Stepping Across the Line: Information Sharing, Truth Telling, and the Role of the Personal Carer in the Australian Nursing Home

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The author draws on an Australian study using multiple qualitative methods to investigate truth telling in aged care. Thematic analysis of data from five nursing homes involving 23 personal care assistants revealed participants' role understanding as influencing their perceptions about truth telling in practice. Five themes emerged: role as the happy comfort carer, division of labor, division of disclosure, role tension and frustration, and managing the division of disclosure. Role emphasis on comfort and happiness and a dominant perception that telling the truth can cause harm mean that disclosure will be withheld, edited, or partial. Participants' role understanding divides labor and disclosure responsibility between the personal carer and registered nurse. Personal carers' strategies for managing the division of disclosure include game playing, obfuscation, lying (denial), and the use of nonverbals. These perceptions about personal carer role, information sharing, and truth telling are paramount for understanding and improving nursing home eldercare.

The findings represented here are taken from a much larger qualitative study in which I explored the meaning of truth telling within the care provider–older person dyad in high-level (nursing home) aged care. This article represents the findings associated with personal carers' perceptions of their role and consequent understanding of truth-telling practices in the Australian nursing home.

For the sake of clarity, in this article, the registered nurse (RN) is "a person with appropriate educational preparation, who is registered and licensed under the *Nursing Act 1992* to practice nursing" (Nesvadba, 2003, p. 6). The RN is responsible for the provision of nursing, the supervision of enrolled nurses and unregulated carers, and delegation decisions. The "second level nurse," the enrolled nurse (EN), has the appropriate educational preparation and is also licensed under the Nursing Act 1992 to practice nursing "under the direct or indirect supervision of a registered nurse" (p. 7). A personal carer, or personal care assistant PCA), also called an assistant in nursing (AIN), is an unregulated care provider who works primarily within the community and aged-care sector. The personal carer is neither regulated nor registered and cannot be described as a nurse, and the level of care provided by the personal carer is similar to that which would normally be provided by a responsible family member (Nesvadba, 2003). Furthermore, in Australia, there are two types of residential aged-care facilities. The hostel (low-level care) generally provides accommodation and personal care, such as help with basic activities of daily living and occasional nursing care. This research was undertaken in the nursing home (high-level care), where care is provided for the frail aged, who often require continuous nursing care (Commonwealth Department of Health and Ageing, 2002).

The findings about the personal carer role, information sharing, and truth telling are paramount for understanding and improving nursing home aged care. In the context of the Australian nursing home, where most of the care of residents is provided by the personal care assistants, insights into communicative practices can assist with improved quality of life of nursing home residents (Colón-Emeric et al., 2006; Edwards, Gaskill, Morrison, Saunders, & Forster, 1999).

Themes From the Literature

Within the scope of this article, the literature reviewed is relevant only to those themes expressed in the forthcoming data. Therefore, to provide an overview of themes from the literature relevant to the forthcoming themes from the data, in this abridged review, I address the caring role and carer characteristics defined by benevolence and nonmaleficence, briefly examine the Australian nursing home context and communication in it, and conclude, contrary to the nurses' understanding in the forthcoming section, that truth telling in clinical practice is not harmful and most patients want to be told the truth about their health.

The reader is directed elsewhere for a more extensive analysis of themes from the literature as they relate to truth telling in clinical practice (Tuckett, 2004b); ethical practice and the nature of the nursing home in the Australian context (Tuckett, 2005d); and care, communication, and control in the context of aged-care provision (Tuckett, 2005b).

Caring Role and Carer Characteristics

It can be claimed that compassion is an intensive form of benevolence and its companion, nonmaleficence (May, 1994). A predisposition to act according to beneficence means that a care provider acts for the good of the resident, for the resident's well-being. Beneficence has been described as "concern for the well being" (Kerridge, Lowe, & McPhee, 2005, p. 53) and, most commonly, "above all, do good" (Johnstone, 2004, p. 40). Relevant to this article is that a "nurse's open and honest communication signals to the patient that the nurse is sincerely concerned for their wellbeing" (benevolence), and "truth-telling...conveys respect [autonomy] that promotes trust and comfort in the relationship" (Appleton, 1993, p. 894).

