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Design Meets Death: Emergent Issues in a Research Study on Reimagining ‘Legacy’ in the Context of Paediatric Palliative Care

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Abstract: ‘Legacy’ is a death-centred adult-oriented concept, conventionally defined and narrowly imagined. Legacy making activities in palliative care are proven to enhance sense-making and offer therapeutic benefits. However, research around legacy and legacy making is limited in definition, outcome, and ambition. This paper reports on an exploratory, interdisciplinary, design-led study aiming to reimagine ‘legacy’, in the sensitive and heavily under-studied context of paediatric palliative care. An inclusive design approach is adopted and children and young people are focused upon as the ‘lead design partners’ with potentially distinct and largely overlooked voices and viewpoints in palliative care. Both chronological and thematic perspectives are used to outline and discuss the issues and barriers emerged throughout the study. Three overarching themes i.e. Conceptual; Ethical; and Operational are identified as key challenges. Critical reflections are summarised under three insights on Legacy, Difficult conversations, and Life design. Future opportunities for research are outlined under four recommendations.

Keywords: inclusive design; palliative care; legacy; paediatric

1. Introduction

“I don’t see the point of measuring life in terms of time any more. I would rather measure it in terms of what I actually achieve. I’d rather measure it in terms of making a difference.”

(17-year-old boy shortly before he died of cancer, 2017)

1.1 Palliative and end-of-life care

Arguments within the healthcare world around patient-centred care (Kane et al., 2015), patient-reported outcomes (Aslakson et al., 2017) and personalised medicine (Lloyd-

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Williams et al., 2008) resonate strongly with the wider recognition of the need to reclaim and reimagine end-of-life as a 'human', rather than a mere 'medical' domain (Davies, 2018), raising questions around power, control, and singular expertise in end-of-life (Author, 2019). This is further aligned with the rapidly growing evidence base in the design world, on recognition of the individuals' right and desire to reclaim, reimagine, and design their own palliative and end-of-life experience in meaningful & desirable ways (End Well Symposium, 2019; Reimagine End of Life, 2018; HELIX, 2015; Open IDEO, 2014).

In the context of paediatric palliative care however, less is known amongst healthcare professionals about how children and young people make sense of their end-of-life experiences (Langton-Gilks, 2017; Warner et al., 2016). Approaches typically used for conducting end-of-life conversations in the adult setting have proven to be ineffective in paediatrics (Pease & McMillin, 2018) due to complexities including consent and legal authority (Thieleman et al., 2016). On the other hand, research leading to an awareness among the public and healthcare professionals of how Children and Young People (CYP) perceive their end of life experience is severely underdeveloped, and much needed (Jones & Weisenfluh, 2003). Consequently, there is, to date, no coherent framework for different disciplines in the biological, social and human sciences to work together to improve end-of-life care for CYP (Langton-Gilks, 2017; Behrman & Field, 2003).

Young adults with life limiting and life-threatening conditions have emphasised the importance of having discussions about death and dying supported by professionals and carers. Interestingly, they also note, efforts should be made to get to know them and their values prior to broaching difficult matters, further highlighting the need for engagements oriented around life, rather than death (Together for Short Lives, 2015). A need for practitioners to work more openly, proactively, and collaboratively with families has also been highlighted (Coad et al., 2014).

1.2 Legacy

A key construct in how individuals envisage their 'end of life' is that of 'legacy.' The concept of 'legacy' is conventionally understood in adult terms and commonly and narrowly defined as something handed down to a predecessor; the remains of a person, material and/or imagined, that lives on, once they have passed on. Hence, in its current limited definition, framed through an 'after-death' perspective, immediately relevant to every dying rather than living person. Such death-oriented understanding, has also been shown to permeate how adults perceive and conceive of the term when referring to children and young people's legacy. Legacy-making activities offer a range of therapeutic benefits and have been identified as a significant enterprise with end-of-life design potentials for adults, enhancing sense-making, familial communication and positive emotional experiences (Allen, 2009).

