# A Friendly Face in the Storm: Self-care Support System Requirements for Individuals with Spinal Cord Injury

**Ameneh Shamekhi**

Northeastern University

Boston, MA 02115, USA

ameneh@ccs.neu.edu


**Ha Trinh**

Northeastern University

Boston, MA 02115, USA

hatrinh@ccs.neu.edu


**Timothy Bickmore**

Northeastern University

Boston, MA 02115, USA

bickmore@ccs.neu.edu


**Theresa Ellis**

Boston Universuty

Boston, MA 02115, USA

tellis@bu.edu


**Bethlyn V. Houlihan**

Boston Universuty

Boston, MA 02115,

bvergo@bu.edu


**Nancy L. Latham**

Boston Universuty

Boston, MA 02115, USA

nlatham@bu.edu

## Abstract

Individuals with Spinal Cord Injury (SCI) have to deal with myriad lifestyle changes including significant reductions in physical mobility, physical rehabilitation, and a variety of self-monitoring procedures. They are also at risk of depression and social isolation. We explored the design requirements for an interactive system to best address the needs of people newly diagnosed with SCI through one-on-one interviews and a technology probe. We gathered qualitative information from ten participants with SCI, and identified key themes regarding the challenges the target population faces in their transition to a new lifestyle, and illustrate how technology can address these. We present rationale and design requirements for a conversational agent-based system as an ideal medium to provide health education, self-care management coaching and emotional and social support for persons with SCI.

## Author Keywords

Spinal Cord Injury, embodied conversational agent, virtual agent, motor impairment, design implications.

## ACM Classification Keywords

H.5.2. Information interfaces and presentation, User Interfaces, Prototyping, User-centered design

Figure 1. Embodied conversational agent (ECA) as virtual coach. The virtual coach, named Tanya, communicates with the user using synthetic speech and synchronized nonverbal behavior, including facial expressions, head nods, and hand gestures.

## Introduction

Every year 17,000 new Spinal Cord Injury cases (80% male) happen in the U.S. resulting in a total of 282,000 individuals with SCI in 2016. A typical case may involve an individual who was just involved in an automobile accident and had his spinal cord severed. Following a stay in the emergency department and hospital (lasting 11 days on average), he spends 35 days in rehabilitation, during which time he learns an entirely new lifestyle that he will have to live the rest of his life. Thus, an individual with SCI experiences dramatic and immediate changes causing numerous new physical and emotional challenges in his/her everyday life. People with SCI have to deal with various health issues including skin problems, bladder and bowel dysfunction, cardiovascular disease, stress, and rapid decrease in physical activity [6]. Among these issues, skin and pressure sore management is one of the most prevalent concerns. Affecting 33% of individuals with SCI, pressure sores occur when the skin breaks down from constant pressure and can quickly become a serious problem if left untreated [2]. In addition, a person with SCI confronts enormous emotional challenges that can complicate the healing process. Grief, denial, anger, bargaining, and depression are considered the five stages one faces after such an injury, before finally accepting their new situation [5]. Both physical and emotional challenges for people with SCI suggest the necessity of having supporting tools and networks, especially in the first few years post injury. However, lack of support to prevent secondary conditions for persons with SCI is a widely acknowledged problem.

## Background

There has been a substantial body of research into the design of assistive technologies that could be used by individuals with SCI. These range from new accessible interfaces, to adapting existing input modalities (e.g. touch input) for users with physical impairments [1]. In terms of healthcare support, telehealth interventions have been developed to provide health services remotely for people with SCI. Houlihan et al. [4] developed the CareCall telehealth system, which uses IVR (phone) technology to deliver a skin care management intervention for people with SCI. Previous research has also explored the use of Embodied Conversational Agents (ECAs) to support health education and promote health behavior change. ECAs are animated characters that use verbal and nonverbal behavior to engage users in a simulated face-to-face health counseling conversation (see Fig. 1). This technology has been shown to be effective and accessible for different user populations, including those with disabilities. For example, a logitudinal study by Ellis et al. [3] demostrated the feasibility of ECAs to promote exercise adherence for people with Parkinson's Disease. However, there is little research on the use of ECAs for people with SCI.

