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The use of digital legacies with people affected by motor neurone disease for continuing bonds: An Interpretative Phenomenological Analysis study

Abstract

Background: Motor neurone disease is a progressive neurodegenerative disease without cure. Little is known about how young people are affected when a family member has the illness and subsequently dies, resulting in a gap in understanding of how best to support them. One psychotherapeutic approach involves creating a legacy to pass onto the young person, but little research has investigated the use of an emerging format, digital legacies, where videos document a person's life, memories and achievements.

Aim: To investigate the views, perceptions and experiences of digital legacies with people affected by motor neurone disease.

Design: A qualitative study underpinned by Interpretative Phenomenological Analysis.

Setting/Participants: People living with motor neurone disease (n=4), bereaved young people (n=3) in the United Kingdom. Open-ended interviews were conducted in person. Ethical approval was granted by a University ethics committee.

Results: Five key themes emerged exemplifying mutual challenges and benefits for people with motor neurone disease and bereaved young people. Creating a digital legacy provides a sense of purpose for people with motor neurone disease and a way to convey personality and life experiences. Bereaved young people can modify disease-related memories of the person and gain comfort from hearing and seeing videos.

Conclusion: This study expands the existing continuing bonds model of grief to include an 'autobiographical chapter', creating 'The Model of Reciprocal Bonds Formation'.

Keywords: "Motor Neurone Disease", "MND", "Amyotrophic Lateral Sclerosis", "ALS", "digital legacy", "bereavement", "continuing bonds", "interpretative phenomenological analysis".

What is already known about the topic?

- Living with motor neurone disease creates a sense of hopelessness and feelings of being unable to continue a normal role within the family
- A vital part of bereavement is the ability to continue a bond with the deceased
- Existing theories of bereavement and grief currently do not consider the influence of people who are approaching death.

What this paper adds?

- This is the first study to explore the use of digital legacy in this population and identify that creating a digital legacy is a feasible project for people living with motor neurone disease and provides a sense of purpose.
- Use of video recordings can provide bereaved young people with a sense of comfort and a way to reconnect with the deceased.
- Unifying existing bereavement theories and adding the term 'autobiographical chapter' to create 'the model of reciprocal bonds formation'.

Implications for practice theory or policy

- Three 'windows of opportunity' are apparent for both people living with motor neurone disease who create a digital legacy and, additionally, bereaved young people who use a legacy.
- Based upon the 'the model of reciprocal bonds formation', creating a legacy can create mutual benefits for both the person who is dying, and for the future bereaved people
- 'The model of reciprocal bonds formation' has applicability to people who are living with other terminal illnesses and create any type of legacy.

The use of digital legacies with people affected by motor neurone disease for continuing bonds: An Interpretative Phenomenological Analysis study

Background

Motor neurone disease is a rapidly progressive neurodegenerative disease¹ affecting roughly 400,000 people worldwide and approximately 5000 people, at any one time, in the UK.^{2,3} With no known cure, palliative care becomes crucial to promote quality of life for both people living with motor neurone disease, and their families.⁴

The dominant ideology regarding grief and bereavement stems from early Freudian theories.⁵ However, later theories acknowledge the changeable nature of grief,⁶ and influence of society and culture.⁷ The 'continuing bonds model' suggests bereavement is a process of adaption and change.⁸ Walter developed this further with his biographical model of grief,⁹ emphasising the social context of death, dying and bereavement. The bereaved talk to other survivors seeking knowledge about the deceased to create a 'durable biography'. The process of 'writing a last chapter'^{9(p.13)} is described in which the bereaved acquire previously unknown information regarding the deceased's life. The concept was further developed by Fearnley,¹⁰ who postulated that young carers create a 'penultimate chapter', precluding the 'last chapter', which is revised as the person living with a terminal illness deteriorates. Consequently, the young person's knowledge of the family member will encompass a plethora of illness-related biographical information. This becomes synthesised with newly acquired information during the writing of the last chapter, at bereavement.¹⁰ One way in which this can occur is through use of a legacy. The concept of creating a legacy for loved ones to support the continuing bonds with the dying person, has gained increasing prominence within palliative care.¹¹⁻¹³

An emerging approach is using technology to create a digital legacy, akin to a digital memory box, including photographs, videos, messages, music or blogs.¹⁴ Digital legacies 'enable storytelling, on-going narratives, memorialization and "renegotiated" relationships with the dead in a digital afterlife'.^{15 p.4} To date, limited research has specifically investigated the concept of people living with motor neurone disease creating a legacy,^{16,17} and no research has explored the use of digital legacies by this group.

