

“I’m Trying to Stop Things Before They Happen”: Carers’ Contributions to Patient Safety in Hospitals

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Bronwen Merner¹, Sophie Hill¹, and Michael Taylor²

Abstract

Patient safety policies increasingly encourage carer (i.e., family or friends) involvement in reducing health care–associated harm in hospital. Despite this, carer involvement in patient safety in practice is not well understood—especially from the carers’ perspective. The purpose of this article is to understand how carers of adult patients perceived and experienced their patient safety contributions in hospital. Constructivist grounded theory informed the data collection and analysis of in-depth interviews with 32 carers who had patient safety concerns in Australian hospitals. Results demonstrated carers engaged in the process of “patient-safety caring.” Patient-safety caring included three levels of intensity: low (“contributing without concern”), moderate (“being proactive about safety”), and high (“wrestling for control”). Carers who engaged at high intensity provided the patient with greater protection, but typically experienced negative consequences for themselves. Carers’ experiences of negative consequences from safety involvement need to be mitigated by practice approaches that value their contributions.

Keywords

carer; caregiver; family member; patient safety; adverse event; medical error; harm; hospital; qualitative; grounded theory; Australia; Asia-Pacific

Introduction

“Patient safety” is the term used to describe the collective efforts of health systems, services, and practitioners to reduce “the risk of unnecessary harm associated with healthcare to an acceptable minimum” (Runciman et al., 2009, p. 21). Despite more than two decades of such collective efforts to improve patient safety, preventable health care–associated harm (particularly in hospitals) remains a significant issue (Lamont & Waring, 2015). It has been consistently demonstrated that adults at greatest risk of experiencing health care–associated harm include people with communication disabilities, intellectual disabilities, dementia, and frailty (Bail et al., 2015; Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008; Thornlow, 2009; Webber, Bowers, & Bigby, 2010). Over time, policy efforts to improve patient safety have gradually recognized the potential of carers to partner with staff to prevent health care–associated harm (Agency for Health care Research and Quality, 2013; Australian Commission on Safety and Quality in Health Care, 2017; Sign up to Safety Patient Engagement in Patient Safety Group, 2016). Carers are defined as people who “provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or general frailty”

(Australian Commission on Safety and Quality in Health Care, 2012, p. 7). Carers can be particularly valuable in hospitals, with patients most vulnerable to adverse events due to disability, chronic illness, or frailty often relying on a carer to support them during their admission (Hemsley, Werninck, & Worrall, 2013; Iacono & Davis, 2003; Webber et al., 2010).

Policy Approaches Promote Partnering With Carers in Patient Safety

In many countries, carers are viewed as stakeholders in patient safety policy (Agency for Healthcare Research and Quality, 2013; Sign up to Safety Patient Engagement in Patient Safety Group, 2016; World Health Organization, 2017). In Australia, the main regulatory instrument shaping safety and quality in hospitals, the National Safety and

¹La Trobe University, Melbourne, Victoria, Australia

²Australian Catholic University, Fitzroy, Victoria, Australia

Corresponding Author:

Bronwen Merner, Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University, Bundoora, Melbourne, Victoria 3086, Australia.
Email: b.merner@latrobe.edu.au

Quality Health Service Standards (Australian Commission on Safety and Quality in Health Care, 2017), requires health providers to work in partnership with carers to improve patient safety in clinical areas such as infection control, preventing pressure injuries, medication safety, identifying clinical deterioration, falls prevention, and clinical handover. Such policy approaches assume that in practice, carers and health practitioners will work together to protect the patient. But there is currently limited research about whether this assumption is reflected in practice, particularly so from the carers' perspective.

Carers' Experiences and Perceptions of Contributing to Patient Safety

At present, the carers' voice in patient safety research is limited. Research focused on carers in hospitals often focuses on the carer's general role in supporting the patient rather than their safety-specific role. Although these studies have provided some insight into carers' safety contributions, for example, that carers advocated for the patient (Hemsley & Balandin, 2004; Hemsley, Balandin, & Togher, 2008; Lindhardt, Bolmsjö, & Hallberg, 2006), stood guard over the patient (Lindhardt et al., 2006), kept a check on practitioners (Lindhardt et al., 2006), gave information to staff (Hemsley et al., 2008), and helped patients communicate with staff (Hemsley & Balandin, 2004; Hemsley et al., 2008), studies with an exclusive, in-depth focus on carers' contributions to safety are lacking.

Studies of patient safety in hospitals that involve similar populations (e.g., carers who are family members) or mixed populations report similar actions as shown in the carer-focused/general contribution studies (Lam & Beaulieu, 2004; Manias, 2015; Oyesanya & Bowers, 2017; Rainey, Ehrich, Mackintosh, & Sandall, 2015; Rathert, Brandt, & Williams, 2011). The findings of these studies tend to emphasize monitoring the patient's progress and condition rather than assisting patients to communicate with staff. Although these studies are informative and demonstrate that carers may make some contribution to patient safety, it is unclear whether these findings are representative of the carers' voice specifically.

