Life Review in End of Life Care: A Practitioner's Perspective

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Abstract

This paper presents an exploratory study of life review as a therapeutic technique performed in the end of life care. We describe interviews with four therapists practicing life review and discuss initial findings showing the benefits of closure and empowerment for patients' emotional wellbeing. Findings also highlight the importance of reflective remembering in life review, together with the challenge of recalling details of significant life events, and of their emotional processing. Another finding relates to the current limited use of technology for end of life review, with an emphasis of printed photos, music and significant objects for supporting recall of key events. Our findings led to design implications for supporting the construction of life review and the recording of life review process. We conclude with a discussion of the challenges of life review in end of life care and of the need to explore such digital tools to support it.

Author Keywords

Life review; end of life; reflective remembering; significant memories; physical and digital aids

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Life review [1] is a therapeutic practice for people approaching death, defined as a natural process of reintegrating or reconstructing life experiences and in particular unresolved conflicts [1][2]. Life review is an interesting process to explore as it brings together several current HCI research interests in temporality, memory technology, and self-narratives. In HCI, life review has been mostly explored as a reminiscing therapy technique for people with memory impairment, with previous findings emphasising its emotional benefits and social aspects [4].

This paper explores a specific type of life review, performed within the therapeutic end of life care. The aim is to understand the therapists' and clients' needs, the setting of life of review in end of life care, and its process. A particular focus of the paper is on the identified challenges and how they may be addressed through the use of technology. The study addresses the following questions:

(i)   What are people's *motivations* to engage in life review and what are its *benefits*?

(ii)   What does the *process* of life review consist of, and which are its main *challenges*? Is the life review organised around self-memory system? Is it private? Are both positive and negative events relevant in this process?

(iii) What is the *materiality* of the life review process? Are there any specific physical and digital artefacts used to facilitate it?

Related Work

Over the last decade there has been an increased HCI interest in the topic of death and dying [8][7]. In this context, life review has been mostly discussed as a technique of reminiscing therapy, focusing on major life events whose recall is supported by physical or digital prompts. For example, Crete-Nishihata and colleagues [4] have developed through participatory practices Multimedia Biographies. These are digital collections of personal photos, videos, documents, music, and narration, structured around major life stages or themes. Their findings show that such biographies not only helped participants reminisce about their past with emotions, but they also supported the sense of self and social relationships when life reviews were performed with the help of family members. Such work emphasizes the value of family in supporting life review for people with memory impairments, albeit with limited focus on life review in the end of life care.

Other HCI research areas that this paper draws from include technologies for reminiscing and temporality. The advent of memory technologies [5][6][16] and quantified self begs for innovative ways of representing temporal patterns of human activity to support reflection on experience [14]. In addition, the focus on user experience has broadened HCI researchers' view on the value of felt-life stories and of narrative methods for engaging with them [9][10].

Time in HCI has been explored in terms of its representation, granularity, and potential for supporting recall. Lindley et al [7] discussed how the timeline metaphoric representation fails to account for the emotional memories and their weight in the memory organisation. This is important, as autobiographical memories form the basis for our sense of self [12][13][17]. The *self-memory system* is a model conceptualizing autobiographical memories, which consists of knowledge of the past, present, and future self, categorized into even-specific knowledge, general events and lifetime periods [3][11]. The event specific

knowledge captures episodic memories and tends to be rich in sensorial-perceptual details.

There have been however less efforts to integrate life narratives within the larger temporal scale of human life. A few exceptions include work on temporality in social media [19] which shows that people experience higher levels of stress due to the introduction of Facebook's Timeline. In particular, the end of life care as a specific sensitive setting [18] has received limited HCI attention so that we know little about the main properties of the life review process, its challenges, and the role of digital and physical aids supporting it. This research gap is the one we aim to address.

Method

The aim of this study is to understand life review and how it is applied in the therapeutic context of end of life care, with the aim of informing the feasibility and development of technologies for supporting it.

Sample
Given the sensitivity of the research area [18], we did not engage directly with dying patients, but employed therapists as proxy, to ask for insights from their experiences of working with and observing patients.

