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Research article

When a child is sick: The role of social tourism in palliative and end-of-life care

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ABSTRACT

Drawing upon transformative service research and social tourism literature, this paper explores the relationship between respite care and childhood illness. It focuses specifically upon the short break opportunities attached to respite care offered in children's hospices in the United Kingdom. Pathographies (illness narratives), shared by patients, siblings and family (n = 23), provide unique insights into ways in which each participate in respite care. Participation prompts inclusivity and normality. It offers a break from illness, and contributes to uplifting feelings of optimism, escapism and new beginnings. Conclusions drawn argue the need for healthcare policy to move beyond 'Dying Well' narratives into ones which celebrate 'Living Well with Dying'. Tourism participation has much to offer such a progressive healthcare policy.

Introduction

When our first ever respite was over, I couldn't even get the kids to go home, the little one, he just cries his eyes out every time we need to go home (…) we have to kind of plan it in stages, where I had all the suitcases in the van and just say 'oh we're just going for a shopping trip' and then just take him home and then come back for the others (…) because he doesn't want to leave, so that to me doesn't say hospice, it's like a family kind of thing if that makes any sense.

(Tama, mum)

The capacity of services to facilitate profound change, at both an individual and societal level, is increasingly celebrated through their positioning within a transformative service research agenda which seeks to redress societal imbalances in service access and consumption (Ostrom, Parasuraman, Bowen, Patricio, & Voss, 2015). It has much in common with the long established social tourism movement which has evolved over time into championing inclusion and uplifting changes for the disabled; ill; older; those at fear of persecution or other factors; the poor; those time poor due to work or caring commitments and ethnic minority groups (McCabe, 2009). Both movements have emerged from a desire to seek inclusion for marginalised, vulnerable or bottom of the pyramid consumers. Both provide important examples of the capacity of services to create "… uplifting changes and improvements in the wellbeing of both individuals and communities" (Anderson, 2010, p. 9). Yet what neither research community has tackled beyond including in agenda setting (Ostrom et al., 2015; Wilson, McIntosh, Morgan, & Sanders, 2018), is the most profound, and uniting service need of all. The service needs attached to life limiting, specifically, terminal illness, our capacity to openly discuss such often muted by a deep-seated fear of mortality (Gawande, 2014).

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This study sits in this space. It contributes to the call for an 'ambitious (research) agenda' in (critical) tourism research (Higgins-Desbiolles & Whyte, 2013) in seeking to better understand the transformational capacity that tourism might play in *living* with dying. Put another way, this paper questions the capacity of tourism to bring uplifting (transformational) changes to the lives of families whose child has a life limiting, terminal illness, where 'life' may be years, but, equally, months, weeks, days or hours. The healthcare sector response to terminal illness involves a journey, a move into a liminal state of healthcare delivery. In this state, conversations shift beyond curative and treatable healthcare dialogues into palliative care where holistic care, psychosocial and spiritual support for patients and their families is prioritised and all mechanisms for managing pain, symptoms and medicines are keenly sought (World Health Organisation, 2015). It is a transitional stage haunted by many misperceptions, a key one being associations with imminent death (Giovanni, 2012). This is not always the case, every disease trajectory is unique.

In the UK, policy rhetoric has attempted to address societal attitudes towards death by championing a 'dying well' narrative. This narrative is built upon offering personalised care, a national choice offering, and equality in healthcare provision through funding, training, integrated care and support (Department of Health, 2008; National Palliative and End-of-Life Care Partnership, 2015; The Choice in End-of-Life Care Programme Board, 2015; Parliamentary and Health Service Ombudsman, 2015; Department of Health, 2016). Tourism, noticeably absent in associated policy rhetoric, on one level has much to offer this 'dying well' narrative. For instance, dialogues narrating a symbiotic health-tourism relationships have a long-established place in the tourism literature. Russell's (1753) account of the powers of seawater and sea bathing is one such example. The more recent burgeoning literatures associated with health, spa, wellness, spiritual retreats, thermal and medical tourism are other examples (Gill, Packer, & Ballantyne, 2018; Kelly, 2012; Smith & Kelly, 2006). Studies of cancer and holiday-taking (Hunter-Jones, 2005), dementia friendly tourism destinations (Page, Innes, & Cutler, 2014) and studies of ageing (Sedgley, Pritchard, & Morgan, 2011), disability (Sedgley, Pritchard, Morgan, & Hanna, 2017) or low income in social tourism research (McCabe, 2009) are further examples.

Yet as valuable as these studies are in sharing the symbiotic health-tourism relationship, and moving us towards 'hopeful', even transformational tourism relationships which might be enjoyed (Pritchard, Morgan, & Ateljevic, 2011), tourism studies to-date have been most concerned with the curative and treatable stages of healthcare delivery, chronic conditions included. How 'taking the waters' ameliorates the consequences of illness. How wellness and hopeful tourism might contribute to behavioural changes. How tourism returns a sense of normality during *curative* cancer treatment (Hunter-Jones, 2005). How complex travel is when caring for an autistic child (Sedgley et al., 2017), or when kidney dialysis services are needed (Footman et al., 2014). Dialogues commensurate with the liminal space of palliative care seldom feature in this literature. Consequently our understanding of the needs of those experiencing life limiting illness is incomplete.

