The Social Lives of Individuals with Traumatic Brain Injury

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ABSTRACT

Traumatic Brain Injury (TBI) can affect all aspects of an individual's life, including physical ability, communication, and mental health, and present chronic health conditions that persist throughout the lifespan. Although prior work documents a decrease in social interaction following brain injury, little is known about how individuals with TBI engage in social behavior during their recovery, how others in their lives participate, and how these interactions occur in both online and offline contexts. We examine these issues through an interview study involving individuals with TBI, as well as caregivers and social contacts of individuals with TBI. Our analysis identifies the concept of social re-emergence, a non-linear process of developing a new social identity that involves withdrawing from social life, developing goals for social participation, disclosing health information for social support and acceptance, and attaining social independence.

Author Keywords

Traumatic brain injury; social interaction; recovery.

ACM Classification Keywords

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

INTRODUCTION

A growing body of work in human-computer interaction (HCI) examines the role of technology in recovery and management of chronic health conditions. Sharing health experiences face-to-face and online can facilitate social support, which is accepted as a positive influence on health outcomes [21, 63]; however, some health conditions, such as stroke and brain injury, can significantly challenge an individual's ability to communicate and participate socially. Complications to social life associated with other significant health conditions and long-lasting illnesses have been examined in various contexts, including maintaining normalcy and supporting disease management [26, 42]. However, questions remain concerning how people negotiate their post-injury social lives in the context of recovery, symptom management, and the participation of others. This paper reports on an interview study with individuals with Traumatic Brain Injury (TBI) and caregivers and social contacts of individuals with TBI as a way of understanding these questions.

TBI impacts millions of Americans each year [22] and can affect motor ability, memory, speech, mental health, and other aspects of wellbeing [16, 29, 37, 39]. Although often viewed as a health event requiring treatment and rehabilitation [48], TBI can lead to chronic health conditions that persist across the lifespan [12, 13, 48]. The impact of injury on cognitive functioning and mental health, in particular, can lead to decreased social connectedness due to challenges communicating with others and maintaining and building relationships [16, 51, 69]. As a survivor of TBI said: *"Brain injury is a minimizer. It makes the world a lot smaller for a lot of folks. Many folks with brain injuries can't drive. Many are not ambulatory at all. There are a lot of us that are dual diagnosed with TBI and PTSD (post-traumatic stress disorder), which means going out in crowds can be absolutely terrifying and overwhelming."*

These challenges have the potential to reduce the number and intimacy of social contacts, which can cause feelings of isolation and depression [5, 55]. Although there is hope that survivors can recover through therapy, medical treatment, and time [29, 53], the concept of recovery implies returning to pre-injury functioning, including resuming prior patterns of social activity. Some literatures examine social activity through a lens of psychosocial recovery, which assesses social interaction in interpersonal relationships, employment, and independent living skills [19, 51, 54]. Through this perspective, a survivor's social recovery is defined clinically by a series of outcome measures (e.g., frequency of social interactions outside of the home) with their life before injury as a baseline [67]. This places the burden of recovery on the survivor, neglects the larger social context in which this individual exists and interacts, and presents a survivor's prior social life as a point of comparison to 'measure' recovery.

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In contrast to this view, we articulate the concept of *social re-emergence* as the process through which individuals reassemble and negotiate their social lives following a significant health event. Social re-emergence is a nonlinear process of developing a new social identity where individuals may withdraw from social life, develop goals for social participation, disclose health information for social support and acceptance, and attain social independence. Regaining social life after TBI involves navigating functional communication challenges and social situations set against a backdrop of stigmatized and potentially invisible health conditions (e.g., cognitive impairment, depression). Survivors participate "in the capacity" that they can and carefully manage disclosure of their experience. However, interactions with caregivers and social contacts assuming caregiving duties can disempower survivors and their goals for social independence. The notion of social re-emergence reveals several tensions that play out in the online and offline lives of individuals with TBI, specifically: social life is a force that pushes and pulls on wellbeing; social support requires balancing disclosure of health-related information with stigma and social acceptance; and social interaction involves power dynamics between survivors and others within their social ecosystem. These tensions highlight design considerations for technology aimed at supporting recovery and a process of social re-emergence for individuals with TBI.

RELATED WORK

Analyzing the experience of individuals with TBI joins and extends literatures on how people use technology to manage health conditions and how people negotiate online interaction in the context of health and recovery.

Living with Chronic Health Conditions

A growing body of literature examines the ways in which technology can support the experience of living with chronic health conditions and surviving various health events. This literature emphasizes understanding an individual as a person rather than a patient [45, 46] and creating information systems that position the individual at the center [61]. There is also a growing awareness of the broader social context in which health management occurs. For example, Park and Chen [58] describe migraine management as involving communication with family, friends, and coworkers through a process of social recognition and assistance during migraine episodes. The unpredictable but recurring nature of migraines, in which individuals must identify and then call attention to their condition, parallels the experience of some individuals with TBI, many of whom also experience chronic health conditions that interfere with day-to-day living [12]. Further, apart from very young children, older adolescents and young adults (i.e., ages fifteen to twenty-four years old) are most likely to sustain a TBI resulting in an emergency department visit [22]. Many of these survivors may still live with their parents or move back in with parents or other family members following injury. Managing chronic conditions in the context of a parent-child caregiving relationship presents challenges to how care is negotiated and how parents empower their adult children to be an active participant in their care [25].