An evidence base is beginning to emerge, which explores the meaning and impact of legacy and legacy-making in the experiences of children and young people with life-limiting and

life-threatening conditions, and their Significant Others¹ (SO) (Ackard et al., 2013). However, more often this has been gauged through the perspectives of health professionals (Foster et al., 2012) or bereaved parents (Foster, 2009). We still know little about how children and young people make sense of their own legacy, how they define and understand the term, as well as their preferences for talking about it in accessible and meaningful ways (Foster et al., 2012).

Moreover, significant differences could be anticipated in how life legacy is perceived, defined, and envisioned by CYP, compared to adults. This could be due to variances in awareness of, and adherence to socio-cultural norms and structures; imaginative and creative thinking; theories of self and personal meaning; length of life experience.

In reimagining legacy, the focus on children and young people would not only ensure their voices and visions are central to paediatric palliative care, but also add a novel and potentially significant take on the whole concept of 'legacy'. Hence, potentially enhancing, challenging and revitalising its current limited perception and potential.

1.3 Design

Beyond a process of opportunity framing and problem solving (Lawson 2007; Cross, 2006), design is an act of meaning creating (Krippendorff, K. 2006). The creative, generative, futuristic, and empathic mindset and practices of design (Johansson-Sköldberg et al., 2013) has a lot to offer to palliative and end-of-life care (Nickpour, 2019) and could inform the process of reimagining legacy. In particular, a human centred (Giacomin, 2015) and inclusive design (Clarkson et al., 2003) approach would ensure that the voices and multi-faceted experiences of users are central to every stage of the design process. Putting the extreme voices and experiences of children at the centre of reimagining legacy can be particularly helpful in challenging and innovating upon the concept for all.

An inclusive design approach implies identifying, empathising, and ultimately designing with those often ignored or excluded user groups at the peripheries, whose experiences pose the most extreme and diverse design challenges and constraints. Such focus on moving beyond the mainstream and bringing the extreme to the centre, could in turn offer rich insights, alternative novel perspectives, and lead to better-informed design challenges, re-framed opportunities, and innovative solutions that benefit all.

2. Research aims and questions

2.1 Scope and Aim

A range of gaps, limitations, and opportunities were identified within the current knowledge

1 By 'significant others,' we refer to those individuals who are both biologically related to, and also provide tangible as well as intangible support for, the child or young person in care. Thus, this category includes parents, siblings, grandparents, aunts, uncles and cousins.

and applications of legacy in the context of palliative care. These included the narrow, death-focused, and adult-oriented existing definitions and dimensions; limited creative and generative outputs; lack of child-centred exploratory research on the topic; multiple confirmed benefits of legacy-making activities; and potential unexplored impacts of reimagined legacy-making activities on life trajectory and health outcomes.

Hence, an interdisciplinary design-led study was planned, aiming to reimagine legacy in the context of paediatric palliative care. The research study was co-defined and co-led by an interdisciplinary team of senior clinicians from a children's hospital and academics, coming from three distinct fields i.e. Paediatric palliative care, Design, and Management.

2.2 Research questions

Accordingly, four research questions were outlined;

- How might CYP receiving palliative care, reimagine their 'legacy'?
- How might CYP's SO, reimagine notions of 'legacy'?
- Based on the data from (RQ1) and (RQ2), how might CYP and their SO co-define, co-capture and co-curate 'legacy' in ways that are cognitively, emotionally, spiritually and psychologically satisfying to all concerned?
- How might legacy-making activities impact life trajectory and health outcomes in CYP and their SO?

The notion of 'legacy is for all' underpinned the exploratory research, aiming for a mentality shift in focusing on legacy as a life-centred, ongoing, dynamic, imaginative, and inclusive concept – for all those living, rather than only for those dying. CYP were seen as one progressive, distinctive and uncontaminated voice to help reimagine legacy. Furthermore, by adopting the concept of legacy as a hook, and through use of generative and creative processes and methods, the study aimed to open up spaces of dialogue around a meaningful life, what CYP wanted to achieve alongside, and how they wanted others to know about or remember them. Figure 1 captures the different approach to 'legacy' in the context of this study.

