2017/18, from 32,975 in 2001/02 to 86,625 in 2017/18 (Together for Short Lives, 2020). They are set apart by the high-cost (Maypole *et al.*, 2020), unpredictable (Jarvis *et al.*, 2016), substantial and long-term (Breneol *et al.*, 2019) level and nature of their needs (Kirk, 1999) and the 'extraordinary quantity and quality of care' that they require (Diehl *et al.*, 1991:170). Technology-dependence, in the context of this study, refers to medical technology which maintains the child's health status (Eaton, 2008), and prevents further disability or sustains their life (Nicholl *et al.*, 2013; Carter, Edwards and Hunt, 2015),

for example, long-term mechanical ventilators, continuous positive airway pressure, bilevel positive airway pressure (Spratling and Lee, 2020), oxygen saturation monitors, and feeding pumps (Nicholl *et al.*, 2013), as well as medicines that might be delivered intravenously (Carter *et al.*, 2018; Wilkinson *et al.*, 2020). Life-saving and non-medical equipment and consumables such as enteral and bladder catheters (de Lima, de Paulo and Higarashi, 2015), tracheostomy tubes, oxygen masks (Israelsson-Skogsberg *et al.*, 2018), nappies, wheelchairs and walkers (Nicholl *et al.*, 2013) are also often required by these children. This population of children tend to rely on more than one item of technology for their survival or to prevent further disability and a multitude of equipment and consumables that are required alongside this technology (Nicholl *et al.*, 2013). The use of each piece of technology or equipment can be ongoing, intermittent or in reserve for emergencies, used only occasionally, or for a few minutes a day to 24 hours a day. Technology-dependent children are set apart from, for example, children with diabetes, epilepsy or asthma, who may require extensive care, but only minimal equipment, so do not tend to be categorised as technology-dependent in the literature (Kirk, 1998; Floriani, 2010).

It can be extremely challenging for parents to manage the complex health care needs, any overlapping disability and/or special educational needs of their children at home (Worldwide Palliative Care Alliance and World Health Organization, 2014; Mitchell *et al.*, 2016). Parents also have to manage the equipment and resources required for their child's physiological and technological needs (Murphy, 2008), which can be stressful, especially given that errors in care 'can result in catastrophic outcomes' (Johnson *et al.*, 2021:911). Caring for their child at home is 'a significant component of daily life' for families (Nicholl *et al.*, 2013:234). Despite these challenges, families and health and social care professionals generally regard home rather than hospital to be the preferred and expected place of care.

Despite home-based care being the model of care for this diverse population of children since the late 1980's (Whiting, 2017), little is known about how medical technology impacts the home and life at home for family members.

## 2. Methods

### 2.1 Recruitment, setting and sampling

This study aimed to identify if and how medical technology impacts upon the home and life at home for technology-dependent children and young people (aged 5-25 years) with complex health care needs and their family members. A generic qualitative methodology (Percy, Kostere and Kostere, 2015) was selected for this study to obtain a broad understanding of how children and their families observe, make sense of and describe their home and life at home with medical technology. The methods selected (photo-elicitation and semi-structured interviews) were chosen as these methods have been shown to support children's cognitive and communication competencies during their interview (Mandleco, 2013; Vogl, 2015; González *et al.*, 2017; Castor *et al.*, 2018).

The decision about age range was based on the definition of child (0-18yrs) (HM Government, 2018) and other key factors. The minimum age of five years old was based on evidence from other studies who had used the methods selected that indicated that children aged 5 years and over would be able to engage effectively (Mandleco, 2013; Vogl, 2015; González *et al.*, 2017; Castor *et al.*, 2018). The rationale for the maximum age of 25 years for technology-dependent children and young people to take part was because the Children Act 2004 (HM Government, 2004) and Children and Families Act 2014 (HM Government, 2014) legislate that when a person aged under 25 needs 'more support than is available through special educational needs (and disabilities - SEND) support', they are included in the reference to a child, in addition to a person under the age of 18 (HM Government, 2018a).

A total number of 14 charity organisations, child and adult hospices in the UK and a Service User and Carer Council (at the host University) were approached to act as gatekeepers. Participants were recruited purposively. Family members could take part even when their

technology-dependent child, young person or adult did not wish or was unable to communicate or provide assent to take part, provided that the inclusion criteria were met (Table 1).