A digital legacy created by a person living with motor neurone disease, may provide an alternative way for bereaved young people to develop their durable biography.⁹ The aim of the study was to investigate the use of digital legacies with people affected by the disease.

Methods

Study Design

The study was underpinned by Interpretative Phenomenological Analysis (IPA).¹⁸ Open-ended interviews were digitally recorded, and transcribed verbatim by the lead author.

Setting

Due to the progressive nature of the disease, alongside the sensitive nature of the study, interviews were conducted in a place, date and time of the participant's choosing. This ensured interviews were conducted in a location deemed 'safe' and limited any inconvenience or sense of disruption through participating in the study.¹⁹ All people living with motor neurone disease were interviewed face-to-face in their own home. One participant requested a follow-up interview after fully completing his digital legacy. Face-to-face interviews were conducted with bereaved young people in locations of their choice.

Sampling & participants

Due to IPA research being idiographic in nature, a small, purposive sample was required.²⁰ Homogeneity between participants was achieved through a shared experience of the disease and creation or use of a video legacy. As such, the inclusion criteria for participants is outlined below in Table 1.

Table 1- Participant inclusion criteria.

<i>People living with MND creating a digital legacy</i>	<i>Bereaved young people using a digital legacy</i>
<ul style="list-style-type: none">• Aged 18 years old and above	<ul style="list-style-type: none">• Aged between 11 to 24 years old
<ul style="list-style-type: none">• Confirmed diagnosis of MND	<ul style="list-style-type: none">• Bereaved due to a family member dying from MND
<ul style="list-style-type: none">• Created, or, in the process of creating a digital legacy for a child or young person in their family	<ul style="list-style-type: none">• Access to a digital legacy made <i>by the person who had MND, or;</i>• <i>Featuring the person who had the disease</i>
<ul style="list-style-type: none">• English speaking	<ul style="list-style-type: none">• English speaking
<ul style="list-style-type: none">• Able to communicate verbally or via alternative methods (augmentative and alternative communication or email)	

Recruitment

Recruitment involved use of 'online' methods through posting research updates and recruitment information on a specially created Facebook page. These posts were then shared to other Facebook groups related to the disease. This approach was similarly duplicated with Twitter, blogs and fora. In addition, various other methods of recruitment were employed to raise awareness of the study. Features were included in newsletters for charities and organisations who provided support for people living

with motor neurone disease and their families. Lastly, the research team visited local motor neurone disease association support group meetings to present on the study and disseminate participant information sheets.²¹⁻²²

Data collection

In accordance with phenomenological approaches to data collection, it was necessary to conduct interviews which provided detailed interpretations, opinions and views of the experience of being affected by motor neurone disease and creating/using a digital legacy.²³ Written consent was obtained and all interviews were digitally recorded. A prompt sheet which featured one of two open questions aimed to stimulate conversational flow and engage the participant (see Table 2).¹⁸ This ensured the interview was predominantly driven by the participant, meaning their experiences of creating, or using, a digital legacy would be discussed in a depth and logical order that was appropriate for the individual participant. It also promoted a free-flowing conversational feel through adopting a reflexive dyadic interview.²⁴

Table 2. Interview prompts

Participant group	Interview prompt
People living with motor neurone disease	<i>“I am interested in your experiences of living with the disease and creating a video-based digital legacy for a child/young person in your family. Please begin wherever you like.”</i>
Bereaved young people	<i>“I am interested in your experiences of being bereaved and using a video-based digital legacy of your family member that had MND. Please begin wherever you like.”</i>