Figure 1 Legacy, a different take; LEGACY reimagined as an ongoing unending concept versus 'HISTORY' as a past concept

3. Study design and Development

Table 1 outlines the study plan comprising multiple stages, running across a 12-month period.

Table 1 Legacy Study plan running across 12 months

Stage & Activity	Length (month)
Review literature on the overarching areas of legacy, CYP, and design	3
Design Initial Legacy-making 'Creative Session', structured around RQs 1, 2 and 3, and informed by the literature review	1
Review initial session design by Steering Committee	0.5
Apply for research ethical approval	2
Recruit participants by approaching guardians for initial interest, if positive, followed by provision of information sheet, followed by a meeting with clinical team conducting the session, who will explain the study in detail and seek consent if the guardian and CYP is agreeable	2
Pilot three Legacy-making 'Creative Sessions' conducted with three eligible CYP and their SO	1
Review and finalise the 'Creative Session' by study Steering Committee	0.5
Conduct eight Legacy-making 'Creative Sessions' with CYP and their SO	8
Design 'Reflection Session' including semi-structured qualitative interviews with CYP, their SO, and facilitating staff	1
Review 'Reflection Session' by Steering Committee	0.5
Conduct 'Reflection Session' with participants involved in Creative Session	8
Data analysis	9

3.1 Ethics and Governance

A substantial ethical approval application was planned for approval by Integrated Research Application System (IRAS) which is the notional body for health, social and community care research permissions and approvals in the UK.

3.2 Sample and Recruitment

The concept of “legacy is for everyone” underpinned the recruitment strategy. Hence, all Children and Young People (CYP) diagnosed with a life limiting condition and their Significant Others (SO) who were referred to the participating hospital’s Specialist Palliative Care team, were considered eligible to participate in the research. Additionally, a clear inclusion and exclusion criteria was outlined to be carefully considered by Specialist Palliative Care team on a case by case basis. Table 2 outlines the study inclusion and exclusion criteria.

Table 2 Inclusion/Exclusion Criteria for participation in the Legacy Study

Inclusion Criteria	Exclusion Criteria
CYP with life limiting conditions referred to the Specialist Palliative Care team at the children’s hospital	Deemed too unwell/too advanced/ not suitable by Paediatric Palliative Care Multidisciplinary team
SO of CYP referred to the Specialist Palliative Care team	Parent or guardian not providing informed consent
CYP Aged 4-18	CYP aged below 4 or above 18
	CYP not providing assent

3.3 Stakeholders Mapping & Steering Committee

Due to the exploratory, complex, and sensitive nature of the research, an interdisciplinary group of stakeholders, who work with the target population in different capacities, were mapped. These stakeholders were also invited to join the study as the Steering Committee. They met regularly as a team, and were consulted separately where needed to review, advise, and steer the study. Figure 2 represents the Steering Committee’s spread of expertise and perspectives.

Figure 2 Legacy Study stakeholder mapping and Steering committee members

The initial study design was reviewed by committee members including two bereaved parents, a music therapist, a clinical psychologist, a patient and parent participation facilitator, and a bereavement counsellor.

4. Issues and Barriers

The study progressed into pilot phase but did not reach the Legacy-making Creative Session stage, due to a number of issues and barriers. Both chronological and thematic perspectives are used to outline these emergent issues. Firstly, an account of specific issues faced at different stages of the study is provided. Secondly, all barriers are categorised under three over-arching, inter-linking themes.

4.1 Chronological issues

CYP PROFILE

The inclusion criteria at the onset of study, included CYP aged 4-18, with normal global development and verbal communication, enrolled on a palliative pathway. This however, needed to be reviewed, in order to ensure CYP were fully involved and their distinct individual voices were captured. It was commonly understood that adolescence was the age, when children began to form their own distinct identity and voice (Briggs, 2002). However, in the context of paediatric palliative care, the confounding factors were the often multiple complex health and social difficulties that accompanied these young people, affecting their development and their ability to verbally communicate.