*Table 1: Inclusion Criteria*

Aged 5-25 years with a medical condition (i.e., the project is not condition specific) that causes them to use at least two pieces of medical technology, to monitor and treat their medical condition or sustain their life, and have used this technology for at least three months, at home in the United Kingdom or:
Parent (or a relative aged at least 5 years old) of a child, young person or young adult who meets the above criterion. If the parent or relative did not live with or care for the child, young person, or young adult in their own home, they must have provided some care for them in their home for at least three months.
Can speak/understand English sufficiently fluently to be able to tell me what life with medical equipment at home is like (using Augmentative and Alternative Communication (AAC) aids where necessary).
Can give informed assent/consent (note: parental consent was also obtained if the participant was under the age of 16).

## 2.2 Data Collection

Inductive face-to-face or telephone auto-driven photo-elicitation interview methods were used with the aim of empowering and engaging children and their family members (Ford *et al.*, 2017) to gain an understanding of their opinions about their home and life at home with medical technology. Auto-driven photo-elicitation was chosen as it involves the participant taking photographs and these photographs being used as a stimulus for conversation during an interview (Epstein *et al.*, 2006; Papaloukas, Quincey and Williamson, 2017). If participants did not wish to or could not take photographs, a semi-structured interview drawing on participatory principles was conducted (McLaughlin, 2012), and although an interview schedule was available, this was not used in a prescribed or rigid way.

All interviews took place for the family members in their homes and were digitally audio recorded. Informed written (or for telephone interviews, verbal) consent and/or assent was obtained before interviews commenced, using communication aids when necessary. Parents transferred the photographs (taken on their own device) to the lead researcher (TKM) via email prior to their interview.

A period of free narrative about general daily life supported the development of rapport between the participant and the researcher (TKM) before the interviews began. Parents chose to start their interviews with a chronology of their child's medical condition(s), health care needs and life. Participants taking part in photo-elicitation interviews were then asked to choose which photograph they wished to start the interview with. Participants taking part in semi-structured interviews were asked which piece of technology they would like to discuss first. Participants were asked why the photograph/technology they chose was important to them and/or how that technology represented their life with medical technology at home. All participants then chose which photograph or piece of technology they would like to discuss next, and the researcher followed the order that they wanted throughout the interview. A list of support organisations was provided to promote participant well-being. The interviews varied in length from seven minutes (with a young sibling) to two hours 38 minutes (with a mother) – mean of 83 minutes - and were undertaken between August 2017 and June 2018.

### 2.3 Data Analysis

The interviews were transcribed verbatim and identifying details such as the child's diagnosis and unique details about the family were removed. Anonymised transcripts of interviews, photographs and field notes were imported into NVivo 11 (QSR International, 2016). The interview transcripts were analysed interpretatively using Braun and Clarke's (2006) seven-stage thematic analysis method - 1) Transcription; 2) Reading and familiarisation, taking note of items of potential interest; 3) Coding – complete, across entire dataset; 4) Searching for themes; 5) Reviewing themes; 6) Defining and naming themes; and 7) Writing – finalising themes. Stages one to three were linear and involved reading each transcript at least three times, keeping a record of each individual participant's code list to check that codes had been grouped logically and were not omitted or duplicated, and to demonstrate how each code evolved or grew. Stages four to seven, however, were recursive and non-linear. To search for,

review, define, name and write up interpretive themes involved moving backwards and forwards between the stages. Overarching themes and sub themes were compared and contrasted to work out the scope and focus of each theme and to define and name the final themes and sub themes (Braun and Clarke, 2013). The raw data were revisited several times over stages four to seven to recheck the interpretation of participants' data, and to check that the themes and sub-themes accurately represented their stories when new codes (or sub-codes) were added (when later participants' data were analysed) or themes (or sub-themes) were renamed.

## 2.4 Ethical approval

Ethics approval was granted by Edge Hill University Faculty of Health, Social Care and Medicine Research Ethics Committee (FOHS 171).

## 3. Findings

Seventeen participants from 10 families living in England, Scotland, and Wales were interviewed. The 17 participants comprised of two young people who used technology (one female and one male), ten mothers, two fathers, two siblings (sisters from two families), and one grandmother. Pseudonyms and limited demographic details (e.g., specific age) are presented to ensure anonymity (Table 2).

