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# The meaning of nursing-home: 'Waiting to go up to St. Peter, OK! Waiting house, sad but true' — An Australian perspective

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## Abstract

### Background

This article is derived from a larger Australian research study using multiple qualitative methods to investigate truth-telling in aged-care.

### Aim

To analyse and discuss findings associated with residents', personal care assistants' (personal carer, enrolled nurse) and the registered nurses' perceptions about the nursing-home. The thesis is that the health of the resident in a nursing-home is directly linked to care provision that encourages autonomy.

### Methods

Research participants' personal journals, group discussions, follow-up in-depth discussions and the author's field journal across five nursing-homes.

### Results

The nursing-home is described as endowed with suspicious awareness and mutual pretence, overloaded with tasks, short of staff and starved of time with little engagement with the residents.

### Discussion

Residency that claims to have as its primary focus 'the resident' ought to take seriously the residents' health and therefore the residents' autonomy. However, the nursing-home, as described here, fails to adequately understand this link.

**Keywords:** Nursing-home; Autonomy; Awareness; Time; Waiting; Qualitative

## 1. Introduction

This article reports on the findings associated with research participants' perceptions about residency — that is, the nursing-home. Arguably, the perceptions expressed here by residents, personal care assistants (personal carer, enrolled nurse) and the registered nurses suggest that the 'home away from home' is much less than that, and not a home one would look forward to going to. The thesis is that the health of the residents in a nursing-home is directly linked to care provision that encourages autonomy. The nursing-home that claims to have as its primary focus 'the residents' ought to take seriously the residents' health and therefore the residents' autonomy. However, a residency that is described as endowed with suspicious awareness and mutual pretence, overloaded with tasks, short of staff and who are starved of time and have little engagement with the residents fails to adequately embody this link.

The palpable absence from this discussion of a positive nursing-home culture requires explanation. My work sought to understand truth-telling in the nursing-home and in so doing, I listened to a negative – not positive – lived experience.

Whilst mindful of an alternative culture, as espoused by the Eden Alternative (Barba et al., 2002, Drew and Brooke, 1999 and Thomas, 1994) the de-emphasis on a positive nursing-home environment is based on what I discovered rather than how it might otherwise be. Furthermore, a view that the portrayal of the nursing-home presented here is 'not new' and 'well known' and therefore unspeakable must be seriously challenged. Such a narrow view would also silence ongoing examinations surrounding equally well documented and equally important healthcare issues such as the AIDS pandemic, cardiology and complementary medicine (Willis & Broom, 2004).

## **2. Themes from the literature**

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, 2004a); ethical practice and the nature of the nursing-home in the Australian context (Tuckett, 2005a); and care, communication and control in the context of aged-care provision (Tuckett, 2005b). In this article, the literature reviewed is only that relevant to those themes expressed in the forthcoming data. Consequently, the review examines the notion of nursing-home as a 'home', underscores the task-orientation to care in a time-starved and staff-depleted context with limited interpersonal interactions. The literature review concludes with a brief overview of awareness theory.

### **Home away from home**

The transition of the older person (resident-to-be) into the aged-care facility (nursing-home) has been discussed as 'rarely ... a positive life transition' for the resident or the resident's family members (Nussbaum, 1993, p.238). Similarly, the observation of resident–staff interactions raises concerns about the notion of the 'home-like' environment (Edwards, Weir, Clinton & Moyle, 1993). With an emphasis on tasks (technical aspects of care) and a 'paucity of social and supportive care', the nursing-home has been characterised as a 'mechanistic warehouse model of long term care' (Armstrong-Esther, Browne & McAfee, 1994, p.271; Clinton, Edwards, Moyle, Weir & Eyesaon-Annan, 1996, p.17) and 'dormitories for those who are near death' (Fiveash, 1998 and Nussbaum, 1993, p.245).

An analysis of home as a place for the care of the aged is important since how the care recipient and care provider conceive of this concept impacts on how persons perceive of their roles and interpersonal relationships (Wilmot, 1995 cited in Nussbaum, Pecchioni & Crowell, 2001). If the older person perceives of her/himself as a patient in a medical facility, it might be expected by her/him that staff define themselves as 'nurses ... whose primary goal is the technical, medical treatment of the patient' with the care focus on formality, the impersonal and efficiency (Wood & Kroger, 1993, p.270). However, in contrast, staff may perceive of their task as the provision of the home-like environment. Residents in one study (Gubrium, 1993) declared that the nursing-home feels like home (Martha Gilbert); like home but not home (Lula Burton); never home (Myrtle Johnson) or a prison (Bea Lindstrom and Don Hughes). The tensions between the differing orientations to the same care circumstance underscore the possibility for miscommunication and misunderstanding.

A number of defining characteristics further add to understanding the nursing-home. Universally, care provision is task-orientated (McCormack, 2003). Task-orientated care is the provision of instrumental care (cure orientation). That is, the provision of physical care rather than affective (socio-emotional) or communicative aspects of care, with the aim to get the work done (Ong, de Haes, Hoos & Lammes, 1995). The majority of this care is performed by the less

educated, often untrained, personal carer (Australian Nursing Journal, 1998, Burgio et al., 1990 and Mezey et al., 1999). 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 ... (The Queensland Nurse, 2002, p.8).

This understanding of 'production line' care resonates with the view that the nursing-home is a 'question of eat, sleep, eat, sleep and play bingo .... You do the same all the time' (Gubrium, 1993, p.135; and see Lyytinen et al., 2002 and Shawler et al., 2001).

### **Tasks and time**

In the Australian context, nurses are equally too busy, short of time and short staffed (Fiveash, 1998, Legge, 2004 and Yates et al., 1995). Serghis (1998, p.9) reported that in Queensland, in some instances, 'one Registered Nurse was caring for between 60–120 residents' and that assistants in nursing and enrolled nurses were being required to 'care for 16 residents each, including having to toilet, bathe and assist with feeding, all in one eight hour shift'. A personal carer's testimony concurs:

We have three AINs in the morning, two on in the evening for half the night and one for the rest of the night, that averages out to fifteen minutes per resident to toilet them every two hours and help them with their showers (The Queensland Nurse, 2002, p.9).

Care providers acknowledge that 'on current staff levels there are residents that we can't even see in a shift' (The Queensland Nurse, 2002, p.9). Three years on and staffing levels and skills mix remain inadequate to meet the nursing-home residents' basic care needs (Australian Nursing Journal, 2005 and Australian Nursing Journal, 2004).

Researchers report residents acknowledging that staff do not listen (Yates et al., 1995), that the nursing-home is a place where rules of conversation silence the resident (Kaakinen, 1992), and that it is an unnatural environment conditioning residents to live with strangers, rather than family (Bitzan, 1998). Additionally, the nursing-home is a place where the resident's life is lived in slow motion with shuffling, pushing, pulling and sleeping (Higgins, 1998, p.860) and that it is 'well known that ... residents ... can be isolated and have limited interpersonal relationships' (Edwards et al., 1993, p.247; Gottesman and Bourestom, 1974 and Harper Ice, 2002).

It seems therefore, that the nursing-home – described as a 'mysterious and depressing place' and 'negative' (Mullins, Moody, Colquitt, Mattiason & Andersson, 1998) – does exist as a place which tends to create formal structures that minimize interactions (Nussbaum, 1993, p.238, p.241; Wiener & Kayser-Jones, 1990).

