Loss of Financial Management Independence After Brain Injury: Survivors’ Experiences

Kathryn Koller, Lindsay Woods, Lisa Engel, Carolina Bottari, Deirdre R. Dawson, Emily Nalder

OBJECTIVE. This pilot study explored the experiences of brain injury survivors after a change in financial management (FM) independence.

METHOD. Using a qualitative descriptive design, 6 participants with acquired brain injury were recruited from a community brain injury organization and participated in semistructured interviews. Data were analyzed using thematic analysis.

RESULTS. Three themes emerged from the interviews: (1) trajectory of FM change, involving family members as key change agents; (2) current FM situation, involving FM strategies such as automatic deposits and restricted budgets; and (3) the struggle for control, in which survivors desired control while also accepting supports for FM.

CONCLUSION. This study identifies some of the challenges brain injury survivors face in managing their finances and the adjustment associated with a loss of FM independence. Occupational therapists should be aware of clients’ experiences when supporting them through a change in independence.


Independent financial management (FM), an important and complex task most adults undertake to live independently (Knight & Marson, 2012), involves simple and complex skills including counting money, paying bills, making purchases, managing a checkbook, and exercising financial judgment (Dreer, DeVivo, Novack, & Marson, 2012; Gaudette & Anderson, 2002; Marson et al., 2000). Cognitive deficits, which commonly arise after acquired brain injury (ABI), increase a person’s risk for FM limitations. However, evidence describing how people experience changes in their FM independence after ABI is absent.

ABI, including traumatic brain injury (TBI), non-TBI, and stroke, occurs suddenly and can have immediate and longstanding implications for FM. Executive function impairments (e.g., problems with planning, working memory, and decision making) are some of the most common neuropsychological sequelae after ABI and are essential in completing FM activities (Bottari, Gosselin, Guillemette, Lamoureux, & Pito, 2011; Martin et al., 2012). People with ABI are required to meet ongoing financial commitments (e.g., rent and bill payments) while in the hospital and dealing with an acute health crisis. Moreover, after ABI people may be unable to return to work, thereby limiting their income. FM may therefore involve new tasks, such as budgeting to account for lost income and applying for disability support. Given the complex nature of FM and the intricacies that may arise after ABI, it is vital to understand how people experience and complete FM tasks and areas in which rehabilitation, support, or both are required.
Little research exists regarding the FM difficulties experienced by people with ABI. People with TBI perform more poorly than control participants on tasks including budgeting (Bottari et al., 2011) and on standardized neuropsychological tests assessing judgment and decision making, which are cognitive skills considered important in FM (McHugh & Wood, 2008). In a longitudinal study of FM capacity, participants with TBI performed more poorly than control participants on simple and complex FM tasks at the time of hospitalization and had problems with complex tasks (e.g., making bill payments) that persisted 6 mo postinjury (Dreer et al., 2012). Case managers and family members supporting people with ABI have expressed concern over people with ABI forgetting to pay bills on time, spending impulsively, and not leaving enough money to purchase essential items (Hoskin, Jackson, & Crowe, 2005; Kreutzer et al., 2009). Research has examined the assessment of FM competency after ABI and developed some standardized measures of FM skills (Bottari et al., 2011; Kershaw & Webber, 2008). Missing from these studies is ABI survivors’ perspective on their FM experiences postinjury and on the supports they have access to or need. People who have experienced a change in FM can provide unique insights and identify areas for improvement.

