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Title

Empowerment through choice: the interplay of choice and control after spinal cord or brain injury

Running Head

Empowerment through choice

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Abstract

Purpose

To gain knowledge of the early phase post-injury experiences related to choice and control for individuals living with acquired brain injury or spinal cord injury, as well as their caregivers.

Materials and Methods

A qualitative study was conducted to understand the experiences of individuals with acquired brain injury or spinal cord injury and their caregivers in the early phase post-injury, focusing on the aspects of choice and control. Nine individuals with acquired brain injury or spinal cord injury and four of their caregivers participated in semi-structured in-depth interviews, and the data was analysed using thematic analysis.

Results

Four themes emerged: 1) Passenger in the system, 2) Can't do it alone, 3) I want to improve, and 4) A new normal. A sense of empowerment or vulnerability may be influenced by participants' experiences of choice and control.

Conclusion

The study offers insights for healthcare professionals aiming to enhance the sense of choice and control for individuals living with acquired brain injury or spinal cord injury. An approach involving shared control and promoting choice, agency, and empowerment may positively influence post-injury experiences for these individuals.

Keywords: Choice, control, choice behaviour; recovery of function; neurological rehabilitation; patient participation

Introduction

Both spinal cord injury and acquired brain injury have a significant impact on a person's ability to participate in their life as they did before the injury (1). Especially in the early stages after injury, a person's participation may be adversely impacted by their ability to make choices and have control over aspects of their life due to the influence of personal, interpersonal, and environmental contexts (2). Choice has been defined as the opportunity to decide between two or more options, and can result in greater personal independence and control (3). Control has been described as the ability to influence an action or course of events(2, 4) (p.5). Specifically, the *ability* to control one's actions and their consequences is referred to as agency, while the *feeling* that one has control is known as a sense of agency (5). Supporting a person's agency occurs when the individual is empowered to understand the choices they want to make and take control of their own lives (6).

There is an emerging degree of understanding that people with acquired brain or spinal cord injuries can take control and make choices when they can find purpose, are assisted to express themself, are provided with learning and adapting opportunities, are supported to plan and prioritise, keep hope and have access to strong social networks and relationships (2, 7, 8). However, a review of the agency in people with a variety of movement disorders found that they often have a reduced sense of agency (9).

A spinal cord injury causes catastrophic physical incapacity and the resulting, loss of functional control can impact a person's sense of agency, choice, and autonomy (10). Spinal cord injuries can occur due to trauma from road traffic accidents, falls, or sporting accidents (11), as well as non-traumatic conditions such as tumours, degenerative and vascular conditions, infections, toxins, or birth defects (12). It is estimated that there are approximately 9 million cases of spinal cord injury globally (13). People who have suffered acquired brain injuries not only face functional limitations that affect their sense of agency,

but they may also experience additional cognitive impairments and more complex incapacities compared to the average person with disabilities (14). These challenges can have additional impacts on their ability to make choices and have control over their lives (14). Acquired brain injuries occur through damage to the brain after birth due to conditions such as stroke, traumatic brain injury, and other non-traumatic injuries like hypoxia and degenerative neurological disease (14). The worldwide incidence of traumatic brain injury is estimated to be 69 million (15) and people who survive traumatic brain injury make up over half of the population with acquired brain injury (14).

The impact of an acquired brain injury or a spinal cord injury is significant, affecting not only the life of the individual with the injury but also the lives of their informal caregivers (16). Informal caregivers are usually family or friends of the person with the injury (16) and find themselves supporting the decision making of the person they are caring for, while also needing to make their own complex decisions. Caregivers who feel in control of their choices tend to have higher levels of life satisfaction and well-being, while those with limited control may experience increased emotional stress and negative health outcomes (17). While caregivers usually have the personal capability to make decisions, their decision-making capacity can be influenced by organisational and contextual factors (18).

