Occupational therapists and physiotherapists weighing up the dignity of risk for people living with a brain injury: Grounded theory

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Introduction

The importance of dignity within health is recognised at a societal level by its prominence in global policy statements. The World Health Organisation and United Nations have principles calling for respect for dignity (1, 2). In Australia, the Australian Department of Health acknowledges all people have inherent dignity and worth (3). More specifically the Australian Physiotherapy Association values “respecting the rights, needs, dignity and diversity of all individuals” (4). Similarly, the Australian Occupational Therapy profession “promotes and respects the needs, desires, knowledge, experiences, beliefs and priorities of the client, and seeks the client’s active participation” in therapy (5).

Physiotherapists and occupational therapists work in the field of rehabilitation. Given the need for therapists to make decisions about client safety within the context of being client centred (6-8), it is somewhat surprising to find that little has been written about the dignity of risk in the field of rehabilitation. This absence contrasts to a growing body of work in aged care and hospital settings, particularly within the profession of nursing (9-13). Within this literature, dignity is defined as an intrinsic absolute and fundamental human right by virtue of being human (14). Consequently, all humans have dignity. Alternatively, a social conceptualisation of dignity explains why some people may not be afforded dignity. Social dignity is understood to be generated through interactions between people, and as such is “extrinsic, subjective, contingent, and dynamic” (14 p. 14). Dignity, therefore, can be transformed, removed and rebuilt through the actions of people as they dignify themselves.
and others (7, 14). This means that social dignity, as a relative construct, is vulnerable to violation through the interaction of people (14). For physiotherapists and occupational therapists, this means one’s own dignity cannot be separated from others, and so when a therapist diminishes the dignity of their client, they diminish their own dignity.

Understanding dignity as an interaction is always important, but there can be events or encounters (14) which bring the meaning of the concept into sharp focus. Robert Perske (15) coined the term ‘dignity of risk’ for a dignity encounter that occurs in the care of people with intellectual disability, where the social processes that contribute to “overprotection” remove opportunities afforded by experiencing the normal risks in life (15 p. 24). Dignity of risk has been more recently defined as “the principle of allowing an individual the dignity afforded by risk-taking, with subsequent enhancement of personal growth and quality of life” (13 p. 2).

Working in healthcare is accompanied by a range of safety, risk and dignity dilemmas regardless of the client population (16). Indeed, working in the context of brain injury rehabilitation, occupational therapists and physiotherapists may frequently encounter risk to an individual’s safety due to the impacts of the brain injury on multiple body systems. People living with brain injury may experience physical problems such as balance and sensory impairments; cognitive issues with memory, concentration, planning and problem solving and inflexible thinking; or emotional difficulties such as depression, emotional instability, and irritability (17).

The complex sequelae of problems secondary to brain injury result in medical, social, psychological and financial risks to the individual and the community (18). Consequently, therapists work in the field of brain injury rehabilitation to support people following brain injury to restore function and manage these risks. In doing so, therapists may be confronted by tensions that include needs/resources; privacy/exposure; crisis/routine; care/production;
These risks create dilemmas for therapists as they balance the need of the individual’s rehabilitation and dignity against their own safety and that of the general public within risk adverse legal, organisational and professional contexts. Therefore, this study aimed to explore how occupational therapists and physiotherapists manage these tensions when providing rehabilitation with people following brain injury. A better understanding of this area of practice reasoning will support development of appropriate and client-centred risk management policy that preserves dignity.

We sought to answer the research question:

How do occupational therapists and physiotherapists manage the dignity of risk for people living with brain injury?

Method

Design

The study took place over an 11-month period from February 2018 to November 2018. The second-generation constructivist grounded theory methodology of Charmaz guided the research approach. This approach was appropriate to build on existing concepts about dignity of risk in aged care with the intent to develop a conceptual framework about how therapists in brain injury rehabilitation manage dignity of risk. We drew on semi-structured in-depth interviews with occupational therapists and physiotherapists to explore how they manage risk and dignity for people living with brain injury.