The ten families represented 12 children (9 boys, 3 girls) aged 5 to 25 years. Two families had two children who required medical technology - a boy and a girl in both families. The children from nine families had siblings living at home with them (6 brothers, 3 sisters). Eight families comprised of a mother, a father and one or more of their own biological or adopted children. Two families were single parent families comprising of a mother and two children in each family.

The children relied upon between seven to ten categories of technology or equipment (respiratory; medicines, medical and health; eating and drinking; personal care; sleeping; seating; mobilisation, and standing; communication; play and leisure; and consumables) for their complex health care conditions.

Families 3 and 9 had moved to their present home after their child was born. All families owned their home and had lived in their homes for around a decade, and their homes were (at least) two-storey dwellings.

Three main themes were generated about the impact of medical technology upon the home and life at home for the family members: 'Altered physicality and look of the home'; 'Altered sounds in the home'; 'It's worth it! Technology enables us to stay as a family'.

*Table 2: Demographic details of families and participants*

Family No.	Pseudonym, Gender, Age range of child/ young person	Pseudonym of person interviewed (listed in order of participation), Relationship to child, Type of interview	Family members living at home, Age range of child or young person's sibling(s)
Family 1	<b>Aiden</b> Male, 11-15 yrs	<b>Amelia</b> , mother, F2F-PE <b>Ruby*</b> , younger sister, F2F-PE <b>Ava</b> , Non-resident grandmother, F2F-SS	Mother, <b>Aiden</b> , younger sister (5-10 yrs).
Family 2	<b>Ben</b> Male, 11-15 yrs	<b>Bonnie</b> , mother, F2F-SS (followed by directing the taking of photographs).	Mother, father, older brother (16-20 yrs), <b>Ben</b> .
Family 3	<b>'Monkey'</b> * Female, 21-25 yrs	<b>'Monkey'</b> , F2F-PE <b>Celia</b> , mother, F2F-PE <b>Colin</b> , father, F2F-PE	Mother, father, <b>'Monkey'</b> , younger brother (partly resident, 16-20 years).
Family 4	<b>Deanna</b> Female, 16-20 yrs <b>Daniel</b> Male, 16-20 yrs	<b>Daisy</b> , older sister, non-resident, (21-25 yrs), Tel-PE <b>Deborah</b> , mother, F2F-PE <b>David</b> , father, F2F-PE	Mother, father, <b>Deanna</b> , and <b>Daniel</b> .
Family 5	<b>Ethan</b> Male, 5-10 yrs	<b>Emma</b> , mother, Tel-PE	Mother, father, older brother (5-10 yrs), <b>Ethan</b> .
Family 6	<b>Finley</b> Male, 11-15 yrs <b>Fern</b> Female, 5-10 yrs	<b>Faith</b> , mother, Tel-PE	Mother, father, <b>Finley &amp; Fern</b> .
Family 7	<b>George</b> Male, 5-10 yrs	<b>Grace</b> , mother, Tel-PE	Mother, father, <b>George</b> , younger brother (5-10 yrs).
Family 8	<b>Hayden</b> Male, 5-10 yrs	<b>Hannah</b> , mother, Tel-PE	Mother, father, <b>Hayden</b> .
Family 9	<b>Isaac</b> Male 16-20 yrs	<b>Isla</b> , mother, Tel-SS	Mother, <b>Isaac</b> , younger brother (11-15 yrs).

<b>Family 10</b>	<b>Jacob</b> Male 11-15 yrs	<b>Jenna</b> , mother, F2F-SS <b>Jacob</b> , F2F-SS (followed by directing and being supported to take the photographs).	Mother, father, older brother (16-20 yrs), <b>Jacob</b> .
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\*Participant's chosen name; F2F-PE, Face-to-face photo-elicitation interview; F2F-SS, Face-to-face semi-structured interview; Tel-PE, Telephone photo-elicitation interview; Tel-PE, Telephone semi-structured interview.

### 3.1 Altered physicality and look of the home

All families were explicit about wanting their child to live at home with them, but this meant that they had little or no choice but to accept the extensions, adaptations, and technology within their home.