Qualitative research has considered the lived experiences of people with ABI in different aspects of their lives, although no studies to date have focused on FM. People with ABI reported a period of adjustment to changes in their cognitive and physical abilities on their return to the community, and changes in their roles (e.g., inability to work) had an impact on their perceptions of independence (Hall, Grohn, Nalder, Worrall, & Fleming, 2012). A change in FM may also bring about role changes for people with ABI and affect their perception of independence. Qualitative studies have shown the importance of informal support (e.g., family) in recovery after ABI (Fleming, Sampson, Cornwall, Turner, & Griffin, 2012; Hall et al., 2012) and have suggested that it is important to consider how involved family or close friends are with FM changes after ABI. In a metasynthesis of qualitative research looking at lived experiences of recovery after TBI, several themes arose, including disconnection with preinjury identity, social disconnection, and reconstruction of self-identity (Levack, Kayes, & Fadyl, 2010). Because FM is an important task in daily living, it has the potential to change perceptions of identity either directly or indirectly by causing a change in social roles and everyday functional activities (Fleming et al., 2012). We build on these findings and explore how people experience FM changes after ABI.

In summary, evidence has shown that people with ABI can experience problems with managing money, such as issues with impulsive spending. However, to the best of our knowledge, no research has looked at changes in FM independence from the perspective of the people experiencing these changes. Such information may guide professionals, including occupational therapists, who may be involved in assessment or treatment of FM skills. The objective of this study was to explore the experiences of people with moderate to severe ABI who have experienced a change in FM independence. More specifically, we aimed to understand from the participants’ perspective (1) how their FM independence changed postinjury and the factors and events that influence FM independence; (2) how participants experienced and perceived their FM independence; and (3) how FM abilities affected survivors’ independence and participation in everyday life.

Method

Design

We conducted a qualitative descriptive study to understand participants’ experiences of FM after ABI. We used a constructivist paradigm, seeking to understand the nature and meaning of FM through participants’ subjective experiences (Creswell, 2013). Ethics approval was obtained from the University of Toronto and Baycrest research ethics boards.

Participants

Purposive sampling was used to recruit participants who had experienced a change in their FM independence after ABI from a community brain injury organization that provided residential services, education, and individualized case management support. Participants were included if they had a moderate to severe ABI as indicated by self-reported duration of loss of consciousness longer than 30 min (Malec et al., 2007); had sustained their injury at least 1 yr earlier; were age 18 yr or older and living in the community; and had reported that they had primary or joint responsibility for FM tasks before injury and had reported a change in their FM independence after injury. Participants were excluded from the study if they had insufficient communication skills in English to participate in an interview.

The clinical director of the community organization identified 6 potential participants who met the specific inclusion criteria, provided them with information on the study, and with their consent provided us with their contact information. Two authors (Koller and Woods) contacted interested participants by telephone to confirm eligibility and schedule interviews. Informed, written
consent was obtained from participants at the time of the interview. The final sample included 6 participants—information-rich cases (Patton, 1990) who had experienced one or more changes in their FM independence since their injury. We analyzed 102 pages of transcribed material and ceased recruitment because the sample had varying levels of FM independence, the key characteristic guiding our purposive sampling.

Of the 6 participants who took part in this study, 5 were male. The average age was 44.5 yr (standard deviation [SD] = 6.1, range = 37–51 yr). The proportion of female to male participants is reflective of the general population with TBI (Chen et al., 2012; Langlois, Rutland-Brown, & Wald, 2006). The average time since injury was 17 yr (SD = 6.32, range = 9–26 yr). The majority of participants (n = 4) had a TBI, and the remaining participants (n = 2) had a stroke or anoxic brain injury. All participants had completed an average of 12 yr of education (SD = 2.1, range = 10–14 yr). All participants were living in the community and receiving either a disability pension (n = 3) or accident benefits through private insurance (n = 3). Before their injury, participants had been working (n = 4), studying (n = 1), or simultaneously working and studying (n = 1). At the time of the study, participants were working (n = 1), volunteering (n = 4), or retired (n = 1).

Data Collection

Either Koller or Woods conducted the semistructured, face-to-face interviews. An interview guide was developed for this study and piloted. The interview guide had five key questions:

1. “Tell me about how you manage your finances currently and how you managed them prior to your injury.”
2. “Tell me about how this change [in your FM since the injury] occurred.”
3. “Can you describe what going through this change in your FM has been like for you?”
4. “How has this change in your ability to manage your finances impacted your functioning and participation in your day-to-day life?”
5. “What has been helpful for you in managing your finances since your injury?”

