

Infrastructuring Work in the Transition from Hospital to Home: A Narrative Account of an Australian Stroke Survivor

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ABSTRACT

The aim of this project is to explore how mobile technology can support stroke survivors and their caregivers in the transition from hospital to home. Situated in the context of a publicly funded healthcare service in Australia, this paper presents a narrative account of a stroke survivor that highlights experiences during this transition and “infrastructuring work” to address gaps in information, services, and support. These gaps did not appear within the healthcare service, but rather in the transition between the healthcare service and home, and also in the transition back to work. Based on these insights, we are currently designing and evaluating a mobile application that tailors information for each stroke survivor and provides timely support.

KEYWORDS

Stroke; transition; experience; infrastructuring work; collaborative design; mobile technology.

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INTRODUCTION

The impact of a stroke, defined as a sudden interruption in blood flow to the brain, affects each person in a unique way. Depending on the area of the brain affected, a stroke can impact on a person’s ability to move their body, engage with their senses (sight, touch, smell), use language, think, and experience emotions. In Australia, more than 470,000 people live with the effects of stroke, with two thirds of them needing assistance to carry out basic activities of daily living like eating [6]. Therefore, to achieve the best outcomes possible, the pathway to recovery must be tailored to meet the needs of each individual, starting in the hospital and continuing in the home and community [10].

The aim of this research project is to better understand the transition from hospital to home for Australian stroke

survivors and their caregivers and to explore ways of improving this transition with the support of digital technology. A crucial starting point in the transition experience is the discharge planning conducted in the hospital, where clinicians, patients, and caregivers develop a plan for managing recovery at home. Unfortunately, when patients leave the hospital, they not only have to deal with the outcomes of stroke, but they also often experience a lack of medical knowledge, a lack of resources to manage their health, and a lack of confidence in their abilities [12]. Research also shows significant gaps in illness related work at home, i.e., gaps in efforts to manage blood pressure, modify lifestyle factors to reduce the risk of another stroke, and to maintain mental wellness [1]. The outcome of stroke can affect everyday life, from household chores to transportation to managing relationships, as well as biographical work to reconstruct a personal narrative [11]. For some younger stroke survivors it may also impact on their ability to continue working or require modifications to their work environment to successfully return to work. To start to address some of these challenges, this project aims to design and evaluate a mobile application that provides personally relevant information aligned to the needs and goals determined by the stroke survivor, caregiver, and the treating clinicians.

In this position paper we reflect on co-design workshops with stroke survivors and their caregivers with a particular focus on “infrastructuring work” during the hospital-to-home transition. Infrastructuring work in general refers to attempts by individuals to connect and re-configure often fragmented resources, like different healthcare services, physical and digital resources, information, support, etc. [2]. In this paper we focus on the experiences of one workshop participant, Gloria (pseudonym), who reported positive experiences with the healthcare service infrastructure, but highlighted gaps and challenges with the existing infrastructures in returning home and back to work. We close with reflections on the narrative account and the envisioned solution.

CO-DESIGN WORKSHOPS

This research took place in Brisbane, Australia, as part of a research project called “Better Individualised Stroke Care Using Technology (BISCUT)”. The aim of BISCUT is to design and evaluate mobile technology to better connect different healthcare services and to tailor support for stroke survivors and caregivers in their transition from hospital to home. The target cohort for this project are stroke survivors who are discharged within a few days following acute treatment of their stroke and who do not require in-patient rehabilitation but are usually referred for community-based rehabilitation which they are required to self-manage at home. This research project has been funded by a large healthcare service in Brisbane, and it was conducted in collaboration between the healthcare service and a university that provides education for nurses and allied health professionals. The Brisbane-based healthcare service is part of a publicly funded universal healthcare system in Australia, which covers hospital inpatient care and limited, medically necessary, home health care for Australian citizens and permanent residents.

The BISCUT project was based on a collaborative design approach that brings together stroke survivors, caregivers, health professionals, health management, and researchers. This approach is based on a conviction that all people are creative and have ideas to improve their lives [13]. Hence, all project efforts, from the conception of the project, to the ethics approval, to co-design workshops were developed and conducted, including this position paper, in collaboration with a stroke survivor, researchers and professionals in health and HCI.

We conducted three co-design workshops with stroke survivors and their caregivers to examine the work and the experiences of their transition from hospital to home in an Australian context. Workshop 1 involved five stroke survivors and one caregiver recruited through personal contacts. Workshop 2 was conducted with participants recruited through the health service (three participants), and workshop 3 was conducted with a consumer support group during their regular meeting (20 participants).