Some parents were particularly resistant to adaptations such as ramps and ceiling tracking and hoists that significantly altered the look of their home. Eight families had no choice but to have a ramp installed for access to their house, because they (and carers) could not negotiate steps with their child's wheelchair. Participants explained that wheelchairs can be '*a metre long and two foot wide*' and '*ridiculously heavy*' (Daisy, sister), weighing '*over 100 kilogrammes*' (Celia), not including the child's weight. Although three families had a concrete ramp or graduated path at the front of their home, other families resisted this and preferred having a ramp at the back of their house.





*Image 1 Ceiling tracks and hoist (no sling). Note the hole cut out of the top of the door for these to pass through.*

Five families did not have hoists in shared family areas (e.g., lounge) because of the visual impact and perceived imposition of ceiling tracks, hoists, and slings on the look of the room (see Image 1). Amelia wanted her *'house to be sort of normal'* and *'didn't want tracks running all the way through'*. Emma described how her house *'looks like a hospital, rather than a home, especially in the living room because we've got the ceiling track hoists going right the way through the [downstairs of the house]'*. Some types of tracking and hoists are particularly invasive, requiring *'a weird hole'* (Emma) to be cut above the doors for the hoist to pass through,

altering the aesthetics of the home.

Parents wanted their child to be included in family routines and activities and *'to access the whole house as much as possible'* (Deborah). Six parents emphasised the importance of having enough space in the kitchen to allow their child access. Hannah and Emma had made the whole downstairs of their homes open plan, but they remained somewhat unhappy about how these changes had made their home look like a hospital. Emma compared her home to friends' homes that look *'cosy'* and said that she will never get used to her home looking *'clinical'* and *'really strange downstairs... cos everything is like a hospital'*.

Spaces in the home such as lounges, dining rooms, bedrooms had to either be given over completely, shared, or used differently to create appropriate and safe areas where their child's medical needs could be met. However, such changes, even when done to meet their child's

needs, often felt strange or wrong as they disrupted typical family living arrangements. Adaptations, changes in usage of the spaces within the home and prioritisation of the needs of their technology-dependent child over other family members were constant reminders for family members that their home had a medical purpose. This resulted in some parents feeling that their home was more their child's home rather than a family home. Amelia talked of how her home 'revolves' around her son, as the extensions and adaptations were 'purpose built' for him. Celia said her house was 'entirely' designed for her daughter and Isla's home was 'all set up' for her son's equipment. The result was that most parents said that their homes neither looked like nor felt like home. Hannah powerfully expressed the impact of the changes to the physical structure and look of her home:

*'We have made such significant changes to our house... we feel out of place in our own house sometimes... It's not our house anymore, it's Hayden's!'*

Some families were distressed by their child's bedroom being downstairs and away from the other bedrooms as this did not feel normal. Bonnie was still distressed a decade after her son Ben's bedroom had been moved downstairs, revealing that the changes to how the home is constructed can be profound and long-term for the family:

*We don't live as a family really, the way your typical family would live. I found that hard at first... There was just no question that I would not be down here with Ben... Then sometimes [husband] will say "I'm going to sleep with you two tonight" and then he'll come down. But then I think that [Ben's brother] is upstairs on his own. What if there's a fire, what if...? I think you think things like that, because ordinarily you would never leave your children sleeping downstairs in a house, would you? (Bonnie).*

The technology, equipment, and related consumables within the home also influenced how parents perceived their homes. Some technology and equipment were described as

'obtrusive' (Deborah), 'clinical' looking (David and Deborah), making the home look 'strange' (Emma) and 'very hospitaly' (Grace). Colin said that 'good' technology fades into the background. Parents wanted to make the technology and equipment as 'unobtrusive' (David, Colin) and 'unmedical as possible' (Grace) so the family could be 'comfortable' (Deborah), 'cosy' and 'relaxed'. Emma and Deborah thought these were essential qualities for their home to feel like home.



Large mobilisation and seating equipment caused families to squash their lounge furniture into corners and alcoves during the day, to create space for their child to be able to mobilise in the room and to be with the rest of the family (see Image 2). This positioning of furniture resulted

*Image 2 Sofas are squashed into corners and alcoves for children to be able to mobilise in the room.*

in their homes looking 'really

*odd*' as some chairs are 'like a giant sofa bed' (Hannah) and Emma described it as being 'like having a boat in the living room!'.