Ethical considerations

Due to the sensitive nature of the research, it was paramount to consider the potential for participants experiencing psychological or emotional harm through discussion of the disease, death and bereavement. Participants were protected from harm through ensuring informed consent was achieved.²² People interested in the study were provided with an information sheet which outlined the study aims, requirements, and potential participation risk. The research team also provided numerous opportunities for participants to seek clarity by asking additional questions regarding the study.²² Where possible, participant consent forms were completed immediately prior to the interview. If the participant was unable to sign due to disease symptomatology, audio consent was obtained.²¹ Upon conclusion of the interview, a service support sheet was handed to each participant. Helplines signposted to external organisations relevant to the participant group (MND

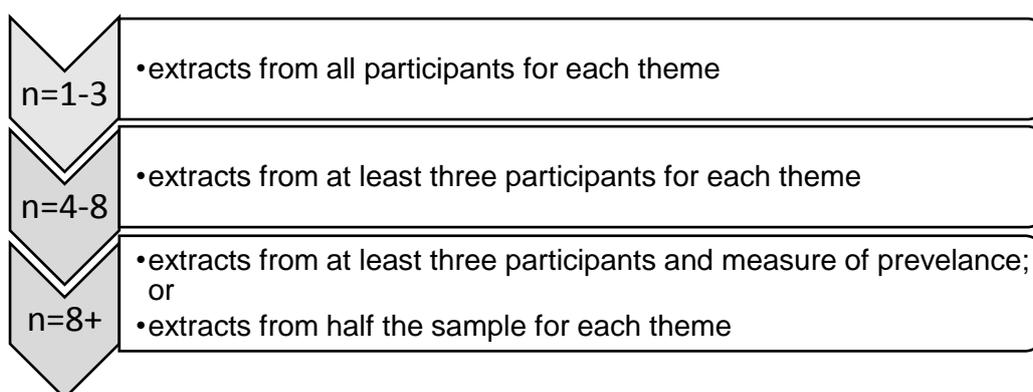
Connect/Child Bereavement UK). Ethical approval for the study was gained from a University research ethics committee (ref: FOHS114).

Analysis

Data analysis adhered to the 'six stages'; immersion in data; initial noting; developing emergent themes; identifying connections across themes; moving to the next case; identifying patterns across cases.¹⁸ NVivo11[®] software was used to organise data whilst also retaining the richness and complexity of each participant's contribution.²⁵ Preliminary coding was conducted by the lead researcher with emergent themes audited by other members of the team to enhance rigour.²² All identifiable information was removed and pseudonyms allocated to protect anonymity.

An additional measure of quality for IPA research is providing adequate evidence for each theme according to the size of the sample. Data was therefore extracted equally from the dataset and presented in accordance with guidance outlined in Figure 1.

Figure 1- Quality evaluation guide for IPA research based on sample size.²⁶



Findings

Interviews were conducted between February 2016-July 2017 with people living with motor neurone disease who had created a digital legacy for a child in their family (n=4), and bereaved young people who had used a digital legacy featuring a person who had died from the disease (n=3) (see Table 3).

Table 3- Participant characteristics

Cohort	Pseudonym	Year of diagnosis / age when parent died	Age at interview	Legacy type(s)
People living with motor neurone disease	Alice, Charlie, John, Tommy	Average=mid/late 2013 (Range Mid 2012- Mid 2015)	Mean= 50.5 yrs (Range 44-67 yrs)	Video story, video diary, digital legacy software, answer phone messages and texts.

Bereaved young people	Becky, Isabelle, Sophie	Mean= 9.3 yrs (Range 7-13 yrs)	Mean= 23 yrs (Range 22-24 yrs)	Recordings of family events
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Five themes were identified; i) underlying purpose of the digital legacy for people living with motor neurone disease, ii) challenges for people living with motor neurone disease in creating a digital legacy, iii) benefits for people living with motor neurone disease in creating a digital legacy, iv) challenges for bereaved young people using a digital legacy, v) benefits for bereaved young people using a digital legacy. Each theme will be discussed supported by anonymised interview extracts alongside analytical interpretations as best exemplars.

i) Underlying purpose of the digital legacy for people living with motor neurone disease

A common purpose of the digital legacy was to convey specific elements of personality or character traits. Charlie (a person living with the disease) described his digital legacy as a way ‘to make sure they knew who [he] was’ before disease onset, and provided a way to convey himself, and his personality, to his future grandchildren. It was a means by which he could remain involved in the lives of future children in his family, and provided a sense of comfort knowing he will be remembered after his death.