During the interview, participants provided demographic information: age, gender, education, type and cause of injury, and primary role (e.g., employee, volunteer) pre- and postinjury. Interviews were digitally recorded and lasted between 40 and 90 min. All audio recordings were transcribed verbatim using InqScribe (Version 2.2.1; Inquirium LLC, Chicago) and checked for accuracy.

Data Analysis

Data were analyzed using thematic analysis, an iterative approach involving (1) becoming familiar with the data, (2) assigning codes, (3) reviewing codes to identify themes, and (4) connecting themes to give an explanatory account of the data (Braun & Clarke, 2006). Interview transcripts were read and checked to develop familiarity with the data. Two authors (Koller and Woods) separately coded transcripts and then met to discuss and form a list of consensus codes. The consensus codes list was checked with a third author (Nalder), and Koller and Woods then reanalyzed the transcripts using consensus codes.

Five steps were taken to identify themes. First, data were examined to identify the most frequently reported codes (within each interview) and the codes present in all interviews to gain a sense of emerging themes. Second, coded data with similar meanings were grouped and named (e.g., the preliminary theme “independence in daily life” emerged from data coded as “events influencing independence” and “perceptions of independence”). Third, transcripts were reread to ensure that the preliminary themes captured the essence of the data, and links between themes were noted. Fourth, a chart was developed that assigned each participant a column and each theme a row. The chart was used to compare themes across the sample and identify links between themes. Fifth, the research team discussed a summary of themes and refined and integrated them with other literature. To enhance rigor, peer checking was undertaken during coding and theme development, and multiple perspectives on the data were obtained through team discussions throughout data analysis. Because of the complexity of FM changes since the injury (>10 yr earlier), these strategies (e.g., chart and team discussions) were essential to manage the dataset. Data analysis was completed in NVivo (Version 10; QSR International, Doncaster, Victoria, Australia).

Results

Three major themes emerged from the data: (1) trajectory of FM since injury, (2) current FM, and (3) struggle to feel in control. Each theme and subthemes are reported using illustrative verbatim quotes with participants denoted as P and the interviewer as I.

Theme 1: Trajectory of Financial Management Since Injury

The first theme describes how participants’ FM had changed since their injury and the events that contributed to their current situation. Immediately after the injury,
all participants described a period during which their finances were managed by either a family member or an appointed public guardian. Information regarding participants’ FM is provided in Table 1.

Four participants who currently have limited control over their FM described a period of time postinjury when they lived in the community and had control over their finances, determined how their money would be spent, and paid bills. All 4 described a change in which their family, often one person close to the participant, intervened to take a larger role in controlling the participant’s finances. Changes in participants’ FM independence were attributed to (1) an accumulation of financial mismanagement events (e.g., spending all of their income, accruing debt, and needing to borrow money to pay rent) or (2) perceived disagreement between the participant and others (e.g., family) about the participant’s spending habits (e.g., purchase of alcohol). Both instances triggered FM support from family.

P2: No, it was more like seeing the problems that I had and having it up to here, like enough is enough, so [parent] kind of, um, overthrew me and took control of [FM].

P3: Like, I never ran short of food . . . just they [family] didn’t like my drinking.

Two participants recalled doing a formal FM competency test, but only 1 felt that it was a factor contributing to his or her FM independence; the other described answering questions on the basis of what the assessor wanted to hear in order to pass the test.

P6: They came to test me on how I can manage my money now. . . . But I just want to tell you this . . . I can answer, but in action I am different.

Theme 2: Current Financial Management

The second theme describes how participants’ finances were currently being managed and the support they received for FM tasks. Two participants reported that they currently had primary or shared responsibility for their FM. One of these participants shared FM with a spouse; the other, who lived alone in social housing and received a disability pension, reported independently paying bills and managing personal bank accounts and everyday spending but accessed support from community services to file taxes and submit paperwork associated with claiming rent subsidies.