Procedure

Sampling: Opportunistic and snowball sampling techniques were used. Therapists were initially included in the study if they were currently working with adults with an acquired brain injury (ABI) and had at least six months experience in this field. Sampling variation
was achieved through recruiting therapists from both public and private sectors, in addition to across the recovery continuum of acute, rehabilitation, and community work settings. To work toward theoretical saturation (20) and maximum variation sampling (21), the inclusion criteria were modified six months into data collection (July 2018). The modifications were twofold. Firstly, therapists with less than six months experience (i.e. early career) were now eligible to participate and secondly therapists who were not currently working in the field but had at least three months experience in the past were included. These changes were in response to an observation that many of the participants had considerable experience in the field, and we anticipated that the variation in our sample would enrich our theory.

**Participant Recruitment:** Registered occupational therapists and physiotherapists working in two different states in Australia were purposefully recruited to explore the context of different health systems. Recruitment occurred through email (personal contacts of the researchers), Facebook and phone calls. Some participants also contacted the researchers expressing interest in being involved following snowball sampling. All participants provided written informed consent prior to their interview.

**Data Collection and analysis:** Therapists explored how they managed dignity of risk through in-depth semi-structured interviews conducted by DF, CM and MS who are all female occupational therapists and had no prior relationship with the participants. The interview guide was piloted with two academic allied health staff members prior to commencement of data collection. Some changes were made to the guide following this process. Interviews were 40-90 minutes duration in a location of the participant's choosing, or over the telephone. All interviews were digitally recorded, transcribed verbatim by a transcriptionist and then checked for accuracy by a research assistant. The interview guide with questions about experiences of risk and working with people with brain injury was developed from our reading of the content and methodological literature and was used to guide the first four
interviews. Example questions were: Can you tell me some stories from your practice experiences that are examples of when you have questioned client safety? How do you balance the need to be client-centred with managing safety? At the end of their interview, participants were invited to choose a pseudonym to preserve confidentiality and anonymity.

In keeping with grounded theory methodology each new transcript underwent line by line initial coding by two researchers concurrently and codes were then discussed with the research team. New data were then integrated into existing data using constant comparison (20). New codes were created when the data were outlying. Where possible coding occurred using the participants words and gerunds (verbs ending in ‘ing’) to capture action and process in the data (22). NVivo software was used for the first round of analysis to shape questions and find gaps in the emerging theory for the second set of interviews.

As findings emerged, theoretical sampling was used and enabled the researchers to look for concepts that were consistent in all findings (the core category), to uncover the basic social process and establishment of theoretical saturation. Some changes were made to the questions asked of new participants to test concepts arising in the theory and to probe further into areas of interest – such as experiences of enabling dignity. Examples of new questions posed from July 2018 were: Can you tell me some stories from your practice experiences that are examples of when you were concerned about a client’s dignity when safety was at risk? How do you balance the need maintain dignity with the need to minimise risks? Excel was used to create an audit of the focused coding of the entire data set completed by two members of the team, one occupational therapist and one physiotherapist. The team met several times to discuss and develop consensus regarding emerging categories and concepts. Memos were used throughout the analysis process to enable discussions amongst the research team and the asking of critical questions. Constant comparison and interrogation of the data enabled development of relationships between the categories and some categorical properties began to
reach saturation. The researchers also used concept mapping to connect and reorganise the data.

Ethical considerations

Ethical approval for this study was provided by the Human Research Ethics committee at the University of South Australia in February 2018 (Application ID 200855). Prior to presenting volunteers with consent forms, they were provided with an information sheet and the study was explained to them. Participants selected their own pseudonym and care has been taken to only provide information about the participants in general terms to protect anonymity and confidentiality.

Interview Participants

The 17 interview participants had clinical roles with people with acquired brain injury at the time of interviewing. The first round of convenience sampling yielded five highly experienced participants (8 years – 35 years of clinical experience) which gave a strong starting point for the emerging theory. However, we were keen to hear the views of less experienced therapists because they were likely to still be working through their strategies for managing dignity of risk. Following the modification of inclusion criteria, we gained a further 12 participants which included both newer graduates and variations in work settings. Years of experience ranged from six months to 30+ years. Most participants (15/17) were female. Ten participants were occupational therapists, and seven physiotherapists; 10 therapists were from South Australia, seven from Victoria. Most therapists worked in a community-based private practice, however, there were also participants from public clinics, acute and rehabilitation hospitals. Most participants (13/17) worked mainly with clients with ABI or other neurological conditions, while four participants worked with a more mixed case
Findings