Yet whilst explicit reference to tourism is missing in the 'dying well' policy rhetoric, in actuality, tourism does contribute through the medium of respite care, described as taking a break from caring, be it a short break, or over a longer period of time, to allow the carer to recharge batteries and be better able to cope with caring (Carers Trust, 2019). In the UK, the caring population includes approximately 6.5 million informal carers (Postnote, 2018). The relationship between holidays and respite care has received scant coverage in the tourism literature to-date, explored within studies of lost leisure (Gladwell & Bedini, 2004), senior carers and cancer carers (Hunter-Jones, 2010), caring for a child with autism on holiday (Sedgley et al., 2017), and medical tourism (Holda, 2019). The dearth in literature led Holda (2019, p. 242) to argue that carers represent 'one of the most misunderstood and unappreciated segments of society'.

To redress the multiple related imbalances emerging in this space: the lack of tourism research linked to terminal illness, either in general, or specific to family tourism, or children; the limited appreciation of the tourism-respite care relationship; the absence of the patient voice in the limited research available, this study applies a transformative service research-social tourism lens to examine respite care provided through a particular service provider, not-for-profit children's hospice care. In so doing, this study extends our understanding of the needs and experiences of the disabled, ill and those experiencing compromised economic circumstances, all at the heart of the social tourism movement (McCabe, 2009), this time within the context of palliative and end-of-life care. It paves the way for an extension of lobbying for 'holidays matter' (Family Holiday Association, 2019) beyond social policy, into healthcare policy too.

Study context

Health and transformative service research

Health has received elevated attention in service research due to its position as a service research priority (Berry & Bendapudi, 2007; Ostrom et al., 2015) and core link to the transformative research agenda. This research agenda acknowledges the capacity of services to transform the lives of individuals and communities creating 'uplifting changes' (Anderson et al., 2013; Danaher & Gallan, 2016; Ostrom et al., 2015). Common research themes emerging in the literature include *value co-creation* and *wellbeing* (Anderson et al., 2013), *networks, systems and service design* (Anderson, Nasr, & Rayburn, 2018) and studies more broadly linked to *'base of the pyramid'* consumers, that is those who fall below levels of consumption adequacy (Baron, Patterson, Maull, & Warnaby, 2018). Whilst multiple opportunities for realising the transformative potential of healthcare are thought to exist, a common theme in associated literature thus far has been a focus upon the curative stages of healthcare. This is illustrated through the edited collection of Danaher and Gallan (2016), along with studies of chronic illness (Sweeney, Danaher, & McColl-Kennedy, 2015). Noticeably absent is any detailed consideration of potentially 'uplifting changes' services might play in palliative and end-of-life care, either in general, or specific to families and children.

Hospices occupy the palliative and end-of-life care space. Hospices provide care to patients and their families transitioning beyond

'medical', treatable healthcare conditions. In the UK, the study location, there are over 200 hospices supporting around 200,000 palliative care patients annually and receiving an average of 32% of their funding from the government, with the rest coming from fundraising (Hospice UK, 2017). Care is audited by the Care Quality Commission which seeks evidence that the service is safe, effective, caring, responsive to people's needs, and well-led (CQC, 2016). Contrary to some parts of the world, hospice care in the UK is not just about the final days of life. For children in particular, this care may be experienced over a number of years through Inpatient Units, Outpatient Units and Day Care Centres. Respite care is embedded within hospice service provision. This care can take multiple forms including short breaks on-site for patients and their families, or time and support for breaks from caring responsibilities.

Whilst largely absent in the service or tourism literature, respite care has been the subject of extensive coverage within the palliative medicine literature in general (Ingleton, Payne, Nolan, & Carey, 2003), that specific to the nursing profession (Ling, 2013) and health service research more generally (Carlson, Morrison, Holford, & Bradley, 2007). Themes common across these literatures include: the positioning of respite care as an intervention; ambiguity over terminology and the particular composition of services provided; needs of particular patient groups including, autistic, Down syndrome or dementia groups for instance; gaps in service provision, including those transitioning between childhood and adult care; and future challenges. The transformational capacity of respite care is under-appreciated in these literatures which commonly focus dialogue upon relieving carer burden and stress (Ling, 2013).

Social tourism

The capacity of tourism services to transform lives and contribute to uplifting changes is evident within the growing social tourism literature. The most direct reference to terminal illness and tourism per se is found in the work of Wilson et al. (2018, p. 268) who calls for a 'reconceptualisation of health tourism to include notions of ill-health and its implication for the tourism industry'. Thinking about travelling with complex conditions, Sedgley et al. (2017) consider the mixed experiences of families travelling with autistic children, and Footman et al. (2014), the dialysis service needs of tourists visiting Italy. Kastenholz, Eusebio, and Figueiredo (2015) and Gillovic, McIntosh, Darcy, and Cockburn-Wootten (2018) both question the social inclusion of people travelling with disabilities, whilst others look more broadly at wellbeing. Smith and Diekmann (2017) for instance, introduce a spectrum and model types of wellbeing and Morgan, Pritchard, and Sedgley (2015) question the contribution of tourism to wellbeing in later life, a lifestage characterised often by health concerns, bereavement and loneliness.

The relationship between families and social tourism more generally can be found for instance in the work of Smith and Hughes (1999), Quinn and Stacey (2010), Minneart, Maitland, and Miller (2009), McCabe (2009), McCabe, Joldersma, and Li (2010), and McCabe and Johnson (2013). Smith and Hughes (1999) investigate the meaning and significance of the holiday to families disadvantaged by social and economic factors. Interviews with ten families reveal a beneficial link between holidays and normality, escapism, relationships and health. Quinn and Stacey (2010) question this from an Irish perspective in their exploration of the benefits holidays can bring to populations experiencing social exclusion. Exploring the link between social tourism and social and family capital, Minneart et al. (2009) conducted interviews and focus groups with families at two stages: the first month after a holiday and six months after a holiday, to again identify the benefits attached in this context. Increases to family capital are observed in the short term and to social capital in the medium term, demonstrable through transformations to family relations, confidence, social networks and a changed perspective on life (Minneart et al., 2009).