Previous research has focussed on the importance of choice and control for people with cancer (19) or older people (20, 21) with less work being done explicitly with people who have experienced an acquired brain injury or spinal cord injury. In a qualitative meta-synthesis of experiences of people with spinal cord injuries, it was found that they perceived their choices to be restricted due to their reliance on others (2). The capacity of people with spinal cord injuries to manage change and make choices was connected to their sense of control and their access to external resources, such as support and information (2). However, when support and information does provide the person with confidence to make their own

choices, control of decision-making is not always relinquished by health professionals to enable this (22). A qualitative systematic review and meta-synthesis exploring the perspectives of people following a brain injury found they experienced a struggle between their feelings of loss and how to start to regain control and become agents of their own choices (7). Research into caregiver choices indicates that they may be limited by a lack of information or the availability of viable options (17, 23). Caregivers can also experience constraints to exercising choice due to attitudes and practices of health professionals (18). In addition to the personal effects of acquired brain injury or spinal cord injury, people and their caregivers often experience barriers in taking control and making choices due to the policies and practices within the health service systems, particularly during the early stages of the injury (24). Within the health care context, literature and policies increasingly recognise that injured people can and should play an important part in the decision making and choice of their health care, with support as needed. Many labels have been given to this expectation including patient-centred care (25), collaborative care (26), shared decision making (26), informed choice (19), and patient empowerment (27). Government health services in many countries have developed strategies to facilitate a shift towards shared decision making within healthcare which in theory affords an individual choice and control over their healthcare. In the United Kingdom, government policy commits to shared decision making stating “no decision about me without me” (28)(p. 3). The Department of Health in Australia has developed guides for healthcare workers to support shared decision-making, for example, a guide for general practitioners to inform shared decision-making with patients at high risk of developing severe illness related to COVID-19 (29).

While there is a growing body of research into developing a greater understanding of how choice and control are experienced by different people, most of the work is in the aged care field. To address this gap in the literature, this study aimed to gain a greater understanding of

the impact on agency in the early phase after diagnosis on the perspectives of choice and control for people living with acquired brain injury or spinal cord injury and their caregivers. The research question was "How do people exercise choice and control in the early phase post acquired brain injury / spinal cord injury?"

Methods

We used a descriptive qualitative study design which is particularly suited to exploratory studies (30, 31) and exploring the subjective experience of individuals.

The researchers were either occupational therapists or physiotherapists with professional experience in rehabilitation and expertise in the use of qualitative research methodologies. The research team shared values and beliefs about client centered care that included listening to, empathizing with, and respecting client experience and perceptions. An advisory group comprising eight external members who represented industry and consumer groups met four times during the study to provide advice and feedback about recruitment, analysis, and dissemination. Prior to commencing the study, ethical approval was gained from the University of South Australia's Human Research Ethics Committee (Application ID: 0000035091). This research is reported to meet COnsolidated criteria for REporting Qualitative research (32).

Participants

Recruitment employed a purposive sampling strategy (30) seeking a diversity of experience regarding the type and severity of the injury. We also used a snowballing approach (31). Participants were recruited through local home support and advocacy organisations and snowball sampling from caregivers of participants with brain injury through posts on social media sites. People with acquired brain injury and/or spinal cord injury were included if they had transitioned to home from hospital and/or rehabilitation services within the last five years

(to assist with recalling their experience). Caregivers were also recruited to provide a source of data triangulation by participating in an individual interview or nominated by a participant with acquired brain injury / spinal cord injury to be present and participate in the same interview. Three caregivers had a connection with a participant included in the study. One caregiver provided care to a person living with SCI who was not included in this study (C1).

Data Collection

Semi-structured in-depth interviews were undertaken by MG [a female physiotherapist with a PhD, experience in qualitative research, and work experience in Gerontology and Rehabilitation for 13 years which included working with those living with an acquired brain injury or spinal cord injury] and a male research assistant [occupational therapist undertaking further study], in a place of the participant's choosing. They did not have a prior relationship with the participants. They established trust by introducing themselves by sharing their backgrounds, and ensuring participants could ask any questions before, or during the interview. The single interview was conducted with open and active listening, without judgement, and the pace was set so that the participant could freely tell their story. After gaining informed consent, including reading forms out loud to ensure they understood the purpose of the interview, the interview began with an invitation for the participant to share their story of how they came to have an acquired brain injury / spinal cord injury and the role of choice and control. The average interview duration was an hour and a half but ranged from 45 minutes to two hours. A particular focus of questions was on the practices of service providers that influenced the person's choice and control. Participants were asked to describe their experience of interactions with allied health and support workers and what that meant to their recovery from injury. The probing questions explored how the person's networks of family, friends, and services could enhance the person's ability to exercise choice and control. The interview guide was developed drawing on the literature on client autonomy, the

methodological literature, and the experience of the researchers [Appendix 1]. A semi-structured approach to the interview enabled the participant to share control over the interview process with the researcher (33). If the participant wished, a caregiver or family member was present to support the participant and assist the interviewer in understanding the participant's responses (with the participant's consent).