The core category: weighing up risk

The weighing up process was consistently described by participants regardless of their professional background. Weighing up risk occurred when they reasoned through an unpredictable or unknown future outcome for the person with brain injury, or themselves, or the public. Within the context of risk, they weighed up the likelihood of positive or negative consequences, often influenced by their own comfort with risk. Risk was commonly described in terms of the ‘potential for an outcome’ and was rarely quantified or described as eventuating. Participants described managing dignity within adverse situations through risk management processes that included allowing, reducing, or mitigating risk. Social processes of control, empowerment, support, and advocacy created opportunities for people with a brain injury to take on a level of decision making within their capacity. Participants explained that enacting their weighing up process often led to client experiences of success or failure, but ultimately contributed to their sense of living a normal life. The process of weighing up risk was influenced by the situation, and by factors such as the importance of the decision, the appetite for risk, the client’s cognitive capacity to make decisions, therapist expertise in understanding client preferences, the presence of family/advocates and the level of available resources. The theory encompassed four categories that described the weighing up process that the therapists reasoned through. These categories are provided in Figure 1.

Category 1: Privileging the client perspective: Participants described the process of privileging the client perspective as understanding their goals and being person-centred.
Participants went to great effort to ensure the voices, feelings and thoughts of clients were privileged in the rehabilitation process. Participants may not have agreed with the goals that clients were presenting to them, but they avoided being dismissive and carefully gave opportunity for clients to make their own choices with support.

...good rehab is about being very person focused, so what is important to them...?'
(Hugo, 35 years).

'[Her]goal was to walk in high heels. Now, that’s inherently unsafe, but ... that was her goal, that was her dream and so we did it’. (Flossy, 34 years)

To privilege the client perspective participants needed to have experience, clinical reasoning skills, and understanding of policy. Therapists respected the client’s goals and priorities, communicated with all team members, solved problems, accessed resources, made compromises, and enabled clients to build skills in judging the likelihood of an adverse event. They worked to involve family, build trust, and support the client to contribute to the risk management process.

'I think as you become more experienced you start to appreciate and realise that things aren’t black and white ... I think you start to recognise that ... there’s always going to be risks and that one of our biggest roles is about trying to work with patients and their families and loved ones to come up with the best solution in what is often not an ideal scenario’. (Charlotte, 14 years).

'So, as you get to know the client a bit more and their story and their way of managing after their accident, you start to - I suppose develop a bit more of a filter of how you’re interpreting the information and how you might approach it. And I know for some clients, you’re constantly thinking about that management. You are thinking on your feet quite a lot’. (Amber, 3 years).
One participant described how she recognised the dignity violation caused by stigma from people living with brain injury being perceived as disabled and explained her approach to supporting the client to make decisions.

‘I had a patient recently who’s desperate to walk outside…. she was happy to carry one particular gait aid and not another one that I suggested because she felt like she was going to look really disabled…. So we sort of negotiated…’. (Sharna, 12 years).

Participants reported that their desire to preserve dignity for the client by privileging their perspective needed to be balanced by other considerations. Participants had to weigh up whether the client had adequate capacity and insight into their abilities to make sensible and safe decisions; whether the client had a low tolerance for risk and change; or whether the client had impulsive tendencies which made them vulnerable to physical harms. A participant explained this weighing up as trying to achieve a balance between competing outcomes.

‘…balancing the wishes of the client and balancing the risk and then balancing I guess wanting to achieve the patient’s goals and support them…. [do they] have the cognitive capacity to make that decision or is there another decision maker that can do that’. (Chloe, 8 years).

**Category 2: Giving opportunity to experience success:** Understanding the clients’ perspective enabled participants to provide clients with the opportunities to experience success through taking a risk. While some participants were sceptical that enabling clients to take calculated risks would lead to successful outcomes, they hoped to be proven wrong. There was recognition that enabling dignity of risk could potentially lead to unexpected positive outcomes. Participants explained the importance of remaining open minded about a person’s ability to accomplish their goal, rather than dismissing their potential.
‘But we are still sometimes surprised by some of the goals that people have and how they can actually achieve them as well... I didn’t feel like he would ever get there.... But we heard that he went to the [rehabilitation unit] and within six months he was cycling again independently.... we told [him] it was probably an unrealistic goal. But again, I think you can never rule anything out with these patients. (Patrick, 14 years).