A care provider that defines her or his practice by reference to nonmaleficence is recognized as one who refrains from acting in a way that will inflict evil or harm (Beauchamp & Childress, 2001). A care provider can generally be expected to benefit others but not everyone, although it is generally expected that a care provider not inflict evil or harm on anyone (Tuckett, 2000).

Care/caring that relies on beneficence and non-maleficence assumes that care providers can make determinations about another's best interests and act accordingly. An alternative emphasis understands care/caring as more than a benevolent, technically competent, one-way care provider interaction. Rather, the essential characteristic of care is being with the proactive recipient of the care, who is more than an object to which the care providers do things (Paterson & Zderad, 1976).

Personal Care in the Nursing Home

Universally, nursing home care is task oriented (McCormack, 2003). Task-oriented care is the provision of physical care rather than the communicative aspects of care, with the aim to get the work done, that is, to do rather than to be (Clinton, Edwards, Moyle, Weir, & Eyeson-Annan, 1996; Shaughnessey, 1989). Most of this care is performed by the less educated, often untrained personal carer (Anderson et al., 2005; "Survey Reveals Aged-Care Crisis," 1998). As described by a personal carer,

we are giving production line nursing...It's just line them up, toilet them, shower them, throw them in the dining room, give them their food, back to bed and that is their day. ("New Classification Structure," 2002, p. 8)

In addition, this home away from home (Thorman Hartig, 1998), as with other nursing care contexts, is time starved (Queensland Industrial Relations Committee, 2002, cited in "New Classification Structure," 2002). Research that has sought to determine the duration of time that nurses actually spend with their older patients has determined that a mere 4% of nurses' time was spent in interpersonal care on a geriatric ward and 50% of the interactions lasted 0.5 minutes or less (Wells, 1975, cited in May, 1990); the mean duration of a nurse–older patient encounter in one study was determined to be 4 to 6 minutes (Keck & Walther, 1977); in another study, student nurse–older patient interactions averaged 2 to 3 minutes (Faulkner, 1980). In a Queensland (Australia) study, 64% of nurse-resident interactions were identified as procedural or instrumental, 11% involved some discussion about the resident's fears or worries, and 33% of the interactions lasted less than 9.5 seconds (Edwards, Weir, Clinton, & Moyle, 1993).

Generally, in the Australian context, nursing home nurses are too busy, short of time, and short staffed (Fiveash, 1998; Legge, 2004). In Queensland, in some instances, "one Registered Nurse was caring for between 60-120 residents," and assistants in nursing and enrolled nurses were being required to "care for 16 residents each" (Serghis, 1998, p. 9). A personal carer concurs:

[Our staffing means we average] out to fifteen minutes per resident to toilet them every two hours and help them with their showers. ("New Classification Structure," 2002, pp. 8-9)

Three years on, staffing levels and skills mix remain inadequate to meet the nursing home residents' basic care needs ("Aged Care System Suffering," 2004; "Inquiry Calls for Higher Wages," 2005).

Furthermore, researchers report nursing home residents acknowledging that staff do not listen (Yates, Dewar, & Fentiman, 1995), that the nursing home is a place where rules of conversation silence the resident (Kaakinen, 1992), and that it is "well known that ...residents... can be isolated and have limited interpersonal relationships" (Edwards *et al*., 1993, p. 247; see also Gottesman & Bourestom, 1974; Harper Ice, 2002).

Communicating in the Aged Care Encounter

Communication is the basis for all aspects of a relationship between people (Demin, 1997). Wilmot (1995, cited in Nussbaum, Pecchioni, & Crowell, 2001) concurs with a relational model of human interaction. This model suggests that the older patient–health care provider relationship is subjectively experienced. Therefore, it is only through communicating that the individual's relational schemas, which give the relationship meaning, can meld to a shared understanding (Hak, 1994). Furthermore, the relationship must be considered in context. The organizational culture and other relationships can inhibit, enhance, or at least influence in some manner the relationship (Wood & Kroger, 1993). Finally, "relationships are not static, linear processes," and therefore, the relationship is "always more or less intimate" and an arena in which the "power dimension is always being negotiated" (Nussbaum *et al*., 2001, p. 29).