Thirteen participants engaged in an in-depth interview including two adults with spinal cord injury, five adults with brain injury, two adults with both brain injury and spinal cord injury, and four caregivers. No participants withdrew from the study. Participants were aged between 30 and 66 years, with most identifying as male and all caregivers identifying as female (Table 1). We followed Braun and Clarke [29] to determine whether we met data saturation by considering whether the detailed and rich accounts of the participants' experiences enabled an analysis that generated a shared meaning and themes that were common to all participants.

Data Analysis and Rigour

Interviews were digitally recorded, transcribed verbatim, and then analysed thematically following the approach outlined by Braun and Clarke (34). All transcripts were read through thoroughly several times by all authors. Coding was done manually with each line or section of a transcript assigned an analytical code in an open coding process, often using 'in vivo' codes. Coding was conducted by at least two authors and then discussed in regular meetings by the research team. Once all transcripts had been open coded, two authors took the lead on bringing like codes together and collapsing them into categories. Through an iterative process of constant comparison, the categories were formed by grouping similar codes. Categories were then examined by the whole research team and collapsed into themes thus arriving at a rich description of participants' perspectives on choice and control. Table 2 provides the coding tree. As the interviews were transcribed verbatim transcripts were not returned to participants to be read and provide feedback to reduce participant burden.

To ensure rigour and trustworthiness we drew on Lincoln and Guba's principles of credibility, confirmability, dependability, and transferability (35-38). Credibility was supported by the relationships built with participants and the use of the advisory group. The research team met frequently throughout the analysis stage to engage in reflexive discussions, discuss emerging themes from the interviews in the advisory committee meetings, and use reflexive writing, and debriefing notes to ensure that the data were interpreted appropriately. Confirmability was supported by triangulation of data from the three participant groups. Having multiple researchers and keeping an audit trail of analytic decisions made assured dependability (see Table 2). Transferability will be determined by the reader but is supported through the sampling strategy, detailed description of our study method, and rich description of findings supported by participant quotes.

Findings

The perspectives from participants with acquired brain injury / spinal cord injury as well as their caregivers aligned in four common key themes across the participants that describe the interaction between agency, control, and life choices: 1) passenger in the system; 2) can't do it alone; 3) I want to improve; and 4) a new normal. Over time, some participants remained in one experience, others experienced more than one, and others experienced one more than once. Even though the findings show there is a process of agency recovery that participants experience, the themes do not intend to describe a temporal linear path.

Quotes are provided as data to ground the findings in the experience of the participants. The quotes are identified by a 'P' indicating a participant with acquired brain injury or spinal cord injury, and a 'C' indicating a caregiver participant. The findings were homogenous with no difference established between the perspectives of people with acquired brain injury from those with a spinal cord injury or caregivers.

Our findings begin with a description of the dynamic interaction of agency, control, and life choices for a person after acquired brain injury or spinal cord injury. Participants described the three elements of agency, control, and choices as an experience of empowerment or vulnerability. Participants exercised their agency either passively or actively. Control was delegated, shared, negotiated, or accepted by participants. Participants referred to the concept of choice as it related to their experience of rehabilitation, or how they engaged in life. Participant 5 described how empowerment was constructed for her:

> "*It's very empowering [to be able to make those choices] … So, I have control, so when I'm at work I can choose the activities that I do … So, to me those choices of how I structure my workday is choices about rehabbing myself because I know that the more I do, the more I use my brain, the better it's going to get. … it makes me feel very empowered and much more in control of myself … I feel like I'm able to influence my future in a positive and informed manner, and also my psychological health is much, much better because I have that control."* [P5].

Agency was defined by participants as personal power that came from taking control.

> "*If I really want control, I just take it. I don't look to control anybody else, but I demand control for myself"* [P7].

The need to exert agency was stimulated by a sense of feeling vulnerable; the more vulnerable the participant felt, the more compelled they felt to exert a greater level of agency. Exercising agency ranged from delegating control to advocating for what they believed to be right.

Participants described control as an ability to influence events in their lives through the direct result of their actions, feelings, and choices.

"*I've got control, I haven't got control over my bowel, but I've got control over how I deal with it"* [P3].

People sought a level of control that was right for them, with some participants accepting a lack of control as this was easier than the effort required to exert agency. Participants reported that regaining control made them feel good, more normal, and calmer, while a lack of control created vulnerabilities with adverse health impacts such as increasing their anxiety.