Participants were able to support risk taking when they were supported by a positive and supportive team culture and were able to plan and control the experience. Working collaboratively with clients to reach their goals and making sure they were fully informed about the potential risks in pursuing their goals was valued by participants. They emphasised the need to take small steps toward goal achievement by breaking them into smaller goals. Other strategies included working toward optimal outcomes by minimising the risk, focusing on the client strengths rather than loss of abilities, giving opportunities for trials followed up by evaluation, and working with clients to build their confidence and trust in their abilities. These strategies seemed to work well when participants were open-minded about different options and worked constructively with a team around them. As an example, one participant explained her process of deciding between getting a client walking or staying safe in a wheelchair.

‘You know what, they’re a bit dodgy on their feet but I really think that they need to be given the opportunity to prove us otherwise’. (Charlotte, 14 years).

In this way, the benefits of experiencing a successful outcome were weighed up by the participants against the potential harms of an adverse outcome.

**Category 3: Giving the opportunity to learn through failure:** As part of the process of privileging the client perspective, participants found that clients and their families benefited...
from opportunities to try different things, even if that led to failure. Having the opportunity to
make some errors in a controlled circumstance may mean some clients learn more about their
abilities, their limitations and their capacities – which may hold more meaning than being
told what they can and can’t do. This decision to give the clients a chance to try may also
enable the therapist to understand the client’s abilities better.

‘...sometimes you do have to take calculated risks and use your clinical decision-
making to decide what amount of risk is acceptable…. and give people the
opportunity to give things a go to be able to determine on whether or not they were
actually likely to fail’. (Charlotte, 14 years).

‘...part of it is a bit of a measured risk.... if you keep saying to somebody, “Well you
can't do that because of X, Y and Z,” but you never give them a chance to try, then
they're not going to actually get that awareness’. (Hugo, 35 years).

All the while, therapists were tempering their decision making with the ethical principle of
aiming to do no harm. A participant described the need to feel comfortable with letting go of
some power and handing over some control to their clients and their families.

‘If I feel like somebody is cognitively strong enough to understand the risks and have
shown to me in practice that they do things to mitigate that kind of risk, then I feel
comfortable leaving them to do it alone’. (Tahlia, 6 months).

An important aspect of this process was therapists reflecting on their decisions, the outcomes
and learning from these experiences.

‘... you make a call don’t you? Are you going to put this man in an even worse
position for his dignity or is it a better position?’ (Frankie, 8 years).
Generally, participants working in an unpredictable or more isolated community setting were less likely to create situations where clients learn from failure, because variables were harder to control. However, providing opportunities to learn from failure may be more possible in controlled environments such as hospitals where participants can rely on a team around them to back them up and monitor the situation. Therapists with more years of experience seemed more comfortable to explore the risk further. Once this decision was made, participants worked with clients and their families to evaluate the possible consequences and outcomes, to consider the pros and cons, and to weigh up the importance of the goal with the risk associated with pursuing the goal. If the attempt was unsuccessful, participants followed up with clients to reflect on their failed performance as a strategy to promote learning.

‘...trying to find the way for us to build self-awareness through graded exposure, supported discovery of their skills, active reflection on how things are going with graded feedback and using that as a graduated approach to build their skills and obviously aim to have a more – a high level of self-efficacy in the end where they can be more in charge of their life and their routines.... you really have to work for a few years to sort of learn this stuff with these tricky people’. (Stanley, 18 years).

Contextual and client factors influenced the weighing up decision making process of providing opportunities to make mistakes that may be perceived as risky, with the aim to do no harm. These included the level of support the client has, the personality of the person prior to their brain injury (i.e. has always been a risk-taker), the client’s perception of what risk means and their sensitivity to having these discussions. Participants found it more challenging to weigh up doing no harm against the opportunity for learning through failure, than against the opportunity for learning through success.
**Category 4: Recognising the importance of living a normal life**

Providing opportunities to experience risk enabled people living with a brain injury to live as normal life as possible, despite impairments. Participants were passionate about advocating for their clients through conversations with family and the rehabilitation team. The social processes of promoting independence and control and normal life experiences were considered critical to dignity.