Yeah so that’s all the videos were for really, to introduce myself to my, future family, my nephew’s kids and my son’s kids. People that I’ll never meet, you know.

(Charlie, living with disease)

In contrast, John recorded milestone events in his digital legacy through creating a timeline to provide ‘almost like a little book about, you know, DVD book about *Daddy*’. Documenting specific milestone events provided a way to inform young people about how the person living with the disease had become who they were.

Because I wanted to put a record down. At one point I did a timeline of, a mini timeline of my life and where I had been and what I done and, you know, it was almost like a, ‘and then after University I went to Africa and I did this, and did that’. Because I wanted him to know what I, you know, what I had done.

(John, living with disease)

The concept of identity conveyance and documentation of past experiences was also reinforced by Alice. In contrast, however, Alice wished to show her son how her childhood, hobbies and interests had made her who she was.

And also doing about me, you know, things from years ago. Things like RaRa skirts, Wham, Adam Ant, all the cartoons we used to watch [...] So, you know, just things that he can look at and think. ‘Because I didn’t know that much about my Gran and when they were younger.

(Alice, living with disease)

There was also a hope that the recordings would provide an alternative method to continue parenting, guide, or influence the young person after death. Alice described a hope that her legacy would allow her to continue to have a presence in her son's life and enable her to impart values to him, that are important to her, even after death.

I still want that kind of input in [son's] life. I want him to know me, but also, I want him to, you know, to have morals, and good family values. That's the thing for me.

(Alice, living with disease)

Similarly, the digital legacy would become a type of resource which could be referred to in the future by a child or young person. Tommy felt the digital legacy will provide 'a *baseline*' which his children can later utilise to form their own ideas and concepts about life and the world.

I mean they may think, what a load of garbage. You know what, I'd probably be happy with that as long as they've got their own minds, questioning, and evaluating everything. But if I can give them a baseline, if I can help anywhere, that'd be good.

(Tommy, living with disease)

ii) Challenges for people living with motor neurone disease in creating a digital legacy

A key challenge in creating the digital legacy was trying to decide what information to include, and how best to capture it. Tommy described planning each video, writing down and reflecting on content before practising the recording. It was important that he was '*not stumbling so much*' in his digital legacy. In contrast, Charlie adopted a more spontaneous approach to convey an element of his personality by being able to record '*off the cuff [...] straight off the top of my head*'. The challenge of recording content with use of age appropriate language was also apparent when creating the digital legacy.

And so part of me is speaking, you know, talking in a way that I'm thinking he's listening as a grown-up boy. And then other times I completely forget about that and I'm talking to him as if he's, four, which he is. So, it is quite hard, sometimes to know what sort of tone to leave messages in because you don't really know which of the two people you're leaving messages for.

(John, living with disease)

Also notable was the emotional challenge of being confronted with imminent death, and realisation of the lack of a shared future with the young person. This often induced a sense of becoming overwhelmed which evoked strong emotional reactions

when recording videos. Tommy *'didn't want to leave any negativity as a legacy for my family and kids'*, and therefore *'re-recorded quite a bit of it'* when his voice struggled due to becoming emotional. In contrast, Alice reflected on the internal conflict that creating a legacy induced and noted the importance of balancing the time spent thinking about the disease and inevitable death.

We talked about this this morning [to husband], I said about, it was a saying someone had said, that thinking about death or facing death is a little bit like looking at the sun, it's too powerful, it's too hot, and you can only look for a little bit and you have to turn away. And that summed it up for me to be honest, because it is. Yeah it is powerful, and yeah, I have to live with that every day, but I have to live as well. So it's kind of, you touch on it but you need to turn away.