McCabe (2009) adopts a three tier methodology to question who needs a holiday. Central to this work is both an exploration of reasons for a holiday amongst low income and other disadvantaged groups, alongside a consideration of the benefits derived from such an activity. Noting the contribution of holidays to happiness, life satisfaction and quality of life, McCabe (2009) concludes by identifying the need for an evidence base which provides more detailed measures of the benefits of tourism. This need is endorsed by a further study uncovering linkages between tourism participation, subjective wellbeing and quality of life (McCabe et al., 2010). McCabe and Johnson (2013) develop a measure of subjective wellbeing to provide a more nuanced insight into the value of social tourism to low income individuals accessing financial holiday support. Transformations linked to happiness, optimism, family life and relationship enhancements are cautiously reported, the potential for short-term benefit only requiring further research.

Research gaps

A number of over-arching, inter-related gaps emerge through the literature reviewed. Services in general have transformational powers, which impact upon both individual and community wellbeing. However, a granular understanding of these powers remains to be determined when it comes to palliative and end-of-life care services. Respite care in particular offers a lens to explore this, and indeed has been reviewed extensively in the palliative/health care service literature. However, associated research most often considers the carer perspective alone, and within the context of relieving carer burden. Social tourism literature does provide a wider appreciation of the capacity of services, tourism services in particular, to transform the lives of particular populations, but falls short in studying the needs of those experiencing life limiting illness. Consequently the remainder of this paper seeks to respond to these gaps in a particular way. It aims to better understand the transformational capacity that respite care, particularly in the form of short breaks, might play in *living* with dying particularly for families whose child has a life limiting illness. This paper focuses particularly upon the respite care offered in children's hospice care. It analyses the empirical data collected from Red Hospice, a UK based children's hospice supporting families facing life limiting illness.

Methods

This study comprises one part of a major, multi-site project that has spanned 5 years and 9 different palliative care providers. The beginning of the project (2015) was a piece of research commissioned to examine hospice experiences amongst patients and their families. The primary aim was to investigate mechanisms for transforming service user experiences of palliative and end-of-life care. The project snowballed and Red Hospice, the children's hospice at the heart of this paper, joined the project in 2017. Respite care, in the form of short breaks, is one of the services provided at Red Hospice. On average, the hospice supports around 300 families, offering over 25,000 h of respite and short break support per annum.

Research design

Securing ethical approval for the work involved a rigorous process. The authors sought ethical advice and approval from their home University Central Ethics Committee. Research involving terminally ill participants is classified as high risk with ethical applications automatically escalated to full Institutional Ethical Review. In certain instances they are also subject to regulatory committee approval too, the National Health Service Research Ethics Committees in the UK for instance. Participants in this study included terminally ill children accessed via hospice providers. Therefore full institutional ethical review was necessary. External regulatory approval was not requested, due to the autonomous nature of the service provider. Red Hospice required University ethical approval to be in place prior to granting researchers permission to be on-site. The researchers pursued this process which took in excess of six months to complete and included University Committee attendance/defence. Our ethical position was influenced by a range of literature. The indicative themes are illustrated in Table 1.

Considerations of anonymity, confidentiality, voluntary participation, informed consent, and vulnerability took on elevated scrutiny for this study resulting in the approval granted being subject to multiple conditions, all designed specifically to protect participants. These conditions include guarantees of anonymity, our independence from Red Hospice and the ability to withdraw at any point being articulated through all communications with participants (written and verbal). We designed a distress protocol which afforded participants the opportunity to contact the hospice counsellor, their family doctor, or their mental health provider. The protocol also included steps to enable us to refer to the hospice counsellor, with the permission of the participant or parent. As a tight-knit research team, we had regular de-briefs and candid discussions between ourselves, and we too had access to counsellors if needed. Means of accessing participants was also carefully managed, facilitated by clinicians at Red Hospice who acted as gatekeepers and determined fitness to participate in the research during their morning ward rounds. For children, decisions were also linked to 'best interests' (Nuffield Council on Bioethics, 2015), with parents central to the decision-making process. To overcome anonymity concerns, the use of broad participant pseudonyms, type of service user and age bracket, were used.

This study was about giving a voice to hospice service users. Desk research identified storytelling to be a particularly empowering tool in healthcare research. It was found to be a humane method of data collection, providing the voice of patients and carers who may otherwise have been unable to participate in research (Gysels et al., 2012). Pathographies are a particular form of biographical storytelling. They focus upon narrating experiences of illness (Frank, 1991; Greenhalgh, 2006). They have been previously found to be suited to both the collection of rich narratives, along with providing agency and a voice to those transitioning through terminal illness, in extremis (Turley & O'Donohoe, 2017). We turned to the 'pathographies' of Picardie (1998), Diamond (1999) and Granger (2012), amongst others, who use storytelling to so eloquently, and tragically, articulate the all-consuming, life-changing and terrifying nature of their terminal illness. Through these narratives, storytelling was shown to be an instrument capable of mitigating multiple problems commonly associated with data capture in health research, sensitive also to methodological challenges in tourism research (Higgins-Desbiolles & Whyte, 2013) (Table 1).