Online Interaction and Health and Recovery

Interacting online, often through online groups and forums, is a way in which people experiencing chronic conditions and recovering from health events share experiences and information, discuss symptoms, seek resources, and connect [26, 28, 41, 44, 66]. Though people are engaging in online activity associated with their health conditions, these interactions tend to remain separate from social interactions on other popular platforms (e.g., Facebook, Twitter). While individuals may be hesitant to share health information online due to the potentially public nature of many social platforms [57], sharing on Facebook groups can assuage privacy concerns for some (e.g., new mothers [23]). Newman et al. explain that some people want to share information about their health online to connect with others and seek social support, but that posting this information conflicts with impression management goals [52]. Specifically, people often manage how certain audiences perceive them by selectively sharing information and attempting to regulate what others share [17, 36, 40].

Issues of social support and online disclosure become more complex in the case of highly sensitive or stigmatized health issues, such as mental health (e.g., depression, anxiety). Understanding online interactions involving individuals with mental health conditions is a growing topic of interest. While some researchers question whether disclosure of these conditions on social media is aimed at seeking support or "[promoting] dangerous actions" [7], others raise awareness of the stigma associated with mental health and suggest we focus on mental wellbeing as a holistic approach to understanding and designing for mental health conditions [70]. Mental wellbeing can be affected by TBI [33, 38, 65], and the present paper helps fill some of the gaps around how and why individuals seek social support while negotiating disclosure of sensitive and potentially stigmatizing experiences.

Technology for Individuals with TBI

Limited prior work within HCI addresses the unique experience of individuals with TBI, and the work that does exist focuses predominantly on functional challenges following TBI. For instance, researchers have designed applications to support cognitive impairment associated with TBI (e.g., memory loss, planning, problem solving) in the form of an activity planner that helps individuals, with support from a caregiver, plan and track activities [43]. Others have examined the adoption of smartphone reminder applications among individuals with brain injury, noting issues of social acceptability [30]. Putnam and colleagues examined games to motivate individuals with brain injury to engage in rehabilitation tasks [10, 62]. Still other work involves interactive learning simulators to help teenagers gain empathy and understanding toward parents who have TBI [20]. Adjacent literature to TBI understands the role of technology in stroke recovery, including functional rehabilitation [1], augmentative communication [60], and the wider social context in which rehabilitation occurs [2].

While related work has focused on physical and cognitive rehabilitation associated with TBI and stroke, far less is known about the role of technology in social aspects of recovery. Scholars in related disciplines present technology as a way of helping promote social interaction following TBI [71], and a review of the literature found that usage of social media by survivors is associated with reduced feelings of social isolation [5]. However, these researchers also note many remaining questions, including how people with TBI use social media and the role of online interaction in rehabilitation.

METHOD

We conducted semi-structured interviews with 14 adults with TBI (ages 22–65; *M*=44 years; 7 female), three informal caregivers, and two social contacts (i.e., a friend and a family member not taking on primary caregiving duties) of adults with TBI (ages 25–38; *M*=30 years; 3 female). Additionally, we conducted informal interviews with four clinicians who provide services for individuals with TBI (3 speech-language pathologists, 1 occupational therapist). Clinician interviews informed the design of our study and were not included in formal data analysis. Our goal of incorporating this diversity of stakeholders is to understand the sociotechnical system surrounding survivors from multiple perspectives, experiences, and values. We distinguish between caregivers and social contacts to describe differences between individuals providing primary assistive support and individuals who may provide support in social contexts. The inclusion of these individuals is not to invalidate survivors' experiences. These perspectives demonstrate how interpretations of survivors' social lives may conflict with actual survivor perspectives.

Fifteen of the 19 adults with TBI spoken to or about had been injured in a motor vehicle accident; others sustained TBI during falls or athletic accidents. At the time of diagnosis, injury severity included mild to severe TBI [32]. This diversity may account for dissimilarities between our study and others involving individuals with TBI, which often focus on survivors of severe TBI and report reduced social activity [18, 68]. Participants were recruited using websites, such as Craigslist, forums, and personal blogs or websites, and the research team's interpersonal connections. Due to the broad nature of our online advertisements, we provided a series of screening questions prior to scheduling an interview. All participants self-reported mild or moderate TBI at the time of the study and were able to consent independently.

Interviews were conducted in person, over the phone, and through text-based mediums (i.e., email and instant messaging). We incorporated remote methods of interviewing (i.e., phone and text) to extend the reach of the study, in particular for individuals who did not feel comfortable meeting in person or communicating verbally. We developed interview questions by drawing from relevant literature and input from clinicians informing our research. Our interview protocol focused on the short- and long-term impacts of TBI, the recovery process, and stigma associated with brain injury. We also asked participants about their use of technology and interaction on social network sites and online forums. For in-person interviews, we asked participants to show and discuss their social media usage. In-person and phone interviews lasted approximately an hour and participants received $30 in appreciation of their time. We audio recorded and transcribed all interviews for data analysis.

Data Analysis

Our process of data analysis followed a constructivist grounded theory approach [8]. We developed emergent themes through iterative coding, memo writing, and constant comparison of data to our emerging concepts. Our research team frequently discussed emergent concepts and iteratively revised the interview protocol to delve into areas needing conceptual refinement. Our analysis focuses on the experience of individuals with TBI and their social contacts but draws on insights from clinicians as a way of further understanding TBI and the process of recovery. Throughout our analysis, we reflected on the ways in which TBI, which is typically defined as a health event, resembled the long-term nature of chronic conditions [12, 48]. We viewed recovery as a continuous, non-linear process rather than a state periodically assessed through surveyable outcomes [4, 15, 34, 74]. Additionally, we use the word "survivors" to refer to adults with TBI, which is common terminology among participants and community advocates. In place of participants' actual names, we use S*x* to refer to survivors, C*x* to refer to caregivers, and SC*x* to refer to social contacts.