> ‘I think everything that we do is just about helping people to live as normal a life as possible, like whatever is normal to them. And helping them to be as independent as possible, be as in control of their lives as possible’. (Nina, 15 years).

Therapists advocated for client’s rights and quality of life. Participants were aware that sometimes clients could have impulsive tendencies or were potentially a risk to themselves; and in these circumstances, they took the time to advocate with key stakeholders about the clients’ need for a normal life. They would try to work through the issues and negotiate solutions. An example includes problem-solving to ensure clients have maximal opportunity for safety and independence to afford them normality and a routine, including things they enjoy.

> I think there is a risk he still travels slightly too fast sometimes [in his powered wheelchair], but when you weigh that up with, well that allows him to access the community, his local community on his own, go and get a few things from the supermarket, go and have a coffee, I think that’s a good risk. (Jade, 11 years).

**Discussion**

The findings of this study support previous work exploring dignity in the health setting from the perspectives of the nursing and medical professions and extend knowledge into allied health professions. The generated theory provides greater insight into the decision-making
process around the tensions that arise in relation to dignity, safety and risk when working
with people with a brain injury in the rehabilitation setting.

The participants explained how they managed the tension between dignity and risk as a
process of weighing up. Dignity for a client with a brain injury is placed at risk when a
therapist errs on the side of caution, giving greater weight to the principle of non-maleficence
and minimising negative outcomes attributed to the situation involving risk. When focusing
on doing no harm, there is lost opportunity to create balance with the benefits of positive
outcomes that can come from risk taking. Trying to protect the person with a brain injury
and/or the public from harm can lead to dignity violations that are associated with a different
set of harms (14).

Therapists experienced a tension in weighing up their own ‘sound’ decision-making
against ‘questionable’ client choices. Therapists with limited work experience did not appear
to recognise the risks of social processes such as being condescending or dismissive and
creating different harms through violations of dignity (12). Our findings support previous
research in aged care settings (9, 10) where participants described tensions in promoting
dignity when working with clients’ whose cognitive capacity was impaired, or whose choice
did not align with the therapist’s advice. Previous research suggests that when health
professionals find themselves in a position where clients resist professional help or advice,
then paternalism, and coercion may arise (23).

Weighing up as a process that respects dignity, not only considers principles of
beneficence and non-maleficence, but also shines a light on the need to respect autonomy and
promote justice for people with brain injuries. Therapists with more experience, or those who
could tolerate a high level of risk were able to describe how they managed this tension
between their expertise and the patient’s experience by shifting their focus from managing
risk as an outcome to managing risk as a process. They gave greater weight to the client’s
knowledge, experiences and wishes, and consequently to the client’s dignity. Experienced
therapists changed the way they weighed up their own expertise and gave greater
consideration to the client’s perspective to promote the dignity of people with a brain injury
during situations involving risk. This led to participants using processes that supported client
learning, either through success, or failure; and to changing the desirable outcome from
minimising risk, to giving clients access to a normal life.

Previous literature exploring the client experience has uncovered the importance of
autonomy to the promotion of dignity in health care settings (6), but participants in our study
explained the tension they experienced between autonomy and authority. Participants
described their struggle to promote client self-determination, but at the same time, maintain
control over risks and abide by their duty of care to the client, themselves and the general
public. Risk, or the potential for something to go wrong, creates an emotional response
undermining therapists’ sense of control and this leads to a default position of risk
elimination. Where fear ruled decisions, the participant’s choice was often made in favour of
‘safety’ or ‘duty’ over dignity and thus authority over autonomy. The therapists’ fear driving
risk management was also influenced by organisational expectations, incident management
processes and the potential for litigation in the event of harm. Preventing risk in the first
place was regarded as a method for avoiding litigation. What was lost in this tension is the
understanding of the dignity violations through social process, such as the intrusion of
personal space, labelling clients as difficult or naughty, or contempt of a person’s worth (12).
Therapists spoke about learning from previous experiences in a positive way that enabled
them to have increasing confidence so that they could become less conservative in their
approach to risk, and not override client preferences.