Accordingly, the participation age was revised as 11-18. Furthermore, a narrow band of specialties i.e. Cardiac, Duchenne Muscular Dystrophy, and Oncology was focused upon,

where CYP were more likely to have typical developmental and communication abilities, to participate with personal agency, see Figure 3. Despite the inclusive “Legacy is for Everyone” remit of the study, the time and budget limitations did not allow specialist support to facilitate participation of CYP with developmental and communication gaps. This excluded certain voices and reduced the already small number of potential participants.

Figure 3 Re-focused CYP participant profile

PUBLIC AND PARTICIPANT FRAMING

The intention was to help reimagine legacy for everyone through an inclusive design approach. However, a necessary ethical and practical consideration in recruitment strategy, was to redress the real possibilities for misunderstanding the concept of legacy, and the overall study, in participant-facing communication.

It was acknowledged that framing the initiative through the lens of legacy, could cause negative emotions, depending on previous conversations regarding the CYP’s condition, and the meaning attached to their prognosis.

From a clinical psychology perspective, the introduction of the study to a potential CYP and their family, could irrevocably challenge the understanding of the family, and the knowledge and understanding the CYP might have of their condition. Such a situation could only be mitigated through communication with the network of healthcare professionals and others involved in care of the CYP, in order to establish where a given family were in their journey, prior to approaching them for participation.

As a rejoinder to this issue, it was decided to explicitly use the term ‘legacy’ in communications and public framing, to maintain the project’s integrity, and to keep intact transparency regarding its intentions. The project heading “Legacy is for Everyone” attempted to convey the relevance of legacy, and participant information sheets, helped to explain in positive terms, how engagement with legacy, could help people think about

what they wanted to do with their lives and their wishes and hopes. Hence, an attempt was made to challenge default perspectives, aligned to death and passing on, by including broad interpretations of the term.

STUDY DESIGN

Adding an 'orientation' phase

Interdisciplinary input from Steering Committee helped identify further issues around introduction, framing, accessibility and vulnerability, and gatekeeping, prior to participation in the Creative Session. Hence, an initial 'Orientation session' was added to the 'Creative Session' and 'Reflection Session' already planned. This was in order to better introduce the study to participants; include preparatory work to help inspire and orient both CYP and their SO; conduct a 'pulse check' in order to identify unique circumstances, current paths, and customise support needs; apply a sensitive stepped approach to make the study accessible and meaningful.

Separation of CYP and SO sessions

The main premise of the study was to elicit the distinct voices of CYP. However, within the sensitive and extreme context of paediatric palliative care, the parent or adult caregiver were repeatedly reported to gatekeep participation and speak on behalf of the CYP. Hence, CYP and SO sessions were separated in order to ensure CYP's narratives. This, however, raised further issues around unsupported separation of CYP from their SO, which could put CYP, SO, and the researchers in a vulnerable position.

Framing & Format

A pilot session with teenagers in a palliative care support group, confirmed issues around framing and terminology. Young people at the group struggled with finding meaning in the concept of legacy, which needed to be further unpacked and illustrated with reference to different examples of legacy making. There was a tangible sense that legacy, was not something that was part of their everyday language and experiences, or held age-appropriate significance.

Young people also noted that the project had to be engaging and fun and provide relevant and appropriate opportunities to think through their lives, in meaningful ways. Tapping into contemporary teenage interests, popular culture e.g. music and digital games, and interesting 'hands-on' ways of generating information and insights, were specifically noted as potential hooks.

PILOT PHASE

Recruitment

Recruitment for pilot phase was led by stakeholder groups who worked closely with CYP and their SO. Early on, the senior consultant co-leading the project had to leave the study due to unforeseen circumstances. This significantly impacted the recruitment as the consultant was well respected as a strong authority and gatekeeper in terms of recruitment, trust and gatekeeping. This raised issues around the sensitive nature, gatekeeping, and hierarchy of

power, authority and expertise in conducting research. Targeting strategies were devised by expert stakeholders based on perceived ability to engage with the activities and appropriate resilience and coping strategies. This raised issues around sample size and purposeful sampling.

