Interactive Memoirs: Coping with the Imminent Death and Leaving Legacies

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Abstract
Terminally ill patients and their caregivers suffer from high levels of stress. Coping is crucial to maintain and increase quality of life at its end. Building on previous research on virtual humans, personality, and legacy, we designed Memoirs, a tool for terminal patients to share experiences through the creation of virtual personas — conversational representations of themselves. We describe the design of Memoirs, as a tool to help patients nearing the end of life to cope with their illness and to offer an interactive legacy for their loved ones after their time has passed.

Author Keywords
Legacy; virtual humans; therapy; virtual selves.

ACM Classification Keywords
H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous.

General Terms
Design, human factors.

Introduction
Albeit uncomfortable, the subject of death is an inevitable one. When dealing with terminal illnesses, patients and their loved ones have to consider that death is imminent and this subject becomes part of their lives. Having a
Our approach is to provide a usable tool for terminally ill patients to create virtual representations of themselves, ultimately creating a virtual human who can converse with other users and share experiences that are a reflection of its creator.

Related Work
Documenting life events and leaving a legacy to loved ones to help coping has been supported by previous research. Allen et al. [1] have shown that constructing a legacy in the form of photo-montages and scrapbooks showing life events helped both the ailing family member as well as his loved ones to reduce stress caused by the imminent death. We bring this idea one step forward, providing the chance for people approaching the end of life to construct an interactive memoir, one which can be left for generations to come and can serve as both a therapeutic experience for the ailing patient as well as an “eternal life” representation of that loved one. The issue of eternal life through the use of technology has been brought up recently by Blascovich and Bailenson [3]. In their book, the authors discuss the idea that someone’s personality can be captured and recovered in the future.

The idea of personality capture was originally proposed by Bainbridge [2]. Here, the author proposes the use of massive questionnaires, with thousands of items, to be answered by a person through the course of his life. Overtime, this dataset of personality-related Q&A would become robust enough to characterize fully and uniquely one particular person. We agree that personality is one important feature of a person’s self, but another crucial component of a virtual representation of oneself is the life experiences of that person. Especially when dealing with the end of life, sharing experiences and leaving something behind as a legacy for loved ones seems to be more
helpful in coping with end of life issues than recording ones personality.

Conversational virtual humans have been successfully employed in many areas of practice, from military simulations [5] to medical education [6]. However useful virtual humans have shown to be, little has been studied in the use of virtual humans to provide virtual representations of a specific person, particularly ones approaching the end of life.

Figure 1: Memoirs Interface. Users fill out an interview, which guide them through self-reflection on experiences. Users can also edit their answers and talk to their virtual selves.

The Memoirs Tool
We have designed a tool called Memoirs, which allows terminally ill patients to create virtual conversational representations of themselves.

Capturing Experiences
Patients who are facing the end of life can benefit from reflecting on their own experiences, both in terms of their illness, but also by looking back at their life experiences and constructing a legacy to be shared with loved ones. In order to allow such self reflection, we leverage technology developed to construct virtual humans, called Virtual People Factory (VPF) [7]. VPF is a database-oriented system that stores virtual human conversational knowledge in the form of questions and answers. Typically, VPF is used for users to talk with the virtual humans by asking them questions in a structured format.

For Memoirs, we have changed the roles of VPF so that the patient is the one being interviewed and answers questions that will encourage self reflection. At the same time, the answers provided by the patient are fed into the database to create the conversational knowledge for the patient’s virtual self.

The patient is asked questions about his personal experiences in his life as well as experiences with the disease. While answering the questions in a user-friendly interface (Figure 1,) the patient may be able to reflect on his experiences and see value in leaving a legacy for loved ones.

After answering the set of questions presented by the system, the patient can create new questions about topics that she would be interested in discussing, but were not included in the initial interview.

Leaving Legacies
As the patient reflects on her experiences by doing the initial interview, Memoirs stores the responses as part of the conversational knowledge of the virtual representation of the patient. Family members can, then, log into the
system and talk to this virtual persona that represents their ailing loved one.

In order to provide a more natural conversational experience, Memoirs recognizes close matches to existing questions and has the ability to store many different forms that a question may be asked. For example, if the family member asks “How did you find out about your disease?” or “How did you figure that you were sick?,” the response will be the same.

Another important element of Memoirs is that, whenever someone asks the virtual representation of the patient a question that he does not have an answer for, the question is added as a suggestion the next time the patient logs into the system. This has the potential to not only improve the set of answers that the patient can respond to, but also engage the patient and family members alike in a positive exercise to cope with the disease.

Ongoing Work
We have developed a functional prototype of Memoirs and in the near future we will conduct an usability evaluation of the system. After iterating on the design based on feedback from the evaluation, we will evaluate Memoirs as a therapy and legacy tool with cancer patients. We are currently recruiting cancer patients from the Shands Hospital at the University of Florida. So far, we have had a high acceptance rate from patients interested in participating.

At its current state, the prototype allows typed or speech-to-text input. We are planning to integrate a voice recorder so that the virtual representation of the patient can also speak with her voice. The patients’ virtual representations will likely contain sensitive information, and we will ensure that privacy will be preserved.

Conclusion
Coping with imminent death and loss is essential for terminally ill patients and their loved ones. We have described the design of Memoirs, a tool for coping using virtual human technology to enable patients nearing the end of life to create virtual representations of themselves. We plan to conduct empirical evaluations with cancer patients in order to demonstrate the effectiveness of our approach.

References