A purposefully designed storytelling instrument, the Trajectory Touchpoint Technique, was developed to understand patient and family experiences of services delivered in palliative and end-of-life care. The instrument utilizes a rich picture methodology

Table 1
Antecedents influencing ethical decision-making.

| Antecedent	Key literature	Comment
Transformative service research	Anderson et al. (2013)	Research agenda for transformative service research
Subjectivity	Churchman, York, Woodard, Wainright, and Rau-Foster (2014)	Perceptions of care and interpersonal relationships
Participant attrition	Candy, Holman, Leurent, Davis, and Jones (2011)	Sampling problems
Snapshot research	Gysels, Evans, and Higginson (2012)	Patient vulnerability and research participation
Children, ethics and 'best interests'	Nuffield Council on Bioethics (2015)	Roles and responsibilities of children, their parents, guardians and researchers in ethical research
Family tourism experiences	Gram (2005); Hunter-Jones (2014); Nickerson and Jurowski (2001)	Children as active research participants
Hopeful tourism	Pritchard et al. (2011)	Empowerment and the values-led humanistic approach to tourism research
Power in tourism research	Higgins-Desbiolles and Whyte (2013)	Critique of hopeful tourism questioning the legitimacy of a dialogue built upon partnership, reciprocity and ethics
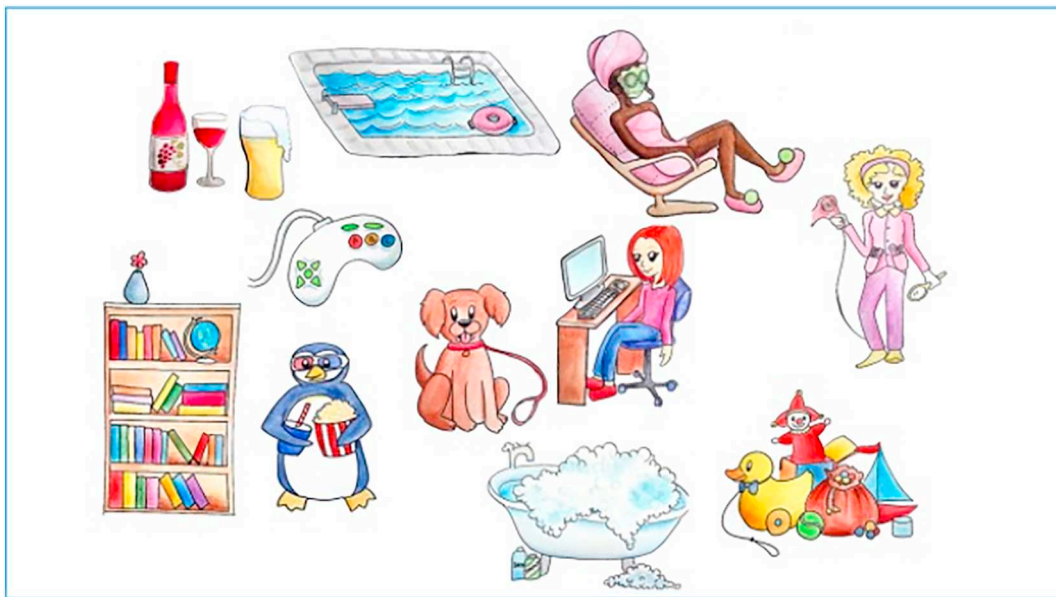
Fig. 1. The little extras touchpoint images.

consisting of clip-art pictures, cartoons, and easy-to-recognize signs and symbols which act as an aide to narrating memoirs. It is structured around seven distinct areas, touchpoints, of service user experience: *pre-arrival; arrival; clinical care and support; facilities; shared spaces; little extras; discharge and aftercare*. It is designed to capture the different tangible and intangible aspects that service users commonly come into contact with during palliative and end-of-life care. Participants share their stories, in their words. In so doing their stories offer a window onto not only what needs changing, but also how it might change. The full development, testing and extension of this instrument, both within this context, and additional service settings subsequently, is detailed in a separate paper (Sudbury-Riley, Hunter-Jones, Al-Abdin, Lewin & Naraine, 2019). An example of the 'Little Extras' touchpoint images are provided in Fig. 1.

Sample

This study adopts a constructivist approach. In this paradigm, reality is seen to be socially constructed with the researcher drawing upon the "participants' views of the situation being studied" (Creswell, 2003, p. 8). Once ethical approval was secured, qualitative data was collected from Red Hospice via the Trajectory Touchpoint Technique. Researchers paired up to capture the first five to six stories together to ensure a consistent style was employed across every conversation. Participants self-selected the visuals that mattered to them when narrating their stories. Conversations ranged between 27 min to 77 min, the timing entirely participant led, in-line with ethical approval. All stories were recorded (with permission) and transcribed verbatim.

Given the holistic nature of hospice care it was important to include all service user voices, with capacity, in the study. Our first application of the Trajectory Touchpoint Technique in 2015 revealed that data saturation occurred at around twenty respondents. Consequently, a purposeful sampling approach was utilized to collect stories, on-site, from twenty-three service users associated with Red Hospice. All categories of service user were included: patients (n = 2), siblings (n = 2), parents (n = 10), relatives (n = 2) and bereaved families (n = 7) (see Table 2). With the help of the clinical team who shared information about the study via the hospice social media group, and approached patients and their families with information sheets, participants were recruited over a 3–4 week period. Bereaved families were recruited via invitation letters which explained the purpose of the study. A further three children, all patients, were also present during parental conversations but did not contribute to the study due to the severity of their health circumstances and the conditions of ethical approval.

Data analysis

To mitigate the potential for unconscious bias embedded within qualitative data analysis, the researchers completed the Royal Society (2015) six part training programme. This programme questions what is unconscious bias? How does it manifest itself? Who is affected by it? What role does behaviour play? How is it identified? And how can it be mitigated? Alongside this, to preserve the richness of the stories shared, we used manual thematic analysis to make sense of the data (Braun & Clarke, 2006). In step one, three researchers separately examined the data identifying core and sub-themes. In step two, these themes were shared and the outcomes of step one reviewed. Core themes included: mother; father; child (patient); siblings; holiday; break. Recurring sub-themes included: experience; escapism; fear; isolation; anxiety; worry; family; identity; place; time; pleasure; special; luxury; extraordinary; fun; and

Table 2
Profile of participants.