Additionally, this home away from home (Thorman Hartig, 1998) as with other nursing care contexts, is time-starved (Armstrong-Esther et al., 1994, Fry, 1988 and Irurita, 1999; Queensland Industrial Relations Committee cited in The Queensland Nurse, 2002). As early as the mid-1970's research sought to determine the duration of time nurses actually spend with their patients. Wells (1975 cited in May, 1990) determined in a study involving elderly patients that 4% of nurses' time was spent in interpersonal care on a geriatric ward and 50% of the interactions lasted 0.5 min or less. Similarly, in another elder patient sample, the mean duration of a nurse–patient encounter was reported at 4 to 6 min (Keck & Walther, 1977), whilst student nurse–patient interactions averaged 2 to 3 min (Faulkner, 1980).

Complementing the finding that 95% of the time elder patients had no contact with nursing staff (Armstrong-Esther, Scandilands, & Miller, 1989), a study that observed nursing staff–patient interactions with lucid, confused or demented elderly patients concluded that, outside the expected routines of care, there were

very low levels of staff–patient interactions (Armstrong-Esther et al., 1994). Edwards and colleague's (1993) study quantified their observations of nurse–resident interactions, reporting that 64% of their observations 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 s. Critically, 'at no time during the observation periods did staff engage patients in social activities or prolonged informal conversations' suggesting 'it would appear that nurses make strangers of their patients who become silent observers of ward/unit routine' (Armstrong-Esther et al., 1994, p.264, p.270; Lyytinen et al., 2002).

### **Overview of awareness theory**

In the context of dying, awareness theory (Glaser & Strauss, 1965) focuses on knowledge and describes the way in which nurses and doctors control the management of this knowledge in their social interactions with patients with a terminal diagnosis. Specifically, this theory of awareness amongst dying patients, their relatives and care providers describes the processes by which information is controlled (Mamo, 1999). Four dominant awareness contexts exist — those in which the patient has minimal or no knowledge of her/his impending death though relatives and care providers do (closed awareness); the patient suspects her/his terminal diagnosis as known by others and tries to verify the suspicion (suspicious awareness); the patient and all other parties define the patient as dying but each actor pretends this not to be the case (mutual pretence); and finally, the patient, relatives and care providers share the knowledge about dying and all act openly toward it (open awareness) (Costello, 2000).

### **3. Methods**

Grounded within the epistemology of social constructionism (Berger and Luckman, 1966 and Crotty, 1998) and the theoretical stance of symbolic interactionism (Blumer, 1969 and Mead, 1934), research data were collected through group discussions, personal journals, follow-up in-depth interviews, and author's field notes. Thematic analysis of data relied on practices within grounded theory to determine participants' understanding and the conditions and consequences of their understanding about truth-telling in the nursing-home (Boyatzis, 1998 and Strauss and Corbin, 1998). To this end, my research took as its objectives:

- to understand why the care providers and aged residents think, feel and act the way they do about truth-telling in practice, and
- reveal the conditions in which this operates and the consequences of the care providers' and aged residents' truth-telling beliefs, feelings and actions.

Specifically, five nursing-homes participated. Nursing-homes A, C and D are 148, 93 and 140 bed (high-care) nursing-homes, respectively. Nursing-home B provides 'private' nursing care within a complex comprising 60 single rooms with ensuite. Nursing-home E is a 78 bed facility comprising shared and single rooms. All five of the 'nursing centres' provide a 'special needs (secure) unit' for residents with dementia.

Across the five nursing-homes a total of 19 residents, 23 personal carers and 15 registered nurses participated. The personal carers cited in this article (8 persons) are all female and range in age 38–52 years. Most (6 persons) of these personal carers reported themselves as Australian, one reported herself to be British and one reported herself to be a New Zealander. In this personal carer group, one participant was a practising physiotherapist. Three personal carers had diversional therapist qualifications and one was a qualified enrolled nurse. Other than the physiotherapist, the group identified itself as comprising personal care assistant levels 1–5, with clinical years experience ranging 6–27 years. The

registered nurses (10 persons) quoted here range in age 38–56 years and all but one is female. Most (7 persons) reported themselves to be Australian, one reported herself to be a New Zealander, one reported herself to be Australian/British and one failed to report her nationality. Two of the registered nurses are Manager-Clinical Care Services (MCCS), two identify as 'RN', one identifies as 'RN Level 1', four are 'RN Level 7' and one identifies as 'RN Level 8'. The residents (8 persons) represented in these findings are all female and range in age from 70–88 years. Most (6 persons) reported themselves to be Australian, one reported herself to be British and one failed to report her nationality. One of the residents in this report required full assistance with cares whilst the remainder needed partial-assistance with their activities of daily living. Residents had been in the nursing-home for a period ranging 6–37 months.

Thematic analysis of my research relied on systematic processes common to the grounded theory 'methodological package' (Glaser, 1999, p. 836). However, because of purposeful (theoretical) sampling limitations (see elsewhere, Tuckett, 2004b), my research cannot claim to be 'pure' grounded theory (Glaser, 1999, p. 837). Influenced by Strauss and Corbin (1998) and Charmaz (1990, 2003) and mindful of Glaser (1999), the analysis process relied on, and rigour was achieved by, those operational techniques and research strategies such as the use of both field and personal journals, audio-taping and the 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) triangulation were also employed (Charmaz, 1990, Charmaz, 2003, Glaser, 1999, Strauss and Corbin, 1998 and Tuckett, 2005c). I carried out all the analysis of the group discussions, follow-up interviews and journal entries.

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

## 4. Results

It is important to note, care providers' data are presented *separately* from and *before* residents' data. The data presented in this way reflects firstly, a binary opposite and secondly, emphasises the dominance of the participants' voices as I discovered and interpreted them, rather than how they ought to be.

### Home away from home

An understanding that the aged-care facility is 'home' is portrayed in a nursing-home B personal carer's journal, when reflecting about being asked repeatedly by residents "When can I go home?"

Why should we feel sad for these people, not knowing at times what to say to them, repeating what we know are, simple white lies .... I ask: ("What do we say?) ... Do we try to convince them that they are at home (a home where they really do not want to be at)? After all, our motto is: "Home Away From Home".

She recognises that residents are reluctant occupants of the nursing-home and she must constantly convince them that they will not be going 'home'. Residency as 'Home away from Home' was poignantly analysed in another journal entry in which the nursing-home E personal carer, in her writing, *becomes* a resident:

Dementia needs to be managed with love & respect — not large doses of medication. We need to be trained to cope with what-ever situation that may arise. Not regimented — not set into a mould of what should happen — should be happening ... (S)o if we do happen to have dementia — provision should be made for the resident — not the staff.

Residency (at least in the context of dementia care) requires multiple skills and specialist 'trained' staff capable of caring beyond merely doing 'what should happen' and not premised on repetition and ward orderliness. The nursing-home is not what it ought to be, namely, resident-centred but is rather staff-centred. Hereafter, the personal carer recognises the inevitability of her own ageing and enunciates a critical concern:

Then suddenly we are old — a nuisance .... We are no longer "useful". To some family and care givers, we are a nuisance. We should be tucked up in a chair in the lounge or in bed — Not able to communicate that we are cold, wet, hungry, lonely or just need someone to really "care" for us — not just do the motions of "caring".