By contrast, the majority of participants (n = 4) reported that their finances were entirely managed by another person, either a family member or a support worker. These participants did not have access to their bank accounts, and any money they had was given to them by the family member or support worker managing their finances. Typically, these participants only had access to small amounts of cash (e.g., <$50 at a time), which was given to them for specific expenditures such as purchasing

Table 1. Description of Participants’ Financial Management

<table>
<thead>
<tr>
<th>Participant</th>
<th>Person Primarily Responsible for FM Initially Post-ABI</th>
<th>Current Person Primarily Responsible for FM</th>
<th>Assistance Received for FM Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Family</td>
<td>Participant</td>
<td>Case manager assists with reporting income for rental assistance and filing taxes.</td>
</tr>
<tr>
<td>2</td>
<td>Participant</td>
<td>Parent</td>
<td>Parent completes complex FM tasks. Participant receives weekly sums of money and assistance with grocery shopping.</td>
</tr>
<tr>
<td>3</td>
<td>Participant</td>
<td>Parent</td>
<td>PSW assists with complex FM tasks. Participant receives weekly sums of money and assistance with grocery shopping.</td>
</tr>
<tr>
<td>4</td>
<td>Public guardian</td>
<td>Participant</td>
<td>Case manager assists with grocery shopping.</td>
</tr>
<tr>
<td>5</td>
<td>Parent</td>
<td>Sibling</td>
<td>Sibling completes complex FM tasks. Participant receives weekly sums of money and assistance with grocery shopping.</td>
</tr>
<tr>
<td>6</td>
<td>Unknown</td>
<td>Case manager</td>
<td>Case manager assists participant with paying bills and rent and with grocery shopping.</td>
</tr>
</tbody>
</table>

Note. ABI = acquired brain injury; FM = financial management; PSW = personal support worker.
Participants with limited responsibility for their FM described feeling forced to accept their current situation. Some participants felt frustrated and perceived that they lacked control to change others’ decisions regarding their FM. Other participants reported feeling resigned to the fact that they had to accept that they needed support, perceiving that they lacked the ability to sufficiently manage their finances.

P2: [They] just handled it [taking over FM] and that was that, I had no choice. I: How did it make you feel? 
P2: Well, I knew there was nothing I could do. There was some resentment there, too.

P5: I realize after I sit back and relax and think about it [that] they’re doing the right thing. It’s tough because brain injury is invisible, and this whole disability—it’s hard to admit to oneself that someone else is better suited to do something for you.

Having trust in the person who was managing their finances and a belief that they had their best interests in mind also led to acceptance of the current situation. The ability to trust others was judged on the basis of the closeness of the relationship with that person and by instances in which support people were respectful and gave participants choices about how to spend their money. The following quotes, for example, demonstrate that the participant valued the support worker’s giving him or her a choice about how to spend his or her money when devising a shopping list; the participant adjusted his or her perception of someone else managing his or her finances because that person was their parent.

P2: But I do enjoy that because every Monday, me and the guy from here [support worker], we go grocery shopping, and we pick it up and devise the list, and so I do that and it is independent.

P2: I would like to say that my [parent] does all my banking . . . sometimes I think [he or she] is going too far, but I let it go because [he or she] is my [parent].

Theme 3: Struggle to Feel in Control
The third theme relates to how participants perceived their current FM situation as an ongoing struggle to feel in control. Two subthemes give context to the struggle to feel in control: (1) independence in everyday life, which highlights why participants felt it was important to have control over their FM, and (2) acceptance, which captures the ongoing tension between participants wanting control but also feeling forced to accept their current situation.

All participants felt that it was important to have control over their FM because it was tied to their independence in everyday life. FM was linked to the ability to be self-sufficient in daily activities (e.g., being able to buy food without asking others for money) and the ability to participate in valued work and leisure activities.

P6: Like my mail goes to the office, we go to the bank to deposit, and to do anything I have to go with support or it’s not going to happen.

