

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

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## Abstract

**Background:** Motor neurone disease is a terminal neurological illness with no known cure. It is often referred to as a 'family disease' with the ripples causing additional implications for children and young people. As such, little is known about how to best support young people (>24 years old (WHO, 2019)) when a family member dies from the disease. One potential solution is through use of a digital legacy whereby videos which document a person's life, memories and achievements are purposefully recorded by an adult during their illness. However, due to this being an emerging area of research, little is known about whether a digital legacy may support or hinder bereavement for young people affected by the disease.

**Aim:** To investigate healthcare professionals, specialists and experts views, perceptions and experiences of using digital legacies with bereaved young people due to motor neurone disease.

**Design:** A qualitative study underpinned by Interpretative Phenomenological Analysis.

**Setting/Participants:** Twenty healthcare professionals, specialists and experts were recruited using a maximum purposive sampling method. Open-ended interviews were conducted in participants place of work either over the telephone or by the lead researcher. Ethical approval was granted by a University ethics committee and Health Research Authority (HRA).

**Findings:** Two key overarching themes were identified from the data; *Perceived benefit and value for bereaved young people using a digital legacy* and *Challenges and barriers for bereaved young people using a digital legacy*.

**Conclusion:** A number of potential challenges and considerations were identified. However, the use of a digital legacy was perceived to be a feasible and valuable method of support for young people bereaved as a result of motor neurone disease.

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

## Background

Motor neurone disease (MND) is a rapidly progressive neurodegenerative disease which affects approximately 5000 people at any one time in the United Kingdom (O'Brien and Claburn, 2016; MND Association 2018). There is no known cure for the disease which means that palliative care is crucial to promote quality of life for people living with MND and their families (Oh and Kim, 2017).

Existing bereavement theories such as the 'continuing bonds model' suggest that bereavement is a process of adaption and change (Silverman, Klass and Nickman, 1996). Walter (1996) postulated there to be a biographical aspect to bereavement suggesting that the bereaved create a 'durable biography' whereby we talk to other survivors about the person who has died in order to create a 'last chapter'. Within this chapter we begin to make sense of the life of the person who has died and find out new or previously unknown information about their life, synthesising this with our existing knowledge of the person.

One way in which the bereaved can acquire information about the deceased is through use of a legacy. The concept of a 'legacy' refers to '*what a person leaves behind – how a person will be remembered and what they will be remembered for (good and bad)*' (Breitbart, 2016, p.1). The concept of building or creating a specific legacy to be passed on to loved ones, within the context of palliative care, has recently gained prominence (Chochinov et al., 2005; Ando et al., 2010; Vukasnovic et al., 2016). An emerging format is that of a digital legacy, whereby people living with a terminal illness purposefully create a 'digital memory box' with content that is personable and representative of themselves (Bassett, 2015). This may include, for example, photographs, videos, messages, music or blogs. It is argued that this type of digital legacy '*enable storytelling, on-going narratives, memorialization and "renegotiated" relationships with the dead in a digital afterlife*' (Allen et al., 2008, p.4).

While not in the scope of this paper, a recent publication from the same authors reports on the experiences of people living with motor neurone disease recording a digital video legacy for children in their family, and bereaved young people using a digital legacy from their deceased parents (Claburn et al., 2019). Subsequently, the aim of the current paper is to report on data collected which explored the views, experiences and perceptions of healthcare professionals, specialists and experts about how a digital legacy created by a person living with MND, may support/hinder a bereaved young person.

## Methods

### Study design

The study was underpinned by Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009). Open-ended interviews were digitally recorded, and transcribed verbatim by the lead author. Approval was gained from the Health Research Authority for England and Wales, the National Research Service for Scotland (ref: 16/NW/0282) and University research ethics committee (ref: FOHS114).

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

### Participants

Twenty healthcare professionals, specialists and experts from across England were interviewed adopting a maximum purposive sampling technique (Saunders, 2012). Recruitment was achieved through NHS-run MND Care Centres, and the extended network of the research team. Participant characteristics are outlined below in Table 1.

### Setting

Interviews were either via telephone or face-to-face in the participant's place of work. Consent (written or verbal for the telephone interviews) was obtained

### Analysis

Data were organised using NVivo11<sup>®</sup> with identifiable information removed and pseudonyms allocated to ensure participant anonymity. Analysis followed IPA's 'six stages' analysis (Smith, Flowers and Larkin, 2009).