Voicing an opinion against labelling or stereotyping the older person generally, and specifically the resident as 'a nuisance', the personal carer perceives that 'some' residents' families and 'care givers' consider the elderly burdensome and best concealed from the mainstream. The nursing-home resident is 'lonely' and risks having unmet needs. This particular personal carer criticises the institutional emphasis on a task-orientation to care ('do the motions') rather than 'being cared for'. She continued:

I may wish to stay up late and sleep in late and have breakfast late. Have my shower when-ever I feel like it — not to have my shower at 7am because breakfast "Will be here in 15 min" and everyone has "too many" showers to get through before lunch. Carer: "You know I go off duty" at 1pm. Come-on. Don't be a nuisance — just do what the staff "want".

Revealed here is the ideal residency akin to 'Home away from Home' where residents' autonomy ('when-ever I feel like it') is given due regard rather than institutional policy and process ('do what the staff want'). Finally, this personal carer-as-resident wrote:

If only some-one had time to talk to me .... How lovely it would be to sit in the garden ... all the things the staff don't have time to do. There are medications to give out, ... Night staff really don't have time to be making cups of tea or sitting with Mrs T. Everyone is supposed to be asleep. There are only five staff on duty and seventy residents, you know ... Everyone should be tucked up in bed — asleep.

Staff are time-starved. Tasks become the care priority. There is, in this personal carer's view, no time for engagement with the resident and no time to get to know the resident. The emphasis is on ward orderliness — 'everyone should be tucked up in bed — asleep'.

Elsewhere, at nursing-home C, a group of personal carers discussed the relatives' reactions to a relative entering this 'Home away from Home', emphasising the entrée as a negative experience:

I think we can see more reality than most people who've never ... been into a nursing-home or, because nursing-homes are pretty shocking places for people who have never ... Oh yeah, it would be ....

Personal carers are accepting of their 'reality' — their experiences embed them in the real world of 'what goes on' in care. Whilst the untrained eye may see that which is 'shocking', the carers know better and are un-phased. In their individual interviews, the 'nursing-home' as a 'shocking place' was described by them as full of residents 'that wet themselves', who 'walk around and who are demented' or are 'laying in beds'. Furthermore, physical violence toward the registered nurse was described:

(A) nurse can come up them (resident) and they (residents) can hit them, or they (resident) can throw their tea all over the floor .... I've had a friend who's put her husband into a nursing-home and she was shocked — what she was telling me happens here everyday and didn't phase me at all.

(T)hey (visitors) don't know what it is like in a nursing-home ....

This maelstrom of incontinent, wandering and the sometimes aggressive residents is the personal carers ordinary, every-day nursing-home experience.

Theirs is a taken-for-granted world of work that for those uninitiated and on the outside, is incomprehensible ('don't know what it is like in a nursing-home'). I asked 'What do you think they see that concerns them?' In response, apart from seeing 'little old people sitting in awful big chairs in different positions, dribbling, making weird noises', a personal carer in the group spoke of aging and becoming entrapped in, and without control of, one's care:

(They're) probably scared that (it) is going to happen to yourself .... We look at people and we think: "Oh my God, shoot me if I am going to get to this stage ... (I)t just seems like you have got no control over what is going to happen. I think it's frightening. It is probably more for us because they don't know what it is like out there (in the nursing-home) ....

Absolutely, this carer does not want to be a resident in this 'Home away from Home'. Knowing what she knows – the attendant loss of control of one's life and surrounded in misery – she would rather be dead ('shoot me if I am going to get to this stage'). They perceive that the nursing-home offers little genuine 'quality of life', pondering:

And yeah, it's a hard thing .... (W)e all find it hard sometimes to come to work and see people ... had their faculties, could talk to you ... and then bang! They're no longer like that, normally like that, ... they are just gone to nothing.

It seems the resident's progression is one of deterioration — from a level of interaction to a state of nothingness. Amid the afore perceived maelstrom, the nursing-home exists as a place where 'either dementia has taken over, or their condition has just deteriorated' and the *home* becomes typified by 'they no longer laugh. They no longer talk to you like they used to. They no longer walk'. At nursing-home A, a registered nurse (team leader) summed it up:

(T)his is the residents' home. This is not hospital. This is their home but it is big ... their whole life ... you wait 'til you get old. You live in a little room that's what becomes your home .... A lot of these people have had everything, their jobs, family then all of a sudden they're just there.

Arguably, a 'residents' home' that has become reduced to a 'little room' is actually only marginally more than life reduced to a hospital bed, and the registered nurse also recognises the residents' overall psychosocial and economic losses. Finally, there is their loss of control:

The relatives are out there, they're doing what they want in their life, going where they want, still able to do what they want. They still have choices. These residents haven't got those choices anymore. We are their choices (Nursing-home A personal carer).

In effect, this 'Home Away from Home' is a place where residents' capacity to do what they want and express their own choices (be autonomous) resides in the control ('choices') provided by the care providers and the institutional ward order.

### **Starved of time**

The care circumstance was considered to be time-poor as a consequence of workloads. Registered nurses at nursing-homes A and B commented:

(Personal carers) they're too busy ... (T)heir workloads are so big here they can hardly get their work done. They don't even have time to say "Giddy, how're you going ...."

(Personal carers) don't have a lot of time, the girls, to talk to relatives or families .... They don't stop and chat because they don't have much of a chance which is probably quite sad in a way ....

With the nursing-home's emphasis on getting the work done, there is little or no opportunity for psychosocial or communicative aspects of care ('don't stop and chat'). At nursing-home D, a personal carer agreed, writing in her journal that 'the Government has cut funding so that staff numbers per ratio of residents has also been cut' with a consequence that 'we nurses often don't have the time to comfort the residents when they most need it'.

The nursing-home is a locus restricted and defined by its temporal feature. That time is a scarce resource emerged across *all* five nursing-homes. A physiotherapist wrote 'it is not physically possible to 'see' 60 residents twice–three times a week in the 20 h allocated to physiotherapy' (Nursing-home B). This was reiterated by a personal carer at nursing-home C who said '(Staff) don't find the time and ... there's so much to do — there is a restriction on time'.

Consistent with the literature, two registered nurses (team leaders) – one from nursing-home E and one from A – concurred that they and the personal carers are too busy, short of time and sometimes just keeping the social order:

... the basis again is always *time* in a nursing-home. Most shifts you can get the shift to go well – a little time for everyone – 39 residents per 8 h shift for 1 reg' nurse and 3–4 personal carers. All you need is a fall – Dr's visit – phone calls (e.g. replacements of shift or relatives' concerns) to put you behind.

For this registered nurse, the home's social order depends on 'a little time for everyone' and absolutely no time for a crisis ('a fall') or communication (most notably, speaking with a doctor or dealing with 'relatives' concerns'). Under these time-starved conditions, her colleague at nursing-home A stressed an inability to give 'quality' care:

I have thirty-nine residents and I'm one registered nurse. How do you think I feel? Do you think I give quality?..(T)hey all have families or extended families and they come (on) that wing sometimes ...they ask to see me... "Has Mum been so-and-so today?" I say "No, I haven't had time". I don't lie ...I tell *you* thirty-nine residents and *you* try to get around them all!

Her frustration is clear. Like her colleague, she is doing the best she can in circumstances in which she realises she is unable to provide quality care but also provide care to each resident. This registered nurse takes on a defensive tone — she is saying quite clearly 'you try and do better!' ('*you* try to get around them all').

### Waiting house

Herein, the care providers (both personal carers at nursing-home D and registered nurses from nursing-home B and C) make clear that the resident entering the aged-care facility is on a pathway to death:

We try to (make them) feel that they are loved for the last time, before they leave. That's the truth, this is their last place....

... we know that the only way these people are going to leave here 99.5% of the time is in a plastic bag.

(P)eople are very aware of this, that this is the last home they'll have.