Service user	Age group	Socio-economic group
John, dad	55–59	AB (now full-time carer)
Alison, mum (bereaved)	25–29	DE
Diane, mum (bereaved)	30–34	C1
Amy, mum	45–49	AB (now full-time carer)
Kenny, dad	45–49	AB (now full-time carer)
Kathy, mum	35–39	AB (now full-time carer)
Susan, mum	40–44	DE
Ilma, sibling	10–14	
Jada, sibling	10–14	
Rhoda, mum (bereaved)	30–35	AB
Becky, mum	40–44	Full-time carer
Paul, dad	40–44	C2
Poppy, patient	10–14	
Janie, mum (bereaved)	45–50	AB
Cheryl, mum (bereaved)	40–45	C2
Linda, relative	35–40	AB
Barbara, relative	65–70	Retired
Tama, mum	35–40	Full-time carer
Chrissie, patient	20–24	
Debbie, mum	50–55	Full-time carer
Joanne, mum	25–29	Full-time carer
Ellie, mum (bereaved)	30–34	AB
Robbie, dad (bereaved)	30–34	AB

happiness. Whilst the training and thematic steps were included to reduce researcher unconscious bias, what follows will be in-evitably, and necessarily selective, as data collection with Red Hospice generated around 150,000 words of individual stories.

Findings

Stories collected provide unique insights into ways in which different participants, patients, siblings and parents, participate in respite care. Consequently, with the exception of Section The hospice respite care offering the findings are separated into three distinct voices: parental (Section Living with life limiting illness: parental insights); patient (Section Living with life limiting illness: patient insights); and sibling (Section Living with life limiting illness: sibling insights). These voices are brought together in the final section (Section Living with life limiting illness: drawing family insights together) where cross-cutting themes are identified.

The hospice respite care offering

Collectively, existing research helps us to appreciate the characteristics common to social tourism activity (McCabe et al., 2010; McCabe & Johnson, 2013; Minneart et al., 2009; Morgan et al., 2015). These studies suggest that social tourism participation is usually linked to a needs based selection process. Some, or all, elements of the holiday are free at the point of activity. It is usually subject to application 'rules', for instance, a specified number of years must have elapsed before a further application can be made.

When it comes to accessing respite care attached to a children's hospice a different picture of social tourism activity emerges. Whilst access is linked to a needs based assessment, and free at the point of activity, the application 'rules' are different. Once assessed as in need, families have access to multiple respite care opportunities within an annual allocation window. These opportunities support the carer (parent), the child (patient) and siblings, either on-site or off-site. Patterns of tourism participation are consequently rich in composition, variety and meaning. For instance, some families stay at the hospice for their holiday:

It's amazing how they can facilitate for the family. You don't have to just bring your child and leave him. They provide us our own room (…). It's really good that we can all stay,

(*Becky, mum*)

whilst others leave their child there and use respite to focus on quality time for themselves:

that's the only time we've dared actually leave him and go away (…) we wanted to go to the Christmas markets, and we'd booked two nights in a hotel (…) we set off over and we went straight to bed almost when we got there!.

(*Kenny, dad*)

For some it afforded an important opportunity to spend time with their other children:

We treat it as kind of like a bit of a holiday weekend to just stay and then at night if they need us we'll be there but then during the day we tend to go off. We take [sibling's name] out and do things with her that we can't normally access when we have [child's name] with us.

(*Amy, mum*)

For others, the flexibility of the provision was comforting in itself:

> I'm very much a hands on mum anyway (…) there's been a few incidents in the hospital where, with medication and other things, so my trust is sort of thin (…) I mean I know some of my friends come and the children stay here and parents go, but each to their own.
>
> (*Susan, mum*)

No other provider was mentioned as capable of offering such an inclusive, flexible experience.

Living with life limiting illness: parental insights

Crisis, despair and prejudice

Policy rhetoric suggests that 'dying well' is fundamentally linked to having access to health resources, be it named clinicians, shared record access and other such policies. As important as this is, the data in this study suggests a serious disconnect between policy rhetoric and the harsh reality of existing in this transitional space. Despair, utter exhaustion, fear, loneliness, and a lack of knowledge about where to turn to for help dominated parental narratives, both verbally and visually:

> …we'd got people telling us from all directions, doctors, nurses, the community team, my parents, my mother-in-law, everyone saying 'you've got to do it, just look at you, you're dead on your feet',
>
> (*Amy, mum*)

parents, who were already being subjected to hurtful exclusion elsewhere:

> We went to [a coffee shop] and we were asked to leave because they said we were [visually] offending the other customers.
>
> (*Debbie, mum*)

Indeed stories of societal prejudices were found through many narratives:

> I don't take him out where we live because he just gets the stares, and I just hate it and he absolutely hates it,
>
> (*Tama, mum*)

echoing the prejudices found more generally in studies of disability and tourism (Eichhorn, Miller, & Tribe, 2013), families with disabled children ostracized through intolerance and ignorance, 'judged' (Sedgley et al., 2017) by those who expect society to 'conform to certain behavioural rules in public' (Sedgley et al., 2017, p. 20). For some, prejudice was compounded by the isolation attached to caring for a severely disabled child:

> I'll be honest with you, when you have a child with such complex needs your friends go, because they can't just pick the phone up and say 'right we're going to the park, are you coming?' I can't do that, I've got to sort out have I got enough oxygen, have I got (…) so eventually they stop asking.
>
> (*Debbie, mum*)

The consequences of this ignorance magnified the feelings of loneliness and isolation expressed by many time and again.