Each workshop followed a similar structure to learn about the transition experience and discuss ideas for a mobile app. After an introduction of the workshop participants and the project, we conducted a drawing exercise to highlight that everyone is creative and can contribute ideas [8]. The main workshop activity was to create a personal collage of the transition from the hospital to home and to share the story with other workshop participants. Each participant received a collage kit that included a large piece of paper, pens, post-it notes, photos

and drawings related to recovery from a stroke, sentence prompts (e.g., when I have a question, I speak to...), and emotion words (e.g., anxious, supported) [7]. Participants spent between 30 and 40 minutes to create their own collages, followed by a 30-minute show and tell session where participants shared their stories with each other. In workshop 1, the collage was followed by a brief discussion of ideas and information that would have made a difference in each person’s transition journey. In workshop 2 we created collages and we discussed an early prototype with participants. Workshop 3 focused solely on discussing a digital prototype with the workshop participants to develop ideas and to refine the information, functionality, and the look and feel of the application. All group discussions were audio-recorded for later analysis.

The findings presented in this paper are based on a narrative analysis [3] to make meaning of the experience of transitioning home after a stroke and the work involved in dealing with gaps in infrastructure. Instead of breaking up the data from many participants into codes and themes (e.g., through a ground theory approach), narrative studies are typically only focused on one or two participants to provide an in-depth account of their experience [5]. In our analysis, we focused on the experience of Gloria, a woman in her early thirties, whose life had been disrupted by a stroke three years prior to the workshop. We chose Gloria, because her account was rich in examples of infrastructure gaps and work. The analysis was based on her collage of the transition from hospital to home (see Figure 1) and a transcript of her verbal account. The first author transcribed the audio-recording and re-told the story of Gloria’s transition and the gaps in infrastructure she experienced. The re-told story has been edited and revised with all co-authors to ensure that both the details and the story as a whole are truthful and in line with the way the story has been told during the workshop.

It is important to highlight the limitations of this research. Firstly, we have not discussed or rewritten our findings with Gloria, which would enhance the truthfulness and may create further insight into her experience. Secondly, we do not imply that the findings from a single participant are applicable to other stroke survivors in Australia. Each person is uniquely affected by a stroke, depending on the impact on their brain, personal history, care received, etc. This account is based on the experiences with a publicly funded healthcare system in an Australian metropolitan area, and other healthcare systems in Australia, e.g., in a rural area, may work differently. Hence, comparisons with other narrative accounts will be useful to enhance the applicability of the findings.