I think it's probably important here to build up a relationship with the family because there's only one ending with their relative.

The nursing-home conceived of as a place residents spend 'their last days on earth' emerged in the first group discussion of the research project (nursing-home A). A registered nurse (team leader) stated:

What are *these* people here *for*? They're just waiting to go up to the St. Peter ... OK! Waiting house ... sad but true ....

Across *all* five nursing-homes, care providers described the 'Home away from Home' as a 'waiting house' for the dying. Registered nurses at nursing-home D spoke of '... the relatives (are) well aware of the fact that they (residents) basically don't leave here as a rule'. Registered nurses at nursing-home E concurred. However, they insisted that they 'don't look at it this way', they 'don't think about it that way'; the point being that the work environment as a 'stairway to heaven' is not the way they approach their work.

### Place of awareness



The nursing-home was well defined as a place of awareness in which the residents are perceived to 'know' prior to any disclosure:

They (resident) can tune into you and say to you "What's wrong?" You may walk into a room and the resident may say "What's wrong? ... I find that often they become attuned to what I must be thinking ... It's really uncanny sometimes.

I did come in and something had happened, I didn't say anything to this resident and he picked up. 'You're angry' — I hadn't said a thing ... They notice a lot more than we think they do ... Just sort of uncanny.

Above, a personal carer at nursing-home D and a registered nurse at C agree that the resident has a general awareness ('attuned to what I must be thinking') about the unspoken. Consequently, the resident knows about her/his defined status along with an awareness of the status of others including the home's social order ('They notice a lot more than we think they do'). Elsewhere, a B nursing-home personal carer reflected on an individual's capacity for sensate knowing when her group spoke about a family's decision *not* to disclose to a resident that the spouse had died. She reflected:

You know if your partner or your family, something ... in your heart you know. If your family or something was happening, you would know and I believe old people have those skills and they would know if something had happened.

Premised on her view that many share this awareness ('in your heart you know') and her own experience, the personal carer acknowledges the resident knows when something is wrong. That is, the resident suspects what others know. In the absence of disclosure, this knowing operationalises as suspicious awareness (Glaser & Strauss, 1965). Alternatively, a nursing-home D personal carer identified the resident's awareness, but assigned it to the context of denial and consequently described her engagement in mutual pretence (Glaser & Strauss, 1965):

You can see he's in denial and he knows there's something really wrong ... but in a way he wants you to tell him and in a way he doesn't ... me, I will just say "OK, we've got that drift you and I. It's there. When I look into your eyes, you know I know and it's left unsaid'.

The resident 'knows there's something wrong' and the carer also knows however, both pretend that neither knows, even though their mutual understanding is 'left unsaid'.

Specifically, the resident's awareness becomes most meaningful in the original context of death and dying (Glaser & Strauss, 1965). A nursing-home D group of personal carers discussed a resident's suspicion about dying. In their recounting of an incident, they acknowledged that the resident 'know(s) in the back of their minds (sic)' and in the case of a dying woman 'she could feel it' and had asked the personal carer 'tell me'. The recollection of this incident evoked one personal carer to suggest that 'people' deny dying ('cover it up') with 'you're just sick ... tomorrow you'll be better'. Of significance, in a follow-up interview, a group of registered nurses and specifically a registered nurse manager (MCCS) at this same nursing-home, confirmed this pretending in the care of a dying resident, revealing:

(S)ome of them (family) have a tendency to talk in front of Mother or Father and I struck this problem the other day. It was like, you know, "Do you think ... Mum will still be here after/over the week end?" and this women (relative) says, sort of looking at us ....

The registered nurse manager (MCCS) and her colleagues perceive that openly speaking about the dying of a family member is a 'problem' — notably, in *front* of the resident! In her recollection, the registered nurse manager continued with 'Oh no she's (relative) not going anywhere. Come outside'. The nurse manager utilises euphemism in the company of the resident and resident's family member. Additionally, concurring with the residents in the study (see forthcoming section) she invites the resident's family member outside the resident's room for a 'quiet conversation'. Even though the registered nurse manager '... did wonder if she

(relative) would possibly die over the weekend' she preferred to say 'No. You are all right aren't you (Sarah)?' and

... then you might give them (family) a little bit more information and say, "Well you know there is a possibility that Mum may well deteriorate" ... so what you are saying in the room and what you will say outside might be not exact opposite but might be a little bit different.

The resident is not included in the conversation nor does the registered nurse express here the possibility that the resident has the previously discussed awareness ('They notice a lot more than we think they do').

Importantly, the existence of suspicious awareness and mutual pretence is established. Family *do* demand of the care providers 'Don't Tell Mum', that is, to not disclose information to the resident about their relative's health. Yet, residents are perceived by care providers to have the capacity to sense and therefore have an awareness of their status. Furthermore, in a forthcoming section, residents know about 'quiet conversations' and have experiences of family exploring 'Don't Tell Mum'.

### **'Home away from home': residents' perceptions**

For a nursing-home A resident with partial self-care deficit, the daily reality of the 'Home away from Home' is being 'only a step away' from 'patients worse off than myself ... but for the grace of God ...'. Elsewhere, a colleague at nursing-home E, in acknowledging she had 'come to the end of the road' lamented:

I feel that my life has no future at the moment .... I watch the tennis and I watch the football and that — on TV, and that just fills in time. And luckily I'm a good reader. I read a terrific lot, otherwise I don't know what I'd do with myself.

For these two women, the nursing-home holds no future or the future is fraught with the risk of slipping into an unwanted degree of dependence and debilitating morbidity. As a place for dying ('my life has no future'), this resident waits, filling in her time watching — the television her company, her books her companions. This resident added 'there is very little social activity here'. Here, an expression of social isolation. I continued by asking, 'In your day to day life, do you have an expectation that they (care providers) can sit and talk to you? Who do you talk things over with?':

I've got two women here, (Margaret) and another one (Joan), I don't know her surname ... they come into my room invariably, sit and talk to me .... (T)hey're patients — inmates .... They're not good friends or anything like that. I realise I can talk to them. We lend each other books and things like that.

This resident's experience and perception defines the 'Home away from Home' as a lonely place, with limited interpersonal interactions. The social interaction that occurs is in her room with two fellow 'inmates' — a term indicative of institutional care with a high degree of external control. Rather than a natural home-like environment in which she keeps the company of friends ('I don't know her surname' and 'They're not good friends') she keeps company with acquaintances confined, unless mobile, to a room — a view consistent with the nursing-home A registered nurse's (team leader) previous view: 'you live in a little room that's what becomes your home'.

At nursing-home C a resident was firm in her opinion about what she understood to be the 'normal part of life here', namely 'musical things':

The normal part of your life which I don't like it — they have musical things ... Like sing old songs and they make you miserable .... But I think they are trained to do it .... It's a 'Long Way to Tipperary' — if I hear that again I'll *scream* .... Yes. I tell them that (these songs upset me) and *they* laugh. They say others love them ....

Memories of her past ('old songs') which are associated with the activities of the diversional therapist ('they are trained to do it') do little to comfort her. On the contrary, such activity makes her 'miserable' and 'upset'. Unlike her colleague, it

is not the social isolation that grieves her rather it is the use of the group activity that silences the requirements of the individual. Her request is laughed away by staff. Her home life is homogenised rather than individualised, failing to foster self-determination and *her* own best interests. This negation of the individual's preference complements a nursing-home A registered nurse's observation that the personal carers 'perceive that that's what everyone (residents) should do and that's why you've got to be very careful that we don't box people (in)'.