FM also influenced participants’ perceptions of their ability to carry out social roles such as gaining employment and being able to provide for themselves. Participants’ independence and everyday living choices were affected by both the amount of money received and the level of autonomy they had in deciding how to spend that money. This effect on independence was evident in both basic (e.g., having to buy groceries at a discount store because of low income) and more significant financial decisions (e.g., where they lived).

P5: I think down the road I would like to take more responsibility. . . . I would much rather be able to be employed somewhere and buy a house instead of renting.
independence; and (3) how FM abilities affect survivors’ independence and participation in everyday life. Interviews with 6 participants elicited three themes: the trajectory of FM since the injury, current FM, and the struggle to feel in control. On the basis of the results, gender did not appear to influence themes, though very little can be said about gender because the study included only 1 female participant.

The first theme described the trajectory of FM since injury and captured family members’ integral role. Participants perceived that family members decided that they were not able to independently manage their finances, and thus it was family who first intervened to assume FM responsibilities. Families also provided financial assistance, loaning participants money to cover expenses and repay debts. Other research has shown that family members assume a primary support role for people with ABI after discharge from the hospital, including managing financial matters (Fleming et al., 2012). Recent research has shown that family members have a high degree of concern about the judgment and safety of people with TBI regarding financial matters and that this worry correlates with caregiver burden and stress (Kreutzer et al., 2009). Supports in the area of FM should be holistic and consider the person and his or her family given the family’s significant role in supporting FM postdischarge. It will be important for future research to explore the experiences of people without family support because they may have a higher degree of vulnerability in relation to FM.

It is interesting that participants rarely described having a professional assess their FM skills. This finding corresponds with lived experience literature that has discussed that informal supports (e.g., family) are important in recovery and are relied on more heavily than formal supports (Fleming et al., 2012; Hall et al., 2012). Future research should investigate how occupational therapists and other rehabilitation professionals address FM with clients and families after ABI, in both the acute and the chronic stages. There is a dearth of evidence regarding how to reliably and validly assess the range of FM skills of people with ABI and how FM measures can guide interventions and supports. Adequate assessment of FM skills and abilities appears particularly critical given the burden placed on family members to assess FM skills and abilities and intervene as required and that the assumption of this responsibility often occurs after events of financial mismanagement build up.

The second theme, current FM, described the supports and strategies participants used in their FM. All participants reported using supports to assist with budgeting (e.g., automatic bill payments) and accessed support from others (e.g., family, a community brain injury organization, or both) to complete FM tasks. This finding corroborates previous research that has shown that people with ABI can have long-term difficulties with instrumental activities of daily living (IADLs), including managing money (Colantonio et al., 2004). Occupational therapists working in hospital- or community-based rehabilitation may play a vital role in assessment, treatment interventions (e.g., education), and referrals for supports to optimize FM skills and independence. Accessing third-party support for complex FM tasks such as filing tax returns is not dissimilar to patterns of FM in healthy people. Rehabilitation researchers may therefore draw on broader fields of research (e.g., financial planning and financial literacy) to develop assessments and intervention approaches that capture the range of approaches to FM evident in society (Fox, Bartholomae, & Lee, 2005).

Theme 3, struggle to feel in control, captured participants’ perceptions of the impact of FM independence on their participation in everyday life; all felt it was important to have control of their finances to participate in their desired activities. Community integration is a key outcome for community-dwelling people with ABI, and it includes the ability to be self-determining, to participate in work and leisure, and to have meaningful relationships (Kim, Colantonio, Dawson, & Bayley, 2013; McCabe et al., 2007). Participants in this study felt that their lack of control affected their ability to be self-determining, and they were unable to participate in leisure or social activities with loved ones (e.g., buying a birthday present) because of financial constraints. Research on lived experience has already identified that people desire meaningful activity and that disruptions in meaningful activity often occur postinjury (Fleming et al., 2012). These findings reinforce that people living with ABI need support to optimize their participation in the activities they need and want to be able to do and that these supports should consider their FM.