FINDINGS

We briefly describe participant experiences to give a sense of the diverse and complex nature of TBI. Some survivors, such as S1, "*went to an urgent care the next day"* or a few days following injury; others were *"rushed by an ambulance… to the nearest trauma center,"* as S2 described. Time spent at hospitals and rehabilitation centers varied with injury severity. Some survivors were *"instantly knocked into a coma,"* such as S3, and remained in a hospital for weeks, while others were *"in and out the same day,"* as S2 commented.

Survivors described the impacts of TBI as reaching across physical, cognitive, and mental health aspects of wellbeing. Physical impacts included difficulty with verbal communication, walking, and sleeping, as well as visual sensitivities (such as to bright light), fatigue, and chronic pain. S4, a retired police officer injured while on active duty, *"couldn't walk, couldn't feed myself, all that good stuff,"* and S3 described a *"separated left shoulder…broken* *clavicle, nose, and cheek."* Many participants received therapy services to address these aspects of injury. In our sample, survivors of severe TBI were most likely to have long-lasting physical impacts, such as motor and verbal impairments. Survivors also discussed cognitive changes following injury; particularly changes to executive functioning and memory loss. S5, a survivor of severe TBI and former professional baseball player, described a slow ascent back to awareness: *"I didn't remember anything until about [a month after the accident]. I came to standing in front of a mirror… I came out of darkness through a fog."* Injury also impacted mental health. S6 described an increase in anxiety and depression: *"My anxiety and depression, they were bad. They weren't that great before, but now they're off the charts."* Many described a sense of not knowing when, if ever, they would fully recover.

Recovery from TBI does not necessarily occur linearly [13] nor have a definitive end destination or plateau [12, 48]. Participants shared how the impact of their TBI changed over time, and not always for the better. Describing TBI as "devastating," S6 mentioned how *"new things (symptoms) come and go all the time. It's terrifying."* Similarly, S2, who was injured while cycling, shared, *"Two months after the accident I lost my ability to read. I couldn't recognize text and characters anymore."* Focusing on healing physically, S7, a student injured while studying abroad, only *"started noticing I was going through some emotional phases, like deep depression and anxiety, and stuff that I'd never, ever felt before"* months following injury.

The changing symptoms following TBI impact all facets of survivors' lives, from coursework and careers to relationships. Across these experiences, we uncovered a complex and nuanced picture of the social lives of individuals following injury. Below we analyze how survivors navigate their experience in a social context and attempt to regain social life – particularly with respect to the role of technology – as well as how their social contacts and caregivers participate in this process.

An Active Process of Social Withdrawal

Following TBI, many of our participants experienced an abrupt disturbance to their daily routines. One significant change participants described involved a period of social withdrawal. For some, social withdrawal was necessitated by injuries requiring lengthy hospital stays or rehabilitation. Survivors, particularly of severe TBI, remained in hospitals, rehabilitation centers, or their homes until they reached a point of functional independence – which was months or years after their injury or, for some, indefinitely. We found similar patterns of social withdrawal among survivors not requiring the same extent of functional recovery. A week following a fall that resulted in mild TBI S8 "*stayed home the whole time. Just feeling exhausted really quickly."* Similarly, S7, another survivor of mild TBI, felt *"incapacitated for about a whole month. I couldn't leave the house. You know – black eye – and it was really ugly."* Withdrawing to the home was based on the need for physical recovery as well as social privacy regarding injury and social familiarity regarding environment.

Out of necessity and choice, survivors described being unable to attend school, work, or other events providing social opportunities. For many individuals – particularly those with mild TBI – withdrawal was an active process motivated by mindfulness around recovery. Participants described new perspectives regarding social interaction and a reprioritization of other aspects of life over social activities. S3, a survivor of severe TBI, talked about his decision to socially withdraw by describing how he *"wanted to focus on 'me' for a while, and then begin rebuilding my life outside of that."* S9, another survivor, described, *"Time is very important to me…therefore I like to make sure that my time is used in ways that will benefit me or others. I generally don't like to just 'hang out'. I don't feel this is…productive…"* S7 also explained:

> *"I've been focusing on school, and I've been focusing on different parts of my life. Before…I was able to have a social life; take pictures with people, and then post it. But, then, I would still get my school stuff done. Now, I'm really just focusing on one area of my life that I'm trying to get better, instead of trying to balance everything."*

Others can interpret turning inward as disinterest in social interaction. C1 described how her brother *"didn't want to be bothered with anybody."* She suggested that his feelings may have been compounded by insecurities around physical and speech impairments. Another family member, SC1, discussed her brother's decreased social drive, describing how he would sometimes speak with friends online, *"but when it comes to face-to-face, I don't know. But he just doesn't do it."* SC1 perceived her brother's withdrawal from face-to-face interactions as an ambiguous decline in social activity. However, survivors may choose to intentionally limit their own social interaction. S8, injured while training for a marathon, discussed going *"home versus [going] out…to just make sure that I was able to rest my eyes and my brain."* S1 also finds opportunities to disengage from social situations while in them: *"I would go out to dinner with friends and suddenly I just couldn't function. I'd just be like, 'Sorry… I just need to kind of shut down for a bit.'"*

While some survivors actively disengage from social interaction following injury, others described a slow awareness of changes in their social life. S10 said, *"It was just an isolating kind of time. It seemed like the world around me had changed. It took me easily a year before I really recognized that it was me who had changed."* For some participants, this led to decreased effort at relationship maintenance. S10 described how many of her relationships languished, and she found herself with fewer social contacts and opportunities for interaction. Further, other survivors described the impact of memory loss on their ability to recall prior social behavior. S11 noted that social contacts perceived differences in her behavior, though she did not: *"People would…say, 'Well, that's not how you were before.' 'Oh, I miss the old you' or 'I like the new you.'"*