In addition, writing in her personal journal, a different nursing-home E resident described the nursing-home as a place with well defined care (task) roles and equally well established behavioural expectations:

There is a lady here who sat at my table for lunch. She had one leg and was blind & deaf .... One day she started using her hands to feed herself instead of using the spoon .... I started to feed her .... One day a Sister (registered nurse) saw this happening and said she'd have to be a complete feed, so they moved her .... She (resident) hasn't spoken to any of us since ... she has gone right back into herself and won't speak to anyone any more even the nurses. A sad case I think. We asked for her to be moved back to our table, but were told, "No can do". We (residents) have to do as we are told.

Residents 'do as we are told'. Her experience of 'home' complements labelling the resident as 'inmate' since her experience clearly portrays institutional care with a high degree of external control. Not only is this resident's request negated, the 'lady' she describes is separated, reverts to silence and mutual social interaction is lost. The conforming resident in a well demarcated care environment with clearly assigned tasks was apparent in an interview with a nursing-home C personal carer speaking of the quiet, non-questioning resident:

If it (resident with rash) was me, I'd be saying 'Look, I've had this for a long time, it comes and goes, it's got to be something. Obviously the cream you gave me is not treating it properly, is there something else we can do?'...

The personal carer can and would speak for herself — but her point is that she is not like what she observes residents to be. Questioning the treatment and actively engaging with the care providers is not what she, the personal carer, experiences as the behaviour of the resident. Her actions ('if it was me') are the antithesis of residents resigned to silence and their acceptance that 'we do as we are told'.

### **Starved of time: residents' perceptions**

At nursing-home A the resident perceives that neither the registered nurse nor the doctor 'have time to tell' her 'things':

The doctors don't have time, they are busy, they have their family. (I) (d)on't want to be additional work. They don't have time to tell us things. So I go outside nurses or doctor within the nursing-home ...

Complementing the care providers' data, this resident supports the view that the nursing-home is time-starved. Perceiving herself to be an added care burden and unable to seek counsel with anyone, this resident turns elsewhere for information. A colleague at nursing-home E added:

I have my clothes out ready ... anything I can do to speed up, because they're always in a hurry first thing in the morning at half past 6. They just do the absolute minimum of what they have to do for you. I mean they have to go and get the breakfasts.

Care provision is necessarily task-orientated. That is, the institution's emphasis is on getting the work done, with the consequence that the care providers 'hurry' to complete basic hygiene and grooming cares. Interestingly, the resident attempts to help the personal carers ('anything I can do to speed up') in order to be less of a demand on their time ('they have to go and get the breakfasts'). When I asked about information disclosure in this rushed environment, the resident's response underscored the absence of psychosocial care. In her experience, they talk to her

about 'their home life' but as a consequence of the lack of time 'to sit down' this talking 'only happens when they're making my bed'.

Fellow 'inmates' at nursing-homes C and A respectively, agreed that the time-starved and, in their view, the understaffed context impacts on care provision. Limited time and staff mean that not only do care providers 'do the absolute minimum of what they have to do for you' but in this resident's experience 'hands on' physiotherapy is neglected:

There is a definite 'busyness' about this place. There's too much work for too few people. And you feel things aren't given enough time. You take my physio' even .... He walks in here but hands on physio there's never time it seems. I should say that's (the) case often. Doctor's visits are very brief.

A fellow resident (an incomplete quadriplegic) recognised her nursing-home's 'busyness' as a consequence of staff shortage. She recounted how she rings the buzzer and 'when they can come, they come. I mean you can understand that they can't always come straight away .... They are short staffed'.

### **Place of awareness: residents' perceptions**

At nursing-home C, residents' group discussion data revealed the commonality of the family's request "Don't Tell Mum" that underscores the residents' awareness: Well they say: "*Don't tell mum!*" (tapping finger on the table).

"Don't tell Mum!"

Now that is common knowledge. That's what your family say: "*Don't tell mum!*" (tapping finger on the table).

These residents see and sense 'quiet conversation' in ward corridors, outside the residents' rooms. They observe the family requesting that the resident not be told of their status ('Don't tell Mum'). The resident is aware of something and the family is aware but will not share what they know — the resident has suspicious awareness (Glaser & Strauss, 1965).

Additionally a resident in this group added about these 'quiet conversations':

Well the majority of doctors, when they come to see a patient or that, they don't (talk) *to* a patient, they get the family outside and tell them. Which happens all the time.

The resident is excluded from conversations about her own status. They are well aware that the family instructs nursing staff and doctors to keep information from them. Not only do these residents 'see them having quiet conversations in lowered voices' they become aware because 'you can hear them'. I sought clarification about who they see and who they hear:

All your family. "What did the doctor say"? After you have seen the doctor they gather around in a group and ... you can hear them....

These 'quiet conversations' that result in suspicious awareness and communication strategies that create mutual pretence, resonate in the data because personal carers, registered nurses and residents' families reason that in withholding or editing information they do so in the residents' best interest. Contrary to this withholding or editing of information based on assumptions about another's best interest, nursing-home B residents seek open awareness since '... it is better to know the truth ...' rather than 'just to hang on, sort of wondering and worrying what is wrong with you' since the latter 'will only kill you anyway. So you might as well know the truth ...'.

For residents at nursing-home C and B, non-disclosure or vagueness causes worry and anxiety in contrast to the care provider's view, that open disclosure is 'harmful, damaging or upsetting' (Tuckett, 2004c and Tuckett, 2004a). Finally, residents at nursing-home B acknowledge truthfulness allows them to be autonomous:

Personally I think it is better (to) be told, so you can get on with your life rather than live in the dark ....

You have got to get on with your life and find out what's wrong with it.

I have accepted it, that it is not going to improve any and I also accept it that my own way of thinking of it as I grow older it will get worse, because age does make these things (better). But it doesn't worry me now that I know it, it's permanent with me. I am glad that the doctor told me that.

Both of these residents want information about their status. Not only does being openly aware of one's status facilitate self-determination, it also promotes quality of life (Cartwright & Parker, 2005).

## 5. Discussion

Residency as 'Home away from Home' (Thorman Hartig, 1998) is described as sometimes chaotic, confronting but also challenging, threatening and a place where power is contested (Tuckett, 2005a and Tuckett, 2005b). It is a dormitory for dying (Gubrium, 1993, Nussbaum, 1993 and Weiner and Kayser-Jones, 1990) and a place where residents have awareness (Glaser & Strauss, 1965). Residents' perception, captured in the phrase 'Don't Tell Mum', amounts to residents having suspicious awareness. In the context described here, the resident suspects what is known by others. Furthermore, their observing of 'quiet conversations' and staffs' acknowledgement that the residents' suspect what others know, verifies mutual pretence (Costello, 2000 and Glaser and Strauss, 1965).

The nursing-home is instrumental or task focused (cure orientation) rather than socio-emotional focused (care focused) (Armstrong-Esther et al., 1994, Clinton et al., 1996 and Edwards et al., 2003). Additionally, it is time-starved (Armstrong-Esther et al., 1994, Forrest, 1989 and Serghis, 1998) with a tendency toward ward orderliness (Edwards et al., 1993, Gubrium, 1993, Tuckett, 1998 and Yates et al., 1995) little time for engagement with the resident and little opportunity for resident autonomy (Nussbaum, 1993 and Roe et al., 2001).