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

Table 1- A summary of participant characteristics

Group	Pseudonym	Job Role	Context of Employment	Location	Method of Data Collection
MND	Jackie	MND nurse	NHS MND Care Centre	North West	Telephone
	Pearl	MND care advisor	Charity	North West	Telephone
	Petra	MND nurse	NHS MND Care Centre	North West	Telephone
	Willow	MND nurse	NHS MND Care Centre	North West	Telephone
	Roxy	MND nurse	NHS MND Care Centre	South	Telephone
Palliative care	Grace	Palliative care therapist	Palliative care charity	North West	Face-to-face
	Kim	Palliative care consultant	Hospice	North West	Telephone
	Mark	Chaplain	Hospice	North West	Face-to-face
	Ada	Chaplain	Hospice	South West	Face-to-face
	Harriet	Day centre staff	Hospice	South West	Face-to-face
	Kirsty	Palliative care consultant	Hospice	South West	Face to face
	Laura	Day centre staff	Hospice	South West	Face-to-face
	Rose	Palliative care nurse	Hospice	South West	Face-to-face
Sue	Diversional therapist	Hospice	South West	Face-to-face	
Child bereavement	Jess	Child bereavement therapist	Bereavement & loss charity	North West	Face-to-face
	Kacey	Child bereavement therapist	Bereavement & loss charity	North West	Face-to-face
	Pam	Child attachment researcher	Academic	North West	Face-to-face
	Billy	Social worker & researcher	Academic	Yorkshire & the Humber	Face-to-face
	Rita	Child bereavement researcher	Academic	Yorkshire & the Humber	Face-to-face
	Kelly	MND children & young people specialist	Charity	East Midlands	Telephone

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

## Findings

In the context of this study, a digital legacy constituted a broad collection of purposefully recorded videos recorded by a person living with MND. While not a prescriptive format, the ubiquitous concept of a digital legacy was that of an autobiography, a children's story, personal messages or 'pearls of wisdom', and finally, a daily diary of living with the disease to inform children and young people.

Two superordinate themes were developed following data analysis; *benefits and value for bereaved young people using a digital legacy*, and *challenges and barriers for bereaved young people using a digital legacy*. Both themes encompass five additional subsidiary themes which are discussed in turn.

### Perceived benefit and value for bereaved young people using a digital legacy

#### *Promoting memory of the person and their voice*

A digital legacy could provide a way to instantaneously evoke and stimulate thoughts and memories of the deceased using technological devices used by the young people on a day-to-day basis. Moreover, the digital legacy may provide the bereaved young person with a sense of comfort due to offering a permanent and readily accessible way to see and hear the person living with MND.

*I think if you've got something that is permanent, or relatively permanent, because if it's a digital thing that you can keep going back to. Children, I think when they're bereaved, my experience would be they get very upset at that thing that 'oh, I can't remember what they sound like. I can't remember what they look like.' And while you might think that's good, and normal process of moving through that grief process, you know that is distressing for some children. And I think they would probably find that quite comforting*

*(Pam, child attachment researcher)*

It was also suggested that the recorded sound of a dead person's voice may have beneficial use with both bereaved and non-bereaved young people. Willow reflected upon a patient with young children she had supported in the past.

*I suggested that she recorded something and then their little babies could actually hear her voice while she was still there. So it may not sometimes always be used when they've passed away, it can be used while they're further down the disease progression. But I think it's just something for the children to hear that person's voice really*

*(Willow, MND nurse)*

Arguably, whilst the physical death of a person with MND creates the ultimate bereavement for a young person, the loss of physical abilities such as movement and speech, may create a succession of bereavements. A digital legacy may therefore

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

provide a sense of comfort by attending to just one of the many losses young people are likely to experience.

An additional consideration is that the recordings may provide the young person with an alternative memory of the person living with MND, prior to significant physical or cognitive decline. The legacy would therefore be more focused on positive memories. Consequently, this content may counteract some of the negative recollections which have been developed by the young person during the later (end of life) stages of the disease.

*[regarding the progressive nature of the disease] it eclipses the memories of them as a well person. So I think if you had this film, even if it is just this short clip, it would really help to remember the person and I think it would really help the bereaved people moving forwards.*

*(Rose, palliative care nurse)*

Also noteworthy was that the digital legacy could assist in building a narrative of the life of the person with MND. It was suggested that young people often have a natural curiosity towards the deceased's life and biography. Therefore, *'a digital legacy would give them maybe a picture of what that person's life was like and what they shared with you'* (Kacey, child bereavement therapist). Moreover, the legacy not only provides the young person with factual information regarding specific life/biographical events, but also conveys detail of what the person living with MND was like, in terms of personality and character.