The limitations of contemporary evidence about carers' contributions to patient safety lead to gaps in policy makers' and researchers' knowledge of (a) the circumstances that prompt carers to contribute to safety, (b) the ways that different carers can contribute to safety, and (c) the consequences for carers of their safety contribution. These gaps are particularly relevant, given current policy approaches assume carers and health care practitioners will work together to improve safety. A focused study of carers' perceptions and experiences of contributing to patient safety in hospital, as presented here, is needed to contribute to filling these gaps.

Method

Study Aim and Approach

The aim of this research was to understand how carers of adult patients perceived and experienced their contribution to patient safety in the hospital. To achieve this aim, the objectives were to (a) explore why carers contributed to patient safety, (b) analyze the different ways in which carers contributed to patient safety, and (c) understand the perceived consequences of carers' safety contributions, from the carers' perspective.

The methodology chosen was constructivist grounded theory (Charmaz, 2014). This is a contemporary version of grounded theory that focuses on the production, quality, and use of data, as well as attending to the research relationship and context, and the subjectivity of the researcher (Charmaz, 2014). The theoretical perspective informing the study was symbolic interactionism. Symbolic interactionism recognizes that we act in situations in response to how we perceive them (Charmaz, 2014). Also, our actions, and those of others, may affect these situations, leading us to alter our perceptions of what is happening and hence adjust our future actions. Symbolic interactionism fits well with constructivist grounded theory because it focuses on the relationships between meanings and actions, and the processes through which people create these meanings (Charmaz, 2014). It also encourages constructivist grounded theory researchers to focus on how our own meanings influence the research, including what we ask of our participants, how we interact with them, and how we render their accounts (Charmaz, 2014).

Setting, Sampling, and Data Collection

In the study, carers were defined as adults who "provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or general frailty" (Australian Commission on Safety and Quality in Health Care, 2012, p. 7). With ethics approval from the Human Research Ethics Committee at La Trobe University (application number 13-069), a maximum variation sampling strategy was used to recruit participants (Patton, 2002). We sought carers supporting people with a wide range of diagnoses, across different hospitals visited and in different geographical locations. Using this sampling approach enabled identification of relevant processes across geographical boundaries, hospital environments, and patient needs.

Consistent with our maximum variation sampling strategy, the researchers advertised the study through a wide range of national- and state-based community organizations in Australia. These organizations included carer-specific organizations, patient safety-specific organizations, general health consumer organizations, and a

number of medical illness/condition-specific organizations. Recruitment advertisements were placed in their monthly bulletins, on their websites, through social media and/or through web-based mail-outs to members.

Potential participants expressed interest in participating in the study through phoning or emailing B.M. B.M. then arranged a mutually convenient time with each individual for a brief phone call to discuss the eligibility criteria and explain the requirements of the study. During this phone call, eligible participants were required to pass a two-stage screening process. First, they needed to meet the following criteria: (a) they were a carer for an adult patient who was admitted to hospital after January 1, 2013 (when the National Standards were introduced in Australian hospitals), (b) they visited the patient at least once during the hospitalization, and (c) they had concerns about the patient's care during the admission. In the second stage, participants' concerns about the patient's care were explored further to ensure their experiences related to actual or potential harm. Participants who passed both stages were then provided with a verbal explanation of the study, including the time commitment required of participants and the anticipated nature of their participation. If the participants were still interested in taking part in the study, they were then sent a participant information statement via post, outlining the requirements of the research, as well as the anticipated benefits and harms to assist them in deciding whether to participate. Participants were offered an AUD30 supermarket voucher as a sitting fee for their involvement. Agreement to participate was signified by a returned (and signed) consent form. Each participant's verbal consent was also obtained prior to the commencement of the interview.

Forty-five people expressed initial interest in participating in the study. Thirty-two passed both screening stages and were interviewed. Of the remaining 13 potential participants, six did not respond to B.M.'s request for a follow-up phone call after they first made contact, five did not meet the Stage 1 screening criteria, one did not meet the second stage criteria, and one did not return the informed consent form. Although participants were free to withdraw from the project at any time, no withdrawals occurred during the project.

Individual, intensive interviews with 32 carers were conducted by B.M. between March 2014 and August 2015. Intensive interviews were chosen as the data source because they allowed the exploration of the participants' feelings, thoughts, and intentions, as well as the meanings they attached to different events (Patton, 2002). A topic guide was used during interviews (see Supplementary Appendix 1) that reflected the symbolic interactionist theoretical perspective taken in the research. Thus, questions focused on how participants changed (or did not change) their actions over time and why. As data collection and analysis occurred

simultaneously, theoretical sampling was used to seek information that would illuminate tentative categories emerging in the data (Charmaz, 2014). To seek this information, the topic guide was regularly revised to include topics that would probe the tentative categories. Two examples of topics added included the relationship between carers' trust of health practitioners and patient safety actions, and how knowing the system influenced carers' safety contributions. Theoretical sampling continued until there were no new properties emerging of the three main concepts comprising the constructivist grounded theory of the process of patient-safety caring ("contributing without concern," "being proactive about safety," and "wrestling for control"). At this point, theoretical saturation had been reached and data collection stopped (Charmaz, 2014).