A general lack of interest and poor response rate to the pilot initiative was reported by gatekeepers. Introducing the project under the banner of 'Legacy' seemed a barrier to participation. More often the term 'legacy' was understood by parents, in terms of its 'after-death' meaning. Overall, the framing of interventions associated with end-of-life and death were not seen as sympathetic with the cultural context of oncology, for example, where narratives of hope and survivorship predominate.

Figure 4 'Tree of Life' exercise

CREATIVE WORKSHOP

The pilot was introduced as part of a legacy project, giving an opportunity for CYP and SO to reflect on their lives, what they had done, the relationships they had made, what they wanted to do in the future and how they could make their own unique mark on the world.

Tree of Life method used predominantly in narrative therapy, (see Figure 4) was presented and participants were invited to reflect on their own lives in relation to each dimension of the tree.

The Tree of Life exercise was generally well received by the CYP as a clear, engaging and meaningful activity. CYP noted that it helped them think about matters not already considered. At the same time, they struggled with the branches level (hopes and dreams). This brought to surface, the inherently different nature of sense of future, perspective and trajectory of life in this context. And while a significant finding in itself, it was seen as a potential negative trigger, reminding CYP of their prognosis.

The small number of participants (2 CYP) was seen as a barrier. Additionally, the invasive nature and considerable level of help needed from support workers to complete typical workshop activities e.g. scribbling or drawing, impacted the information privacy and agency of CYP. Hence, the nature of data collected, was seen as major accessibility and gatekeeping challenges. CYP noted that participants should be given a choice of whether, or not to talk about their tree with the facilitator (for some, this might be considered private information).

4.2 Thematic issues

Various issues captured chronologically, are classified under three overarching themes, and discussed here.

1. CONCEPTUAL; PERCEPTIONS OF LEGACY IN PAEDIATRIC RESEARCH

There are challenges in engaging with, or implying, death in paediatric legacy interventions, which can be mis/understood as taking away hope and associated agency from the perspective of adults involved. Accordingly, researchers and practitioners using legacy interventions, have reported various difficulties in framing their work.

A key barrier, was the research focus itself, that of legacy. The impact and consequences of using legacy as an explicit framing device, was noted in both adult and CYP participant groups, across study design, gatekeeping, and recruitment.

Perspectives and attitudes towards legacy vary depending on age and position; while there is an implied onus on a post-death perspective in adult perceptions including SO (Ackard et al., 2013) and healthcare professional (Foster et al., 2012), CYP have differing viewpoints. Ackard et al. (2013) explored children with cancer's interest in legacy-making and contrary to what the research team anticipated, child participants aged 7 to 12, did not articulate or stress end-of-life concerns. Instead they expressed their wishes for others to know about: their personal characteristics; things they like to do, and; their connectedness with and love for others.

Such perception has also been uncovered in health care professional's reflections on interventions in paediatric palliative care settings (Foster et al., 2012). A thematic analysis of key perspectives noted that legacy-making activities are more often introduced at the very end of the child or young person's life, reinforcing the connection between legacy-making

and the termination of life. Interestingly, in qualifying this perspective and endorsing the need for legacy-making interventions at an earlier point, paediatric health care professionals, noted that legacy making interventions could add considerable value to child ‘survivors’, providing a tangible record of their journey (Foster et al., 2012), opening up new possibilities for the application of legacy interventions. This near uniform adult meaning attributed to legacy, turned the concept, in its context of vulnerability and life-limiting conditions, into something akin to a ‘hot potato’ that no one was particularly keen on handling.

CYP’s feedback also revealed that the term didn’t resonate with them and was neither a relevant term to them as teenagers, nor allowed much scope to explore and make sense of their individual life circumstances.

From a study design point of view, the time, resources, and coordination required to prepare the study sensitively for the target population were significantly increased considering the very nature of ‘legacy’.