(Alice, living with disease)

Regardless, it was essential that people living with the disease have reached a level of acceptance about their disease and mortality, before being able to begin recording a digital legacy.

When you've got all this time, coming up to your funeral, because you know it's going to be soon, you tend to do a lot of thought about it, you know? When you're diagnosed it's denial and all that, and then, you come to accept it, you lie here thinking for hours on end. Then you accept that you're going to die, so then you put things in place, so certain songs you want playing at your funeral [...] then a video for your grandkids.

(Charlie, living with disease)

Yet, it was clear that recording the legacy was highly sensitive to the passage of time and disease progression. As suggested by John, a decline in physical capabilities meant additional support was required to record his legacy. However, there was a reluctance to record personal messages to his son when other people were present. He was therefore faced with a conflict between needing other people there to help him with the equipment, but not wanting them in-situ during his recording.

It's getting harder for me to use that computer. Not impossible, but I kind of need someone to help give me the keyboard and the mouse and then I can sort of get onto it on my own. But, I'm more conscious when I've got somebody in the house, you know. I obviously don't want someone, sitting behind me when I'm leaving a message

(John, living with disease)

Consequently, there is an optimal period of time prior to significant disease progression in which people living with the disease should create a digital legacy. In a sense, there was a type of 'race' between being psychologically ready to record the digital legacy, and being physically able to record it before significant disease progression.

Tommy: Yeah, 'cus I noticed when I started [digital legacy], and when I finished, the decline in my voice. So, it's just got to be done early.

Int: As soon as?

Tommy: As soon as you read about it.

(Tommy, living with disease)

iii) Benefits for people living with motor neurone disease in creating a digital legacy

While participants commonly explained the benefits for children receiving the digital legacy, it was clear that the people themselves benefited from creating it. Firstly, it was a project which time and efforts could be channelled towards. This was important as progression of the disease meant participants had become increasingly house-bound. The digital legacy therefore instilled a sense of purpose in people once more.

Most people who get ill, you know, there is a feeling of helplessness, and not feeling that they've got any purpose at all, and, it does give you a sense of purpose to leave something, that you wouldn't ordinarily have left, you know?

(John, living with disease)

This was similarly reinforced by Alice who suggested whilst her physical condition worsened, her legacy was one of the few things she could continue to do herself, thus providing a sense of control and independence. It therefore offered therapeutic benefits through encouraging acceptance of her illness, and grieving the loss of her future.

I think that with MND, that's the thing 'cus it's always one step ahead. [...] but the things I can do myself is personal to me and it's, a way of me, I dunno whether it's acceptance or I'm grieving, I dunno, but it's a positive thing for me.

(Alice, living with disease)

An additional benefit of creating a digital legacy was that it provided an opportunity to reflect upon memories. For Tommy, informing his children of his achievements through reminiscing during his digital recordings, instilled him with a sense of pride.

I left school with no qualifications and I went into a factory job because I didn't have any confidence at school and one day I thought, 'I'm better than this'. So, I went to college, and I moved up in life. I think, bettered myself and I'm grateful for other people but [in] my experience, you can achieve if you put the effort in.

(Tommy, living with disease)

iv) Challenges for bereaved young people using a digital legacy

A key challenge for the bereaved young people was that the videos were not purposefully recorded for them by the person who had motor neurone disease. Consequently, the compiled legacies lacked biographical information and a narrative about the person's life and beliefs. This content was desired by young people as it would have provided a *'sense that he prepared for his illness and his death because*

he'd come to terms with it' (Becky, bereaved young person). Therefore, whilst Becky valued her compilation of videos recorded during special family events, it did not contain desired biographical information.

We don't have him telling us what he had gotten up to or what he'd believe in everything, so you kind of have to make up your own assumptions of what he'd say and the advice he'd give

(Becky, bereaved young person)

In contrast to this, Isabelle described knowledge of the video legacy content as a challenge to viewing it again.

Isabelle: I definitely want to see it again, I've only seen it that one time. I think I'll probably be even more taken aback the second time because I know what's coming, and it's like, 'oh wow' [tearful], it's amazing

Int: yeah, you know what's on there so you know what to expect, which would kind of make it nicer but also harder as well?