In addition to these in-person contexts, tensions between survivors' 'old' social lives and present experiences contributed to social withdrawal in online settings. S3 *"quit Facebook…for over a year. I had things I wanted to accomplish and it was only distracting me with a bunch of crap I didn't care about anymore from my 'old' life."* SC1 also described how her brother was offline for several months: *"When he came back home, he was still adjusting. It took some months to start getting back into that type of stuff (social media).*"

Survivors may face challenges regaining their social lives following social withdrawal. S3 explained, *"I'm trying to work on [my social life] currently. Nobody is going to give me a social life. I have to go and 'take' it."* Going and taking it, however, often requires that survivors work toward regaining functional communication and understanding nonverbal social nuances (i.e., body language), which can be affected by TBI [49, 50].

Regaining Social Communication and Participation

Interacting in social situations, both in person and online, following TBI can present many challenges. In terms of face-to-face communication, survivors in our study described struggling with memory and attention, which introduced challenges to social communication such as maintaining conversation and applying information from previous conversations to new ones. S5 described his experience with memory loss; saying, *"When I was going through…memory loss my friends would come over and I couldn't remember their name… The harder I tried to remember their name, the more impossible it was."* S9 also wrote about his long-term memory loss: *"When I woke up from the coma I had forgotten who my mother was. I also had forgotten my other family members."* Though not severely impacted by memory impairment, S7 also noted challenges to maintaining focus in conversation.

Environmental factors, such as fluorescent lighting and ambient noise, can also present challenges to communication in certain social contexts. S9 explained his difficulty focusing on conversation while in crowds: *"There is much more sensory stimulation that my brain has to handle and process. This makes it more difficult for me…*" He also succinctly described his preference for quiet locations and small-scale interactions: *"I prefer to keep the sensory stimulation to a minimum."*

Survivors also discussed reduced confidence in face-to-face social interactions due to stigma associated with physical and communicative impairments. S3 described speech production challenges; saying, *"I've noticed that I can be the 'silent type' now. I am too self-conscious, especially about my speech, and I get reluctant to make conversation."* Similarly, C1 said of her brother: "*When we're in public he doesn't really talk as much, 'cause it still bothers him that he has the impediment, even though it's not bad… It's obvious when you have a speech impediment or you're walking with a cane and you're only seventeen. Those type of things bothered him.*"

Further, communicative challenges can be unrelated to speech production and memory. S9 explained social pressure to spontaneously react with an appropriate emotional response. Speaking about his post-injury emotional lability, which has impacted his ability to "control" his emotions, he said, "*I sometimes feel embarrassed – especially [if I become angry] in a public setting like a movie theatre*."

Regaining social participation is a process that occurs in stages. S3 feels comfortable speaking with friends and family, but is still "*trying to get out of my little bubble with strangers… That all just comes down to self-confidence…and that's coming.*" When survivors feel ready to re-enter social life, they participate "in the capacity" that they can, S8 explained. This involves creating communication strategies and reconfiguring social expectations around their participation. For example, some participants need to take breaks cognitively, even when out with friends, and have strategies for "shutting down" temporarily, as S1 described. Others discussed using notecards to support their memory and engagement in face-to-face situations. S9 described how these situations are less difficult when he can prepare responses in advance and has familiarity with whom he is speaking. He also *"[writes] things down for future reference and then [tries] to memorize appropriate responses for different situations and settings,"* such as responses to questions about weekend activities. S10, with help from her partner, *"had two reminders that we would use to remind me to at least pretend [to use social cues], so that I could make eye-contact, sit up straight. So, it looked like I was paying attention, even if I didn't have the energy…"*

Survivors also described adapting technology to support their social communication needs. For example, S9 takes to his blog and to email, which allow for revision and reflection before contributing to a conversation. Additionally, S9 explained how in written communication *"there is generally a communication trail that I can refer to that helps me remember what was discussed. This greatly reduces the possibility of me feeling embarrassed and self-conscious."* S3, who also described verbal communication challenges, frequently uses text messaging when he wants to be easily understood – often during negatively charged social interactions. He explained, *"When I'm excited or angry I become near incomprehensible. [Using text], I can get sentences out a whole lot more fluently…"*

In addition to using technology to communicate effectively, survivors use technology to seek online social spaces in which they feel accepted and comfortable. S3 described feeling comfortable online because *"I don't feel like anyone* *would know I'm disabled unless I told them… I just hate being disabled, but…I'm stuck with it, so I'm trying to make the best of it."* Similarly, C1 explained that *"social media was helpful"* for her brother *"because he didn't have to have face-to-face interaction. I think that's what was easier for him in a sense because he didn't feel judged.*"

Some survivors found online TBI forums and support groups helpful in providing resources and acting as a safe space for accessing and regaining social interaction. C1's brother used forums to regain comfort interacting with others, particularly those who shared similar experiences. Some survivors, however, described TBI forums as challenging due to the diverse experience of living with TBI. Further, S6, a survivor of severe TBI, described online TBI groups as "depressing after a while" and as "dead ends." He explained, "*Nobody got better. Or you would see new people with concussions come and go as they got better, and you'd just get depressed."* His experience with irregular activity on TBI forums also presented challenges to building and maintaining relationships. *"There are some [people] that are regular, but not regular in the way that you chat back and forth. People leave a post and run."* He turned to political forms as a source of social interaction; saying, *"I've made friends. If it wasn't for those boys, if it wasn't for chat boards to give me some company – I made a few friends off of them – who knows where I'd be?"*