This relational model for human interaction resonates in a study in which the care provider–patient relationship became defined by the task orientation toward care that, consequently, constrained both the relationship and communication. Knight and Field (1981) noted that the division of labor between junior staff (patient carer) and senior staff (administrator) resulted in weak communication between staff and restricted information with the primary care provider (junior nurse). The nurses were guided by policy that restricted what information could be given to patients, in turn limiting the nurse-patient interactions and setting the care provider up in situations requiring avoidance and evasion.

This consequent division of disclosure is suggested by Parathian and Taylor (1993) as the reason why patients do not necessarily ask for more information (even though they would like more) and the reason why nursing staff do not invite questions from patients. That is, nurses "may be unable or are not allowed to answer the patients' questions" (p. 802; see also The, Hak, Koeter, & van der Wal, 2006). Colleagues agree, proposing that nurses'"desire to be honest" is in tension with disclosure that "oversteps the mark," risking censure from medical staff (Kendall, 1995, p. 161; see also Tuckett, 1998).

Truth Telling as Harmful

In telling the truth, intention is important (Bok, 1973; Higgs, 1998). Therefore, discussion of "bad news" might be avoided, as it contravenes duties of benevolence and nonmaleficence (Sidgwick, 1966; The *et al.*, 2006). Beneficence and nonmaleficence might then direct another to be deceptive on the grounds that truth disclosure to a patient will cause distress (Rosner, Berger, Kark, Potash, & Bennett, 2000), anguish and depression (Downs, 1999), and anger (Brewin, 1977).

Interpreting truth as harmful and, therefore, counter to another's best interests is reasonable only if the truth is, in fact, harmful. In her seminal work, Bok (1973) proposed that "the damage associated with the disclosure of sad news or risks are rarer than physicians believe" (p. 247). Others agree (Sheldon, 1982) and denounce the harm principle as a rationale for not telling the truth as probably false and premised on a mere shred of evidence (Moutsopoulus, 1984), grossly overestimated (Lavit, 1988), "just speculation" (Hebert, 1994, p. 2108), and hypothetical (Wright *et al.*, 2002). In addition, any claim that a patient cannot cope with the truth is for some an "insult" to that person (Morris & Columbia, 1982, p. 2659) and is inconsistent with research that demonstrates that most patients want to be told the truth and that most patients do not believe that they will be harmed with truthful discussions about their health (Moutsopoulus, 1984; Tuckett, 2004c).

Method

Grounded within the epistemology of social constructionism (Berger & Luckmann 1966; Crotty, 1998) and the theoretical stance of symbolic interactionism (Blumer, 1969; Mead, 1934), research data were collected through personal journals, group discussions, follow-up in-depth interviews, and the author's field notes (see Tuckett & Stewart, 2003/2004, 2004). In the analysis of data, I sought to determine participants' understanding and the conditions and consequences of their understanding about truth telling in the nursing home (Strauss & Corbin, 1998; Tuckett, 2004b). To this end, I took as my research objectives

· to understand why the care providers and aged residents think, feel, and act the way they do about truth-telling in practice; and

· to reveal the conditions in which this operates and the consequences of the care providers' and aged residents' truth-telling beliefs, feelings, and actions.

All participants were asked to keep a personal journal. The journal was a small, ruled, exercise book. Each participant's journal contained a nurse's story. Participants were asked to reflect on the story. Personal carers, registered nurses, and residents received the same story set. Four stories were used from my earlier study (Tuckett, 1998). Participants were asked to make notes about what the story meant to them and how they understood the story, and to record any personal clinical incident that related to it. Research participants were free to ignore the story and write about their own perceptions (opinions, feelings, and views) about truth telling in their aged-care circumstance (Begley, 1999). The personal journal was distributed to participants prior to the group discussion and collected either at the time of the group discussion or at a later prearranged time. Additional detail about the research

participants' personal journals and the story as a method for data collection can be found elsewhere (see Tuckett & Stewart, 2003/2004).