Isabelle: yeah. And it kind of makes you feel like, not angry, but it's not fair [...] 'this is what it could have been like, but, we don't have that'. And it almost makes you more sad because you know what they were like, a little bit, like you can see them.

(Isabelle, bereaved young person)

Like patients creating the digital legacy, a final challenge for young people was regarding the time in their grief journey that the recording were accessed.

I watched them [videos] I think pretty soon after [death]. I think you have, I feel, like a six month period, where you are numb and you don't know what's happened to you.

(Becky, bereaved young person)

Similarly, Sophie discussed the optimal timing in the grief journey when the videos are accessed. Prematurely watching the videos could be overly emotional and potentially result in a type of dependency due to the potency of videos.

You need time to, not get over it as such, but kind of find peace with what's happened. And then once you're over the pain, I think it's beneficial to relive the memories [...] Photographs are different, you look at them and get sad, but you can put them down. Whereas maybe something so visual as a video, I know I would probably replay it for weeks. If you're having a bad time, then you probably would, and I know that I would if I had it with me.

(Sophie, bereaved young person)

v) Benefits for bereaved young people using a digital legacy

The participants described a number of benefits to using a legacy. Firstly, the recordings provided a repository of evidence regarding the person who had the disease. Watching the legacy was a way for bereaved young people to see their

parent, almost living a different life, prior to onset of the disease. Isabelle, commented:

It was nice, but, it was just weird because I've never seen him as a person that could do all those things. I just remember him not being able to do the things, and it's nice to know that he wasn't always ill [...] he is happy and he's not what I remember him like. He's having fun and was able to do stuff, for himself.

(Isabelle, bereaved young person)

Poignantly, Isabelle describes that the video provides her with a sense of comfort from seeing an alternative version of her father as able-bodied which contrasted with her existing illness-related memories. Isabelle explained that the video legacy presented her Dad as being 'happy and he's not what I remember him like'. The videos therefore provide a way to modify existing memories of the person being ill. This idea was also discussed by Sophie, Isabelle's younger sister, who similarly described that watching the video legacy provides her with a way to:

Think 'yeah, he was happy before'. Because I don't remember him smiling, at all. Obviously you don't really remember things when you're a baby [...] I think my earliest memories are of when he was ill. Which is a shame.

(Sophie, bereaved young person)

The videos also presented a way to witness the once shared parent-child relationship which had been forgotten. Sophie described the value in being able to see how her father physically played with them as children by 'squeezing [them] and throwing [them] in the air'. For her, this provided evidence of his love as she did not have concrete memories of time with her father.

Similarly, Sophie indicated that the videos not only provided an invaluable way to visually 'meet' a physically able version of her father but also to hear how he once sounded.

The voice was, I wouldn't even picture that voice, for him, and that's a weird thing to say. But when you can't really remember what your dad sounds like and then you hear a voice and putting the two together. That again makes you feel dead happy and kind of like, 'ah, that's who my dad is'. Yeah, there's no other way to describe it. It's just a really nice feeling like 'ah'.

(Sophie, bereaved young person)

In contrast to Isabelle and Sophie who gained a sense of comfort from hearing their father's voice, according to Becky, her sister experienced less desirable emotions and feelings to accessing the video legacy.

My younger sister, yeah. She's jealous, like, such a ridiculous amount. Well not ridiculous but an extreme amount of sadness in them. She hears this voice in the video and goes 'but I don't know who that is'. Whereas I

look at it so fondly and go 'ah' I love hearing that again. And I suddenly have moments, and it's such an amazing thing [...] how sound triggers things and triggers memories and you know, the same as smells, and as soon as you hear something and it takes you back to the time. And I walk past someone now who's got a really strong welsh accent and I instantly go 'ohh'

(Becky, bereaved young person)

The legacy also offered a platform for young people to not only learn about the person's identity and life, but also begin to understand how they had influenced the young person through a type of self-comparison. This was highlighted by Isabelle, who felt that the legacy provided a way to:

See if you're anything like him or if you're a lot different from him. I don't know. It's all those questions that never really get answered. Obviously mum will tell you about him and all your family members will, but it's not the same as actually knowing the person [...] so] seeing a video or listening to a voice message, kind of brings you a little closer to that. It's comforting, isn't it?