2. ETHICAL; FLEXIBILITY, GATEKEEPING AND INCLUSIVITY

The nuances and sensitivities of employing the concept of legacy in paediatric contexts, has also been discussed in relation to the ethics of practice.

Flexibility

Building on the seminal work of Bluebond-Langner (1978), Moxley-Haegart (2015) attempts to articulate to parents and primary care-givers, the CYP’s capacity to talk about death, and employs alternate approaches to legacy-making that respond to, and are led by the CYP and SO. These approaches move between ‘open awareness’, where it is safe to talk about death and, ‘mutual pretence’ where CYP have trouble talking about death. This has led Moxley-Haegart to omit the term ‘legacy’ when working with some CYP, adopting alternative frames of reference that still enable meaningful engagement with legacy-making activities, such as: ‘a project which lets others learn about us’; ‘messages for family and friends’; ‘a way of helping others who might have similar experiences’.

Gatekeeping

Gatekeeper refers to an adult able to control or limit researchers’ access to participants. Gatekeepers have a positive function in ensuring that children are protected from research that could potentially be exploitative, invasive or coercive (Royal College of Paediatrics and Child Health Ethics Advisory Committee 2000).

The default perception in paediatric research, paints a picture of CYP as ‘vulnerable’ research subjects that need protection, placing responsibility onto adults to monitor and control access (Carter, 2009). While this can promote a keen and necessary safeguarding sensibility, it can also constrain and downplay children’s abilities, competencies and understandings (Campbell, 2008). It also impacts on the perception of research and the position of researchers as potentially ‘dangerous’ (Carter, 2009).

In paediatric palliative settings, the notion of vulnerability is amplified by an order of magnitude, and argued to impact opportunities for CYP to participate and have their

voices heard (Carter, 2009). In other related research, clinical gatekeepers excluded eligible families due to: perceived burden research would place on the family and their well-being (Beecham et al., 2016; Stevens et al., 2010; Shilling et al., 2011); concerns about anticipated benefits (Westcombe et al., 2003) as well as; the likely impact on patient/family-professional relationships (Castell, 2006).

Accordingly, many studies are hampered by low rates of invitation (Hinds et al., 2007), the highest refusal rates (Gattuso et al., 2006), and identifying issues with recruitment (Tomlinson et al., 2007) due to gatekeepers deeming research with CYP and families, as inappropriate (Crocker et al., 2015).

In the context of this study, all the above were observed to be true. The explicit focus on legacy impacted most acutely on adult stakeholders' protection of perceived 'vulnerable' CYP and their SO, and monitoring and controlling access to the study.

In discussing all these ethical barriers, Tomlinson et al (2007) make a crucial point that whilst research in paediatric palliative care contexts can touch on extremely sensitive issues, none-the-less, research is still required, and perhaps more so, to better understand the context and its challenges, and to help uncover insights and strategies to support CYP and their families.

Inclusivity

Issues of accessibility and inclusion were also paramount. Some stakeholders acknowledged perceived difficulties in recruiting and bringing together CYP from different specialities in the peer-based Creative Session. In more detail, it was felt that such a scenario could bring together CYP at different stages in the journey, privy to different interpretations about the meaning of their condition, as well as create issues in group dynamics.

In addition, the stakeholders noted that the resources required to support the participation of CYP and SO, could prevent potential participants' access to and inclusion in the initiative. These were mainly due to complex and diverse range of CYP support needs, as well as logistical difficulties of bringing together CYP and their SO from across a vast geographical area.

3. OPERATIONAL; PREPARATION AND GROUNDWORK

Beecham et al. (2016) summarise operational barriers to conducting paediatric palliative care as limited time and other resources, small sample sizes, limited funding, difficulties with research ethics committees, the unpredictable nature of the illnesses and professional perceptions of the potential physical and psychological burden for participants.