Carers were recruited from three Australian states/territories: Victoria ($n = 23$), the Australian Capital Territory ($n = 8$), and New South Wales ($n = 1$). Most interviews were conducted face-to-face ($n = 27$) in a venue of the participant's choice (e.g., home, nearby cafe). Five participants opted for a telephone or Skype interview. Mean interview duration was 1 hour, but ranged from 30 minutes to 2.5 hours. All interviews were recorded and transcribed verbatim. All participants were offered the opportunity to member-check their transcripts, and around 40% actually did so.

Data Analysis

In the initial coding stage, B.M. coded the early transcripts line-by-line with gerunds, consistent with the symbolic interactionist emphasis on identifying actions and processes. NVivo software was used to store the coded data (QSR International, 2012). Examples of line-by-line codes were "addressing the snapshot rather than the whole," "being there," and "being an expert." Early memos (or informal analytic notes) were also written at this stage to probe what was happening in the participants' accounts. Memo writing is a crucial step in grounded theory because it prompts the researcher to analyze the data and codes early in the process (Charmaz, 2014). The prompt questions used to probe the data in early memos were reflective of the symbolic interactionist theoretical perspective of the research. For example, "what are the participants doing?" and "what do participants' actions and statements take for granted?" maintained the focus on the participants' actions and the meanings shaping them.

Focused coding began once the initial coding yielded strong analytic directions in the data. Focused coding involved using the most significant initial codes (e.g., noticing deterioration, picking your battles) as well as more frequent codes (e.g., knowing the patient, perceiving the patient's vulnerability) to sift through large chunks of data. These codes were tested against the data to see whether

they were adequate to categorize large amounts of data in ways that made the most analytic sense. At this stage, advanced memos were written that focused on understanding and distinguishing between the properties of the main concepts of the process of “patient-safety caring.”

Throughout data analysis, the constant comparative method was used to establish analytic distinctions (Charmaz, 2014). Our emphasis on actions and processes led us to compare actions and incidents within the same participant’s account and then across participants. Through these comparisons, it emerged that some participants acted with more intensity in response to perceived safety hazards than others. This led us to probe the data further for the historical, social, or situational conditions or circumstances that were more likely to affect the intensity of the response. We used theoretical sampling during interviews to further explore these conditions. For example, early in the data collection, we theorized that carers may become more intense in their actions when speaking with nurses rather than doctors. Thus, we added a question to explore this to the topic guide. However, we found the explanation did not resonate with participants and so ultimately removed it from our analysis.

Further analysis led to the refinement of the constructivist grounded theory of the process we referred to as “patient-safety caring.” The process involved the following three concepts: contributing without concern, being proactive about safety, and wrestling for control. These concepts encompassed temporal sequences with beginnings and endings that were linked in a process that led to change in carers’ intensity of safety involvement. An example of the coding tree (initial code to focused code to theoretical concept) is shown in Supplementary Appendix 2.

The rigor of the research was ensured in different ways. First, B.M. discussed all stages of the research process with S.H. and M.T. These discussions included an examination of whether the raw data matched the initial codes, whether the focused codes were inclusive of the initial codes, and whether the theoretical concepts reflected the data set. B.M. also kept a research journal that helped her to be aware of the assumptions and potential biases she brought to the data collection and analysis in her different roles as a student researcher, allied health practitioner, and patient. The constructivist grounded theory of the process of patient-safety caring was also presented to a meeting of the peak lobby group for carers in Victoria. The group felt the theory was highly plausible and generally reflected the experiences of their membership.

Results

Description of the Participants

The 32 participants ranged in age from 24 to 74 years, with a mean age of 56 years. Most participants were

female ($n = 29$) and university educated ($n = 23$). The majority of participants were support for a parent (or parent-in-law) ($n = 12$) or were patients’ partners ($n = 10$). Two participants reported speaking a language other than English at home.

Participants supported patients with a wide range of underlying medical conditions, illnesses, or diseases (including intellectual disabilities, dementia, frailty, physical disabilities, chronic diseases, and mental illnesses). Most participants ($n = 23$) visited the patient at least daily during their admission, with some participants staying continuously at the bedside. See Supplementary Appendix 3 for safety threats and harms reported by the participants.

The Process of Patient-Safety Caring

The constructivist grounded theory of the complex social process described here as “patient-safety caring” is presented in Figure 1. The process involved three main concepts, reflecting the different intensity with which different carers contributed to patient safety during a hospital admission. These concepts, in order of increasing intensity of patient-safety caring, were (a) contributing without concern (low intensity), (b) being proactive about safety (moderate intensity), and (c) wrestling for control (high intensity).