(Isabelle, bereaved young person)

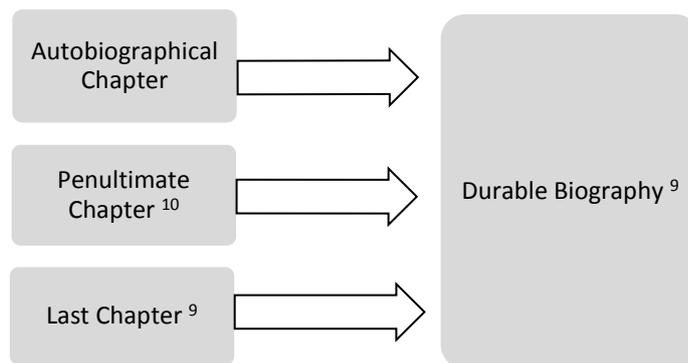
Discussion

This is the first study to explore the views and experiences of digital legacy use by people affected by motor neurone disease. Based on the findings, it is clear that recording a digital legacy creates a number of benefits for people living with the disease. Most notably, it can reinstate a sense of purpose by engaging in a project that can be carried out independently. Moreover, it provides an opportunity to reminisce on memories and document key personal achievements. However, it is clear the creating the legacy is not without challenges such as planning, language and delivery of videos; acceptance of disease; emotionality; physical use of equipment and, importantly, timely recording of the legacy. Challenges were also identified from the findings with bereaved young people. It was necessary to consider timely usage of the legacy in accordance with their unique grief journey. Identifying the optimal time to use the legacy was identified as a key challenge by the bereaved young people as was the lack of biographical content within the legacies. Regardless, young people benefited from using the legacy to see, hear and learn about the deceased.

The findings from this study resonate with the continuing bonds model of grief which suggest that bereaved people seek to retain a sense of connection with the deceased.^{8,27} Use of a video-based digital legacy can provide a platform for bereaved young people to remember the deceased and learn new biographical information. As suggested by Walter, obtaining this knowledge allows the creation of a last chapter and, therefore, durable biography.⁹ Similarly, Fearnley described the importance of developing a 'penultimate chapter' which features information regarding the person's illness.¹⁰ Following death, the bereaved synthesise this penultimate chapter with the last chapter to create a holistic understanding of the deceased's life.

A limitation of these bereavement models is the lack of consideration regarding how the dying person may contribute to, and influence the development of, that durable biography. According to existing theories, the deceased are entirely passive in the biography developed by the bereaved.⁹ In contrast, findings from this study highlight that dying people can actively contribute towards shaping the durable biography. 'The Model of Reciprocal Bonds Formation' developed from this study, highlights the need for a third type of chapter, an 'autobiographical chapter' which was purposefully created by the person living with the disease through recording a digital legacy. It is suggested that this chapter, like the penultimate and last chapters, contributes to the development of a durable biography regarding the deceased. However, unlike the last chapter which is written by the bereaved the autobiographical chapter is purposefully created before death. It is argued this autobiographical chapter becomes a resource which features a wealth of information to stimulate and inform the bereaved young person. Additionally, use of this autobiographical chapter (the legacy), provides a sense of comfort and continuing bonds through watching the videos and learning about the deceased's life, identity and character.

Figure 2- The Model of Reciprocal Bonds Formation



The digital legacy gave patients a sense of comfort in knowing that their autobiographical chapter (the recordings) would provide a substitute for their physical presence. This finding is reinforced by existing literature regarding the creation of broader legacies.²⁸ However, the digital legacy captured more *implicit* information such as identity and character within the newly coined 'autobiographical chapter'. This was often provided through 'hidden' elements within the legacy, such as the sound of their voice, or evidence of the parent-child relationship.