We learned that survivors relying heavily on online communities for social interaction may feel unsatisfied with the medium of their primary social activity. S3 explained, *"Online interactions are sorta social in my eyes. It's social, but social-ness you can do in your PJs."* Further, some caregivers and social contacts described how they provided social opportunities for survivors. *"We invite them over,"* SC1 emphasized when speaking about her brother's friends. Transportation was a key barrier to face-to-face social interaction for several participants. SC2 explained, *"If [survivor] wants to come to my house, he cannot drive by himself. His mom has to drive him."* S3 also described how his lack of a car limits social opportunities: *"I've had very little in the way of a social life since my accident, I've become a loner without trying."* He continued, *"When [my friends] can hang out they do not want to come and shuttle me…"* Therefore, online social interactions, although perceived as less social than "getting out of the house," are an important aspect of survivors' social lives as a whole.

Managing Disclosure for Support and Acceptance

Given the complexity of injury and recovery, survivors have an abrupt influx of health information to manage following TBI. In addition to formal medical settings, information management occurs in a variety of social contexts. Survivors may share explicit experiences, raise general awareness, and excuse behavior perceived as socially inappropriate. Survivors are mindful about the perception of their injury, and carefully consider the impact of stigma prior to sharing experiences and disclosing information. For example, survivors described disclosing information in face-to-face social contexts to raise awareness and gain support. S12 explained: "*I don't have any problem telling people that I have a TBI… I definitely emphasize that it's definitely a silent disability. It's one of those things that people can't see…but…impacts your life the same way being an amputee can….*"

Similarly, S10 talked about disclosing health information *"because there are flukes about me. Quirks that otherwise look odd… It's better for people to know."* S12 mentioned that she does act differently *"as far as the way I think about things and approach things,"* but wants her social contacts to be aware that *"people can still be normal even though they've had a TBI."* Disclosure in face-to-face contexts may occur repeatedly if a survivor's injury is not visible. S7 talked about having to *"explain myself over and over again, because [my friends] do forget."* She described how *"they just think, 'Oh, the same old [S7] as before.' Well, yes and no. I am, but a lot has changed…"* Survivors may also disclose health information in face-to-face social contexts where they perceive an increase in the visibility of their injury. S4 described a time at the bank: *"I feel it's necessary to tell them that I have a brain injury, so they don't think I'm just stupid or something."* S2 described a similar impulse to increase awareness: "*I wish there were times that I had a t-shirt…that said, 'You know I'm handicapped'… So that when I'm…trying to remember…my four-digit pin…you might be a little bit more patient…"*

Survivors also described feeling comfortable sharing experiences with other survivors who, presumably, have an intimate understanding of the impact of TBI. S8 connected with a former educator upon learning they had a shared experience through TBI. *"She would kind of be the resource of the emotional; [the] friend resource of someone who's gone through it,"* she explained. *"She understood the severity of it."* Support groups also offer in-person spaces where survivors can connect to share experiences and receive support. S2 described his first support group experience: *"It was the very first time I didn't feel alone. It was just an amazingly cathartic, emotionally overwhelming, emotionally validating experience… And the challenge that we faced is we only saw each other once a month. So, I started a smaller Facebook group.*"

Brain injury online support groups and forums offer additional opportunities for survivors to seek and share experiences; although they do not necessarily portend social connection or relationship building. S12 talked about losing her *"sense of smell, which has been the most depressing long-term effect of the TBI"* and looking *"for people on Reddit with that similar problem."* In addition to seeking symptom-specific experiences, survivors may join online communities to connect with others who share a similar recovery experience. C1 explained how her brother and other survivors on a brain injury forum *"[bonded] over trying to do things or… Just talking about whatever…they* *say stuff like…'I used to be able to do this and now it's difficult.'"* Survivors may connect with other survivors on forums unrelated to brain injury. S6 described how, on a political forum, he *"joked…'What [do you expect] from me? I got a brain injury.' And somebody asked if it was true and…before you know it, you meet two or three people (with brain injuries)."* Survivors may also share experiences on forums or in groups "to help other people," as S12 explained, though this sharing may never be acknowledged. S2 explained, *"My experience has value, and I can use my experience within this social space to maybe lift somebody else higher; offer them hope."*

Participants described their disclosure practices in TBI communities as distinct from their behaviors on other social platforms, particularly platforms that include an audience of social peers without TBI [52]. C2 explained that his brother used to post a lot of pictures of himself on Facebook and Instagram, but now "*doesn't post pictures of himself at all. I think it's because he's just insecure about the way he looks…*" S7 described being *"very, very, very hesitant to [make an announcement regarding her injury on Facebook] because…I'm not a showy person. I don't do things for likes…"* In fact, announcing or calling specific attention to an injury on social platforms such as Facebook, Instagram, and Twitter was not common among participants, although some posted recovery-related status updates to reach a broad audience at a single time. SC1's brother, for example, *"every now and then"* will say *"'I'm doing fine.'… I think he does that because so many people try to talk to him about, 'How you doing?'"* Many survivors keep health information off their social media accounts due to the public nature of these platforms. S8 explained, "*I debated [posting an announcement] for a while… I just didn't want people probing. It was a very confusing and personal thing that happened to me."* She also talked about the expectation for responding to condolences: *"I didn't want a random person…[commenting] 'I'm worried about you'… How am I supposed to continuously update?"*