Parents knew that equipment, technology, consumables, and spares were essential to keep their child safe at home but described how storage was a genuine struggle in terms of space and visual aesthetics. All the families, even those who acknowledged that they lived in larger houses, were 'really struggling with space' (Faith) and not knowing 'where they can put things' (Jenna) 'because there is just so much stuff' (Hannah). Storage issues and lack of space arose not only from the amount and size of technology and equipment (e.g., powerchairs, trolleys, walkers, ventilators, oxygen concentrators) but also the consumables required for their child's

technology and equipment, as well as nappies, feeds, and medications (see Image 3). Hannah explained:

*All the equipment also comes with supplies, so the equipment itself has an impact and you think, like, 'Oh well!' Whereas how much space they take up is not so bad, but when you add it all up with all this stuff that you need to make the stuff work, it's huge! (Hannah).*



*Image 3 Storage of only some of one child's feeds, feeding consumables and nappies.*

Homes looked *'like a storage facility'* (Emma) and shared spaces such as the conservatory were lost because *'everything is sort of squashed in'* there (Faith). Several families spoke about having an upstairs bedroom or even the whole *'upstairs of the house'* (Hannah) being the place where *'everything is dumped'* (Jenna) and being *'literally floor to ceiling with boxes'* (Emma). No photographs of these upstairs storage rooms were shared.

### 3.2 Altered sounds in the home

The families could not escape the *'low level'* (Hannah), *'constant'* (David), *'background'* (Hannah) sounds and alarms of the technology. Emma, Deborah, and Daisy (sister) said that home should be a place where family members can rest and relax. However, the sounds of the technology had a considerable and negative impact upon the ability of the family to achieve physical, psychological, and emotional rest and relaxation. Parents often felt controlled by the sounds of the technology and equipment and this altered the feeling of home for them.

Most parents expressed exasperation about the intrusiveness of the sounds of the feeding pump as could not regulate the volume of the sounds emitted to suit their family's needs. The sound of the feeding pump was described as *'really irritating'* (Emma) because it *'keeps beeping... It keeps going until you get up and sort it out'* (Jenna) corroborating Colin's description of this technology being *'domineering [and] relentless'*. Feeding pumps were talked of as being the only piece of equipment that *'drives me... mad'* (Isla) and *'annoys me... and gets on my nerves'* (Jenna) because, like Colin, David and Emma said, the sounds from the feeding pump also disturbs their child's sleep.

Parents' sleep was disturbed by the sounds and alarms of respiratory and feeding equipment even if their child's bedroom was downstairs at the other end of the house. This occurred even when night carers were looking after their child as *'even though you are not dealing with it, you are still hearing it'* (Faith). Hannah added that *'the noise... is hard to switch off at home.'* Parents said that they were *'never not on call'* (Hannah) as they are *'so used to being vigilant and on high alert'* (Hannah). Hannah and Grace spoke about their difficulty in *'switching off'* from the sounds of the technology even when they are effectively off-duty. This resulted in parents feeling stressed and anxious about whether their child's health was deteriorating and whether they would be called to a life-saving situation. Grace, Hannah, and Emma talked about how non-medical technology sounds such as wireless doorbells, used to alert parents of their child's deterioration, or telephones always needing to *'be on loud, ... never...on silent'* (Grace) also impact upon their ability to be at-ease or relax inside and outside their home.

The impact of the sounds from the technology upon siblings varied. Emma explained that Ethan's brother *'completely panics when he hears a noise he doesn't know'*. George's brother, however, was *'familiar'* and *'comfortable'* with the sounds of the technology because he knew *'which machines make which noise'* (Grace) and was able to tell his mother which piece of technology was alarming.

It was clear that the technology and the children's health care needs altered the soundscape of homes, and thus, the feeling and meaning of home for the families. Although parents and siblings can escape the look of their home when they are asleep, they cannot easily escape the sounds of the technology. Some parents said that the sounds of the technology impacted upon their mental health and ability to feel relaxed in their home more than how the technology impacted upon the look of their home.

### 3.3 'It's worth it! Technology enables us to stay as a family'

Parents talked of how their home was the best place of care for their child. Home was described as an environment that gave their child the '*most experiences*' (Hannah) and Grace saw home as a place where she could occupy George's '*mind with other things that are going to be good for learning*'. In contrast, most family members said that their child could not '*thrive in hospital*' (Grace) as hospital was not a stimulating environment, lacked play opportunities, social interaction, and the stark décor in the hospital resulted in their children becoming '*institutionalised really quickly*' (Bonnie), having a negative impact upon their children's development.