Group discussions did not "follow predetermined questions" in the form of an interview guide but relied instead on the nurse's story as "one question" (Morrison-Beedy, Cote-Arsenault, & Fischbeck Feinstein, 2001, p. 48) or as a "prompt" (Higginbotham, Albrecht, & Connor, 2001, p. 241). In the discussions, I focused on certain themes but avoided guiding the research participant toward certain opinions about these themes and allowed other themes to emerge as significant (Kvale, 1983).

The group discussion captured the process of communication in everyday interaction. In capturing this everyday interaction, my aim in using a group discussion was to "draw on people's normal, everyday experiences of talking and arguing with families, friends, and colleagues about events and issues" as they might in their everyday lives (Wilkinson, 1999, p. 225). A hallmark of the group discussion was this interaction between members (Morgan, 1988). This encouraged further communication and debate, leading to a wider range of information and the clarification of ideas among research participants (van der Heide, 2001). For further analysis and description of the group discussion as a method for data collection, see Tuckett and Stewart (2004).

Individual participants were also engaged in follow-up in-depth, or focus, interviews (Rice & Ezzy, 2000) as a mechanism for me to investigate in more detail the participants' descriptions of persons and events. Questions were grounded in emergent themes and seemingly contradictory cases from the participant's group discussion and personal journal (Morgan & Spanish, 1984). Furthermore, the interviews allowed member checking after the initial coding, writing, and theorizing following the group discussion and personal journal analysis (Guba & Lincoln, 1989; Morse, 1991).

Finally, the field journal (or research diary) contained notes of my "perceptions and interpretations of events" (Grbich, 1999, p. 89). Journaling the research process also provided me with a record of the research context, critical incidents, and aspects of data collection. The keeping of field notes started with the very first meeting with the Manager–Nursing and Personal Care Services of the organization and continued throughout the entire research project.

Analysis began with my taking notes as they were fresh in my mind, notably during the group interview as a thematic log or record and immediately after the in-depth interview (Morrison-Beedy *et al.*, 2001). Elements of this record, "interwoven with the final presentation of text" (Grbich, 1999, p. 90), allowed me to present a more ordered, plausible and authentic report. My journal format and notes' style evolved as a unique text that borrowed from Schatzman and Strauss (1973). The exact style and format has been discussed elsewhere (Tuckett & Stewart, 2003/2004).

Research ethics approval was granted through the appropriate institutions' authority. Consequently, the research was guided by a number of ethical principles, specifically confidentiality, autonomy, and informed consent.

Sample and Setting

Across five nursing homes, 19 residents, 23 personal carers, and 15 registered nurses participated. The total personal carers' sample was female, with clinical experience ranging from 1 to 37 years. One of the carers was a practicing physiotherapist, 2 identified themselves as enrolled nurses, 1 described herself as a diversional therapist, and the remainder (19 people) were personal carers across Levels 1 to 5. The majority (15 people) of the personal carers reported themselves as Australian, 4 personal carers reported themselves as British, there was 1 South African and 1 New Zealand participant, and 2 personal carers did not report their nationality. The 2 female registered nurses cited in this report had 23 and 35 years of clinical experience, described themselves as an "RN," and are both Australian.

As I was seeking rich data about a particular phenomenon, the sample was derived purposefully rather than randomly (Ezzy, 2002). In addition, participants were sought serially (Higginbotham *et al.*, 2001), that is, depending on who and what had come before, so that ongoing sampling supported the emerging theorizing. Therefore, in the case of the follow-up in-depth interviews, research participants were selected according to the following criteria (Ezzy, 2002). The participants' data

- either confirmed in some way ideas that were emerging (typical case) (Morse, 1991), or their data offered an insight deemed to be atypical (negative case) in the context of what was being theorized (Morse, 1999); and,

- whether typical or atypical, required confirmation and verification (contributed to member checking) (Keith, 1994) or

- could be compared with participants in other settings (contributed to constant comparison of data).

Sampling continued until I recognized that no new data were forthcoming—a point of data or information redundancy (Lincoln & Guba, 1985). This point of data redundancy was an ideal dependent on some effort to seek out disconfirming, or "negative," cases (Miles & Huberman, 1994). Furthermore, the point of data saturation was contingent on concurrent data analysis and data collection. I asserted that I had saturation "grounded in the empirical confidence attained from repeatedly comparing data to additional data" (Cutcliffe & McKenna, 2002, p. 614). To discover more about sampling, the reader is referred to another source that complements this report of findings (Tuckett, 2004a).