Mindfulness of health information disclosure to non-survivors also occurs in offline contexts. C1 described how her brother was *"starting to feel more comfortable"* talking about his injury in face-to-face situations. Similarly, C3 mentioned how her cousin told most people that *"he was 'busy,'"* but did disclose to a few closer friends that he was *"'having these health problems, so I'm taking a leave of absence.'"* Discussing stigma associated with brain injury, S7 said, *"sometimes [TBI] scares people away. Like, 'Oh, she's got problems'… I really [reserved] who I tell this to, 'cause not everyone needs to know things about my life."*

Attending to both the words and actions of others, survivors are mindful of how their brain injury is perceived in certain social contexts. For example, dating can introduce challenges to disclosure and acceptance. Speaking about the depression and anxiety she experienced following her brain injury, S7 said, *"I feel that that is kind of a taboo in society… A lot of guys think, 'Okay, girls are prone to being psycho girlfriends.'"* Additionally, prior to dating his current wife, S4 was acutely aware of how he could be perceived in a romantic situation: *"You're damaged goods. And who wants to marry somebody that's taking a lot of medicine and can't do anything?"*

Concern regarding support and acceptance impacts to whom survivors disclose health information and in which contexts they share this information. However, once information is disclosed, caregivers and social contacts may feel they have a right to act on it – often in ways conflicting with a survivor's preference for disclosure.

Negotiating Social Support and Independence

Many survivors described having supportive caregivers, social contacts, and strong support networks following injury. Talking about her friends, S7 explained, *"If they didn't wanna be my friends, they probably would have been gone a long time ago… They understand me, and I understand them, and we have a great time."* Similarly, SC2 discussed how *"[survivor's] still my friend, but it's really different"*; noting how his friend had changed following TBI. Further elaborating, he said, *"[Survivor] has a group of people that really care about him, and took care of him in his bad times."*

Caregivers often "pushed" survivors towards functional independence. S11 described how her mother did not have *"any limitation in what she felt that I would be able to do or what she felt I would be able to accomplish… It left me knowing that I could achieve more than the doctors were saying."* SC2 discussed how his friend's mom, who acted as his friend's primary caregiver, *"had to be in class with [survivor] at the same time"* because his friend would call professors inappropriate names. *"His mom had to say, '[Survivor], shut up. Control.'"* Support from caregivers may seem "tough." S10, a survivor, described her wife's approach to caregiving: *"You (survivors) never recognize that anything's wrong, and they don't advance. They don't improve. So, you need somebody who lets you burn dinner every night, but doesn't let you burn the house down."* However, achieving balance between support and independence is challenging [25].

Caregivers and social contacts may be supportive without knowing how to appropriately demonstrate that support to survivors. C1 expressed pride and enthusiasm over her brother's recovery, but disregarded his continued need for certain assistive technologies (e.g., speech-based text entry) by saying, *"He was always a little bit lazy."* Further, S6 described an aunt who *"thinks I'm a drug addict"* and *"stands by me for the wrong reasons."* When individuals are supportive of a survivor's recovery, they may *"want to help; they just don't know how,"* S5 explained. Many survivors discussed similar sentiments. S10 described how people's *"way of helping me out is to speak very loudly."* She finds these situations humorous, knowing "it's meant well," even if these actions are not actually helpful.

Caregivers and social contacts can act in unsupportive ways because they do not understand the long-lasting impact of TBI on cognitive functioning and mental health, particularly when physical symptoms are no longer apparent. S2 described how individuals have said, *"'You look normal. You sound kinda normal…it's just bullshit. You're just making it all up.'"*

The complex and potentially 'invisible' nature of brain injury further complicates how other people interpret and act on a survivor's need for support. While caregivers and social contacts may be well-intentioned, they may also act in ways that stifle social independence. C2 discussed his brother's new "behavioral issues" with his brother's employer: *"I said, 'If there's behavioral issues with him, please let us know immediately so we can address it.' Versus just letting him fly on anything."* Continuing, C2 explained how this disclosure resulted in his brother's employer limiting his brother's social interaction at work as a way of preventing inappropriate outbursts or socially aggressive behavior.

Survivors may feel that their caregivers and social contacts are infringing on their social independence as an adult. S3 described how his father *"is a little overprotective. I feel like he treats me like I'm a kid…because of my injury."* S1, a graduate student, described how, in the middle of a seminar, a professor inappropriately *"grabbed me by the arm and said, 'You really need to lie down…' She just took me to this [faculty] restroom."* SC2 talked about how *"[survivor's mom] usually just leaves him at my house, and you have a small kid with you. She tells me, 'You should not let him drink. Watch out with what he does. Let me know when to pick him up.'"* These instances illustrate the complex relationship between supporting and limiting a survivor's social interactions and, ultimately, their social independence.

As indicated in prior work [59], caregivers and social contacts may track and monitor the behavior of survivors. C3 described asking her cousin questions about his activities to *"get a sense of where he's going."* Tracking survivor behavior occurs in online spaces, as well. C2 talked about monitoring his brother's online activity by checking his Facebook feed to "*see what he's looking at…"* Specifically, he installed *"a parental control tracker, so you can monitor what he's been looking at… We haven't blocked any sites for him…it's just monitoring."*

Some survivors may not be aware of measures taken by their caregivers and social contacts. Others, however, described how these actions introduced tensions to relationships. Talking about how her mother had been granted "legal temporary guardianship," S11 described, *"When I realized that, I got really ticked off… I was twenty-one years old. There's no reason that my mother should be telling me what I can and can't do…"* S10, a survivor and professor of medicine, explained how her relationship with her wife was *"no longer equal partners. All of a sudden you've taken this marriage and you've turned it into a parent-child relationship."* She described resentment on both sides: *"You really have really horrid judgment [due to TBI], trust me, but that doesn't mean that you don't resent that someone else is telling you what to do. And they resent that they have to, and they resent the loss of relationship."*