Figure 1 shows each concept was characterized by a set of conditions, actions, and consequences. Depending on the historical, social, or situational conditions or circumstances faced by the carer during the current or a previous admission, carers entered the process of patient-safety caring at a particular level of intensity. For example, a carer who had positive prior experiences of hospitalization with the patient would be more likely to enter at “contributing without concern,” whereas a carer who knew there were gaps in hospital processes would be more likely to enter at “being proactive about safety.” Carers’ safety actions could become more intense (indicated by the dotted line between concepts in Figure 1) if they faced new conditions during an admission. For example, a carer who commenced the hospital admission at the intensity of “being proactive about safety” could move into “wrestling for control” if they experienced the patient suffering harm during the hospitalization. Engaging in patient-safety caring at different levels of intensity resulted in different consequences. For example, engaging at “contributing without concern” could result in feeling guilty after an adverse event, whereas engaging at “wrestling for control” could result in experiencing hostility from staff.

The three concepts of patient-safety caring are described in detail below. For clarity, the individual actions, conditions, and consequences within each concept are italicized. Further data supporting each of the concepts is shown in Supplementary Appendices 4 to 6.

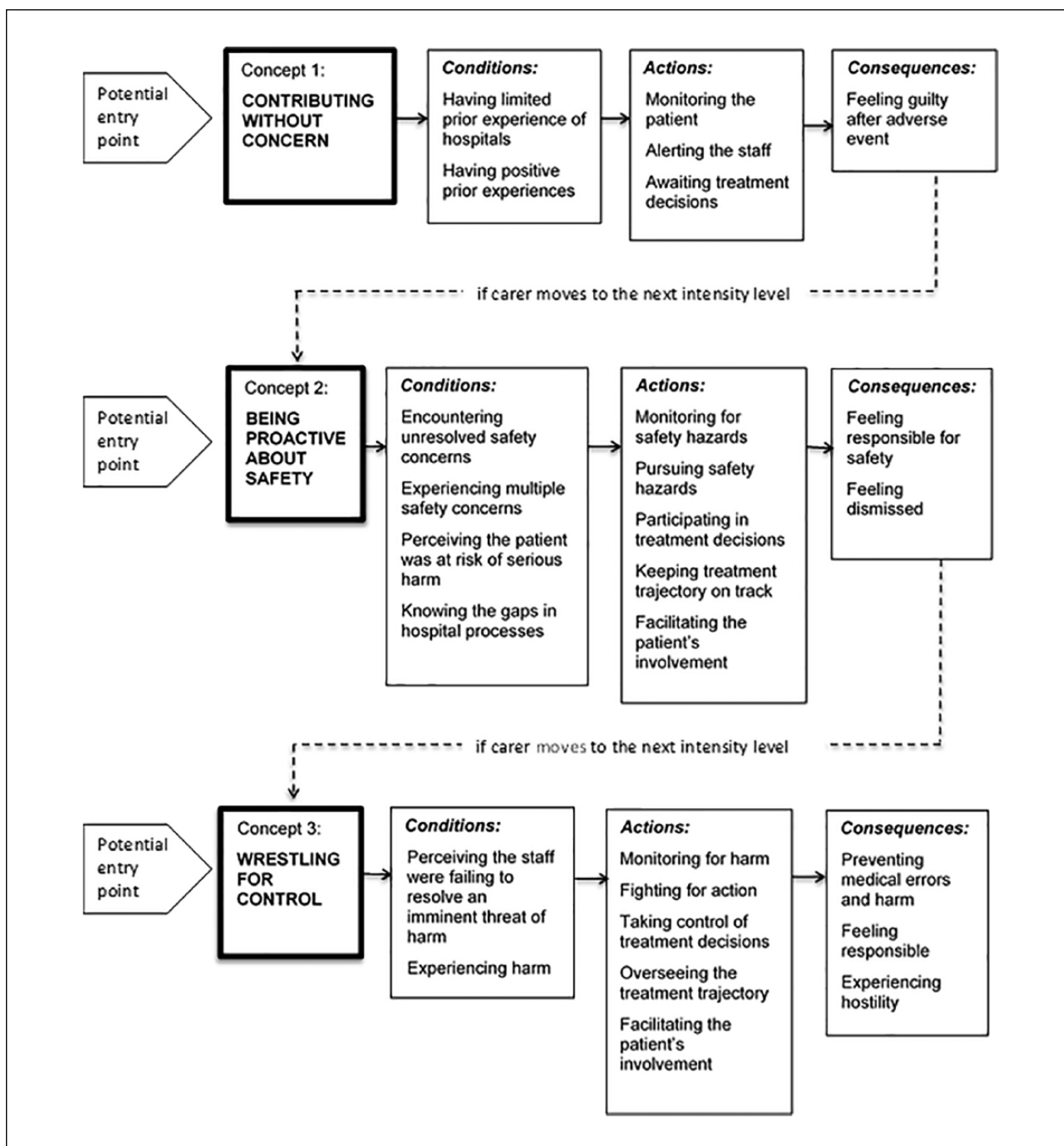


Figure 1. The process of patient-safety caring.