Thematic Analysis and Rigor

Thematic analysis of data in this research relied on systematic processes common to the grounded theory methodological package (Glaser, 1999; Tuckett, 2005a). However, because of purposeful (theoretical) sampling limitations (see Tuckett, 2004a), the research cannot claim to be "pure" grounded theory (Glaser, 1999). The analysis process relied on, and rigor was achieved by, operational techniques and research strategies that included the use of both field and personal journals, audiotaping and use of a thematic log during discussion and interviews, and meticulous transcript auditing and coding. Operational techniques such as atypical (negative case) analysis, the constant comparison of data, member checking, peer review, and method(ological) and investigator triangulation were also employed (Charmaz, 1990, 2003; Farmer, Robinson, Elliott, & Eyles, 2006; Strauss & Corbin, 1998; Tuckett, 2005c).

Findings

In the following theme, the personal carers identify themselves, and therefore their role, as happy comfort carers. Consequently, their role emphasis on comfort and happiness, and a dominant perception that telling the truth can cause harm, mean that disclosure will be withheld, edited, or partial.

Happy Comfort Carer

The personal carer emerges as the happy worker who aims to comfort and to make residents' lives comfortable. As two personal carers described it,

> I think our position is to make these people's last days as pleasant and... comfortable.

And happy as possible without dragging up grief or making them feeling uncomfortable.

Complementing these views, a personal carer role responsibility in the sustaining of a quality of life (Donna, Beth) was confirmed in a personal journal:

As a [personal carer] in a Nursing-home...it is our job to make [residents'] last days as happy, comfortable, and love-filled as possible. If that means we have to "stretch the truth" occasionally, so be it.

Later, the personal carer went on to say, "We're very *up* people...very happy, cheerful people." Therefore, the personal carers require an optimistic, positive disposition.

These personal carers are, by their own understanding, the happy comforters. Telling the truth is avoided or tempered by the personal carer committed to the resident's "happiness" and "comfort." A personal carer reiterated this view premised on her personal experience within the care circumstance of her family:

Did you know the biggest lie I ever told? My sister... they opened her up and shut her up, said she had a couple of weeks to live . . . [and] my dad had just had a heart attack and...I had him in...the house... And the biggest lie of my life was having to lie to her husband and lie to my father and lie to my mother and saying [Margaret] is fine she will be fine...They're the lies I have had to tell. And there's that word again—to keep people happy and to me that's what we do [in the nursing home].

The lie is considered an essential response, as truth telling can invoke harm.

Another group of personal carers' role perception emerged as like big cushions understood to mean "to ease all," to ease "everything for them [residents]." The personal carers described their role as big cushions as frustrating, but

at the end of the day we're here to look after them. You look after them like you look after your own parents. What hurts them hurts you so if you don't think they could stand that kind of blow [truth telling] you cushion it.

As truth telling can come as a hurtful blow, the personal carer's role is to "soften it along." Truth telling is understood as an instrumental good. This means that rather than having intrinsic worth (an end in itself), truth telling is evaluated and operationalized for goodness's sake (with a focus on outcome) (Johnstone, 2004). Unless a good (a benefit) outcome results, neither a lie nor truthful disclosure is an option.

Division of Labor

In addition to how they perceive themselves in terms of character traits, the personal carers articulate their role in terms of what they can and cannot do. Two nursing home personal carers contributed,

[If someone] asked us "What's Mum's results?" or "Do you think this and that." We can't really say anything. We just say you go up and ask an RN, so we get asked a lot.

We can't really go about saying...but it's part and parcel to the RN.

The registered nurse (team leader) is the information manager. The personal carer sees this as the nurse's role, have been instructed as such, and generally follows this instruction. The conversation continued, highlighting the division of labor and the consequent handling of information:

They tell us what we need to know to do our job. I mean we ask question and they tell us.

We have a lady now who has a constant rash...so her family speaks to the team leader. The team leader tells them one thing. They believe it's another. They come and actually ask you if you know. We have to send them back to the team leader because we are not qualified to tell them what it is, even if we think we know.