The contributions of this formative work include the identification of main themes regarding the physical and emotional challenges of individuals with SCI, and an exploration of how an ECA-based system could be used for health education and health behavior change.

## Prototype Embodied Conversational Agent System

We developed a prototype ECA system, in which an animated character named Tanya, plays the role of a virtual coach to support skin care management for

Figure 2. A user with Spinal Cord Injury interacting with the ECA on a 21" touchscreen. User input to the conversation is obtained via multiple choice selection of utterances.

*P9-Q1: "When they leave rehab and are getting into inpatient care and they don't have their doctors around them 24/7 you know that stage is the most anxiety producing and it can also be the most depressing time. You also don't feel like you have the same support that you used to, friends and family don't visit as much. … you're left to your own devices. Leaving rehab and transitioning back to home is like the hardest part for people."*

people with SCI [Figs. 1&2]. Each conversation begins with a brief greeting and social chat that serve to build rapport with the user, followed by a menu of three educational topics to discuss: skin inspection, bed pressure relief, and chair pressure relief. During the discussion, Tanya incorporates images and videos to explain skincare-related information, as well as audio recordings of real people with SCI who share their knowledge and experience. We used the prototype as a technology probe to explore users' perceptions of the ECA technology and its potential to support longitudinal health interventions for people with SCI.

## Formative Study

To explore the design requirements of an interactive healthcare system for people with SCI, we conducted an exploratory study with 10 participants with SCI (mean age=39.7, range=26-62), 2-10 years post-injury (mean=5.7). Nine out of ten participants were male, which is consistent with the general demographics of individuals with SCI in the US. 70% had tetraplegia (severe dysfunction of use of all four limbs and torso), 70% were white, and 80% reported using a computer regularly.

**Procedure:** The study consisted of a single session lasting 90 to 120 minutes in a usability lab. Following informed consent, we carried out a semi-structured interview, asking about general healthcare issues and how participants use existing technologies to improve their health and wellness. Next, participants were given a brief orientation to our prototype ECA system, then interacted with the system using a Think Aloud protocol. After the interaction, we conducted a post-test semi-structured interview to assess participants' attitudes towards the system. The interview questions were designed to uncover participants' impressions of

the overall interaction, the character, and the conversation content.

**Data Analysis:** All interviews were audio recorded, transcribed and analyzed by two researchers in our team using thematic analysis techniques. Our interview analysis started with open coding, followed by clustering of relevant codes into common themes using the affinity diagraming method. In the next section we describe the emerging themes from the interviews.

## Qualitative Findings

We first contextualize the situation and challenges that people with SCI have to deal with, based on the pre-test interviews, then discuss the participants' impression of the agent and how they believe such a system could empower them to face SCI-related challenges. Finally, we suggest several design implications for a ECA-based system to address the needs of this population.

### Existing Situation
CRISIS OF OUTPATIENT LIFE

Our participants described their transition from hospital to home as a very challenging step they faced after their injury. The challenges of rehabilitation are not limited to accessibility issues, and outpatients often struggle with a variety of other problems, including self-monitoring health, emotional tensions, establishing new routines, and troubles in accessing social support. P7 described this transition as going "*outside of the bubble*" . P1 used the term "*warm blanket*" to describe the safety and the peace of mind of inpatient hospital care. The sense of denial, depression, anxiety and isolation are common feelings that people experience while transitioning. P9 described this time as the hardest part of the journey [P9-Q1] (see sidebar).