Even though the altered physicality, look and sounds of the home had a detrimental impact upon the meaning and feeling of home, families were willing to accept the negative impacts of adaptations and technology if it meant that their child could live at home and if it helped prevent or reduce the duration of their child's hospitalisation. Deborah explained that even though some technology metaphorically '*stinks of hospital*' she also noted that it was a "*good thing... it does enable him to be at home*". Parents had a love-hate relationship with the technology '*wishing that [they] didn't have to have*' it (Faith), whilst also being grateful for it. Celia, Faith and Jenna all said that the technology makes their life and caring for their child safer and easier. Isla suggested that parents '*just have to come to the acceptance that you need this kit in your life, and if you haven't got it, then you are not going to have your life, really*'. Hannah

added that the technology is *'as much to help us [parents], as it is to help Hayden'*. Typically, as Bonnie explained, caring at home instead of in hospital made *'family life easier... [because] you're at home with your other children'*.

Respiratory technology was key to preventing or reducing hospitalisation enabling *'a quick transition from hospital back into the house'* (David). Deborah was *'thrilled to bits'* that she could bring Daniel *'home [from hospital] when he's not completely well'* recalling the time when Daniel would have been in hospital *'for two whole weeks'* had they not got the *'sats [oxygen saturation] monitor... the oxygen concentrator and so forth'* at home. Faith also said that if she did not have Finley's *'ventilator and... oxygen'* at home that they would *'be in hospital quite a lot of times'*. Bonnie added that having a *'Airvo... oxygen and... suction machine... equipment at home'* meant Ben now had *'nowhere near as many'* hospital admissions and the amount of time they would *'normally would be in hospital for [had been reduced by] at least... six weeks'*. David, Deborah, Faith and Bonnie mentioned that fewer hospitalisations reduced National Health Service (NHS) costs.

Although families were initially very resistant to mobilisation technology (e.g., tracking, hoists), this technology made *'a massive difference to every day'* (Deborah) and became one of their favourite types of technology as it enabled children to be included in family activities, socialise, and be stimulated. Families said they *'wouldn't be without'* (Celia) the tracking and hoists as they *'couldn't live'* (Daisy, sister), *'cope'* (Jenna) or *'function'* (David) without this technology and described it as being *'really marvellous'* (Colin) and *'amazing'* (Emma). The tracking, hoists and wheelchairs enabled the children to be showered and dressed and be *'fully involved in the family space'* (Daisy, sister), rather than being *'stuck... in bed'* (Deborah and Faith). Daisy (sister) said that the tracking, hoists, lift, and wheelchairs have *'definitely helped me to stay more involved in Deanna's care'*, highlighting how the technology can enhance access to much needed family support.

It was clear that the technology enabled families to be a family, David explained ‘we are a family.... [the technology] enables us to stay as a family.’

#### 4. Discussion

This study explored how living with medical technology impacts upon the home and life at home for technology-dependent children and young people with complex health care needs and their family members. It has revealed the impacts of living with technology upon the physicality, look and sounds of the home. Whilst the work of other researchers who have written about place attachment or the impact of environment upon health and wellbeing, social relationships or human experience were considered (Relph, 1976; Tuan, 1980; Gesler, 1992, 1996; Casey, 1993, 2001, 2009; Zingmark, Norberg and Sandman, 1995; Scannell and Gifford, 2010, 2017; Williams, 2010; Moore *et al.*, 2010; Lewicka, 2011; Öhlén *et al.*, 2014; Årestedt *et al.*, 2016), it was Seamon’s (1979a) work that was the most relevant and applicable to the findings of this study. In this discussion, the findings are presented in the context of the five aspects of Seamon’s (1979a) concept of ‘at-homeness’: appropriation (being in control of home space), regeneration (the sense of home being restorative), at-easeness (feeling comfortable and relaxed in the home), rootedness (a secure place to leave and come back to), and warmth (positive physical and emotional atmosphere). All five aspects of at-homeness were challenged by the child’s need for medical technology.

