Loving to care / Caring to love: Stories of nursing home life

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This paper draws from research done as part of a Social Sciences Humanities Research Council (SSHRC) funded program of work entitled “Creating home in the institution: Community development in the context of dementia”. The specific objectives of the research are to: provide a window into the functioning of the dynamic social environment of a dementia care unit of a publicly funded and operated nursing home in a large Canadian urban centre; to better understand how individual staff contribute, beyond role definition or job description, to the environment as a home like setting; to gain insights into the complex interaction between individuals’ personal and professional commitment to caregiving; and to contribute to the limited knowledge base on caregivers to people with dementia in institutional settings. The research is broadly qualitative and, more specifically, situated within a community centred, arts-informed, reflexive life history framework. Data collection methods include: in-depth interviews with the diversity of staff on one dementia care unit, the examination of pertinent institutional and personal artifacts, and observations made in context while spending time on the floor as volunteers.

Our broad intention of making nursing homes and the people who live and work in them more accessible, more understandable and more inviting to the general public identifies our research as advocacy work. In celebrating caregivers as people, we also promote the act of giving care, as a worthy activity. In order to do so, the research is founded on “the search for goodness” as a methodological orientation (Lawrence-Lightfoot & Hoffman-Davis, 1997). This is “an approach to inquiry that resists the more typical social science preoccupation with documenting pathology and suggesting remedies” (Lawrence-Lightfoot & Hoffman-Davis, 1997 p.141). Following Tom Kitwood’s directive that “good care needs to find a voice”, this is research into care that works (Kitwood, 1997, p.54). Representing knowledge in ways that people beyond the academy can access, so that it might have relevance and make a difference to affected individuals and their communities is central to our work. In order to best render the research results and to remain congruent with our commitment to research accessibility, we present our work in a manner that can generally be described as arts-informed (Cole & Knowles, 2001; McIntyre, 2000; & Eisner, 1993).

We begin by exploring ‘care’ and ‘home’, as separate concepts and map the terrain of their intersection through academic theory and everyday discourse. We consider how, in the institutional context of the nursing home, these concepts are brought to life and made real through the practices of staff. Focusing particular attention on the points of congruence and tension between individual staff members values and beliefs about care, and the structures in which they work, we detail how the institutional structure supports or constrains their efforts to give care and make home. In exploring how individual staff members make home in the
institution, we deconstruct “homemaking” and reinvent the meaning and significance of homemaking as care.

We invite the reader to experience ‘home’ and ‘care’ as psychological constructs through storied text and in-role performance. Direct quotations from staff appear in italics. In the live presentation of this paper these quotations (and additional ‘staff voices’ that space constraints don’t permit us to include here), are given to audience members to read aloud in a readers theatre presentational format. This process of deconstructing practices of homemaking through alternative forms allows us to inform and educate diverse audiences—including the general public, family caregivers and academics alike—about the people who work in nursing homes and the complexity of making home in the institution. As audience members join us in celebrating the work of staff and honoring their capacity to care, we broaden and extend the community supporting people living lives with dementia. In so doing we operationalize the agenda of adult education as social education, and provide impetus for educators to reflect on the value and meaning of practices that currently guide education for adults.

In everyday discourse our notions of home and its significance as a social and psychological construct pepper our conversation. When we use the term “housewife”, or the somewhat less politically outdated term “homemaker”, we delineate occupation, identity, and gender. On the other hand, do we imagine someone described as a “homebody” as male or female, young or old, vaguely anti-social or grounded and calm? And what is implied when a place is described as “homey”, or a person is seen as “homely”?

We extend hospitality and warmth by inviting guests to “make themselves at home”. We refer to feelings of comfort and connection by distinguishing between feeling “at home” or “not at home”. A “home away from home” comes close to satisfying our yearning for belonging. Conversely, the euphemism “there’s no one home” suggests a kind of psychological vacantness. In keeping with this construction, the sense of stigma surrounding a “homeless person” suggests that they lack much more than a fixed address. “Home is where the heart is”, and “there’s no place like home”.

The word “house”, on the other hand, tends to refer less to feelings and qualities of experience and more to physical setting. Lawless and Pietropaulo (2002) describe “house as the structural form of a site that exists in real time and space and that is a relatively stable entity” (p.2). Our house is the roof over our head at any given time. It is the floorboards, the apartment, the dorm room, and the address. Our sense of home, on the other hand, “usually can be, but not always is, contained or enclosed by a house” (p.2). A home is in process, it is fluid not fixed, it can exist in a garden, in a person, or in a house, it involves coming and going and returning home once again. “Home represents an ideal place to experience our sense of intimacy” (Lawless & Pietropaulo, 2002, p.xi). We make and remake home thus imbuing our notions of home with significance and meaning.