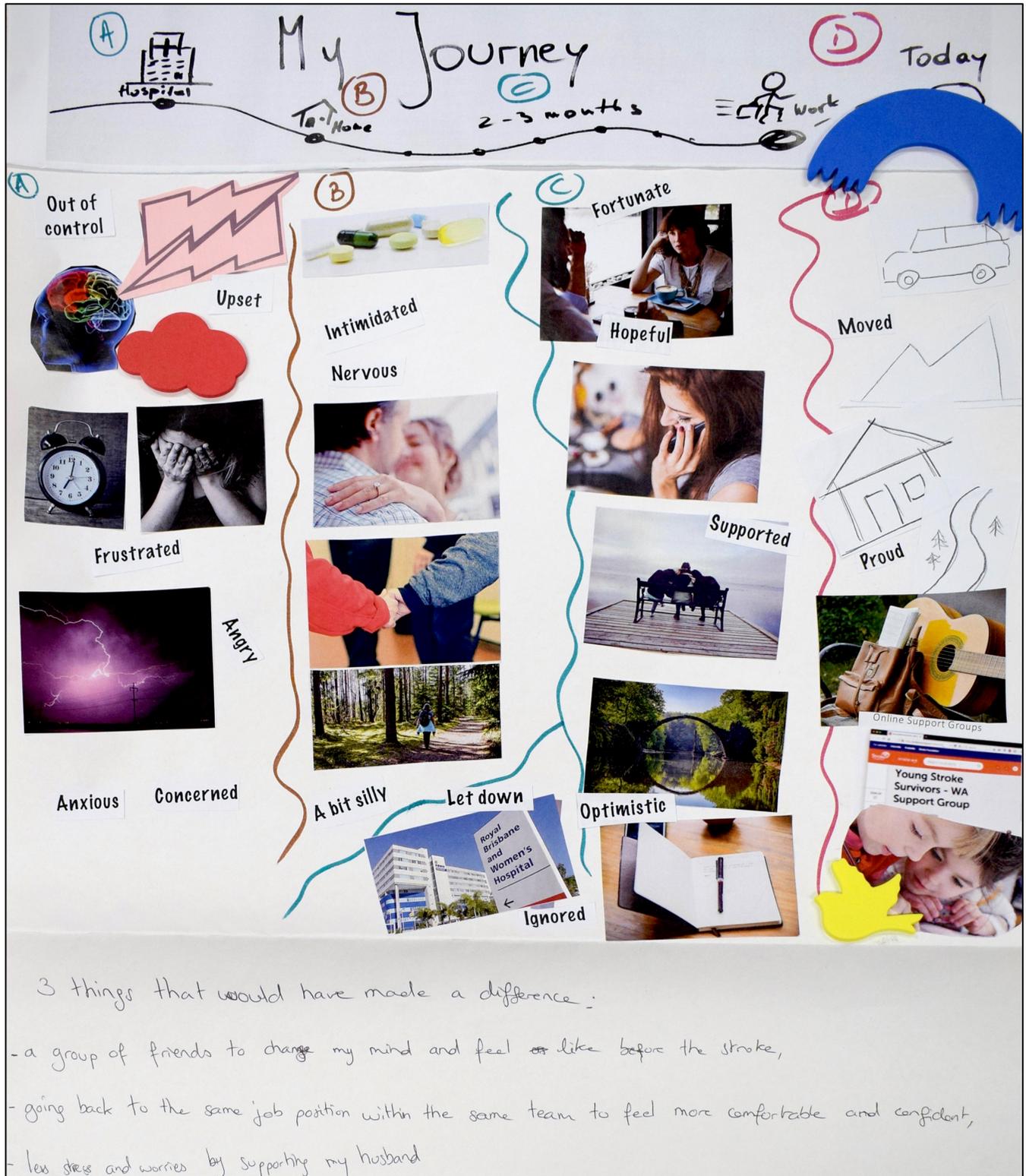


Figure 1. The collage was used in the workshop to illustrate and talk about personal experiences in the transition from hospital to home after a stroke. Gloria's collage shows her transition from hospital (column A) to home (B), including the first few months of being at home (C) to the present day (D). The text on the bottom lists information that would have made a difference in her transition.

FINDINGS

Gloria is a young adult stroke survivor in her early thirties. Three years ago, a stroke disrupted her life. Gloria's collage (see Figure 1) and her verbal account provide rich insights into the impacts to her personal life and marriage, the disruption to her professional work as a fitness instructor, and the emotional journey of recovering from a stroke. Below we re-tell her story of transitioning from the hospital to home and of the infrastructuring work performed by Gloria and her husband.

Transition Experiences

Gloria's account of transitioning from hospital to her home, up to today's situation, was structured into four phases (see also collage in Figure 1).

Firstly, the experience of the immediate aftermath of the stroke in the hospital was characterised by feelings of losing control and frustration. Gloria was young and living a very healthy lifestyle, and hence the stroke was a surprise and shock to her: *"I was a fitness instructor, and I was into eating healthy and everything. So it was really out of the blue when it happened. It felt really like out of control, like in the picture, like a storm, without understanding it."* Furthermore, Gloria felt upset that it happened to her and also frustrated with the loss of her abilities, i.e., her inability to speak and the slow recovery process: *"I felt really frustrated, because I had very strong aphasia. I couldn't say anything really. Then I could just say one word. There was a lot of time, I couldn't say much. I felt very frustrated, and then I felt angry."*

Secondly, the experience of transitioning from hospital to home could be summarised as intimidating. Gloria explained that *"it's been really hard in the recovery [in hospital], but I think the hard work started at home. So I felt really intimidated and nervous thinking that, how is it going to happen [at home]?"* Gloria's husband provided crucial support throughout this time to continue rehabilitation, manage everyday life, and to offer emotional support.

Thirdly, Gloria described that it took several months to even begin to come to terms with the effects of stroke, both for Gloria and her husband. Looking back, Gloria stated that *"I have to admit that I was fortunate. I lost a bit of balance, but I could get back into exercise and I was hopeful. My family of in-laws supported me. It's not the same as family. But my husband was a really big support."* Whilst feeling fortunate, Gloria also highlighted that she struggled with her situation, i.e., with the effects of stroke on her emotions: *"I've always been a very optimistic person, but it's tough. It's taking a toll on you."*

Finally, looking at the present time, Gloria had achieved a lot that she was proud of. She was able to get back to paid work, move into her own home, and start a family. There have also been other achievements, like being able to enjoy listening to music and being able to dance again, which have been important for Gloria's wellbeing and sense of progress: *"I've always been enjoying music. Although I find it very overwhelming, having it in the background and doing a thing at the same time is still a bit much. But it's a good exercise."* None of these achievements came without challenges and work, which are described next.