P10-Q1: *"A lot of guys have been injured longer than me and so its a way I see to get good informatiom they have more experience than me and been in the chair longer than me so I have some guys that I can turn to for some quesitons that I can get the answers to."*

P3-Q1: *"I try to track as much as I can especially if I am not feeling good. I use the notepad to track for how many pills that I take daily and how I am feeling. Then I use [app X] to track calories."*

P5-Q1: *"I really think that there needs to be a way for them to connect to local resources. So they can't just be at their homes and just sit. … what is going to help the most is to be able to connect to real people."*

P8-Q1: *"I think a lot of people like to share information with new people with SCI or even they're not new just if other people have some questions."*

INFORMATION RESOURCES

Most participant reported the "*lack of enough information*" as one of the main challenges as they moved back home after their hospital discharge. Patients are offered a lot of information in rehabilitation. However, they might not be ready to receive information at that time, due to the "*hectic*" [P1] and unsettled nature of their situation. These concerns highlight the importance of delivering reliable information in a way that is timely and that does not cause patients to feel overwhelmed.

Our participants also reported different information resources they used based on the sensitivity of the information they sought and the accessibility of the resources. They indicated that "*depending on the information and the importance*" they would seek knowledge from different resources. For example, "*If it is more on the clinical end, I guess that maybe I lean towards the medical profession. But if it is more for activities of daily living, I would probably rely on my peers more than a physician*" [P7]. They expressed a strong preference toward a trustworthy resource from which they could obtain accurate information quickly. Some participants reported using the internet as an information resource. However, a few of them mentioned that they could not rely on online resources in the beginning. For example, P9 said "*I never really trusted what I read on the internet if it was something that affected me medically I would always go to the docs and make sure*."

Our participants also emphasized the influence of their peers and mentors on their health improvement and emotional support: "*my mentors, they really taught me a lot more information, more than my doctors did*" [P9]. Newly injured people who do not have a clear

perspective of how their life will change feel particularly empowered by their peers' experiences [P10-Q1].

TECHNOLOGY

People with SCI use different technologies in order to manage their problems. For example, assistive technologies like voice dictation and voice activation, tracking applications that monitor health status, and reminders applications are widely used by patients, and help them become more independent. Six of our participants reported using healthcare technology for tracking their progress, and documenting and scheduling health-related activities [P3-Q1]. However, few participants reported using technology specifically for health care, indicating a market need for health applications adapted for individuals with SCI.

CONNECTION AND COMMUNICATION WITH OTHERS

Most participants talked about the importance of having a support group: either peers that they find in online SCI communities, mentors, or their family and friends [P5-Q1]. Many participants stated that they felt disconnected and had difficulty returning to their communities and rebuilding social ties following their injury. Several also described the "*anxiety of getting out and being in the public*" [P9]. Several also mentioned the risk of having depression, as P7 said "*when you get home that support system is gone so the depression can set in*".

In the process of connecting with other people, one of the most important concerns of people with SCI was to become advocates of their own health and to be able to request help from others. For example P1 said: "*You have to be your own advocate to see what you can do for yourself instead of depending on everybody.*"

Our participants also expressed a strong willingness toward sharing their own experiences with newly

injured people. Several participants experienced the transition from being a mentee to a mentor [P8-Q1], and they clearly remembered the time they "*didn't think that [their current life] was possible*" [P8].

*Impressions of the ECA*
Results of our post-test interview analysis demonstrate that all participants were highly receptive to the ECA technology and found the conversation content useful and relevant. Here we describe the four main themes related to the users' perceptions of the ECA and its potential future improvements.

ENGAGEMENT IN INTERACTION
Many participants felt motivated and entertained by the agent. They commented positively on the mannerism of the agent: "*The character is enthusiastic and promotes wanting to keep going and she is smiling and on a first name basis. Friendly*" [P3]. On the topic of increasing engagement in longitudinal interaction, several participants proposed the use of goal setting and positive reinforcement as an engagment booster. However, the design of goal setting dialogue requires in-depth attention to benefit this population, due to their sensitive life circumstances. Individuals with SCI try hard to get back to normal life, and excessive goal setting could actually lead to disappointment, decreased self-efficacy, or annoyance [P4-Q1].

Participants also suggested other ways to make the ECA interaction more engaging. Repetitive dialogue is one of the factors that leads to decreased engagement and could be avoided by enriching the dialogue content. Regarding the design of the ECA, participants preferred to see more human-like physical characteristics, as well as more interactive behavior, and more attention grabbing features in the agent's simulated

environment. They also suggested having the agent demonstrate the procedures she is promoting [P4-Q2].