> *"It's [control] very calming and soothing thing because when you don't have control there's a lot of anxiety and a lot of thought … of, not necessarily helpful thought going on … when you have control … it makes you feel better, it makes you be able to do things more easily, it makes you be able to think more clearly, makes you be able to deal with problems more easily as well."* [P5]

Participants recognised that the need to choose to reengage with the daily occupations of life was essential to giving them a sense of control over their health and their recovery.

> *"…engage back in life here, otherwise I'm just going to sit here and do not much … you do have to choose, what am I going to do? Where, how do you see this working out for you? Are you going to keep trying things and keep practicing or are you just going to sit here and just rock back and say, I'm, I'm done, I'm never going back to the shops, I'm never going back to work, I'm never going to drive a car."* [P1].

Participants described choices in relation to many aspects of their lives including how they interacted with health system staff, health care options, finances, where they lived, the type of work they did, their daily activities, and their relationships.

> *"If you've got choice, then that kind of leads on to control a bit because you've got a path that you can go down. So, I think one leads into another."* [P6].

Passenger in the system

Participants and their caregivers talked of their experience within institutional systems such as hospitals, rehabilitation, vehicle licensing, insurance, and return to work and described this experience as a vulnerable feeling of, "*you're a passenger through the system and you just go along with it"* [P5]. During the early phase of their experience, some participants consciously *delegated* their control over the immediate choices that needed to be made about finances and health care. This contrasted with participants who were passive and made no conscious efforts to exercise choice and control, were not well enough, or were not provided with opportunities to make choices.

Some participants and caregivers described feeling overwhelmingly powerless and at "*the whim*" [P2] of others. Being at the mercy of existing processes within health settings was described as *"like being at school"* [P1].

> "*I don't have control … with the professional staff that one time in ICU that I didn't feel that we were in control"* [C1].

Delegation of control to enable focus on recovery needed to be temporary so that as people began to recover, they could seek more active control over their choices. Even when ready to reclaim control, participants often found themselves expected to know things in an unfamiliar environment or make choices without having the full information, leaving them in a position of vulnerability and blind trust.

> *"From brain injury point of view, just trying to read documents, sign return to work plans while you actually can't see the words, and often there's nobody there to support you…that's really scary"* [P2].

Throughout the post injury time, access to resources was seen as critical to empowerment as noted by caregiver 2 that limited finances can constrain the amount of rehabilitation that can be accessed, "*Money gives you more options to be able to do things."* [C2]. The same

participant (caregiver 2) noted the short-term nature of the rehabilitation being offered and the potential influence of these resource limitations on recovery.

> *"Yeah, only for 10 weeks [rehabilitation] … even if you are making gains really. You don't really have the option to do any more"* [C2].

Can't do it alone

This theme encompassed the support needed from caregivers and health professionals for participants to have control and choice in their rehabilitation. Caregivers could support a person having a choice by giving choices where possible or advocating for others to provide an opportunity. Participants felt empowered by health professionals who were respectful and collaborative in their approach to the delivery of information and decision making. The initial delegation of control shifted as time passed. Some participants attempted to exert agency to *share* their control when they recognised they needed assistance but wanted to assume more responsibility over their choices, particularly around daily activities and the nature of the care they received.

> *"if it's something like a phone call … I have to rely on other people to make those calls for me, because otherwise what chance do I have?"* [P9]

This contrasted with participants who railed against external controls seeking a level of independence potentially outside of their capacity or remaining passive.

> *"when I made him those appointments, he was like oh everyone just tells me what to do and I think by cancelling in some ways he did that whole – you can't tell me what to do but knowing full well that he still had to follow it up but when he did, he did it in his way and his time*" [C4].

The tension between needing help and striving for greater autonomy often led to a necessity to manage emotional responses. Access to information and respectful collaborative relationships were important influences on how participants experienced a collaborative approach to care.

> *"Yeah, I put myself in control. When I was in hospital and I had – I call them my team and I told them this – I said you're my doctor; you're my physio; … you're my team so you've got to come to me and tell me all the information because you guys specialise in this area"* [P4].

Both participants who were people living with acquired brain injury or spinal cord injury and their caregivers recognised the need for good information to exercise agency and make effective choices to exert control. Knowledge of health and social support systems helped them to know the right questions to ask and who to approach for support.