Transition Challenges and Infrastructuring Work

For Gloria, the primary concern was not the health service infrastructure per se. Like other workshop participants, Gloria praised the healthcare infrastructure: *"The medical system was really good in terms of health. I've been checked very well and looked after."* Instead, the challenges emerged in managing the transitions from the hospital and rehabilitation services back home and returning to work.

Transitioning Back Home

Transitioning back home brings multiple challenges: independent rehabilitation efforts and other efforts to manage the impacts of stroke (e.g., medication); managing everyday life from household chores to personal relationships; and work to reconstruct a personal narrative and identity. Importantly, this transition also starts in hospital, to prepare stroke survivors and caregivers for life at home through information about the stroke and how to manage its effects independently at home.

One of the challenges highlighted by Gloria was the overwhelming amount of information received in hospital: *"All of the information I was given at the hospital – it was just too much reading."* This was particularly problematic, because Gloria experienced both impairments to express and comprehend language as well as fatigue.

In Gloria's situation, her husband performed the work of filtering the large amount of information on how to manage the effects of stroke. However, her husband's time was limited due to paid work and household work: *"It took me months to read something and understand so I didn't feel like looking. So my husband would have to, but he didn't have time."*

On the issue of emotional wellbeing, Gloria reported that she received too little information and too late. Feeling strong and uncontrollable emotions, feelings of anxiety, and having depression are common after having a stroke. These impacts of stroke are not always experienced

immediately but rather emerge over time. Gloria commented that she wished that she had personally received information about the impacts of a stroke on your emotions whilst still in hospital. Furthermore, she wished she had received information about peer support groups which provide an important infrastructure for people to discuss and normalise their experiences. *“When I was in the rehabilitation, nobody gave too much information. Nobody said to me about depression really. They told my husband, but nobody told me to explain to me the possible outcome. So anyways, it’s good with all these groups to get this connection to be able to share and to understand you are not alone, which is really good.”*

Transitioning Back to Work

Gloria described that she felt “let down and ignored” by the medical system when she had to return to work. However, Gloria also stated that *“the medical system was really good in terms of health”* and that *“there is nothing else you could do much more”*, acknowledging that the responsibilities of the medical system are obviously concerned with her health, which may at times clash with other needs, like the ability to return to work.

The first challenge was that Gloria could not go back to her previous work because of the need to drive a car and the lack of public transport infrastructure in her area. *“Basically I was told that I can’t drive, because it was too far. So I had to either move somewhere else, but we had a contract for a rental. So we couldn’t just move out like this. Or change my job, but my job was on a contract, and I didn’t want to leave my job like that. So I just been left like that and I had to deal with it.”*

Hence, a second challenge was to find suitable work. Finding a new position can be stressful for anyone. However, living with the effects of stroke made it particularly challenging for Gloria due to fatigue, speech impairments, and the impact of stroke on her self-confidence: *“I still had to apply for a job and nobody gave me any support. And my interview – this was very stressful at the time, because you don’t feel confident.”*

As a form of personal infrastructuring, Gloria included a personal diary in her collage (Figure 1) which she used to manage information during phone calls. The stroke impacted on Gloria’s ability to speak and remember information. Hence the diary was useful to prepare for phone calls, e.g., with health services or prospective employers: *“making phone calls was a very challenging thing. I had to write down to say this, explain why – you feel a bit stupid to express yourself normally.”*

Gloria was able to resolve these challenges and find suitable work. She found a sympathetic doctor who offered support for getting back to driving. Going back to work also enabled her to afford to move house, which reduced the length of the commute. *“I went back to work in May. And then we bought a house and moved to a lovely place – in the glasshouse mountains. We wanted some space in the nature. We can’t complain – we work really hard, but it worked out.”*

DISCUSSION

The narrative account of a stroke survivor presented in the findings highlights that the healthcare services in an Australian metropolitan context provided excellent treatment and rehabilitation services. However, the account also highlighted challenges in the transition from the health service to the home and back to work, which involved various types of work: emotional work to come to terms with the impact of a stroke, support work by the spouse, and informational work by family members to cope with the wealth of information offered in hospital.

In terms of infrastructuring work, the narrative account highlighted infrastructure breakdowns and infrastructuring work at the boundaries between health services, home, and work. We presented evidence of personal infrastructuring by the stroke survivor to: work through diaries to scaffold telephone conversations, deal with gaps in transport infrastructure that adversely affected the stroke survivor’s ability to return to work and, gaps in conveying information about access to peer support group infrastructures to cope with strong emotions and depression after stroke.