Many of the caregivers and social contacts in our study also discussed these changing roles and relationship dynamics. C3 described how she was no longer *"just [survivor's] friend or cousin"* because of the duties she adopted following her cousin's accident. Similarly, C2 talked about how his relationship with his older brother had become *"like the relationship you have with your parents. They used to take care of you and, then when they get old, you end up taking care of them."*

Power dynamics created through changing roles played out in the ways caregivers and social contacts disclosed information about survivors or forced survivors to disclose information to others. C3 *"told [survivor] that he had to tell his best friend [about his injury]"* or she was going to disclose the information. Social contacts and caregivers may not only disclose information about a survivor's injury when it first occurs; they may update or remind others about it, often to excuse or apologize for behavior perceived as socially inappropriate. C2 described a time when his brother "was really upset" during a family gathering and acted in a manner that was perceived as inappropriate. C2 said, *"We talked to my uncle, and my grandparents, and…explained the situation. They knew that he had an accident…we just reminded them that a lot of [his behavior] is probably because of that."* SC2 talked about disclosing information about his friend online: "*If I had friends, [survivor] would add them on Facebook and talk to them on Facebook. And I'd tell them, 'He had a brain injury and he might say weird stuff.. If you don't want to talk to him, you don't have to talk to him.'*"

Similarly, S11 mentioned a time when her mother told another individual, *"'Oh, don't pay attention to [survivor]. She just had a brain injury; she doesn't know what she's talking about.'"* As these examples illustrate, some caregivers and social contacts disclose information in ways that further highlight stigma associated with TBI in an attempt to excuse and normalize a survivor's social behavior. This disclosure may be related to stigma-by-association, in which individuals feel implicated by the disability and mental health of another [56].

As survivors regain independence, the need for assistance and support from caregivers and social contacts may change. Power dynamics, however, may transition more slowly. While some relationships get "much better" with time, as C1 explained, others remain tense or damaged by the abrupt transition from social equal to an individual involved or implicated in the social care of another. C3 described *"periods where [survivor] hasn't been talking to me for a couple days, because he sussed out that I was* *intruding,"* even though that has not been the case recently. Trust can also be difficult to regain for survivors. S10 talked about how rebuilding trust was "a slow transition." Her family *"need[ed] the help of outside people to help them recognize what some of [my] strengths are, and what some of [my] achievements are."* Yet, sometimes relationships are unsalvageable. S6 felt abandoned by many of his friends: *"Forget most friends, period. Everything's gone when you get a brain injury. Nobody can understand and everybody walks away, except for family, and [my partner], and my cat."*

Social contacts and caregivers may have difficulty understanding the lasting impact of TBI, further contributing to relationship tensions emerging throughout recovery. Survivors may actively assess the benefits of others' support and the ways in which this support can conflict with re-entering social life, including managing disclosure of their personal experience in tandem with the complications of a lifelong health condition.

DISCUSSION

Recovery from significant health events can drastically impact all aspects of an individual's health and wellbeing. While related studies understand social interaction for survivors in specific contexts (e.g., employment [73], conversation [49]) and assess recovery by measuring social outcomes (e.g., frequency of interactions [4, 74]), our analysis illustrates social life as far more nuanced. We offer the concept of social re-emergence as a way of understanding the complex process of social interaction in the context of recovery and symptom management following TBI. Our analysis uncovers social interactions between survivors and family members, friends, and colleagues in informal caregiving roles and contexts. Survivors must negotiate these relationships in offline and online contexts while progressing toward recovery and independence. Further, we describe social re-emergence as an individual process that reveals tensions between various facets of social life and wellbeing. We discuss these tensions below and then reflect on how the concept of social re-emergence informs technology design.

Social Life Pushes and Pulls on Wellbeing

Some recent TBI literature references the positive nature of social support during recovery and rehabilitation [14, 35]. Similarly, a growing body of work within HCI views technology as a way of providing social support during recovery and management of health conditions [24, 26, 27]. Discussions of social support, however, rarely consider how social life can be both a positive *and* negative force on recovery. As a nonlinear process, social re-emergence supports ebbs and flows in social life, including survivors' active engagement in social withdrawal as part of their broader recovery. Social withdrawal may involve spending extended periods of time at home, "shutting down" while out with friends, or temporarily leaving social media. The act of turning inward may not be indicative of a decreased social drive; rather, it may indicate that survivors need time and privacy to tend to their health and wellbeing.

When changes due to TBI are not readily visible (e.g., cognitive fatigue, memory loss, anxiety) caregivers and social contacts may not understand a survivor's needs regarding social interaction. Others may misinterpret an individual's choice to withdraw and attempt to encourage, facilitate, or even force a survivor into social situations based on that individual's previous patterns of social activity. These actions, though often well-intended, may be at odds with survivors' own goals for participation. A focus on social re-emergence rather than recovery helps counter the comparison between a survivor's past and present social self, and, as part of an ongoing process, enables survivors to re-emerge to social life with a new sensitivity towards interaction in terms of how they are perceived, their unique needs for communication (e.g., prompting memory, social cueing), and their goals for social participation.