Creating the autobiographical chapter by recording a digital legacy, instilled a new sense of purpose that efforts could be redirected and channelled towards.^{11,15,29} Generating the digital legacy provided patients with a platform to reaffirm their life role as a parent/grandparent and continue to guide and influence the young person following death.³⁰ This reaffirmation of roles has been described as providing a comforting sense of '*parenting beyond the grave*',^{31 p.932} and a means to bolster a sense of spiritual wellbeing for people approaching death.³²⁻³³

However, creating a digital legacy also generated a number of challenges. Most prominent was the idea of there possibly being three 'windows of opportunity'. Firstly, a '*physical window of opportunity*' was essential to be able to use technological devices before disease progression. Similarly, a '*vocal window of opportunity*' whereby speech was still clear. Lastly, a '*psychological window of opportunity*' to which acceptance of the illness and mortality had been reached meaning they were able to consider the future and their absence from it. However, similar to traditional written legacies, these windows may overlap. For example, psychological readiness may occur after the patient has lost physical capabilities.¹⁶

There were also optimal windows of opportunity for bereaved young people to use the digital legacy, as premature use could act as a reminder of the young person's loss rather than providing comfort. Ground-work was needed to ensure that the young person had reached an appropriate place within their grief journey.³⁴⁻³⁵ Upon reaching this, the legacy could provide a sense of comfort for bereaved young people offering a means to intentionally remember the deceased. This resonates with existing literature suggesting young people actively search for ways to remember and reconnect with the deceased.³⁶⁻³⁸ The Model of Reciprocal Bonds Formation, suggests that the young person must first develop a robust durable biography of the person who has died, before establishing this sense of a continued bond. Only after this, will use of the digital legacy provide a sense of comfort for the young people - once they have found '*an appropriate place for the dead in their emotional lives*'.³⁹ p.16 Interestingly, the digital legacy may provide the young person with flexibility and control regarding the time and location of their engagement with grief work.⁴⁰ Furthermore some of the digital legacy could be transferred to a mobile device, breaking grief work down into 'small chunks'.^{10,37}

Comfort was also gained from hearing the deceased's voice. This was not always explicit vocal content, simply hearing them laughing could provide solace. As suggested in existing literature, it was possible to reinforce cherished memories regarding the deceased's physical appearance or mannerisms.⁴¹ Moreover, seeing them smile gave evidence that they were happy before becoming ill, and provided a balanced picture of the person's life.⁴² This benefit of the digital legacy resonates with the continuing bonds model of grief,⁸ and reiterates the concept of bridging relationships between the living and deceased through the collective use of sight and sound.⁴²

Study limitations

Participants self-selected to take part in the study, so it could be suggested they were potentially coping well with their illness. Therefore, their experiences may not reflect those who did not participate. Despite employing numerous recruitment methods, it was not possible to interview bereaved young people who had used a purposefully created digital legacy. Recording a video legacy in the past would have been far less spontaneous than currently possible due to emerging technologies. Instead, three bereaved young people were interviewed about their experiences of using a video legacy recorded on cassette-based camcorders. Whilst in accordance with the IPA methodology, this small sample reflects the likely low population of

young people who have this type of video footage of their parents, let alone parents who have died from motor neurone disease.

Future research

Whilst it can be suggested that creating an autobiographical chapter is beneficial for people living with motor neurone disease, future research is suggested to investigate the transferability to international populations and other terminal illnesses. Future research regarding the optimal stage within the disease trajectory for the legacy to be created, and the appropriate point within the bereaved young person's grief journey to use the legacy are needed. Finally, it would be pertinent to explore additional research with young people for whom a digital legacy has purposefully been created and includes personal messages.

Conclusion

Creating, or using, a digital legacy by people affected by motor neurone disease generates challenges and barriers, but also benefits. It provides a way for people living with the disease to capture their identity and biography enabling a continuation of existence after their death, in a digital form. Similarly, bereaved young people gain a sense of comfort from using a digital legacy, to see, hear and learn about the deceased.

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Declaration of authorship

All authors i) made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Consent for publication

All participants signed a consent form to enable publication of interview extracts.

Data sharing

The data for this study consists of audio-recorded interviews, and subsequent verbatim transcripts. The authors do not have consent from participants to share this with third-parties.

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