*I think it is so powerful to be able to have those [memories/stories], for the young people to be able to remember. And even if it's a younger child whose parent or grandparent has died, when they're older and they're actually more inquisitive about 'well, what was mum, dad, grandad like?' You know? 'What were they like when they got married?' And to be able to have that narrative and to be able to actually hear that from the person in terms of, a biography almost [...] So to be able to actually hear it from them*

*(Rita, child bereavement researcher)*

#### *Endorsing connection and continuing bonds*

An additional perceived benefit of using a digital legacy, was the idea of a continued bond or connection between the young person and the deceased.

*I'd have thought for children who have lost parents and they've got this digital legacy, like I said, it just keeps that thread, that reassurance that they were thinking of them so they can still touch base with mum or dad with using that digital legacy*

*(Willow, MND nurse)*

Interestingly, Willow mentions that a digital legacy *'keeps that thread'* between the deceased and young person. This is a pertinent analogy as it suggests that the digital

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

legacy provides a delicate connection between the young person and their deceased parent.

Similarly, Kelly also highlighted that watching the digital legacy would enhance a sense of connection and strengthen bonds with the deceased. This was due to the young person being 'able to keep that person in your life', albeit in a digital form (Kelly, MND children and young people specialist). Kelly also suggested that using a digital legacy 'would be helpful for a young person to actually go through the stages of grief in a much more healthy way'. This was similarly reinforced by Sue, who described how people living with MND can help 'to ease that loss' and provide comfort for young people through leaving 'something of them' (Sue, diversional therapist). The digital legacy therefore becomes this 'something', which enables bereaved young people to continue 'remembering that person and hearing their voice' (Sue, diversional therapist). It provides bereaved young people with a sense of 'still being connected to them by watching or listening to them' (Jess, child bereavement therapist). A digital legacy was therefore likened to being a multi-dimensional object:

*A bit like a hologram really, isn't it? [...] You know, it's there and you can keep looking at it and it has that sense of being real. And you can sort of look at it from different angles and it's there for you to keep coming back to. It doesn't stop you living your life and I think it's important that people move on and live their life, but it's giving them that point of contact when they need it*

*(Sue, diversional therapist)*

#### *Accessibility and usability*

Of importance was that a digital legacy would be a tangible and physical resource to be used by a bereaved young person.

*[young] people will have something concrete that they can turn to for when they're feeling or when they're experiencing some grief. Or when they just feel that they want to get close to the person that they've lost.*

*(Pearl, MND care advisor)*

Additionally, the digital format of the legacy would enable young people to access it independently. This highlights a sense of autonomy and control for the bereaved young person, allowing them to use the digital legacy whenever they deem it appropriate.

*In the grief journey, there's things that you don't want to do in the first week, first month, first year. And some of it may be that you don't actually want to look at digital legacy for a little bit and you want to get on with your grieving, but it's always there. But the fact it's there doesn't mean you have to do anything, you're in control of it, aren't you?*

*(Mark, hospice chaplain)*

The sense of flexibility uniquely afforded by digital technologies was also described. A limitation of physical items such as memory boxes, is that they are 'very physical, and



Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

*you have to take it with you' (Kirsty, palliative care consultant). In contrast, stimuli created and stored in a digital format, provides a way of 'accessing them really easily, potentially wherever you are. So, actually, you could have little things recorded on your phone, couldn't you? [...] that could be a real comfort (Kirsty, palliative care consultant). This could provide young people with 'an opportunity to self-soothe' (Kelly, MND children and young people specialist), and offer a sense of security knowing that the digital format means that 'it's always there' (Mark, hospice chaplain). Moreover, providing stimuli in this format is argued to be responsive to the wants/needs of current generations of young people who regularly use digital technologies within their normal day-to-day life.*

#### Challenges and barriers for bereaved young people using a digital legacy

Two ordinate themes relating to the perceived challenges and barriers for using a digital legacy were identified.