Contributing without concern: Low intensity. Carers who engaged in “contributing without concern” (low-intensity patient-safety caring) were keen to contribute to the patient’s general care, but were not concerned specifically about safety. They engaged in safety actions requiring less assertiveness with staff. This concept involved a minority of participants ($n = 5$). Further primary data to support each of the conditions, actions, and consequences

of “contributing without concern” are shown in Supplementary Appendix 4.

Conditions. Carers who engaged in low-intensity patient-safety caring were those *having limited prior experiences of hospitals* or *having positive prior hospital experiences*. This meant carers’ trust in health practitioners was generally high, their level of concern

about safety issues was low, and though they contributed actively to general caring, their contribution to safety was typically indirect. For example, one participant explained why she was not more assertive when her husband was discharged prematurely with a serious head wound:

I'd probably be much more assertive [next time] . . . and I am quite assertive I think I was just . . . [my husband] has been to the [same hospital] on a few occasions and they've always been wonderful so this was a real surprise to me.

Actions. A key action at this level was *monitoring the patient*, which mostly involved looking for visible signs of deterioration. One participant stated,

[My mother was admitted on] Friday and the Saturday morning we went down to see her and she was like a zombie. And so she was, obviously, doped up to the eyeballs. So that, that was a real shock . . . I was really distressed and I went and saw the nurse.

Another action was *alerting the staff* to safety hazards. Safety hazards were those things or actions that carers perceived presented a threat to the patient's safety. Potential hazards identified by carers contributing without concern included issues with clinical deterioration, the side effects of scheduled treatments, and the patient being discharged before he or she sufficiently recovered.

Finally, carers contributing without concern *awaited treatment decisions* from the medical team. Carers at this level were typically reluctant to question or challenge treatment decisions.

Consequences. At the low intensity of contributing without concern, the main consequence for carers was they could *feel guilty after an adverse event* occurred during the admission. For example, a participant expressed regret for not speaking up when her son's medication was stopped suddenly (leading to a seizure):

But after this doctor say "stop [the] medication," I didn't have [a] second thought. I just . . . forget about it. Just get on. But I just think, if I were more suspicious or ask[ed] [a] different doctor or find out more information about this medication . . . Is it really safe [to stop the medication suddenly]? . . . I can do better, you know. Yeah. I can do better.

Being proactive about safety: Moderate intensity. "Being proactive about safety" involved those carers engaged in moderate-intensity safety actions. Their actions were typically assertive, but not forceful, and in the spirit of cooperation, rather than confrontation. Carers at this level had a greater awareness of different patient safety hazards and how to prevent them than those at low

intensity. Twenty-nine participants engaged in moderate-intensity patient-safety caring at some stage during the patient's hospitalization. Further primary data to support each of the conditions, actions, and consequences of "being proactive about safety" are shown in Supplementary Appendix 5.

Conditions. Some carers who began the admission contributing without concern increased the intensity of their safety actions to moderate (being proactive about safety). This typically occurred when carers faced one or more of the following conditions: *encountering unresolved safety concerns*, *experiencing multiple safety concerns*, and/or *perceiving the patient was at risk of serious harm*. As one participant explained,

If Dad needed an extra blanket, big deal. But, if they're not getting medication they need and they can't walk or they're choking . . . you learn really quick when it's life-threatening and, you know, so serious. So you have to. You have to find a way.

Carers could also commence an admission engaging in moderate-intensity patient-safety caring rather than starting at the lower intensity. These were carers who had spent time in hospitals previously and learnt about the *gaps in hospital processes*. For example, a participant explained,

And you say "Go back [to the medical record]" and they say "Oh it's all in the computer" but it's not. They try and give him medication that you say "Well, no, he's allergic."

The presence of these conditions meant carers retained some trust in health practitioners but realized they, themselves, also needed to be proactive if safety hazards were to be adequately addressed.

Actions. *Monitoring for safety hazards* reflected that carers at a moderate intensity had an awareness of a greater range of different patient safety hazards and how to prevent them than those at low intensity. Monitoring for safety hazards involved observing the patient for threats and harms, including clinical deterioration; development of hospital-acquired infections; development of pressure sores, falls, errors, or harms associated with dispensing of medication; development of errors or harms relating to the patient's diet and nutrition; as well as a range of other threats or harms to the patient's physical and/or emotional well-being.