Theme 3 also captured the ongoing tension between wanting control and accepting their current situation and that participants felt acceptance was forced on them. Participants felt that they lacked choice about their FM because injury-related changes meant they were unable to appropriately manage their finances and their finances were controlled by others. Future research should consider how to provide support to people who lack the capacity to manage their finances so that they have some autonomy regarding FM. Moreover, this study’s results highlight the importance of addressing the emotional adjustment that people experience after a loss of independence in FM. Social cognitive theory (Bandura,
1991), attribution theory (Kelley & Michela, 1980), and models of learned helplessness (Weiner, 1985) that address issues of controllability, motivation, and emotional reactions to life stressors may inform the development of supports for people who experience changes in FM independence after ABI.

Limitations and Future Directions

Although this study used methods to maximize its rigor, such as using two initial coders and an individual coding consensus process, it does have limitations. First, all participants were recruited from a single community organization, and all were accessing case management or community support. Future research should examine the FM experiences of people who are not receiving FM supports, either formal (i.e., legally mandated) or informal (i.e., family), and who reside in different geographical locations with differing service delivery models or cultural assumptions around FM.

A second limitation, despite the information-rich cases and in-depth analysis, is the small sample size. Future research should be conducted with a larger sample. It may be helpful to include input from family members or service providers to understand their experiences of the assessment of FM skills and FM supports and interventions for people with ABI. Currently, we are pursuing research in the area of FM after ABI by exploring instruments used in FM assessment of people with acquired cognitive impairments (Engel, Bar, Beaton, Green, & Dawson, 2016) and interventions to address financial planning deficits after TBI (Poncet et al., 2015).

Implications for Occupational Therapy Practice

FM falls within the occupational therapy scope of practice because it is an important IADL. It is valuable for occupational therapists to understand lived experience and gain an appreciation for the complexities related to FM change.

- During assessment, occupational therapists should obtain comprehensive client-centered information, including (1) clients’ FM goals, (2) current and preinjury FM strategies, (3) whether supports are in place or needed, (4) areas of distress or priority related to FM, and (5) any change in roles or identity associated with change in FM.
- Interventions should aim to find a balance between promoting autonomy and preventing harm from financial mismanagement. Techniques commonly used in cognitive rehabilitation include goal setting, graded cues, metacognitive strategy training, and use of feedback, which may support learning and enable more independent performance of FM tasks.
- In addition, education should be provided to family members on how to optimize the FM independence of the person living with ABI, and alternative interventions (e.g., counseling) may be required to support the person’s emotional adjustment after an FM change.

Conclusion

This study provides preliminary insight into how people experience and perceive changes in FM independence after ABI. More specifically, it provides information regarding the events that brought participants to their current situation and the complexity of these issues because participants perceive an ongoing struggle to regain control over their FM independence. This study highlights the need for valid, reliable, and timely assessments, interventions, and supports in both the acute and the chronic stages after ABI to target FM skills to promote independence and autonomy in this critical IADL.

Acknowledgments

The authors acknowledge the participants who made this work possible. This work was supported through pilot grants from the Ontario Neurotrauma Foundation and the Réseau Provincial de Recherche en Adaptation–Réadaptation. Members of the research team were supported through personnel awards including a Canadian Institutes for Health Research (CIHR) strategic research training postdoctoral fellowship in health care technology and place awarded to Emily Nalder; the Ydessa Hendeles Graduate Scholarship awarded to Kathryn Koller and Lindsay Woods; and the CIHR doctoral Allied Health Professional Fellowship, Canadian Partnership for Stroke Recovery trainee grant, and Men’s Service Group Graduate Student Fellowship awarded to Lisa Engel. This project was completed while authors Koller and Woods were students of the Department of Occupational Science & Occupational Therapy, University of Toronto, Toronto, Ontario, Canada, and Rotman Research Institute, Baycrest, Toronto, Ontario, Canada. This research was presented at the Canadian Association of Occupational Therapists conference in May 2014 and the Toronto Acquired Brain Injury Network Conference in November 2014.

References