The transformational power of hospice environments: from darkness to light

At first reference, hospices were anything but the answer to such dark times. Indeed without exception, *all* participants described overwhelming feelings of apprehension at the word 'hospice' before they arrived for the first time, many simply scared stiff by mention of this space. For parents the word was commonly linked to old people's care homes:

> In my head it was just going to be this dark and dismal horrible place, doom and gloom,
>
> (*Tama, mum*)

or imminent death:

> Jody was 9 months when we went in, one of the nurses said to me about Red Hospice, it was a hospice, and I immediately thought 'oh my god is she seriously…' (…) and they explained it was for respite (…) but obviously I was very worried.
>
> (*Susan, mum*)

Arrival on-site, without exception challenged all misconceptions:

> You expect it to be a very sad place, don't you? It's not, it's the total opposite, and I was really surprised (…) when you go outside and they're out there playing, it doesn't seem like a hospice, if you know what I mean?
>
> (*Barbara, relative*)

Just as Morgan et al.'s (2015) study of wellbeing in later life found, tourism activity taking place in a space of hope and security offered an opportunity for all involved to escape from the trials of everyday life.

Hospice as a leisure resort

Such is the capacity of a hospice to transcend loss, in the eyes of participants, the hospice is not a hospice. It is a conduit through which new life stories can be created and pleasure-inducing experiences enjoyed. Narratives emerging could be reasonably found in studies of family holidays per se (Gram, 2005; Hunter-Jones, 2014; Nickerson & Jurowski, 2001).

Guests described their experiences as:

> …like staying in a hotel for the night,
>
> (*Linda, relative*)

where they were treated as hotel guests, the welcoming atmosphere commented upon time and again:

It was all really calm and quiet and peaceful as you walked through. So, coming in to here just felt peaceful, it just felt right.

(Cheryl, mum)

Guests enjoyed the beautiful, well-equipped family rooms:

…they're spacious, they're nice and light and airy, they've got the door that opens out straight on to the garden, and you've got your own en-suite,

(Kenny, dad)

and versatile social spaces:

…but if you wanted to just be left alone, they did, but if you wanted company, if you wanted to be involved, you could go and be part of it. So that was really good.

(Rhoda, mum)

Guests received outstanding hospitality with great food, lots of choice, prepared and served by wonderful kitchen staff. Feelings of being pampered came with a rare treat of an alcoholic drink:

In fact before [child's name supplied] was end-of-life this was the only place I could have a glass of wine, because I was always on standby with him, and it was always 'you need to be able to drive', and so here was the only place where I could just have a little glass of wine.

(Debbie, mum)

Respite care as regenerating emotional and psychological well-being

Echoing the work of Smith and Diekmann (2017), Morgan et al., (2015) and McCabe (2009), experiences of a short break were associated with social engagement, increased self-esteem, enhanced subjective wellbeing and a re-affirmation of self-identity. For this cohort particular benefits emerged from participation, linked often to emotional and psychological wellbeing. This included an opportunity for families to re-evaluate their lives, their attitudes towards medical regimes and their experiences of loneliness, pre- and post-bereavement. These echo the holiday attributes shared in the work of Morgan et al., (2015) who explored the contribution of tourism in ageing.

Feelings of wellbeing and a profound impact on quality-of-life ran throughout narratives:

This hospice has been our lifesaver, basically. It pulled me from a very dark, dark place,

(Joanne, mum)

with many living for these moments of sanctuary:

…to you as a family, oh god that's all you hold on to, 'next week we're going in there',

(Debbie, mum)

and the wellbeing generated:

They get him to do all sorts. Just stuff with me being on my own is quite difficult to do, because trying to do it with him and then trying to do it with my two daughters it's like, where is he? I've got help at hand so there's someone with him and I can do something with the girls (…) it's amazing.

(Joanne, mum)

Such was the power of the experience that any changes to respite plans, necessary during times of crisis for another family, were devastating:

We were all packed (…) and the phone rang and they said 'I'm so, so sorry we've just had an emergency admittance and we're going to have to cancel your stay', and she threw herself on the floor and cried for about 20 minutes.

(Amy, mum)

These situations were all the harder to manage due to a lack of alternative options elsewhere:

…sometimes it's quite difficult because we have no other respite now.

(John, dad)

That the hospice relationship could develop over an extended period of time:

They've helped us through 5 years of respite,

(Debbie, mum)

generated profound feelings of trust and confidence when looking ahead to future circumstances:

Now I feel like it's brilliant that we've had all that time as respite, because we're quite prepared now (…) I just feel like I trust them and I know that they'd never, you know and I know that they'll do their best for us.

(Debbie, mum)

Living with life limiting illness: patient insights

At a time when children and young people are ordinarily engaged in socialization processes, developing friendships, establishing self-identity and negotiating their path through childhood and adolescence (Hunter-Jones, 2014), the patients in this study were

navigating their way through serious illness, often with only family to turn to:

> Yeah I was frightened of staying on my own because I'd never stayed on my own without my mum before, and I was 12/13, so I used to cry every time my mum left me.

(Chrissie, patient)

Mirroring feelings of isolation shared by parents, opportunities to develop their own friendships prior to hospice engagement were few and far between:

> Yeah, I didn't have anywhere to go, I didn't go to any respite services or anything, my mum did all the hard bit.