Limitations
The data collection period was constrained by the limitations of the research grant timelines and recruitment was slow; however, there was considerable variation in the sample with regards to length of time since graduation and experience working with clients with brain injury as well as across different service delivery contexts. The number of participants with very little experience was low despite theoretical sampling seeking these individuals; this outcome may have been because less experienced therapists were reluctant to expose themselves to judgement through sharing of their clinical reasoning. The study may have attracted more therapists with a high tolerance for risk to volunteer due to the nature of the investigation and the framing of the topic. As in all qualitative studies the findings are bound by the context of the study the reader will need to make a judgement of the transferability of the findings as they relate to their own discipline, sector and setting. Given the situatedness of the theory it is likely to hold for other settings and other health disciplines in Australia but that may not be the case in different health systems in other countries. The developed theory is grounded in the data which will benefit from further empirical testing with other groups.

Clinical Implications

Occupational therapists and physiotherapists’ dignity work could incorporate the weighing up process within their existing clinical and ethical reasoning frameworks and processes. Workplace supervision arrangements could explicitly support staff to reflect on how they manage their power appropriately within the therapeutic relationship. The participants in this study identified factors that contribute to their difficulties in managing dignity of risk. These included inexperience, lack of guidance, competing priorities, or limited awareness of the relevance of dignity. Previous researchers have also indicated barriers to promoting dignity including a lack of knowledge (7, 9), stress or lack of time (24), confusion and fear related to legal responsibilities (10) and a lack of mentoring or supervision (16). This suggests that providing good supportive supervision would be one strategy to increase novice therapist
knowledge, reduce their stress, and fear of reprisals. Undergraduate curriculum could specifically include learning outcomes framed around the social processes that violate and promote dignity and integrate these with learning outcomes that address risk management skills.

**Qualitative Rigour**

To evaluate the rigour used in our research, we drew on the four criteria proposed by Charmaz (20) for critique of constructivist grounded theory. These are credibility, originality, resonance, and usefulness. Credibility can be assured by our sample size and our systematic process of analysis including use of multiple data analysts and memoing to minimise bias. The demonstration of clear links between our data and the reported findings using quotes also supports credibility. Our research is original as it builds on the concept of dignity of risk that has been explored in the aged care context and gives new insights in decision-making processes of therapists working to maintain and support dignity for a vulnerable and ‘at risk’ population (i.e. people living with brain injury). Resonance of the research was assured through employing maximum variation and theoretical sampling to ensure multiple perspectives contributed to the development of the theoretical categories. Resonance was established through the inclusion of a stakeholder forum in November 2018 which included research participants and other invited guests from the brain injury field. The purpose of this was to check if our theory had ‘grab and fit’ in practice contexts, to support theoretical sensitivity (20) and as a form of knowledge translation. The findings were well received at the stakeholder forum giving support for its ‘grounded’ nature.

The ‘weighing up’ theory contributes to unpacking the ‘black box’ of situational analysis and decision-making processes that therapists enact when working in goal-directed practice with their clients. This study relied on the experiences of occupational therapists and
physiotherapists. Whilst there were some differences between types of risk identified between occupational therapists and physiotherapists, their process for managing risk were consistent. Similarly, the experiences of therapists in community and acute settings were consistent. However, both these areas may be worthy of further research. Future studies could also explore other allied health experiences of and management of dignity of risk in relation to their clients. It is likely that management of risk and the tensions described for therapists in this study are also present with other client groups.

**Conclusion**

We explored how occupational therapists and physiotherapists manage dignity of risk in the rehabilitation and community settings when working with clients with a brain injury. The findings extend theoretical advances in dignity work by identifying the social process of weighing up as a collaborative and client centred interaction between therapist and client to promote dignity of risk. Key elements of control, empowerment, support, and advocacy are critical in managing the tensions of balancing therapist expertise against client experience, and therapist authority against client autonomy. Effective management of power within the therapeutic relationship can facilitate occupational therapists and physiotherapists to reduce dignity violations and the subsequent harms to health for people living with a brain injury.

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**Declaration of Interest**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.
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Figure 1: Overview of grounded theory of weighing up