At a follow-up interview, an RN highlighted this information-sharing tension. She revealed, "experiences where people really get distressed by what [personal] carers have said," adding, "[Personal] carers don't have the full knowledge, they're not talking to doctors. They're not reading the charts." In her view, the personal carer is "not *au-fait* with what's really happening with the resident."

It follows, in the domain of practice, that the division of labor is thus: Nurses are information gatekeepers; personal carers are the hands-on workers. This palpable distinction between doing (the hands-on work) and disclosure (information gatekeeper) was agreed on by two nursing home personal carers:

> *Danah*: I gave my opinion...to a resident...she was complaining of diarrhoea... and I said "Try charcoal tablets." . . . So she went to the RN and said, "I want some charcoal tablets," and the RN said, "Who told you about charcoal tablets?" "That girl that comes to see me." . . . So RN heard about it, "[Danah]... can you please keep your ideas to yourself. No diagnosis please."

> *Donna*: You stepped over that line.

This "line," the division between doing and discussing, was reinforced by a registered nurse (team leader), who stated, "[Personal carer] shouldn't be assessing things, diagnosing things, fixing things." This limited personal carer role is equally understood by some residents' families. Two personal carers (Donna and Danah) spoke of family members who perceive the personal carers as merely "there to do," as performing "that duty" or "just to clean up."

Division of Disclosure

The personal carers, identified as happy comfort carers and who understand their role in terms of what they can and cannot do, articulated further an attendant division of disclosure. When a personal carer stated, "If you know the resident...well, you know whether they could cope with the truth or not," I asked the group to discuss "a situation in which you make the decision about whether or not [a] person can cope." Although one personal carer said she makes her own decisions ("I decide me self"), another added, "But I don't think we go against the team leader [RN]." The general consensus was

> The team leader gets that final decision.

> You'd never go up [against an RN]. You'd never do.

> You'd be in Head Office.

The care provider data suggest that they are aware of the hierarchical nature of the nursing home. This was expressed by a registered nurse (team leader) (*italics* representing her emphasis):

> The doctors play a big role in this, an *extremely* big role because that's when you go through your pecking order and ethics and... *you* know what I'm saying (directed at AT), the profession. *You* know there is a professional ethics that we . . . as a team leader.

The RN makes it clear that the information management process resides in an established culture, a "pecking order," an "ethic" covering the doctor, the nurse, and only then the personal care provider. This "ethic" was clarified in a follow-up interview:

> With the pecking order they're [residents] first...I think probably you have the doctor, the team leaders, the registered nurse and they're in-line, as I said they're professional, and then you have the [personal] carers who look after them [residents]...It's organisation. Without it there's chaos.

Decisions about a resident's capacity to cope with truth telling, to "handle it," and therefore to disclose or not disclose, rests with the registered nurse, notably the team leader. In fact, as expressed by an RN, the personal carers "talk" with family amounts to "Mum needs a whole lot of new singlets."

However, other personal carers revealed that the resident's relative do question them. Two personal carers explained,

> *Carer 1*: The relatives do ask you..."What do you think is going on?"
> *Carer 2*: And we get friendly with a lot of the relatives.
> *Carer 1*: And that makes it very hard, because you really want to tell them the truth. Say "Look you know I don't think your mum is going to be here tomorrow," or...
> *Carer 2*: But I think they know . . .
> *Carer 1*: I think, well I do. I tell the ones that I know, I mean we are not suppose to, but you do.

Although there is an honest appraisal and possible acceptance of the resident's circumstance, the personal carer's role understanding means that this appraisal and acceptance must be shared through mutual pretence or suspicious awareness (Glaser & Strauss, 1965), or by the carers' breaching their communicative role restriction.

Specifically, in the context of death and dying, the personal carer moves across this division of disclosure:

> You can't help but say, "Well, they haven't got long."

> Or if they say "They're going aren't they?" You say "Yes," because it is. You do know.

A nursing home personal carer's knowing as "friend" makes it hard for the personal carer who wants to share an opinion openly. Her role perception dictates she cannot, but premised on relatives' suspicious awareness, she does.