Overall, we argue that transitions are central to understanding experiences and infrastructuring work, improving health outcomes, and designing digital technologies. Transitions are a central concept in nursing research [14]. Particularly transitions in and out of the health system are critical for the overall wellbeing and recovery of people with stroke, and more work is needed to address gaps and breakdowns during transitional periods. As highlighted by others [4], a narrow focus on managing the effects of illness in hospital and at home is not sufficient, because chronic conditions like stroke also affect everyday life work and relationships as well as a person’s sense of self. Hence, looking at the transitions and work performed at home opens up several opportunities for HCI researchers: instead of narrowly focusing the design of digital on supporting rehabilitation and other illness work, it highlights opportunities to support stroke survivors in everyday life work to recognise fatigue, to promote

relationships with peers, or to providing opportunities for reflection and forming a personal narrative [11]. This is also an opportunity to collaborate with occupational therapists, who visit stroke survivors at home to support them in their transition to the home and to work.

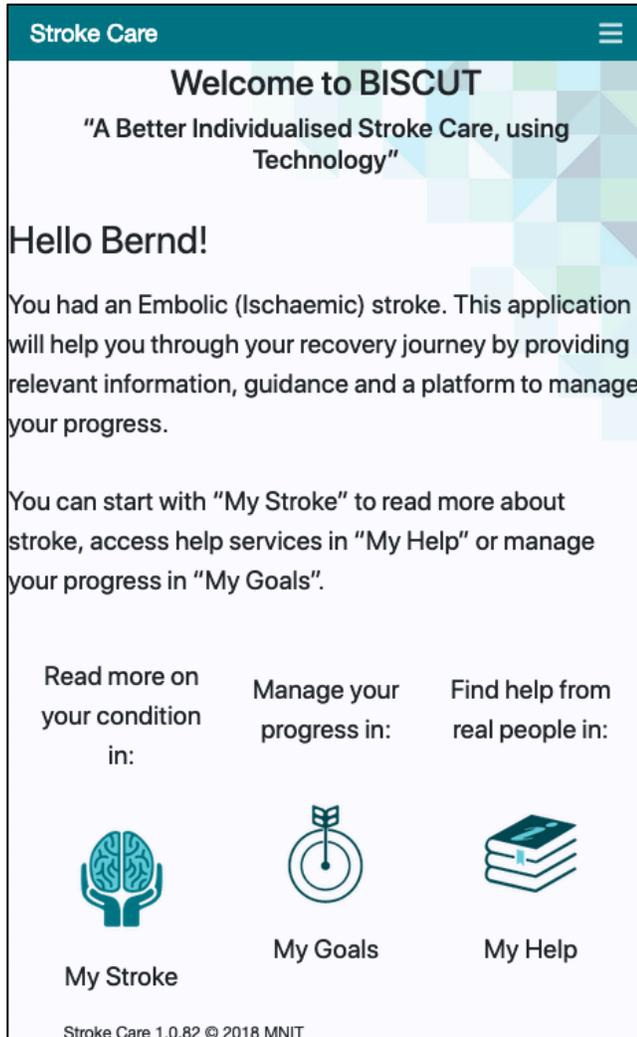


Figure 2. BISCUT prototype used in co-design workshops to discuss how to tailor information for stroke survivors.

In the Better Individualised Stroke Care Using Technology (BISCUT), we seek to address challenges with too little or too much information in the transition to home and back to work. In particular, we are working on a mobile application that tailors information to each stroke survivor and their caregivers to provide personalised information at the time when it is needed. We hope that this will mitigate challenges highlighted by Gloria about feeling overwhelmed with the need to read through large amounts of information as well as gaps in access to information about emotional wellbeing. Figure 2 shows a

mobile application prototype, which we use in co-design workshops to discuss how to tailor information in a meaningful way to provide information about the stroke and its effects, support people in their goals, and provide resources to connect with peer groups and health services.

CONCLUSIONS

This paper highlights gaps and infrastructuring work in the transition from hospital to home and in returning to the workplace, such as gaps in information about the effects of stroke and access to infrastructure like support groups. To address such gaps, this research project is currently working on the design and evaluation of a mobile application that tailors information to individual stroke survivors and their caregivers. We are aware that standalone information from a mobile application will not be sufficient to address all the gaps identified in this paper. However, it will serve as a technology probe [9] to further explore the issues experienced by stroke survivors, as well as an opportunity to continue to refine how stroke survivors, caregivers, and health professionals can collaborate to achieve a better transition to home and a successful pathway to the best recovery possible for each individual including returning to work.

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