Residents identify the task-orientation to care, limited time, and the nursing-home as short staffed with some resignation (Diamond, 1992, Serghis, 1998 and The Queensland Nurse, 2002). Furthermore, they noted the consequential limited communicative engagement with either the personal carer or registered nurse. (Armstrong-Esther et al., 1989, Armstrong-Esther et al., 1994, Farrell, 1991, Nussbaum, 1993 and Patterson, 1995).

In this analysis of the nursing-home, it is clear that the care circumstance is temporal. As such, the nursing-home that fosters residents' (open) awareness must be time-rich rather than time-poor. The nursing-home described as time-starved greatly reduces the staffs' availability for openness and greatly increases the probability for residents' suspicion and mutual pretence (Glaser & Strauss, 1965). That is, say little and omit the detail, save time. With limited time, there is limited talking.

However, care providers knowing what the resident wants to know is a function of how much time a personal carer or registered nurse spends with a person. The nursing-homes described here have neither enough task-time nor is there any time allocated for *being* with the resident. With the priority on tasks or the *doing*, there is no time for *being* with a resident, to interact with in conversation, to understand more fully or to know or learn about the resident (Oliver and Redfern, 1991, Ong et al., 1995 and Serghis, 1998).

Furthermore, time is perceived to be limited with an increasing workload. Whilst effective communication is contingent upon time, this ideal brings to the care relationship a (an additional) 'burden of care' (Anonymous, 1980). More, not less, communication adds to the 'burden of care' in a context already time-depleted and understaffed. A care context of limited time with a *doing* or task focus would not claim to desire nor is capable of, absorbing an additional care burden without adding to nursing staff turnover. Consequently, in the context of awareness, the management of information becomes a strategy for time management.

What is needed is a shift in practices to emphasise affective care and communication. Simply, talk rather than tasks. A shift of this kind can be met through better educational preparation (at undergraduate, tertiary level and at staff development level) and the re-orientation of work practices (institutional policy) that underscores affective care as important alongside instrumental care, reassures the care providers that openly talking with another is therapeutic and reclaims care that is resident-centred so promoting improved openness (Kitwood, 1997). In practice and in the curriculum, talk would be given 'a central place in learning the work, not tacked on to the end of a set of procedures or separated as a quasi-scientific task that staff performed on residents' (Diamond, 1992, p 218). Therefore, the personal carer or registered nurse would be permitted to stop *doing* and accept the view; 'I get paid to talk'.

Furthermore, the health of the resident in a nursing-home is directly linked to care provision that encourages autonomy. Writers contend that 'limiting autonomy leads to potentially negative health consequences' as a result of the loss of control over one's own life (Pecchioni & Nussbaum, 2000, p 317). The ability and opportunity to exercise autonomy is important for physical health (Moutsopoulos, 1984), psychological health for all persons (Hummer & Morgan, 2001) and is generally a component of a good quality of life (Harper Ice, 2002). Consequently, the importance of maintaining control by older persons facing a decline in these aspects of health may be heightened (Carpenter, Van Haitsma, Ruckdeschel & Lawton, 2000). Colleagues concur and add that negative physical, social and psychological outcomes attached to loss of autonomy, include poorer health, diminished morale and self-esteem (Pecchioni & Nussbaum, 2000).

Argument exists whereby the evaluation of autonomy that underlies the position in this article – emphasising the individual and self-determination – may not be useful for those who hold to a more socio-centric view (Johnstone, 2004). Whether or not a person ascribes to a more 'individual(istic), independent, self-contained' view or a more collective, interdependent and socially connected view of self amongst others (Johnstone, 2004, p 71–72) the significant issue is this — staff (personal carers and registered nurses) must not assume a homogeneity of older people. The very point is to ask and to evaluate, rather than assume.

By way of definition, the autonomous person is said to be self-governing through the exercise of rational decision-making. Hence, rational deliberation is an essential feature of the autonomous individual (Kerridge, Lowe & McPhee, 2005). Meshed into the self-determining and self-governing components of autonomy is a further element — to act freely. The nursing-home resident can only be acting freely and autonomously when acting independently from controlling influences (Beauchamp & Childress, 2001). Controlling influences can include incomplete information or impaired comprehension.

Perhaps as a natural consequence, the stereotypical image of the elderly as 'frail and vulnerable' has caused carers to 'infantilise and patronize' the older person, and prevent them from making their own life choices (Becker, 1994 and Herring and Thom, 1991). Pecchioni and Nussbaum (2000) report on research that associates the acceptance of the stereotype of the older person as frail and incapacitated with care giver determinations about the elder's ability to make decisions. Whilst for some older people it may be the reality that they decline physically and become forgetful, for most it is not (Feldman, 1999 and Gibson et al., 1997). Even in the absence of cognitive impairment in the older person, care staff associate an increased need for physical care with a decreasing assessment of the ability of the elder to make decisions. It is the stereotype of the aged as frail and incapacitated that may 'play a factor in assessing an elder person as less capable (of decision-making) than he or she is at any given point of time' even in long-standing relationships (parenthesis added) (Pecchioni & Nussbaum, 2000).

However, what of those residents deemed to have impaired comprehension? Diamond's ethnography revealed that 'residents, even if intermittently confused, had a lot to say about their care and how they would like it to be different' (1992,

p229). For those residents with dementia, care providers are warned about assuming that residents are not aware of what is going on and what people are saying. The assumption that 'the person with dementia just does not understand any longer and cannot express an opinion of their own is downright wrong' (Hamilton-Smith & Cluning, 2001, p 275, p 278).

Autonomy, argued for here, is about giving the nursing-home resident the opportunity to be self-determining and maintaining control over the decision-making element of their care. I have recommended elsewhere that this can be achieved by care staff utilising a 'psychological registration sheet' that notes what information is given and reactions to it to improve communication with residents (De Valck and Van de Woestijne, 1996 and Tuckett, 2006). The nursing-home that claims to have as its primary focus 'the resident' ought to take seriously the residents' health and therefore the residents' autonomy.

## **6. Conclusion**

The nursing-home that is described as endowed with suspicious awareness and mutual pretence, overloaded with tasks, short of staff and starved of time with little engagement with the residents fails to adequately understand the autonomy-health link. This 'Home away from Home' must re-orientate itself to be built on affective and effective communication. If the fundamental link between health, resident and autonomy is to have practical reality, it is necessary for nursing-homes to review not only their expressed policies, but also their daily practice with a view to strengthening their efforts to promote and support autonomy. Where resources (time as well as human resources) appear to conflict, or inhibit resident autonomy, efforts must be made to adjust organisational culture to prioritise resident autonomy.