Role Tension and Frustration

As a product of the rigid role restrictions that assign the personal carers doing tasks and suppress their capacity for disclosure, a role tension and frustration emerged.

Asked about how the personal carer felt about this division of disclosure—specifically, in a case of family-sanctioned nondisclosure—a group of personal carers added,

> Frustration there that the family didn't tell them, and frustrated because you [I] can't tell them because it's not your [my] place. You accept the family's decision from that and the doctor's, whatever, whether that person should be told.

> And yet you [we] are coping with the behaviour.

Personal carers want disclosure but accept that their role is to follow orders. Family, or doctor, or registered nurse are the fact controllers, even though the personal carers perceive that they manage the resident totally, as a human being comprising physical (somatic) and emotional (psychic) components. The personal carers here suggest the consequences of the rule "Don't tell Mum" (acquiescing to the

family's demand not to disclose and evidenced in my study's residents' data) are matters that they alone must manage. Their work falls outside the realm of the nurse, doctor, or family (Tuckett, 2004b).

Managing the Division of Disclosure

In the extracts that follow, a number of personal carers describe how they manage the division of disclosure in their clinical practice. Although it is not claimed that the personal carers do not refer persons on to the registered nurse, it is the case that such a requirement provides the personal carer with disclosure dilemmas. The following conversation occurred between Donna and the author:

> *Donna*: It's not up to us, the carers, to speak to the family. There is where the line is drawn...we are doing the hands on...This particular relative is trying to find out something.... [He says] "Oh, why? Why not? Is it really bad?" [I reply] "No. I think you're going to have to ask the RN that question?" [He says] "Oh, she just gives me the run around love ...You would tell me the truth, wouldn't you?" [I say] "I can't." [He says] "Oh, so there's something to tell?"...[I respond] "No there's not." AT: OK. In this specific situation when you say "I can't," is that because you don't know?

> *Donna*: Oh no, I do know. He puts us in an awkward position, because we don't wish to tell a lie. He's actually setting us up to tell a lie....It becomes a game actually. It's like chess. He makes a move and I counter move it.

In this communicative combat, the personal carer is caught in a wordplay—statements of truth but not openness—to which the relative responds with further questions, and the personal carer counters with statements that neither confirm nor deny. A personal carer described this game playing as a "vicious circle" that "goes round and round," because residents' relatives ask for information from the personal carer, who is obligated to instruct them to go and speak to the registered nurse. Although often the queries are "simple things that [we] could answer," the personal carers risk censure, because "that's not our job" to share information with the relatives.

Furthermore, the personal carer (Donna) spoke and wrote about obfuscation—implying a false conclusion about what is known to be true (Barnes, 1994):

> [A] lot of the residents have to leave their much loved pets behind... When they [family] let you know that the dog has died and...resident will say, "Can't wait to see Toby" (laughter) and you know damn well Toby's dead....It's up to [the family] to tell them. Again, "The last I saw of him he was fine." Which is the truth! Because I haven't seen him since the last visit. The fact [is] that I know he's dead.

She offered an additional insight confirming another practical implication of her role. When asked over the telephone, "How's Mum," the personal carer "buckpass[es]"—avoids responsibility for disclosing - even though she is aware that the resident has "been given a whack of oxygen because she's choking on mucus."

Elsewhere, the personal care providers' communicative limits were described as putting the personal carer "on the spot":

> It's awful, because, I'm really quite fond of [a few residents] and you know I talk to their families and they do put [me] on the spot and sometimes, you know [ask], what should be done and you tell another lie and say, "I really don't know." But you do know. But you still think it's best that they go to maybe the office or management.

Her role obligates her to lie: deny knowing what she knows to be the case. In addition, this being "put on the spot" is made treacherous when the relative asks, "The RN said this. Is that true?" There are times when the personal carer would like to acknowledge that she does not "believe it" and that what has been said is "a load of crap" but replies with "Oh, well, it could be."

Furthermore, a personal carer described a situation in which a resident's daughter "kept asking." Although the carer suggested that the relative "ask the Sister" (RN), the relative's response, "she's not telling me anything" and "she's not helping" meant

> I just kind of looked at her. I didn't outright say it. You just communicate, without actually [saying it]... they can't say you've said it. I can do it with my face - something like "She's [resident/mother] no good" or something like that. So they know.