> *"they talk about the knowledge being power, the couple of times where the couple of specialists did take the time to actually explain from A to Z and having an understanding of what all that meant, certainly made me feel a lot better, probably a little bit more in control"* [P1].

> *"They had good systems and protocols in place before you could even leave so you had the education and the understanding because you can't control everything now – it's not possible so I really think that the education and the understanding gives you that power to control what you can and know what you can't"* [C2].

Participants were keen for health professionals to respect their goals and opinions, even if considered risky. They wanted health professionals to treat them as individuals and allow them to make safe mistakes, which would help them learn.

"I said I think I'll walk; I'll climb Mount Everest. And I was probably at the time quite serious, but I knew it was impracticable, but [health professional] said 'okay, we'll start training'. But all the others were so risk averse, so that impacts on your choices" [P8].

I want to improve

As participants developed self-efficacy, they began to exert agency to *negotiate* for more control so they could exercise important choices over where they lived and the type of work they did. Other participants remained overwhelmed and passive in their exercise of agency, or some lacked the resources required to successfully negotiate for more control.

"I just want to put an email out saying I'm not going to be at work for a while … I managed to open it up and I just couldn't handle all the emails … get me out of here" [P6].

Opportunities offered with effective communication from health professionals empowered participants, enabling them to control the choices they made about how to adapt their routine and their activities to accommodate what they could and wanted to control. Sometimes participants took control and attempted activities that often resulted in them learning more about what they could tolerate and the limits of their current abilities.

"I want to improve; I realise that it's going to take a lot more time than I thought it was going to take …but hey it's my choice, my life, I want to improve" [P9].

Participants appreciated being given opportunities to test their abilities, but often, they made these choices independently of rehabilitation; sometimes going against the advice they were given.

313 *"I couldn't understand, why can't I use … powered equipment I'm sure I can use*
314 *powered equipment. So, I got a circular saw out and cut through the cord. Ooh that's*
315 *why you shouldn't use powered equipment"* [P1].

316 Some participants requested opportunities to work with health professionals to decide what
317 they could and could not attempt within their abilities rather than having this imposed on
318 them.

319 *"I'm not interested in using a full walker… I know I'm faster … on the full walker but*
320 *that's not what I want; I want to walk with the canes … and I just say, 'I'm not doing*
321 *the walker'"* [P9].

322 Communication ability was recognised as an essential element of effective negotiation for a
323 positive experience of choice and control. In particular, efforts made by others to help the
324 person overcome communication impairments provided a sense of agency.

325 *"…just having an allied advocate with understanding … it's a voice. At, at least it's a*
326 *voice and for people with severe apraxia from the brain injury or for people with just*
327 *a general communication problem it's a voice, as I just, I don't mean that a physical*
328 *voice, I mean metaphorical voice."* [P8].

329 Caregivers played an important role in gathering information about the injury and the
330 rehabilitation system to support the participant having choice in the rehabilitation process.

331 *"So, we had to source our, get other opinions and stuff and yeah basically that's what*
332 *we did but I think that's what needs to be part and parcel with the peer support.*
333 *Continually tell whoever they're visiting you need to ask questions. You're not sure,*
334 *ask me I'll go and sort it out"* [C1].

A new normal

Participants experienced a significant loss of their old selves after their injury but had begun to understand who they had become and how they fit into their community. Through getting to know their new identity and abilities, they were able to focus on what was individually meaningful for them to control. This contrasted with participants who continued to have negative experiences despite their efforts to actively exercise choice and control, or participants who remained passive and did not exercise their agency. Some participants were able to describe their agency in being able to *accept* their level of control across a range of life choices.

> *"I do some stuff, it's a lot of therapy, I do some personal stuff, I go to, I have become a repurposer which if you like is a TBI [traumatic brain injury] version of the trendy hipster maker. I'm no longer a maker I'm more of a repurposer, I love doing that"* [P8].

Participants experienced a change in their sense of self and identity. Caregivers also observed this change in the person's personal and social identity, "*you're in a new normal – it's a brand new normal"* [C2]. Adjusting to a new or different body with a different set of capabilities and limits was an ongoing process of discovery and involved making conscious choices about who they were going to be or wanted to become.

Participants began re-constructing their old selves into a 'new identity' as part of the natural trajectory of recovery from injury.

> *"I guess one of the biggest things …that I had to come terms with was that, old [name] may never come back, you need to just, just forget about it. What's new [name] going to look like and what are you going to do, or what steps do you need to take to get to whatever your new reality is going to be? …I still don't know what that*

is, but I think from a conscious choice perspective that is something you …have to decide. I think, for me clinging to the past was probably the biggest hurdle to overcome" [P1].