Seeking Social Support

While some survivors described feeling self-conscious about their physical appearance following injury (e.g., black eyes, scarring, using a cane to walk), many also described experiencing stigma and challenges to social acceptance regarding *invisible* disabilities (i.e., cognitive impairment and mental health), many of which can persist long after physical symptoms diminish. Throughout the process of social re-emergence, survivors weigh the benefits of disclosure for social support with stigma associated with brain injury. Survivors described disclosing their experiences through online forums and in-person encounters to raise awareness about TBI, self-advocate, and gain social support and acceptance. However, health information disclosure may also involve normalizing actions perceived as discrepant from previous social interactions or from socially normative behavior when survivors perceive their injury has become visible (e.g., feeling they have said something "stupid").

Some survivors may not disclose health information or may limit what they share, particularly with social contacts met post-injury. Given the prominence TBI has in many survivors' lives, individuals want to be perceived as more than just "a brain-injured person." Social re-emergence may involve navigating disclosure to minimize injury as a new social identity develops. Stigma adds a new dimension to the disclosure process for survivors; it does so, as well, for their caregivers and social contacts.

Power Dynamics in Social Interaction

Our analysis of social life following TBI revealed complex power dynamics that survivors navigated as part of the process of social re-emergence. Despite a survivor's effort to carefully manage sharing their experience, we learned that caregivers and social contacts often overstepped boundaries and threatened privacy by disclosing information about a survivor's condition to others in their social network. These actions can conflict with how the survivor chooses to manage disclosure in the context of stigma and social support (e.g., being forced to tell a best friend). Additionally, caregivers and social contacts did not always disclose information that was supportive or empowering of a survivor. Some forms of disclosure trivialized or entirely rejected the survivor's experience.

Caregivers and social contacts sometimes acted in ways that impeded a survivor's ability to regain social independence, despite intending to support and protect survivors. The transition from parent, spouse, sibling, or social peer to a caregiving role, even in strictly social contexts, presents complex challenges [9, 11, 25]. However, from the survivor's perspective, social re-emergence involves negotiating these relational changes in a broader social context, and tensions can arise when survivors begin to seek independence in their social life. Many social contacts beyond caregivers were implicated in social-facing caregiving behaviors, such as monitoring a survivor's whereabouts, activity at a party, or computer use (similar to [59]). Therefore, a survivor's social contacts may attempt to protect and support the individual, while stifling the survivor's ability to regain social independence.

Designing for Social Re-Emergence

The concept of social re-emergence questions the assumption that social interaction is an inherently positive force on recovery. HCI research and design tend to view social interaction related to health and recovery from this perspective, though some recent research calls into question the impact of social media use on wellbeing [6, 7]. Survivors negotiate their social lives in nonlinear ways (i.e., social withdrawal) that may be viewed as apathy or inconsistency by others. While abstaining from social media has been connected to religious observance or seeking a healthy lifestyle [64], we find that similar behaviors also occur as part of the broader recovery process. Technology that pushes social interaction on survivors without understanding their idiosyncratic needs could pose additional stressors and distract from the recovery process. For example, user-retention features among many social platforms (e.g., email notifications of social updates) encourage people to re-engage with aspects of social life through the platform, and may be harmful to survivors actively engaging in social withdrawal.

Social re-emergence accepts that a survivor's network and patterns of social activity may never return to what they were previously; nor is that the goal. The concept of social re-emergence suggests refinement of the social self in both online and offline contexts [72]. System design could support the shifting social needs of survivors by allowing users to reconfigure their social network relationships and privacy settings in ways that suit their current goals for social participation (e.g., rehabilitation, dating) without necessarily reminding them of their past social life. Although social comparison often occurs in the context of others online [31], technologies that exploit a history of social interaction (e.g., Facebook On This Day feature) have the potential to invoke unproductive, and potentially distressing, comparisons with an individual's prior social life. Emphasizing events in the present over events from the past may help survivors develop appropriate, post-injury goals for social participation.

Further, in online contexts prone to context collapse [47], tensions also arise between seeking social support and needing to disclose potentially stigmatizing information about TBI. Survivors of TBI, however, are not alone in this experience; others with significant health conditions face tradeoffs between seeking social support and broadcasting a private experience to their social networks [52, 66]. Increased user control over social network organization and information accessibility is not the only way to address this challenge. Social re-emergence highlights a larger issue of systems being ill-equipped to support the negotiation of multiple goals for social participation within a singular platform and to adapt as these goals change throughout the course of a health condition.

In addition to designing for survivors, research in HCI should take into account the social ecosystem in which these individuals interact and exist. Particular design consideration should be paid to caregivers and social contacts who may be involved in a survivor's recovery process. Some research points to the importance of integrating caregiver observations of a survivor's mental health and subjective behaviors (e.g., personal hygiene) to inform treatment during recovery [3]. However, technology that promotes tracking survivor behavior without providing a means to modify this activity over time may invalidate a survivor's experience, introduce tensions to relationships, and present yet another obstacle to a survivor's ability to regain social independence.

CONCLUSION

TBI is a complex and diverse health event that can have lasting impacts on all aspects of a survivor's life. Survivors grapple with questions of when, if ever, they will recover, and experience a range of physical, cognitive, and mental health changes that impact their social lives. The notion of recovery in the context of social life misses the nuance of picking up the pieces and reconfiguring social interaction to support a new, post-injury reality. Underlying this process are challenges of navigating social situations with changed abilities and living with stigma associated with cognitive impairment and mental health conditions. While caregivers and social contacts try to help survivors regain social participation and independence – often by performing social-facing caregiving behaviors – they can invalidate a survivor's experience, and also experience associated stigma. There are many opportunities to design technology to support the dynamic and nonlinear process of social re-emergence. A sensitivity towards the experience of a renewed social self – rather than a return to an 'old' social life – is at the center of this issue.

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