Consistent with a more proactive approach to patient safety, carers acting with moderate intensity were more dedicated toward *pursuing safety hazards*. This contrasted with carers at low intensity, who generally alerted

staff and waited for the staff to act. For example, a participant recalled needing to be proactive in getting pain relief for the patient:

I can remember one occasion . . . when they're doing the fluid extraction from the lungs, which is enormously painful. And I remember trying to make sure that the staff knew what had happened last time [fluid was extracted] so that this time they could administer some prophylactic pain relief so that it wasn't so excruciating.

At a moderate intensity of patient safety action, carers' trust in health practitioners to make the right decisions needed verification. As such, they realized they needed to be more proactive in *participating in treatment decisions*:

So you, as a carer, you also have to reinforce the message because you often get the perception that they want you to say he's A-Okay, and they want them to move out, to be discharged, [as they] want to free the bed. And you have to be honest in how you perceive things because actually last year my brother was discharged after four months, and it was totally inappropriate.

Keeping the treatment trajectory on track involved actively encouraging safe delivery of the patient's treatment. To do this, some participants would ensure they were present when new staff were rostered on, so they could update them on the latest developments in the patient's care and treatment.

Facilitating the patient's involvement in safety referred to the carer intervening to assist or encourage the patients to protect themselves from harm. These actions were limited to those carers supporting patients who had (at least some) decision-making capacity. Examples of facilitating the patient's involvement included supporting the patient to make treatment decisions, encouraging the patient to ask for help when needed, and assisting the patient to give accurate information to staff.

Consequences. There were two main consequences for carers who engaged in "being proactive about safety." The first consequence was carers' *feeling responsible for safety*:

So I try to sort of get there at the crack of dawn or whenever they allow you in, and then leave when, as late as they're ready to throw you out. I'm trying to stop situations before they happen because I'm scared.

The second consequence was *feeling dismissed* by staff in their safety concerns. Many carers found their concerns were often disregarded or ignored by the staff:

And all night this nurse kept coming in, shoving stuff into his drip, and we kept saying "What's that?" "Diazepam . . . diazepam . . . diazepam . . . just to stop the spasticity." And I said "But he doesn't *have* spasticity." "Yeah, look, we know what we're doing. We know what we're doing."

Wrestling for control: High intensity. "Wrestling for control" represented the highest intensity of patient-safety caring in the participant group. Carers who wrestled for control engaged in more assertive, and sometimes aggressive, safety actions as they desperately sought to achieve an outcome they perceived would keep the patient safe. Twenty participants engaged in high-intensity patient-safety caring at some stage during the patient's hospitalization. Further primary data to support each of the conditions, actions, and consequences of "wrestling for control" are shown in Supplementary Appendix 6.

Conditions. Carers who moved from being proactive about safety to wrestling for control were generally those who faced the following two conditions: *perceiving the staff were failing to resolve an imminent threat of harm* and/or *experiencing harm*. As a result of these conditions, carers' trust in the staff to protect the patient from harm was very low or nonexistent and thus the need to become more assertive in their patient safety actions. For example, a participant became more assertive as she experienced staff failing to resolve an imminent threat of harm:

When we go to hospital and [my daughter] turns up with her adrenal crisis that needs urgent attention, with a protocol letter that says "Treat me urgently or I can die" three times out of the last four times we've gone to hospital we've had to fight with them about that, even though she has that letter. We've had to fight and fight and fight to get the help.

Actions. *Monitoring for harm* involved watching vigilantly to avoid the patient experiencing unnecessary harm. Consistent with carers' other actions at this intensity, their approach when they detected the patient was at risk of harm was more assertive than at low and moderate levels of intensity. One participant decided to accompany her husband to X-ray when she became concerned he was being taken for the wrong test:

They were going to take him for a chest x-ray, and I said to them "A chest x-ray? I thought he had one of them a couple of days ago. Hang on! No. I'm coming with you. I don't, there's something not right in what you're telling me."

Fighting for action on safety hazards generally resulted from carers' frustrations with a lack of staff action about safety hazards. Fighting for action represented carers' willingness to resolve serious safety hazards at all costs, including risking alienating the staff:

I raised merry hell about [the patient's oxygen being disconnected] because I was really cross and the [nurse] said to me "Well we thought she was going to be moved really quickly." I said "I'm sorry, this is actually not okay" you know. Like "She's actually there. She's really, really vulnerable and she's got no oxygen, and you still can't tell me when she's going to move. Get the [expletive] oxygen!" I lost it completely.

Taking control of treatment decisions occurred when carers wrestling for control perceived wrong treatment decisions were being made for the patient. In taking control of decisions, carers risked alienating the staff. However, carers were more willing to take this risk given the perceived high risk to the patient of not acting. For example, one participant told the staff she would not leave the ward until she was involved in a treatment decision about her friend, for whom a double leg amputation was proposed.