Additional time needs to be afforded to setting up research in paediatric health settings (Coyne, 2010), with the groundwork required to carry out research, even more time, support and resource intensive in palliative settings (Tomlinson et al., 2007). This matched the findings from this exploratory interdisciplinary study, leading to time slippage in implementation plan. It could be argued that the effort, time and resources required to undertake research in this context were too great for an exploratory study of this size.

Early involvement of stakeholders in applied health research is understood as crucial in ensuring the relevance and cultural competence of research (NIHR, 2015). This would seem even more necessary in sensitive contexts, such as paediatric palliative care (Tomlinson et al., 2007). In assessing challenges in conducting paediatric palliative research, Tomlinson et al. (2007) identified project completion success criteria, which included engaging the opinions of key stakeholders, and crucially families, at an early stage including their involvement in study design. While the study was co-designed with key stakeholders, this was not considered detailed enough in order to hit the ground running, alluding to the highly complex, sensitive, exploratory, and interdisciplinary nature of the project. In this context, the study was deemed as ambitious, and underfunded.

5. Insights and Recommendations

5.1 Insights

LEGACY IS (NOT) FOR EVERYONE?

One major point of discussion is if and how to best communicate the explicit focus on a challenging concept such as legacy, while the aim is to reimagine that very concept. The study's underpinning "Legacy is for Everyone", attempted to convey an obvious yet sensitive insight. In the context of paediatric palliative care however, adult stakeholders and gatekeepers perceived engagement with it as too sensitive for majority of the target population. As with CYP, the concept did not seem to have enough relevance or traction.

DIFFICULT CONVERSATION ARE FOR EVERYONE?

There is evidence that timely difficult conversations can support better outcomes in paediatric palliative care (Jack et al., 2018; Coad et al., 2014; Lotz et al., 2013; Dyregrov, 2004; Scott et al., 2002). Research can pose difficult conversations that haven't happened, but could, and perhaps need to. There is an evident need for CYP and their SO to enter this conversational space.

The challenges identified in this study are not limited to its specific scope, but reflect on broader systemic and palliative care disciplinary challenges. They also reflect on the organisational culture within a children's hospital that has to deliver within extremely complex and sensitive boundaries, whilst also encourage efforts to make boundary crossings into difficult conversation spaces, worthwhile. CYP and SO need evidence and confidence that more open and potentially difficult conversations can enrich the journey. Equally, adult stakeholders and gatekeepers need evidence and support on why and how to navigate such vulnerable, yet potentially invaluable pathways. The adopted design approaches could be re-purposed to facilitate entering the difficult conversations space, in a creative and inclusive manner.

LIFE DESIGN IS FOR EVERYONE?

Beyond its 'legacy' focus and the healthy tensions embedded within it, this study intended to promote and enhance CYP's agency by adopting a human centred and inclusive design approach. Design's empathic and imaginative approach was deemed suitable in both eliciting how CYP define and evaluate their lives, as well as ideating and leading what CYP want to do with its remainder.

Design and making opportunities are not only expressive but inherently linked to connecting with others (Gauntlett, 2018). These acts of creating, making, and connecting can help CYP and SO navigate the palliative and end-of-life landscape, and communicate and develop coping resources and strategies (Foster et al., 2015). A design-led mindset to CYP life, could assert more agency about the what, when, why, how and with whom of their lives.

5.2 Recommendations

Planning for systematic, extensive and extended research co-design phase with a well-orchestrated network of interdisciplinary expert and lived experience stakeholders.

Capturing paediatric palliative care stakeholders' existing practices and experiences of engaging in difficult conversations with CYP and their SO. This will be instrumental in better adoption and adaption of design approaches to enhance and facilitate difficult conversations.

Linking challenges identified in this study to broader, deep-rooted systemic and organisational challenges in engaging paediatric service users and their significant others, within a default culture of parental and adult gatekeeping. Without acknowledgement of such systems issues, any project within similar realms, will likely fall short.

Exploring diverse and truly inclusive methods of participation where neither creativity of process or output, nor agency and privacy of CYP is compromised. Given the complexity of CYPs and SO lives on the palliative pathway, alternatives to a one size fits all data collection phase, should be considered.

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