##### *Providing and accessing the digital legacy*

There was suggestion that young people may feel pressured into watching or accessing the digital legacy prematurely. Mark, a hospice chaplain, described how young people may *'really feel [that they] need to watch this'* due to an awareness that it had been specifically created for them. As such, the young person might *'be a little bit pressurised'* into using the digital legacy, when they are *'not necessarily [at] the right part of the grief journey'* (Mark). The concept of an optimal period to using the recordings was similarly described by Jess, a child bereavement therapist:

*Sometimes it's very, very difficult, it could be very difficult for them to see, the person. You know, sometimes people, even children, are not ready. So there's that denial process that they cannot go there. So that could be quite difficult sometimes, for them to have to see the person, if they're watching them on a video or something like that*

*(Jess, child bereavement therapist)*

Extending this further, the digital legacy could act as a negative reminder for the young person that their parent has died.

*We do know cases, for example, where parents have written birthday cards for every birthday up until they're 18. And actually, for some children that sounds like it's a lovely idea, but after the first couple, they don't really want them anymore [...] They want to be able to move on and not feel that sadness every birthday. They know it's there but they don't necessarily need that concrete, tangible reminder of it*

*(Pam, child attachment researcher)*

The young person should therefore be advised that there is no prescribed usage of the digital legacy. The importance of groundwork to acknowledge the young person's developmental understanding and acceptance of the death was reinforced.

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

*For me there are the issues there in terms of, how it is handled very, very sensitively and being aware of the children's understanding that that person can't come back and isn't coming back and this [DL] is not them talking from beyond the grave, 'it's something that they've done before they've died, and do you remember when we did this, and you were there at the time'. So they're fully, aware of that and it's not going to be something almost like [gasp] I didn't expect to hear that voice again, where you know, where are they, why aren't they here with me, where's that voice coming from?'*

*(Rita, child bereavement researcher)*

Withholding access to the digital legacy may be appropriate for some bereaved young people until they are deemed developmentally ready. Similar to Mark, Grace suggested there to be an optimal period in which the digital legacy would be beneficial.

*I don't think it should be given initially, I think you've got to give that child room to grieve, and that can take a long time. And then introduce it to them as 'you have it, and it's theirs for whenever they want to visit it'. But have somebody with them when they visit it because that can be very, very stressful as well. So I, at that point, would hand it over to the child and give the child the rights to decide, when they want to do it. But the grieving process can take an awful long time and I think you've got to let them go through that grieving process before it's then introduced*

*(Grace, palliative care therapist)*

*Content of the digital legacy.*

Of pertinence, was the idea that the digital legacy would provide evidence and a reminder of the effects of illness due to their parent's physical appearance in the recordings. As such, the digital legacy could stimulate disease related memories of the person living with MND, instead of the intended positive ones.

*Makes it all flood back in a way. It takes them back to that time when it was a bad time for illness because as you know, with MND, it can be quite traumatic I'm sure if you're a child, to see mum or dad deteriorating like that*

*(Willow, MND nurse)*

*My only thing would be if you do any filming of people, particularly in people with both cancer or motor neurone, I think it's best to film them when they're looking fairly okay and fairly well, because it would be quite difficult I think to go back on seeing how the downfall came.*

*(Grace, palliative care therapist)*

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

In contrast, Pam noted that whilst the person living with MND may feel that they have recorded an accurate version of themselves, the bereaved young person may feel differently.

*I think there is also that assumption, I guess underlying all this, that those parent child relationships are all lovely and harmonious and everything that we would wish them to be. Whereas, what we know is the reality is, that's not always the case [...] If you've had somebody who's been quite difficult and then you've got this lovely 'let's play happy families' thing, which is sometimes, I think, a bit of a pressure when you've got a terminal illness in the family*

*(Pam, child attachment researcher)*

Finally, it was also suggested that the recorded sound of the voice of the person living with MND may create additional challenges for a bereaved young person. As described by some participants, the digital legacy may have captured degradation of the person's voice living with the disease. As such, their recorded voice may include disease related characteristics such as slurring, or perhaps background noise from ventilation machines. This finding is pertinent as the concept of sound was outlined earlier as being one of the fundamental benefits of a digital legacy. In contrast, hearing the sound of the deceased's voice '*could actually be really quite distressing*' for some young people (*Rita, child bereavement researcher*), a point further reinforced:

*It depends on, how you connect with your own senses, is what's going through my mind [...] that could give a lot of comfort to hear the person. But it could also, bring up those painful emotions that they may not want to go there, because it makes them realise that the person has died and, they're no longer with them*

*(Jess, child bereavement therapist)*

## Discussion

The aim of this paper was to explore healthcare professionals, experts and specialists' perceptions and experiences of using digital video legacies for bereaved young people affected by motor neurone disease. The participants outlined a number of perceived benefits for young people accessing the digital legacy created by a deceased family member. However, these positives should be balanced in light of challenges, barriers and concerns for bereaved young people using a digital legacy.