PERCEPTION OF THE AGENT
Participants had different perceptions of what the role of the agent should be. A few preferred the agent to represent an "*expert with a white coat*", while some strongly preferred the agent to represent a peer in a wheelchair: "*Since she is coaching me on something personal, just for my own visual perception, I would prefer somebody in a wheel chair*" [P7], because "*it is good to connect with someone that knows what you are going through*" [P5]. They also proposed that the agent's role and appearance need to be customized based on the topic, user's age, and injury level.

A few participants found the agent's cartoonish appearance and conversational style oversimplifying and "*childish*" [P5-Q2]. There were a few participants that perceived the agent only as a computer, and one of them stated that he would prefer to talk to "*an actual person*" about emotional topics such as depression. However, many participants saw the agent's value as a companion to provide emotional support and discuss sensitive topics [P10-Q2].

ECA AS AN INFORMATION RESOURCE
Participants appreciated the flexible and interactive format of the simulated dialogue, and embraced the idea of having a centralized SCI information resource, especially compared to unguided searches on the internet for help. They envisioned the agent covering a variety of topics, from nutrition, to skin management, emotional support talk, and PCA education. They especially liked the idea of turning to the agent to discuss sensitive topics such as bowel and bladder movement and sex [P2-Q1, P8-Q2]. At the same time, they affirmed that the content of the conversation

P2-Q1: *"I think she should, especially for more some more sensitive subjects that maybe people would initially would be embarrassed to talk to somebody else about…Like bowel and bladder, I don't think anyone likes that."*

P8-Q2: *"At that point I think that I would just like to talk to her, to Tanya. I would be ready to because in my case I was shy and afraid to talk to person face to face so talking to someone like Tanya would make it better."*

P2-Q2: *"I liked how they brought in people with spinal cord injuries' experiences. They gave you choices on different types of issues, choices that you could listen to."*

P5-Q3: *"Ultimately it would be great if there were a part of the system that can connect to support groups and other people. And say there is a particular time of the week where they could be on skype… For people in chairs, you have no idea the amount of people who are apart of small communities that are out in the boonies and have no access to anything. Let alone a place where they ask questions and get responses."*

needs to be delivered in an interactive way, and should be customized based on the user's characteristics, the sensitivity of the topic, the time of delivery, and their injury level. They also liked the multimedia format of the information delivery; especially the incorporation of audio recordings made by peers with SCI [P2-Q2]. Participants' comments about the ECA indicate that the system could both be a reliable central source of information about SCI, and a source of inspiration and help from peer mentors, since hearing real personal stories made the "*information more powerful*".

ECA AS FACILITATOR OF SOCIAL COMMUNICATION
Some individuals with SCI need assistance in managing their interactions with people around them. Participants suggested that the agent could be designed to assist them both by providing tips about *"public relations"*, and educating their family and friends who are *"afraid to ask a lot of stuff"*. Many participants also suggested that the agent could perform effectively as a facilitator to connect them to support groups [P5-Q3].

## Discussion and Future Direction
Our findings reveal that individuals with SCI confront many challenges while transitioning to a new life style, and that the presence of a trustworthy companion, who can provide accurate and quickly accessible information could be of a great value. Our participants were highly receptive of the ECA technology and thought it would be useful, especially for newly injured patients.

Findings from our study indicate several directions for future enhancements of the ECA. For example, different ECAs could take on different roles (peer vs. doctors), enabling users to interact with different agents for different topics. Given the positive reactions to audio from peers, users could be provided with the ability to answer questions asked by other users of the system.

By enabling users to share their experiences and involving them in the content generation process, they would be more engaged in the system. Responding to questions asked by other peers could also increase their self-efficacy which may improve health behavior change for involved individuals.

Participants also felt there is significant potential for technology to facilitate connections in the form of social support groups, as well as to assist communicating with their PCAs and other people more effectively. Thus, these represent important areas for future exploration.

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