The study involved semi-structured interviews with four practitioners who regularly employ life review in their work. Participants were recruited through email and phone calls to a local UK hospice with long standing experience of providing end of life care. The sample included four practitioners working in palliative care and consultancy with terminally-ill patients. They are all Psychology graduates and three have doctoral studies.

Procedure
The interviews took place face to face, were audio recorded and fully transcribed. Participation was voluntary. Questions concerned practitioners' understanding of life review, its perceived benefits, and the context in which it takes place. We asked: *Why people attend life review activities and what is their aim?* We also explored the process of life review through questions such as: *Please describe the life review process. How do you help people reconstruct their life events? Do you support the recall of both positive and negative events?*

We also looked at the perceived benefits of life review: *How do you evaluate the success of life review process?* Other areas of interest were what technologies and materials are being used in life review, the challenges of engaging in life review and ways of addressing them. For example, we asked: *What physical or digital materials you use to support the life review?* and *How do you capture patients' stories?*

We employed a thematic analysis which offers a flexible approach to data exploration. It allows the identification of major themes which are further described.

Findings

This section introduces the key findings related to our three research questions: people' motivation for life review and its benefits, the main characteristics and challenges of the life review process within the end of life care, as well as the materiality of this process and its associated physical and digital artifacts.

Motivation: Closure and Empowerment
Patients' interest in life review is triggered by the desire to look back at their life and its main events. The aim

here is to build a coherent story, reach conclusions and come to terms with conflicting feelings and relationships: "*Because people approach end of the life, they may want to summarize or review their life […] to reach a final conclusion*" [P3].

Besides providing the patients with new perspective on their lives, the main value of life review is that it empowers people to look both back at what one has done and into the future, albeit near and short, to what is left and yet desired to be done.

"*Life review gives the patients the perspective that they have come to the end points of their life. The conclusion is like what they did of their whole life or need to finish before leaving the world. It is the concept of completion […] The patient is aware that even though he couldn't do a lot in this period of his life, there are some things he could do: final wishes such as seeing somebody dear*" [P1].

The end of life care raises important ethical issues and the therapists highlighted the sensitivity required throughout this process. First, most patients are terminally-ill with short life expectancy. They could be afraid to talk about their situation, suffer from pain and sadness, or worry for their families [P1]. Moreover, in life review people also focus on negative events in their lives that they regret happening. In these situations, the therapists support people to gain perspective and suspend judgment: "*there is no more right or wrong. It is just one event that happened in their life and in some way we hope it will help them to feel peace*" [P1].

Reflective Remembering of Significant Events
Recall and reflection [14] are important aspects of life review. In the end of life care, the life review process tends to consist between 2 to 6 weekly sessions lasting

around thirty minutes each. In addition, the overall life review acts as springboard for bringing forward significant issues in people's lives: "*[Through life review] people gradually remember things. And sometimes they don't realize things being significant. When they do realize it, they often come to understand why they made themselves the way they are. In order to help them I use open questions beginning with how, not why*" [P4].

Within the breadth of life's major events, the therapist helps the patients to focus on those which are particularly significant. The recall of such events employs a strong phenomenological perspective:

"*I always ask them to describe what they were like at that moment in time: what it looked like and what it smelled like. People will come to do the details they still remembered. And I give them the opportunity to go back to this situation and reconstruct it*" [P2].

Challenges of Recalling and Processing Life Events
One of the most challenging aspects of life review is recalling the specific details of important life events:

 "*Memory is quite difficult [and] old patients can't remember the details of the events. Cancer patients get tired very easily so then we should stop and start another day. And also the emotional breakdown is really difficult to deal with*" [P1].

Dealing with intense, often negative emotions is difficult both for patients and therapists, as acknowledged by all four participants.

Materiality of Life Review: Photos and Objects
The life review process needs to support the recall of significant events, as people experience difficulties in identifying and remembering them. An effective

memory aid for reflective remembering is the *scrapbook*. This offers a template for structuring the life review through the major events typical to life scripts. Events such as birth, marriage, first job or first born are suggested for guiding the reviewing process.

"Sometimes people cannot remember or don't know where to start […] So we give them this little book, telling that they don't have to fill in everything and hope they could write down important events" [P1].

All participants highlighted the value of photos and significant objects in initiating the life review: *"I will use the photos and objects brought by the patients"* [P3].