Overseeing the treatment trajectory was similar to *keeping the treatment trajectory on track* in "being proactive about safety," with one additional feature: case management. Becoming a quasi-case manager demonstrated the carer's need to wrestle back control of the patient's treatment trajectory, for fear the staff would overlook vital treatments or appointments:

You've got to do a checklist . . . You ring him up and say . . . "have they given you medication? . . . Has your dressing been changed?" . . . 'Cause, do you have to ring up the hospital and say "[the patient's] supposed to have his x-ray today" or "[the patient's] supposed to have his nephrology visit."

Facilitating the patient's involvement in safety at a high intensity of patient-safety caring involved the same actions as described for this action in moderate intensity.

Consequences. At the intensity of wrestling for control, carers perceived a positive consequence of their actions for the patient, but negative consequences for themselves. The positive consequence they perceived for patients was *preventing medical errors and harm*. This involved preventing or allowing premature death, preventing medical errors and harm, and buffering the impacts when harm did occur. For example, a participant who moved from being proactive for safety to wrestling for control after her son experienced harm recalled, "If you didn't have somebody like us [me and my husband] there, then [my son] would not have survived, I don't believe." Carers at this intensity of patient safety action perceived they prevented at least one medical error that may have resulted in physical or emotional harm for the patient. These errors included medication errors, hospital-acquired infections, pressure injuries, falls, clinical deterioration, and communication

errors between staff.

The perceived positive consequences for the patient at wrestling for control were offset by the negative consequences for carers themselves. As for carers in being proactive about safety, carers wrestling for control also experienced *feeling responsible* for safety as a consequence. Added to the feelings of responsibility felt by those engaging in moderate-intensity safety actions, many carers at high intensity felt frustrated and angry the patient's safety relied on them undertaking tasks they believed were the staff's responsibility. These carers felt undertaking safety tasks deprived them of the opportunity to either have time away from caring or to spend quality time with the patient. Occasionally, carers accepted safety responsibilities as a part of their caring role, but felt the hospital could be more supportive of their assistance.

As carers often needed to take assertive, and sometimes aggressive, action for safety, *experiencing hostility* from staff was common. Experiences of hostility included sensing the health practitioner's disapproval, being told by the medical team not to intervene in the patient's care and treatment, making the carer feel guilty, and experiencing conflict.

Discussion

To our knowledge, this is the first in-depth study specifically focusing on the safety contributions of carers of adults with a range of support needs. Many of the patient safety actions identified in this study are supported by the safety-relevant findings of carers' general contributions in hospital. These included monitoring the patient's progress and condition, keeping a check on practitioners, and facilitating the patient's communication (Hemsley & Balandin, 2004; Lindhardt et al., 2006; Oyesanya & Bowers, 2017). The results of this study support and extend these findings by demonstrating there are a range of intensities within each of these actions. Thus, monitoring the patient's progress and condition may range from monitoring the patient (low intensity), to monitoring for safety hazards (moderate intensity), to monitoring for harm (high intensity). Similarly, keeping a check on health practitioners may range from keeping the treatment trajectory on track (moderate intensity) to overseeing the treatment trajectory (high intensity). Advocating for the patient, a type of action suggested by previous research, was also supported by the findings of the current study; however, it emerged in two different ways. The first involved advocating for a response to a safety concern (alerting the staff, pursuing safety hazards, and fighting for action) and the second involved advocating during treatment decision making (awaiting treatment decisions, participating in treatment decisions, and taking control of treatment decisions).

The results of the current study also contribute to existing knowledge by theorizing why carers engaged in a particular intensity of safety action, and why their actions could become more intense over the course of a hospital stay. Often, carers increased the intensity of their contribution because they became less trusting of the staff to keep the patient safe, and thus felt they needed to become more proactive in their own safety role. The existing literature shows lower levels of trust could lead to greater involvement in patient safety. In particular, having less trust in health practitioners was linked with reports of needing to be present to a greater extent on the ward (Iacono & Davis, 2003; James, Andershed, & Ternstedt, 2009; Rainey et al., 2015). The results of the current study demonstrated that in addition to an increase in spending time with the patient, loss of trust could lead carers to become more assertive in their attempts to protect the patient. As their trust diminished, carers began to challenge staff, ask for meetings, request safety actions, and, if they were sufficiently concerned, wrestle for control. In this way, rather than solely engaging in increased presence as protection, carers also changed their safety actions to become more assertive.

The consequences for carers who engaged in patient safety actions were perhaps the most important findings of this research. Although we anticipated carers would make at least some contribution to protecting the patient from harm, the high level of assertiveness needed by carers to secure a positive safety outcome was unforeseen. This shows how potentially difficult it is for carers to prevent errors, even when they can see them coming. A possible reason carers needed a high level of assertiveness could have been that their safety actions were perceived by staff as intruding on their technical expertise (Rodriguez, 2015). Future research, including the views and experiences of staff members about carers' involvement in safety, would help to support or dismiss this explanation. Also, given the carers who were the most assertive became that way only when they perceived the risk to the patient was very high shows how reluctant the carers were in general to potentially upset the staff. Carers' concerns that they would negatively affect their relationship with staff by raising safety concerns are supported by the existing literature (Davis, Savvopoulou, Shergill, Shergill, & Schwappach, 2014).