Without speaking and thus, in her belief, without contravening her role restriction on (verbal) communication with resident's relatives, she communicates what she understands, as requested by the relative.

Discussion

Perceived as happy comforters, personal carers "stretch the truth" or edit it premised on their assessments that the resident will be harmed by "bad news" (Sidgwick, 1966). A role understood as promoting a "pleasant" and "comfortable" nursing home life means that any disclosure that puts this at risk ought to remain unsaid. Truth telling is wholly instrumental. This means that rather than having intrinsic worth, truth telling is evaluated and operationalized for goodness's sake (Johnstone, 2004).

A clear institutional division of labor exists between the personal carer and the registered nurse (Knight & Field, 1981). The division of labor that defines the role of the personal carer as hands-on and the RN as information gatekeeper results in an institutional division of disclosure (Knight & Field, 1981; Tuckett, 1998). Personal carers subjugate their "self" for the sake of their professional role, so that good personal carers adhere to their role perception by doing what they are told. By both subjugation and adherence to role, truthful disclosure might necessarily be forfeited or tempered.

Where the registered nurses, as the care providers responsible for sharing information, are few in number (Legge, 2004; Serghis, 1998), it follows that the quality and volume of information sharing diminishes. In the nursing home depleted of staff and time, an edited truth telling risks becoming a time management strategy rather than a benevolent response, that is, say little and omit the detail to conserve time. Furthermore, seeking information among the few care providers responsible and available for discussion means that the resident or family risks slipping toward resigned silence (Kaakinen, 1992).

Data reveal that residents might, and family do, turn to the personal carers to become informed and seek their opinion. This means the personal carer's role limit is challenged and the personal carer is asked to go beyond his or her perceived and institutional role to become an informant. However, given the information gatekeeping function of the RN, the personal carer in this challenging situation might not be able to share informed information. Pressured by such circumstances (to keep the customer happy), the personal carer risks misinformation. Institutional processes that create a communicative environment in which sharing information openly is rigidly divided lend themselves to being bound by suspicious awareness and mutual pretense (Glaser & Strauss, 1965; Kendall, 1995; Tuckett, 1998).

Restricted by their role, personal carers of necessity manage the division of disclosure by engaging in a communicative "game," obfuscation, the lie in the form of denial, the use of nonverbals, and "buck-passing." In the game, the relative is recognized as having suspicious awareness (the personal carer recognizes that the relative is being given the "runaround") (Glaser & Strauss, 1965). As a consequence of this communicative "chess," the personal carer expresses feelings of role helplessness, a role difficulty or tension ("difficult," "awkward") that manifests itself as avoidance behavior and a contemplation of lying.

Sufficient data demonstrate that the personal carers will, however, cross the information disclosure "line." Increasingly, the pattern of openness between personal carer–resident or personal carer–family in the context of role mirrors that described by the RNs set against doctors in the author's preliminary study (Tuckett, 1998). However, the data suggest that communicative, and therefore truth-telling, practices are far from universal. Although covert communicative practices might serve the resident's best interests, some telling (disclosure) practices serve only the interests of the personal carer.

These perceptions about personal carer role, information sharing, and truth telling are paramount for understanding and improving nursing home aged care. Equally, additional studies of this kind within other care contexts will generate a more complete understanding of the phenomenon and care contexts, and greatly improve nursing care.

Conclusion

A role emphasis on protection, comfort, and happiness, and a dominant perception that telling the truth can cause harm, mean that disclosure will be withheld, edited, or partial in another's best interests. Furthermore, there exists a role understanding that divides labor and disclosure responsibility between the personal carer and the registered nurse. Personal carers' descriptions and perceptions dichotomize care provider tasks and relationships, with the resident and resident's family, in turn, fragmenting who knows and can say what about and to whom. Personal carers do breach their communicative role limit (division of disclosure) in some circumstances, premised on a relational and situational assessment that they believe benefits the resident but might equally benefit the personal carer. Personal carers' strategies for managing the division of disclosure, that is, telling or not telling according to care provider role expectation - include game playing, obfuscation, the lie in the form of denial, and the use of nonverbals.

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