Participants stressed it necessary to consider the timing within the young person's unique grief journey when the legacy is watched and used. This reinforces findings generated from the data collected with bereaved young people who had used a digital legacy which had been created without their input (Clabburn et al., 2019). Premature use of the recordings could act as a reminder of the young person's loss, rather than provide a sense of comfort. As identified here, it is imperative that preliminary groundwork takes place to ensure the young person has reached an appropriate place, within their grief journey, before accessing the digital legacy. It would then be possible to ascertain whether the young person was psychologically ready to 'revisit the person living with MND', albeit in a previously recorded digital format. With this in mind, a potential solution to overcome potential distress could be centred upon young

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

people co-creating the digital legacy alongside the person living with the disease. This would ensure a sense of familiarity with regards to the content of the digital legacy.

A perceived challenge for bereaved young people using the digital legacy was identified with regards to the content of the recordings. The digital legacy has scope to evoke disease related memories of the person living with MND. Whilst for some bereaved young people this would provide an opportunity to modify their 'last chapter' and memories of the deceased (Walter, 1996), for others, the digital legacy may act as a negative reminder of illness. As suggested by the professionals in our study, use of the digital legacy may reinforce, or create, illness related memories built upon symptomatology meaning watching the recordings will '*make it all flood back [... and] take them back to that time when it was a bad time for illness*' (Willow, MND nurse). However, it has been reported that bereaved young people actively seek good and bad memories in order to develop a holistic picture of the deceased (Foster et al., 2011; Wood et al., 2012). This would suggest that bereaved young people may benefit from exposure to illness related memories in order to develop their 'last chapter' (Fearnley, 2015).

Regardless of these challenges, participants perceived the use of a digital legacy by bereaved young people to be a platform to intentionally remember the deceased and gain a sense of a continued bond with them. This resonates with existing literature suggesting that bereaved young people actively search for ways to remember and reconnect with the deceased during their grief journey (Field, Gao and Paderna, 2005; Gibson, 2014). As such, video recordings of the deceased were perceived by our participants to be a potentially useful resource to support bereaved young people. Furthermore, the nature of digital platforms means that the digital legacy would provide a readily accessible way for the young person to connect with the deceased when needed (Root and Exline, 2014). This could be of particular value within a therapeutic context to be used as a means of facilitation by bereavement specialists who are supporting young people. Existing literature suggests it to be common for bereaved young people to want to feel close and connected to the deceased (Field, Gao and Paderna, 2005). Arguably then, the presence of a digital legacy made by the person living with MND was perceived to allow the young person to '*keep that person in [their] life*' by accessing the recordings (Kelly, MND children & young people specialist).

### Limitations and recommendations

To the best of our knowledge, this is the first study to investigate perceptions and views of healthcare professionals, specialists and experts of using digital legacies with young people bereaved due to MND. Whilst this study has added key contributions to the field, it should be viewed in light of some key limitations. Firstly, the study focussed specifically on one disease, MND. Therefore, findings may not be wholly transferrable to other populations of bereaved young people. However, recruitment of participants was achieved through maximum purposive variation meaning specialists and experts were selected from a broad, yet related, field of expertise. It is worth recognising that following data collection, some participants arranged digital legacy training sessions for their colleagues, as prompted by their involvement in the study. This suggests that there is scope for the findings from this study to be transferred to alternative, non-MND populations.

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

As the use of technologies and digital recordings is an emerging area, there is a great deal of future work to be done. Poignantly, little is known about using digital legacies as a resource by bereavement specialists within therapeutic contexts with children and young people. This warrants further investigation to identify their appropriateness as part of a therapeutic intervention by bereavement practitioners. In turn, this would advocate closer examination of the appropriate timing in which a digital legacy is first accessed and its frequency of use by bereaved young people.

### Conclusion

This research is based on the views, perceptions and experiences of healthcare professionals, specialists and experts regarding the use of digital legacies with bereaved young people affected by motor neurone disease. It is suggested that a digital legacy may be a feasible and useful resource for practitioners to support bereaved young people. However, due to being an emerging area, further work is clearly necessary.

Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

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Digital legacies with people affected by motor neurone disease: The views, experiences and perceptions of healthcare professionals, specialists and experts for use with bereaved young people.

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