The negative consequence of feeling responsible for safety was a particularly notable finding. Previous research by Rathert et al. (2011) showed family members felt anxious when leaving the patient alone in the hospital, suggesting they felt some responsibility for their safety. Our finding builds on this research by theorizing that increased feelings of responsibility for safety stem from carers' perceptions that the staff do not listen to their safety concerns. When the staff do not take action about safety issues, carers feel they cannot rely on the staff to

keep the patient safe from harm and therefore start assuming this responsibility.

Implications for Policy and Practice

Working in partnership with carers is an important policy objective as well as a key principle underlying person-centered care (Institute for Patient and Family-Centered Care, 2018). The results of this study showed that carers perceived they worked in isolation, rather than in partnership with staff. This perceived lack of staff support led to negative consequences for carers, particularly by increasing their feelings of responsibility. Solutions to this lack of partnership in safety require a greater emphasis on person-centered care, which is respectful and inclusive of the views and experiences of patients and carers (Entwistle, 2007; Hovey et al., 2010).

Person-centered strategies to increase feelings of partnership for carers could include staff providing regular, structured opportunities for carers to share information and raise safety concerns, such as during bedside ward rounds or family meetings. Encouraging (though not requiring) carers to share their observations of the patient's progress, supporting carers to ask questions about particular treatments or medications, and allowing the carer to accompany the patient during diagnostic tests or procedures may also help carers to feel valued. Such strategies should ideally be accompanied by training for staff to recognize the valuable contribution that carers can make to safety. In addition, when carers feel their contributions (including safety contributions) are valued, they may feel more comfortable to both raise concerns, in the first place and, second, have more trust in the staff to resolve them (Entwistle, 2007).

The results also suggest health practitioners should be aware that carers contribute to safety in different ways and at different intensities. Those carers with more experience of the hospital system may engage in more proactive safety actions, whereas those with less experience may have a reduced repertoire of safety actions. Irrespective of intensity level, responding positively when carers raise concerns is likely to help carers feel valued, less anxious about the patient's care, and less of a personal responsibility for the patient's safety.

Strengths and Limitations

The results of this study reflect the experiences of the participants, but do not intend to explain the experiences of all carers of contributing to patient safety. Recruiting participants from the community across southeast Australia potentially broadened the applicability of these results though, through a wider sampling base and potential diversity of experiences.

Targeting carers who perceived there were safety problems, but had not necessarily experienced (or reported) an adverse event was a strength of this study. This population is more reflective of routine, rather than extreme hospital experiences, therefore potentially increasing the applicability of the theory to a wider range of care experiences. Focusing on this population also promoted an analysis of adverse event prevention, rather than just response. An important caveat, however, is that there may be intensities of patient-safety caring at either end of those presented, which encompass populations outside of that studied.

A limitation of the data collection method was participants' potential for "hindsight bias" in recounting their experiences (Roese & Vohs, 2012). This may have led the participants to focus on a single causal interpretation for past events, rather than considering other reasonable explanations, and to be overconfident in the certainty of the interpretation. Although B.M. requested the opportunity to observe carers in the hospital setting from a number of hospitals in the early stages of this project, unfortunately the request was not received favorably. The reasons for this included the sensitivity of the subject matter (patient safety) and also privacy concerns related to observing carers and patients rather than staff in the hospital environment.

Directions for Further Research

Future research could explore other stakeholders' perspectives on carers' contributions to safety, such as patients and health practitioners. A study involving carer-patient-health practitioner triads, focusing on perceptions and experiences of carers' contributions to safety, would allow a broader interpretation of the carer's role.

Conclusion

Carers contributed to protecting the patient from health care-associated harm by engaging in patient safety actions at different levels of intensity, dependent on the conditions faced during the hospitalization. Carers experienced negative consequences from contributing to safety, even when they secured a positive outcome for the patient. Providing structured opportunities for carers to contribute to safety, and responding positively when they do, may help to facilitate their safety contribution in a way that minimizes negative consequences for carers. It is recommended policy efforts promoting carers as safety partners are supported by practical measures to help staff recognize the value of carers to safety and facilitate different carers to contribute in different ways. Carer contributions have substantial intangible costs for carers themselves, and policy approaches must endeavor to mitigate these harms also.

Authors' Note

Michael Taylor is now affiliated with Victorian Bar, Melbourne, Victoria, Australia.

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Author Biographies

Bronwen Merner, PhD, is a research fellow at the Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University in Melbourne, Victoria, Australia.

Sophie Hill, PhD, is an associate professor and head of the Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University in Melbourne, Victoria, Australia.

Michael Taylor, PhD, is a reader at the Victorian Bar, Melbourne, Victoria, Australia.