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## References

- Anonymous, 1980 Anonymous, In cancer, honesty is here to stay, *The Lancet* (1980, August 2), p. 245.
- Armstrong-Esther et al., 1994 C. Armstrong-Esther, K. Browne and J. McAfee, Elderly patients still clean and sitting quietly, *Journal of Advanced Nursing* 19 (1994), pp. 264–271.
- Armstrong-Esther et al., 1989 C. Armstrong-Esther, M. Scandilands and D. Miller, Attitudes and behaviours of nurses towards elderly in an acute care setting, *Journal of Advanced Nursing* 14 (1989), pp. 34–44.
- Australian Nursing Journal, 1998 Australian Nursing Journal, Survey reveals aged-care crisis [Electronic version], *Australian Nursing Journal* 6 (1998) (4), p. 6.
- Australian Nursing Journal, 2004 Australian Nursing Journal, Aged care system suffering [Electronic version], *Australian Nursing Journal* 12 (2004) (4), p. 8.
- Australian Nursing Journal, 2005 Australian Nursing Journal, Inquiry calls for higher wages [Electronic version], *Australian Nursing Journal* 13 (2005) (2), p. 7.
- Barba et al., 2002 B. Barba, A. Tesh and N. Courts, Promoting thriving in nursing-homes: The Eden alternative, *Journal of Gerontological Nursing* 28 (2002) (3), pp. 7–13.
- Beauchamp and Childress, 2001 T. Beauchamp and J. Childress, Principles of biomedical ethics ((5th ed.)), Oxford University Press, New York (2001).
- Becker, 1994 G. Becker, The oldest old: Autonomy and the face of frailty, *Journal of Aging Studies* 8 (1994), pp. 59–76.
- Berger and Luckman, 1966 P. Berger and T. Luckman, The Social Construction of Reality: A Treatise in the Sociology of Knowledge, Penguin, London (1966).
- Bitzan, 1998 J. Bitzan, Emotional bondedness and subjective well-being between nursing-home roommates [Electronic version], *Journal of Gerontological Nursing* 24 (1998) (9), pp. 8–15.
- Blumer, 1969 H. Blumer, Symbolic Interactionism: Perspectives and Method, Prentice Hall, Englewood Cliffs, NJ, USA (1969).
- Boyatzis, 1998 R. Boyatzis, Transforming Qualitative Information: Thematic Analysis & Code Development, Sage, Thousand Oaks (1998).
- Burgio et al., 1990 L. Burgio, A. Engel, K. Hawkins, T. McCormick and A. Scheve, A descriptive analysis of nursing-home staff behaviours in a teaching nursing-home: Differences amongst NAs, LPNs and RNs, *The Gerontologist* 30 (1990), pp. 107–112.
- Carpenter et al., 2000 B. Carpenter, K. Van Haitsma, K. Ruckdeschel and M. Lawton, The psychosocial preferences of older adults: A pilot examination of content and structure [Electronic version], *The Gerontologist* 40 (2000) (3), pp. 335–348.
- Cartwright and Parker, 2005 C. Cartwright and V. Parker, Ageing, health and illness. In: C. Rogers-Clark, A. McCarthy and Kristine Martin-McDonald, Editors, *Living with illness: psychosocial challenges for nursing*, Elsevier Churchill Livingstone, Sydney (2005), pp. 54–69.
- Charmaz, 1990 K. Charmaz, 'Discovering' chronic illness: Using grounded theory, *Social Science & Medicine* 30 (1990) (11), pp. 1161–1172.
- Charmaz, 2003 K. Charmaz, Qualitative interviewing and grounded theory analysis. In: J. Holstein and J. Gubrium, Editors, *Inside interviewing: New lenses, new concerns*, Sage Publications, Thousand Oaks (2003), pp. 311–330.
- Clinton et al., 1996 M. Clinton, H. Edwards, W. Moyle, P. Weir and M. Eyeson-Annan, Report on stress in nurses caring for residents with Alzheimer's disease in a dementia unit, Centre for Mental Health Nursing Research, Queensland University of Technology, Kelvin Grove (1996).
- Costello, 2000 J. Costello, Truth telling and the dying patient: A conspiracy of silence?, *International Journal of Palliative Nursing* 6 (2000) (8), pp. 398–405.
- Crotty, 1998 D. Crotty, The Foundations of Social Research: Meaning and Perspective in the Research Process, Allen & Unwin, St. Leonards (1998).



- De Valck and Van de Woestijne, 1996 C. De Valck and K. Van de Woestijne, Communication problems on an oncology ward, *Patient Education and Counselling* 29 (1996), pp. 131–136.
- Diamond, 1992 T. Diamond, Making gray gold: narratives of nursing home care, Chicago University Press, Chicago (1992).
- Drew and Brooke, 1999 J. Drew and V. Brooke, Changing a legacy: The Eden alternative nursing-home, *Annals of Long-Term Care* 7 (1999) (3), pp. 115–121.
- Edwards et al., 2003 H. Edwards, D. Gaskill, F. Sanders, E. Forster, P. Morrison and R. Fleming *et al.*, Resident–staff interactions: A challenge for quality residential aged care, *Australasian Journal on Ageing* 22 (2003) (1), pp. 31–37.
- Edwards et al., 1993 H. Edwards, D. Weir, M. Clinton and W. Moyle, Communication between residents and nurses in a dementia facility: An issue quality of life, *Article presented at the Alzheimer Association (Australia) 3rd National Conference, Melbourne* (1993).
- Farrell, 1991 G. Farrell, How accurately do nurses perceive patients' needs: A comparison of general and psychiatric settings, *Journal of Advanced Nursing* 16 (1991) (9), pp. 1062–1070.
- Faulkner, 1980 A. Faulkner, Communication and the nurse, *Nursing Times* 76 (1980), pp. 93–95.
- Feldman, 1999 S. Feldman, Please don't call me 'dear': Older women's narratives of health care, *Nursing Inquiry* 6 (1999), pp. 269–276.
- Fiveash, 1998 B. Fiveash, The experience of nursing-home life, *International Journal of Nursing Practice* 4 (1998), pp. 166–174.
- Forrest, 1989 D. Forrest, The experience of caring, *Journal of Advanced Nursing* 14 (1989), pp. 815–823.
- Fry, 1988 S. Fry, The ethic of caring: Can it survive nursing, *Nursing Outlook* 36 (1988), p. 48.
- Gibson et al., 1997 Gibson, D., Mathur, S., & Racic, L. (1997). *Older Australians at a glance*. Canberra: Australian Institute of Health and Welfare and the Office for the Aged, Department of Health and Family Services, Commonwealth of Australia.
- Glaser, 1999 B. Glaser, The future of grounded theory [Electronic version], *Qualitative Health Research* 9 (1999) (6), pp. 836–845.
- Glaser and Strauss, 1965 B. Glaser and A. Strauss, Awareness of dying, Aldine Publishing Company, Chicago, IL (1965).
- Gottesman and Bourestom, 1974 L. Gottesman and N. Bourestom, Why nursing-homes do what they do, *The Gerontologist* 14 (1974), pp. 501–506.
- Gubrium, 1993 J. Gubrium, Speaking of life: the horizons of meaning for nursing-home residents, Aldine de Gruyter, New York (1993).
- Hamilton-Smith and Cluning, 2001 E. Hamilton-Smith and T. Cluning, Responding to dementia. In: T. Cluning, Editor, *Ageing at home: practical approaches to community care*, Ausmed Publications, Melbourne (2001), pp. 270–295.
- Harper Ice, 2002 G. Harper Ice, Daily life in a nursing-home: Has it changed in 25 years?, *Journal of Aging Studies* 16 (2002), pp. 345–359.
- Herring and Thom, 1991 R. Herring and B. Thom, The right to take risks: Alcohol and older people, *Social Policy and Administration* 31 (1991), pp. 233–246.
- Higgins, 1998 I. Higgins, Reflections on conducting qualitative research with elderly people, *Qualitative Health Research* 8 (1998) (6), pp. 858–866.
- Hummert and Morgan, 2001 M. Hummert and M. Morgan, Negotiating decisions in the aging family. In: M. Hummert and J. Nussbaum, Editors, *Ageing, communication and health: linking research and practice for successful aging*, Lawrence Erlbaum Associates, London (2001), pp. 177–203.
- Irurita, 1999 V. Irurita, Factors affecting the quality of nursing care: The patient's perspective, *International Journal of Nursing Practice* 5 (1999), pp. 86–94.
- Johnstone, 2004 M.-J. Johnstone, Bioethics: a nursing perspective ((4th ed).), Saunders, Marrickville, NSW (2004).
- Kaakinen, 1992 J. Kaakinen, Living with silence, *The Gerontologist* 32 (1992), pp. 258–264.