As participants reclaimed their identity or crafted a new identity, they found that being able to control things sustained them and enabled them to enjoy life and create a sense of belonging to the community and contribution.

"one of the guys had a – it was a fatal cancer of the brain and we went down there one day and trimmed up his big hedges that were out of control and stuff like that. It was a fun day in that sense … we did something positive and supported him, got something done for him. Us blokes had a good time doing it. It was good all around." [P6].

"…he has gone back to work and it's the thing he now lives for is his work because it's all that he knows, and I think that's the thing that he does feel in control of. While he can still work, he can still provide for us, and he is still a valuable member of society." [C4].

Discussion

Our findings indicated that people following an acquired brain injury or spinal cord injury experience expressions of agency which led to either empowerment or vulnerability with their choices. It was important to have choice and control in interactions with the health system and staff, health care options, finances, where they lived, the type of work they did, their daily activities, and their relationships. This was experienced in different forms, including delegation, sharing, negotiating, or acceptance, in an iterative manner described by both people with an acquired brain injury or spinal cord injury and their caregivers through

four themes: 1) passenger in the system; 2) can't do it alone; 3) I want to improve; and 4) a new normal.

Recent reviews about the concept of empowerment have privileged the researchers' voice through their reliance on literature as the data source (39-41). This has led to a narrow consideration of empowerment, focussing on the ability to access, understand, and use health information. However, the participants in this study had a more comprehensive view, emphasising the importance of having choices over finances, living arrangements, occupations, and relationships. While previous empowerment concept reviews have identified processes such as enablement (40, 41), participation (39, 40), self-management or determination (39, 41), health literacy, and a person's sense of coherence about their condition (39), the participants in this study described their experiences of choice and control as processes that enabled their agency. They emphasised delegation, sharing, negotiating, or acceptance.

Previous research suggests that the experience of exercising agency differs depending on the stage of recovery (7, 41-44). Van de Velde and colleagues (45) identified a moment in the early stages where there is a switch from a passive role to choosing to take control and act. In this study of the early stages after injury, participants described being a passenger in a system as a passive experience of decision-making because their focus was on survival and immediate recovery. Participants adopted the identity of a 'patient' and often felt overwhelmed by the need to make critical decisions beyond their current capacity. They could be unaware, or not involved in the decisions being made around them. However, some participants did describe being able to take an active approach to decision making by either deliberately delegating control to a trusted person or attempting to gain some control over important choices at that time. Early choices driven by the need for social support and connectedness have been recognised as important (43).

Consistent with the theme of “can’t do it alone”, Haggstrom and Larsson (46) found that even when their participants needed support with decision making, it was essential that they could exert choice over elements of their activities where possible. When therapists don’t enable the level of choice the client is capable of, they increase the client’s vulnerability and reduce their sense of agency and empowerment (47). This suggests that therapists need to have skills in assessing not only the level of agency that a person is capable of but the level of agency they desire at any point in time.

Enabling client choice and control requires therapists to have effective communication skills so that they hear when the person is delegating control to them when they are asking to share control, and also when they are ready to resume control (2). Therapists also need to be mindful that they may need to hear what the person’s advocate is trying to convey as they can be representing the client’s voice at a time when the person is having difficulty expressing their choice. A key component of empowerment is providing relevant information in accessible formats. People who feel supported and well informed are more likely to exercise more control over the choices that present themselves within daily experiences (2, 48) through shared decision making processes (2, 48, 49). When agency is supported by therapists, or an advocate, patients feel empowered. When therapists do not genuinely include clients in decisions about important choices, they are perceived as insincere (10, 43) and this can lead to patients feeling they lack control or have limited choices resulting in a sense of vulnerability (50). Therapists need to adapt and apply effective communication strategies to include the person and their supporters in the process of decision making to ensure accessible opportunities for individual views and choices to be heard.