(Poppy, patient)

Patients worried about their reliance upon family, not in terms of a loss of friendships for themselves, but rather in terms of anxieties of being a 'burden' to their families:

> And some of us don't get any other care, like I don't so my mum has to look after me. At home my brother has to chip in and help, which makes him not have a life, and my mum doesn't have a life really,

(Chrissie, patient)

so much so that opportunities to try out hospice respite care held different meanings to that of parental associations. No associations with imminent death were made. Instead patients saw it as an opportunity to meet others which in turn would help their families too:

> It was brilliant as soon as I come in the door, it felt like home, and everybody was welcoming and friendly and laughter.

(Chrissie, patient)

Patients welcomed the opportunity to participate in short breaks at the hospice. Such is particularly powerful given this population was used only to a tight knit home or hospital community. It induced a sense of normality into the lives of patients. It enabled them to enjoy activities others take often for granted, along with their siblings, in a safe, inclusive environment:

> Our first ever stay they did us a cinema night, they opened the cinema up, got us some popcorn, put a movie on. That was good, because my girls (…) well, they've never been to a cinema. They've never done anything like that. Yes, they've opened up to a lot. Gave the girls a bit more of a childhood rather than they need to be adults. They've been able to be who they are.

(Joanne, mum)

The capacity of the hospice to accommodate the needs of different age groups was appreciated. Smaller children welcomed the availability of:

> …loads and loads of toys, a soft play area, (…) the dolls, the pushchairs, the ride on toys, the trampoline, the scooters, the bikes.

(Poppy, patient)

The cinema was a firm favourite with guests of all ages, as was the spa, the hot tub, and the big Jacuzzi bath. So too was the capacity to engage in active and passive leisure activities, as and when desired:

> We have so much fun, baking and stuff, and just having fun really, talking, hanging out, listening to music.

(Chrissie, patient)

That this all took place in a non-judgemental place of safety and sanctuary generated profound contributions to the wellbeing of all involved:

> …when they come here they have a life, they have fun, and to be honest with you it's the memories aspect, that I've got to do, and as a mum I've got to make sure I do them.

(Tama, mum)

Living with life limiting illness: sibling insights

Just as serious illness impeded patient socialization, it also compromised sibling socialization too. Siblings, healthy and sick, demonstrated powerful bonds with each other, neither necessarily wanting to be parted during their social time:

> …because [brother] started to get ill and my mum just thought that we need to do something about it and then she found out somewhere [hospice] and then she said, have you got free space available? And they said they had and I wanted to be with [brother] (…) then I went there.

(Jada, sibling)

The inclusiveness of the hospice environment was welcomed by parents who, already struggling with often complex logistics, did not have the capacity to attend more than one social environment at a time, even if alternative facilities could be found:

> There isn't anything out there apart from places like the hospice.

(Janie, mum)

Echoing the experiences of both parents and patients, siblings associated periods of respite care at the hospice as enabling them to take a break from family illness, achieve a sense of normality, and raising the spirits of family members too:

> Dad used to go on it all the time [pool table], and that helped him.

(Ilma, sibling)

Respite care presented an opportunity to develop friendships. For some, not all, these friendships blossomed over a considerable period of time:

Fourteen times [days] every year [for three years],

(*Jada, sibling*)

acting at times as a conduit for healing, particularly for siblings seeking solace in bereavement:

[My son] was with another little boy and they were chatting away and this little boy went 'yeah, my sister's dead now' and my son said 'oh really?' he said 'yeah, but she was a bloody nuisance anyway' so you know, it was just, they can say whatever they want to say and it doesn't matter, it doesn't matter, they need to say it, they don't mean it but they need to say it, so that's why the hospice is brilliant.

(*Debbie, mum*)

Living with life limiting illness: drawing family insights together

The previous sections have illustrated how respite care breathes life and value into the palliative care experiences of siblings, patients and parents. From these insights a number of common, cross-cutting themes and contributions emerge. Collectively, narratives illustrate that for siblings, patients and parents, respite care, whilst experienced in different ways, fundamentally affords opportunities to *live* with life limiting illness, overcome crisis, despair and prejudice, and regenerate emotional and psychological well-being. It contributes to uplifting changes in the form of inclusivity and meaning-making, even where its capacity is only to nudge, not correct or cure, human fallibility:

…all the way through his illness, we like said, think of positives. You can still do all these positives. You've gotta think positive. So, he (…) whenever he were like, well, I can't (…) I can't play football anymore. I know you can't but we could still go to the cinema. We can still do this. We can still do that….

(*Janie, mum*)

We learn that short breaks facilitated through respite care induce a sense of normality, generate new interests, conversations, friendships and ways of living at a time when so much is predicated upon feelings of loss (Ramanayake, McIntosh, & Cockburn-Wootten, 2018):

I mean, they took us to The Butterfly House on our last stay, which is something we'd have never been able to experience. We've always all wanted to go, we've just never been able to.

(*Joanne, mum*)

Respite care prompts optimism, escapism, and new beginnings. The experiences generated are not only experienced by the carer, but by siblings and patients too, voices so often neglected in respite research (Ingleton et al., 2003).

These narratives also extend our understanding of social tourism, particularly in terms of the relationship with terminal illness and our understanding of family tourism. They are drawn from participants who, prior to the onset of personal or familial illness, would not necessarily have had recourse to utilise social tourism support, in so doing adding a temporal dimension to social tourism research:

Our 6 year old (sibling), if she was here today she would tell you that this is like [our trip to] Disneyland, she loves it!,

(*Amy, mum*)

They extend our understanding of the 'uplifting changes' commonly associated with individuals and communities in the transformative service research literature (Anderson et al., 2013), this time allowing us to appreciate familial 'uplifting changes'. They shift the focus of respite care, often premised upon carer burden, to one which celebrates the profound contribution tourism plays in *living well* with dying. In so doing they add health benefits to the previously acknowledged social and economic benefits derived from social tourism participation (McCabe, 2009; Minneart et al., 2009). They extend similarly the subjective wellbeing literature (McCabe & Johnson, 2013). They pave the way for an extension of lobbying for 'holidays matter' (Family Holiday Association, 2019) beyond social policy, into healthcare policy too.