Such objects are not only reminders of important events but also landmarks depicting one's life which allows for distance and emotional expression: *"I use objects to help them to see their lives, i.e. anger"* [P4].

Other participants emphasized the reconstruction of memories involved in life review, as well as its diagrammatic representation: *"They may do a lifeline by drawing a line from beginning of their life to where they are now"* [P4].

Materiality of Life Review: Digital Artifacts
Apart from visual material, music is another important aid during the process of life review: *"I will use the photos and music in their room, like I will ask wow, this is a nice photo, could you tell me the story of it?"* [P2].

Interestingly, most of the artefacts used to support life review appear to be physical. When asked about digital artefacts, all participants noted the potential value of technology in supporting online life reviewing: "*Nowadays everyone uses digital media [it] could be a good way in the future to use the digital support […] For people who can use computers or internet

technology, patients can log into a website and build a life review stories for themselves"* [P1].

Temporal representations could be also exploited for end of life review: *"People today may have videos [of themselves on social media]. They can be used like a digital history of one's life. So I think people can use their Facebook to review their life"* [P3].

Other participant suggested the value of drawing novel lifetime representations, both prior and during therapy sessions: "*I think people could use creative apps to draw and annotate lifelines […] I think it would be easier for them to do this [online] rather than face to face. And between sessions they can bring the technology with them to share with the therapist"* [P4]. However, selecting the most relevant photos for life review is challenging, and requires support: *"In the future, there will be more digital pictures [and a] selection process is necessary"* [P2].

Life review in end of life care appears to be exclusively for the benefit of the patients, and highly authentic: *"[Online life review systems] can be an idea to provide structure but I think it is a really private thing. We can prepare some questions or internet programme to put everything in"* [P2].

Implications for Design
We now reflect on the value of these findings for HCI researchers and designers.

Scaffolding Life Review
An important finding is the value of artifacts in supporting life review in end of life care. While visual printed material such as photos or drawings are extensively used within the practice of making scrapbooks, digital artifacts are predominantly absent.

Interestingly, all participants suggested web interfaces with scaffolding questions where people with digital literacy skills could upload media and construct their life review. Another important outcome is that life review in end of life care does not have to start at the end of life. Findings suggest the value of lifelogging technologies which can allow the capture of important life events throughout one's lifetime, and which can be used as a starting point to engage in life review in end of life.

Supporting Privacy and Authenticity
Another important outcome is that life reviews tend to be private and authentic without an audience intended to consume them. The stories are shaped within the therapeutic settings and often without the presence of family members. This contrasts with the self-presentation characterizing most of the life stories within the social media [15], and highlights that the value of privacy for memory systems [5] extends also to the life review in end of life care.

Capturing the Life Review Process
Most participants noted the limited use of technology in the life review process. Except from P1 who *records* the life review process for training and feedback purposes, there is no other use of technology during life review: *"We don't really have digital materials. But we do record the story told by the patients and we have monthly staff meetings to share the stories and to see if there are some common themes"* [P1].

The rest of the therapists listen and make notes to remember patients' stories. Some mentioned the lack of access to such technologies, while other noted the value of recording the narratives for supporting patients' recall: "*I don't really capture the stories. I remember them by taking notes. It could be useful for the clients to hear themselves tell the stories*" [P4]. This suggests the value of recording the life review process in a secure and confidential way, through easy to employ technologies.

Conclusions and Future Work
Our findings suggest that the emotional benefits of life review [4] found in the reminiscing therapy also extend to the end of life care. Specific motivations in this context are shaped around empowerment and reaching closure on "unfinished businesses".

The main challenges of life review consist of remembering important events and their significance in one's life, as well as dealing with their emotional burden. Unlike the narratives in social media where self-presentation features highly, mostly around positive events, life review in end of life care is a private and deeply authentic process organised around significant positive and negative events in one's life.

There also appears to be a paucity of tools to support life review. Most therapists employ physical prompts while emphasizing the need for selecting the most appropriate ones. One important challenge which deserves future attention is exploring innovative ways of constructing and representing life review, beyond the limited timeline representations. Tools to support the recall and organisation of life events from self-memory system should aim for novel visualisation within the larger temporal scale of human life.

Acknowledgements

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