Seamon (1979a) proposes that appropriation is a person’s sense of possession and control over their home space and having ‘places for things’ so they have order over their living-space (Seamon, 1979a:74). Appropriation was challenged as the families had little or no choice but to accept the extensions, adaptations, and technology to be able to care for their technology-dependent child at home. Families also had no control over how much space the technology, equipment, and consumables took up in their home. Some of the large equipment could not be hidden or camouflaged, and it intruded and took control of the space in the home. Although



other literature on technology-dependent children does not directly refer to appropriation, other studies report that technology, equipment and consumables can negatively impact upon the space in the home and that parents can face difficulties in positioning (de Lima *et al.*, 2015) or storing it (Lindahl and Lindblad, 2011). Literature also alludes to parents' strategies to gain a sense of control through exploring how families conceal (Carter *et al.*, 2016), hide or camouflage (Carnevale *et al.*, 2006) the technology inside their homes. A unique finding was that parents tried to retain control over how their home looked to other people including avoiding having ramps at the front of their house and the physical changes to the house resulting from tracking. Other studies have revealed parental concerns about 'an excessive appearance of disability' (Michalko, 2009:65) and the 'public stare' (Jones, 2013:33) of visitors to the home.

As with other studies, parents disliked their home looking, sounding, functioning, and feeling like a hospital (Lindahl and Lindblad, 2011). However, the dislike of having a home looking like a storage facility is a new finding. All families struggled with the appropriation of space to store not only the technology and equipment, but also the consumables (e.g., nappies, feeds, and medication) and the impact that these had on the visual aesthetic of the home. The scale and regularity of delivery of large quantities of consumables that would last months was efficient for suppliers but not supportive for parents, who would prefer smaller, more frequent deliveries. This appropriation of space reminded parents and a sibling that their homes are different to the homes of other families, as also found by Moore *et al.* (2010). Lindahl and Kirk (2018:7) also call for technology to be integrated 'into the existing style of the home and ... [to fit] with habits of social interactions'.

Seamon (1979a:81) proposes that the regeneration aspect of at-homeness relates to the 'restorative powers of the home' for physical, emotional, and psychological health and wellbeing (e.g., through gaining sleep and physical rest in the home). Seamon's (1979a:87) third, and closely linked, aspect of at-homeness is at-easeness which encompasses people's

ability to feel physically, emotionally, and psychologically 'comfortable and relaxed' in their home. However, the sounds of the technology impacted upon the regeneration and at-easeness aspects of at-homeness for the families as they could never escape from the 'audibly apparent' (Moore *et al.*, 2010:4) constant background sounds and domineering alarms from the life-saving and non-medical technology and equipment. Spratling and Lee (2020) also found that alarm-related sounds were a key contributor to parental sleep deprivation. Disruption to sleep quality and quantity increases the risk of morbidity and mortality (World Health Organization Europe, 2009) and impacts upon the body's ability to regenerate. Fraser *et al.* (2021) report higher incidence rates of common physical and mental health conditions in mothers of children with a life-limiting condition. They also report a 50% higher mortality rate in these mothers linked to their child's risk of premature death (Fraser *et al.*, 2021). Lindahl and Kirk (2018:11) report that the sounds of the home can influence how families conceptualise their 'place and space'. Research on sound levels in recognised specialist areas of care such as paediatric intensive care units (Kramer and Heard, 2018; Greenfield, Karam and Iqbal O'Meara, 2020) and adult post-anaesthesia, coronary intensive care and intermediate surgical care units (Cunha and Silva, 2015) show that noise levels exceed recommended levels but our findings are the first to describe the profound psychological and physiological impact on family members of never being able to escape from the constant sounds of medical technology in their home, even when trying to sleep, and to highlight the detrimental impact of the sounds of the technology upon the regeneration and at-easeness aspects of at-homeness. Cunha and Silva (2015) recommend that all health and social care professionals must be aware, and raise awareness to others, of the detrimental physiological and psychological impacts of noise.

The fourth aspect of at-homeness is rootedness and this refers to the home 'providing a physical centre for departure and return' (Seamon, 1979a:79, 1979b). Although the adaptations and technology could be disruptive, the respiratory technology in particular helped establish a sense of rootedness by enabling parents to care for their child at home, ensuring the child could be included in shared areas of the home and keeping the family together. The

desire to keep their child out of hospital, whenever possible, because of the impact that their child's hospitalisation had upon their child's development and the functioning of their family has been reported elsewhere (Castor *et al.*, 2018; Sobotka *et al.*, 2020). Our families reported a reduction in the incidence of hospitalisation as seen in other studies, for example, Boss *et al.* (2020) who noted hospitalisation was reduced as a result of the parents providing vigilant care and having technology at home. Although having their child at home was key to rootedness, a consequence of being able to care for their child at home was that the geographies of parenting were stretched beyond usual boundaries, requiring parents to develop skills in caring tasks more typically associated with nursing (Wilkinson *et al.*, 2020). This creates tensions within the home and family.