Therapists can support positive rehabilitation outcomes by empowering clients through effective communication and information sharing mechanisms to support their agency to take control and exercise meaningful choices. They can help people feel normal (51), live a

productive life (41), and experience good mental health (48). On the other hand, when the therapists' approach contributes to people experiencing limited choice and control, the subsequent feelings of vulnerability prompt the desire for greater agency and can lead to seeking more control over their identity (41). Theme 4 describes how this can occur through choosing to accept a new identity, leading to a "renewed and valuable sense of self" (41)(p. 1927), or by examining their definition of self, their approach to life, and the priorities in their lives (48). An important choice is the one to choose to recover (theme 3) (42). Therapists can assist clients in building a new life by envisaging function and occupation in new ways. This can include supporting people to find ways to give back to others and their communities, which can have important effects on wellbeing (52).

The desire for normalcy is emerging as a common theme in the qualitative literature exploring the experiences of people with an acquired disability (2, 42). However, what is meant, and desired by people with a disability regarding an individual or social sense of 'normalcy' is still not clearly understood. There is potential for further research to support an understanding of what is best practice in enhancing the agency of people with acquired brain injury or spinal cord injury to exercise control over their life choices with the goal of living life in their new normal.

Study limitations

A limitation of this study is that to participate in this study people had to have the capacity to engage in an in-depth interview. Thus, the sample does not include any participants with moderate to severe speech language impairments. However, this limitation is common to much qualitative research utilising interviews as a data collection approach. The voices of people who lack agency or have other barriers to participation are therefore missing in the research. The data from the people with brain injury and spinal cord injury were analysed as both participant groups have experienced trauma and some participants had both. We were

surprised to find homogenous themes despite the differences between these populations. We recruited caregivers to triangulate the data and overcome this limitation to some extent but acknowledge that the caregivers' views may not accurately present the perspectives of people who lack the agency to participate in interviews. A further limitation is that our study was conducted within one region, meaning findings may be limited to this region's health system, cultural norms, and societal attitudes. Further research in implementing interventions that support empowering choice and control needs to be conducted possibly drawing on methodologies that are empowering such as through co-design or participatory action research.

Conclusion

In conclusion, the findings of this study provide rich insights into the complexity and challenges of the experiences of choice and control during the early stage of recovery for the person living with acquired brain injury or spinal cord injury, and caregivers. The study identifies four themes: "passenger in the system," "can't do it alone," "I want to improve," and "a new normal." Within these themes, the participants described how temporarily disengaging or delegating, as well as regaining control to manage their choices gave them a sense of agency over their life. The findings suggest that an empathic approach from health care professionals may lead to more agency in exercising choice and control and empower a person to adjust to a new normal after experiencing an acquired brain injury or spinal cord injury.

478 **Table 1. Participant characteristics**

Participant	Overview	Age bracket [years]	Gender
P1	ABI one year	40-59	M
P2	ABI five years	50-59	F
P3	ABI and SCI one year	50-59	M
P4	SCI 18months	30-39	M
P5	ABI 18 months	30-39	F
P6	ABI 3 years	60-69	M
P7	ABI 3 years and 1 year	50-59	M
P8	SCI one year	60-69	M
P9	ABI & SCI 3 years	40-49	M
C1	Caregiver for person with SCI 8 years	50-59	F
C2	Caregiver for person with SCI one year	30-39	F
C3	Caregiver for person with SCI & ABI 3 years	50-59	F
C4	Caregiver for person with SCI &ABI 3 years	40-49	F

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480 **Table 2. Coding tree**

Codes	Categories	Themes
individualised care	resources	
financial choices determined by system		

control limited by time factors		Being a Passenger in the system
limited care giver resources		
choice on amount of therapy		
resources increase options		
lack of resources		
dependent on others to exercise choice		
hierarchy	trust	
taken advantage of		
staff conflict of interest		
caseworker to help gain control and understand choices	knowledge	Can't do it alone
sharing information between patients		
lack of staff knowledge		
decision made on research		
existing knowledge		
recognising the process of decision making		
too much information or choice is difficult		
control through learning		
decision based on recommendation		
gaining information forming expectations		
planning to control body		
manage your emotions		
I'm treated like I'm stupid	respect	
building a relationship		

not listened to		
ask them first		
deserve a choice		
refusal	communicate	I want to improve
lack of information frustrating		
seeking information		
network of staff knowledge		
control through feedback		
request refused by staff		
control through being listened to		
questioning choice		
lack of motivation	opportunity	
desire to improve		
control through opportunity		
the right to choose unapproved therapy		
unsafe choices		
avoid choice		
decision so as not to lose more	identity	A new normal
brain injury identity		
you are second hand		
owning the choice -it's my choice to work out		
I made the most of what I had		

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482 Disclosure of Interest

483 There are no interests to declare.

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