- Keck and Walther, 1977 V. Keck and L. Walther, Nurses encounters with dying and non-dying patients, *Nursing Research* 26 (1977), pp. 465–469.
- Kerridge et al., 2005 I. Kerridge, M. Lowe and J. McPhee, Ethics and law for the health professions ((2nd ed).), The Federation Press, Sydney (2005).
- Kitwood, 1997 T. Kitwood, The experience of dementia, *Aging and Mental Health* 1 (1997) (1), pp. 13–22.
- Legge, 2004 K. Legge, Nursing-home staff numbers are 'dangerously' inadequate, *The Australian* (2004, August 12), p. 4.
- Lyytinen et al., 2002 H. Lyytinen, T. Liippo, P. Routasalo and S. Arve, Older patients' first 72 hours in hospital, *International Journal of Nursing Practice* 8 (2002), pp. 191–197.
- Mamo, 1999 L. Mamo, Death and dying: Confluences of emotion and awareness, *Sociology of Health and Illness* 21 (1999) (1), pp. 13–36.
- May, 1990 C. May, Research on nurse–patient relationships: Problems of theory, problems of practice, *Journal of Advanced Nursing* 15 (1990), pp. 307–315.
- McCormack, 2003 B. McCormack, A conceptual framework for person-centred practice with older people, *International Journal of Nursing Practice* 9 (2003), pp. 202–209.
- Mead, 1934 G. Mead, Mind, Self, Society, Chicago University Press, Chicago (1934).
- Mezey et al., 1999 M. Mezey, L. Miller and L. Linton-Nelson, Caring for caregivers of frail elders at the end of life, *Generations* (1999, Spring), pp. 44–51.
- Moutsopoulos, 1984 L. Moutsopoulos, Medicine and law, Springer-Verlag, New York (1984).
- Mullins et al., 1998 L. Mullins, L. Moody, R. Colquitt, A.-C. Mattiason and L. Andersson, An examination of nursing-home personnel's perceptions of residents' autonomy [Electronic version], *Journal of Applied Gerontology* 17 (1998) (4), pp. 442–461.
- Nussbaum, 1993 J. Nussbaum, The communicative impact of institutionalisation for the elderly: The admission process, *Journal of Aging Studies* 7 (1993) (3), pp. 237–246.
- Nussbaum et al., 2001 J. Nussbaum, L. Pecchioni and T. Crowell, The older patient–healthcare provider relationship in a managed-care environment. In: M. Hummert and J. Nussbaum, Editors, *Aging, communication and health: Linking research and practice for successful aging*, Lawrence Erlbaum Associates, Mahwah, NJ (2001), pp. 23–42.
- Oliver and Redfern, 1991 S. Oliver and S. Redfern, Interpersonal communication between nurses and elderly patients: Refinement of an observation schedule, *Journal of Advanced Nursing* 16 (1991), pp. 30–38.
- Ong et al., 1995 L. Ong, J. de Haes, A. Hoos and F. Lammes, Doctor-patient communication: A review of the literature, *Social Science and Medicine* 40 (1995) (7), pp. 903–918.
- Patterson, 1995 B. Patterson, The process of social support: Adjusting to life in a nursing-home, *Journal of Advanced Nursing* 2 (1995) (1), pp. 682–689.
- Pecchioni and Nussbaum, 2000 L. Pecchioni and J. Nussbaum, The influence of autonomy and paternalism on communicative behaviours in mother–daughter relationships prior to dependency, *Health Communication* 12 (2000) (4), pp. 317–338.
- Roe et al., 2001 B. Roe, M. Whattam, H. Young and M. Dimond, Elders' perceptions of formal and informal care: Aspects of getting and receiving help for their ADLs, *Journal of Clinical Nursing* 10 (2001), pp. 398–405.
- Serghis, 1998 D. Serghis, QNU survey uncovers aged-care woes [Electronic version], *Australian Nursing Journal* 6 (1998) (5), p. 9.
- Shawler et al., 2001 C. Shawler, G. Rowles and D. High, Analysis of key decision-making incidents in the life of a nursing-home resident [Electronic version], *The Gerontologist* 41 (2001) (5), pp. 612–622.
- Strauss and Corbin, 1998 A. Strauss and J. Corbin, Basics of qualitative research: Techniques and procedures for developing grounded theory, Sage Publications, Thousand Oaks (1998).
- The Queensland Nurse, 2002 The Queensland Nurse, New classification structure and rates of pay for nurses in aged-care. Report on findings of the Queensland Industrial Relations Commission (QIRC), *The Queensland Nurse* 21 (2002) (2), pp. 9–11.

- Thomas, 1994 W. Thomas, *The Eden alternative: Nature, hope and nursing-homes*, Eden Alternative Foundation, New York (1994).
- Thorman Hartig, 1998 M. Thorman Hartig, Expert nursing assistant care activities, *Western Journal of Nursing Research* 20 (1998) (5), pp. 584–602.
- Tuckett, 1998 A. Tuckett, "Bending the truth": Professionals' narratives about lying and deception in nursing practice, *The International Journal of Nursing Studies* 35 (1998), pp. 292–302.
- Tuckett, 2004a A. Tuckett, Truth-telling in clinical practice and the reasons for and against — A review of the literature, *Nursing Ethics* 11 (2004) (5), pp. 500–513.
- Tuckett, 2004b A. Tuckett, Qualitative research sampling — The very real complexities, *Nurse Researcher* 12 (2004) (1), pp. 47–61.
- Tuckett, 2004c Tuckett, A. (2004c). *Truth-telling in aged care: a qualitative study*. PhD thesis, Kelvin Grove: Queensland University of Technology. Available at <http://adt.library.qut.edu.au/adt-qut%1EQUT20040827.093416/>.
- Tuckett, 2005a A. Tuckett, Residents' rights and nurses' ethics in the Australian nursing-home, *International Nursing Review* 52 (2005), pp. 219–224.
- Tuckett, 2005b A. Tuckett, The care encounter: Pondering caring, honest communication and control, *International Journal of Nursing Practice* 11 (2005), pp. 77–84.
- Tuckett, 2005c A. Tuckett, Part II: Rigour in qualitative research — Complexities and solutions, *Nurse Researcher* 13 (2005) (1), pp. 29–42.
- Tuckett, 2006 A. Tuckett, On paternalism, autonomy and best interests: Telling the aged care resident what they want to know, *International Journal of Nursing Practice* 12 (2006) (13), pp. 166–173.
- Weiner and Kayser-Jones, 1990 C. Weiner and J. Kayser-Jones, The uneasy fate of nursing home residents: An organisational-interaction perspective, *Sociology of Health and Illness* 12 (1990) (1), pp. 84–104.
- Willis and Broom, 2004 E. Willis and A. Broom, State of the art: A decade of health sociology review, *Health Sociology Review* 13 (2004) (2), pp. 122–144.
- Wood and Kroger, 1993 L. Wood and R. Kroger, Forms of address: Discourse and aging, *Journal of Aging Studies* 7 (1993) (3), pp. 263–277.
- Yates et al., 1995 P. Yates, A. Dewar and B. Fentiman, Pain: The views of elderly people living in long-term residential care settings [Electronic version], *Journal of Advanced Nursing* 21 (1995) (4), pp. 667–674.