Seamon's (1979a) fifth aspect of at-homeness, warmth, relates to both the physical and the emotional atmosphere of the home. The mobilisation technologies became some of the favourite types of technology for all family members because they enabled the home to become what Relph (1976:38) describes as a 'field of care'. This concept of a 'field of care' meant that home was a place where the children could be cared for whilst being fully involved in the family space, routines, and activities, rather than being confined to bed or their bedroom.

The emotional warmth aspect of at-homeness for the families, like rootedness, had more to do with their emotional and psychological attachment to their home and their family than the practical impact of living with the technology, resonating with the saying that 'home is not a place, it is a feeling'. The adaptations, technology, equipment, and consumables enabled the families to be together as a family at home. This supported the emotional warmth and rootedness aspects of at-homeness (Seamon, 1979b), with benefits for the family as a unit and as individuals.

The children's medical and technological needs brought uncertainty and unpredictability into the lives of the families, as also reported by O'Brien (2001). However, by caring for their child

at home, the families could adopt a routine that suited their 'own rhythm' (Rasmussen and Edvardsson 2007:127). Initiating routines is important for feelings of safety, security and rootedness to the home (Seamon, 1979b; Tuan, 1980; Relph, 1976) and can strengthen family functioning at home (Toly *et al.*, 2017; Castor *et al.*, 2018). Also, routines can have a positive impact upon adult family members' wellbeing (Årestedt *et al.*, 2016) and children's health, wellbeing and developmental needs (Bourke-Taylor, Cotter and Stephan, 2014). These routines at home had a positive impact for the emotional warmth aspect of at-homeness.

Any negative impacts on how their home looked and functioned (physical warmth) and the health, wellbeing and quality of life of the family members were worth it for their child to live at home. Indeed, the families' lives were more complete and enriched with their child at home, as also discussed by Camara and Callum (2020).

Although the sense of at-homeness was altered, home was still a place of everyday living (Dunbar, Carter and Brown, 2019) and belonging (Lindahl and Kirk, 2018). This was not only because parents had parental responsibility for their child(ren), but also because of the love and emotional connection between the family members. Similar to Zingmark *et al.*'s (1995) findings, being able to care for their child at home, in the place where family members felt like they belonged was a central feature of the rootedness and emotional warmth aspects of at-homeness that symbolised home for the families.

## 5. Conclusion

This study presents the impacts of living with technology upon the physicality, look and sounds of the home and all five aspects of feelings of at-homeness for technology-dependent children and young people and their family members. Family members felt that the detrimental impacts of living with medical technology upon their home and feelings of at-homeness were worth it because the technology kept them out of hospital and enabled them to stay as a family. Home

was not home, and family felt incomplete without their child at home.

## 6. Strengths and limitations

This is the first qualitative study to identify how medical technology impacts the home and feelings of at-homeness for different members of a family who have a technology-dependent child in England, Scotland, and Wales. The information is of value to health and social care professionals and those involved in the planning, funding, delivery, and supply of home adaptations or medical technology.

The findings of this study are not representative of and cannot be generalised to all families and family members who have a technology-dependent child. However, qualitative researchers do not seek generalisation of the data (Edirisingha, 2012; Braun and Clarke, 2019).

A limitation of this study is that all ten families owned and had lived in their (at least) two-storey house in England, Scotland and Wales for around a decade. The impact of medical technology upon the home and life at home for technology-dependent children and their families who live in apartments, privately rented accommodation or social housing, or in countries who have different health care systems are likely to be very different to the families who took part in this study. Families who are newer to the alterations to their home and technology might find them to be more disruptive than the families who participated in this study, who were familiar with them. The perspectives and experiences of same-sex parent families, families with single fathers, multi-generational families who live together, and black, African, Caribbean or Black British, Asian or Asian British, mixed or multiple, or other ethnic group families might be different to those of the mixed gender, single mother and white British families who took part in this study.

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## Declaration of interest

None.

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