Conclusions

This paper set out to question the capacity of tourism to bring uplifting (transformational) changes to the lives of families whose child has a life limiting, terminal illness. It has focused upon respite care services provided by children's hospices. Philosophically, hospice services aim to provide emotional and physical comfort not only to patients as they reach the end of their life, but families too. Listening to the voices of all affected by terminal illness has been a central methodological driver. A number of contributions to our understanding of transformative service research, our understanding of social tourism, and, particularly powerful of all, contributions to the 'dying well' policy rhetoric have been uncovered.

Experiences shared in this study demonstrate the capacity of social tourism to temporarily overcome, or at least support, exhaustion, fear, loneliness and isolation. To enable *living* with loss, lost childhood, lost siblings, lost hopes and aspirations, lost economic livelihoods. To offer a support mechanism, a sanctuary, to those *living* with hurtful prejudice, having to think carefully before engaging with services that society takes for granted. To those excluded from even home-based leisure activities, a glass of wine for instance, without fear of terrifying consequences. Social tourism is about adding life experiences to a period of dying which might in fact be a considerable period of time, five years not unusual in this study. It is about giving confidence, optimism, enjoyment,

and hope to times when all messages are predicated upon mortality. It is about meeting like-minded people, non-judgemental, empathetic to complexity. It is about relieving the burden of illness which no child should feel, and enabling socialization processes for siblings too. These are the messages social tourism participation has uncovered, messages of what can be achieved when support, not sympathy, is in place. How progressive a society would be to have policies capable of generating these experiences embedded in healthcare policy and practice.

The transformational capacity of social tourism in terminal illness is carefully nuanced. It lies in its ability to take an extraordinary service, holidays, and help participants to feel ordinary, normal, by being able to participate in them, whilst also retaining the extraordinary multi-faceted emotions attached to participation, be it anticipation, excitement and enjoyment for instance. Ultimately this study shows that in circumstances dominated by life-limiting illness, social tourism transforms darkness, despair and mixed emotions into a celebration of normality, a break from illness, an opportunity to be included in services which generate uplifting memories, optimism, escapism and new beginnings. These echo the mechanisms acknowledged by Ramanayake et al. (2018) as ingredients for positively *living* with loss. Policy rhetoric needs to move beyond 'Dying Well' narratives premised upon traditional healthcare services alone, and instead celebrate opportunities for '*Living Well* with Dying'. As this study has evidenced, tourism has a substantial transformational contribution to make to such a progressive healthcare policy.

Given demand for palliative and end-of-life care services is increasing, fed in part by an ageing population and increasing co-morbidity, there is much work to be done. This study has shown care delivered through purposefully designed hospice units to be responsive and make a difference to the lives of not only patients, but families too. The care offered makes people feel welcome and safe. People have trust in this care. By studying respite care in particular, this study has added a further evidence base to the need for such support. However, to offer more breaks, in turn enhancing the experiences of a wider population, requires action at a policy level. In influencing policy change, multiple stakeholders have a role to play. Service providers have a role to play in lobbying for extensions to healthcare policy to include more support for respite care. Researchers have a role to play by adding to the emerging evidence base. This study has considered respite care and hospice provision. Studies of community care and acute care more generally are needed, across a range of healthcare policy contexts. Policy makers have a role to play in gathering evidence from a wider advisory panel than previously the case when developing palliative and end-of-life care strategies. Service users have a role to play in sharing their stories with others to raise awareness and inspire hope. Collectively such actions will start the process of shifting the importance of respite care to more centre stage than previously the case.

Limitations and opportunities for future research

This study demonstrates how many of the emotions and circumstances found to be common in studies of social tourism and ageing such as bereavement, anxiety and poverty for instance, actually are not age specific. They dominate the narratives of even young families with small children where a life-limiting illness is present. A growing awareness of these difficulties accompanies ageing research. There is hope that the physiological, psychological, social and spiritual research called for in studies of ageing (Morgan et al., 2015) will transpire. What is far less obvious, possibly even palatable if we take account of the prejudices documented in this study, and the disability literature more widely, is whether children and family research will necessarily receive the same level of research attention. Multiple opportunities to move understanding forward exist including reviewing further the patterns of what might be termed 'respite tourism' emerging through this study: the ongoing relationship with the hospice; the ability to, and implications of, taking a holiday elsewhere away from the caring role; services geared towards the parent, the child and the sibling.

What tourism activity looks like in a hospice setting was relatively unknown prior to this study. With such limited existing research to build upon, this study has necessarily been exploratory in nature. Whilst we have no reason to believe the findings are atypical, further research is needed. For instance, our dataset is collected only from UK participants. Palliative care carries different meanings and care models in different geographical settings. Further testing in an international setting and within multiple research environments beyond hospices would make a valuable contribution to the debate. We also spoke only with families able to access and accept palliative care support. We know nothing of the circumstances of non-participants. Whether non-participation is linked to choice, or, tragic exclusion, is unknown. Short breaks, facilitated through respite care, have been shown to profoundly transform the lives of those in their darkest days. Forensically understanding non-participation and any barriers prompting such a situation needs to be a critical function for future research.

Acknowledgements

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