Clare Cooper Marcus (1995) further distinguishes between the concepts of house and home. “House” she suggests, we use as a “symbol of our place in society” (p.12). Buying a house is a rite of passage that is associated with settling down, domesticity and a certain level of prosperity. How we give place meaning, Marcus suggests, comes from the interplay of our unconscious and
conscious selves. While our houses contain representations of conscious self expression, that is they convey identity and say who we are through choice of colour, objects and furniture, our homes also contain expressions of the self that are unconscious. She suggests that the “soul-seeds” of feeling rooted in place have to do with emotional connection and are sown during the “innocent openness” of early childhood (Marcus, 1995, p.254). Later in life when we feel deeply “at home” we are reconnecting with that soul-nurturing place where we experience emotional attachment. Home is thus constructed as “a symbol of psychic wholeness” (Jung, 1969 in Marcus, 1995, p. xvi).

In keeping with this distinction between house and home we consider efforts that have to do with improving the physical plant of a place—things like wallpaper, knickknacks and furniture—to be quite different than acts of care made by people. While these “home improvements” are not without significance and in the nursing home environment effect the well being of staff, residents and visitors alike, their impact on the sense of home of the place pales in comparison to the impact of the presence of the people in that place.

I think that what makes it a home first and foremost is the caring attitude of the staff. They treat residents as though they’re part of their own family. They do for them what they would do for their own family member and although the environment has a lot to do with it, you can go into a nursing home that has the ensuite washrooms and everything else, but it can feel very, very, cold.

As with our houses, a nursing home can perpetually renovate and decorate and the place can feel no more like a home than when the initiative to make “home improvements” began. As Gaston Bachelard (1958) describes, our need for home cannot be completely satisfied through cosmetic improvements because the “images of protected intimacy” of which notions of home are made resonant on a much deeper level (p.6). Throughout our lives “we comfort ourselves by reliving memories of protection” that we overlay with images of home (Bachelard, 1958, p.6).

Even a surface reading of everyday talk reveals the images of care and love that are embedded in our notions of home. Conversely, an exploration of the qualities of love and care reveal their close relationship to our notions of home. Even when people have had no actual experience of a “loving home”, powerful images of an ideal home remain throughout the life span (Gubrium, 1993, 1976). When nursing home residents repeat the refrain “I want to go home”, or when people suffering from dementia engage in so-called “exit seeking” behavior, it is likely that they long for this psychological home, an ideal separate from time and space.

In The Philosophy of Existentialism (1956), Gabriel Marcel characterizes love and care together as “creative fidelity”, “attentive listening” and “meaningful solidarity”. Tom Kitwood (1997) names love as the main psychological need of people with dementia. In Kitwood’s model of person-centred care love is active; love is as love does. Loving care brings to the person with dementia opportunities for attachment, identity, inclusion, occupation and comfort (Kitwood, 1997). The boundaries between these needs overlap and combine, and, Kitwood points out, even in people who are independent and well they are not necessarily in evidence most of the time (Kitwood, 1997). The meeting of even one of these needs, however, can advance the fulfillment of another.
Attachment is a universal human need that can become more pronounced in people with dementia because they frequently find the familiar strange. Feelings of attachment are at the root of our capacity to feel “at home”.

We make sure that we have lots of magazines available, open shelves, things residents can pick up. It doesn’t matter that it disappears, the staff can pick it up at some other point and bring it back. We have hats, things for the men, dolls, stuffed animals, purses, things that were familiar.

Attachment is reciprocal.

I feel very much alive when I am able to cry when a resident dies. I recognize that that’s a healthy place to be in. I remember once not too long ago a resident passing away and I started crying and I think if the charge nurse cries it almost gives other people on the team permission to feel, and I think as long as you’re feeling, you’re living fully. I think the more closed we become, the more emotionally shut down we are. Ultimately that’s not a healthy or an empathetic place for caregivers to be. It’s better to stay close to your emotions.

The need to feel occupied in a way that is consistent with individual ability also begins very early in life and persists across the life span. Occupation, however, should not be confused with “busy work”. Occupation is tied to agency, and for people with dementia, agency is as linked to self-esteem as it is to people who are well (Kitwood, 1997).

We’re getting residents involved now in washing clothes. And ironing. That’s why the breakfast club is so popular, it’s a normalizing environment. I bought griddles and coffee percolators because we want them to smell the coffee perking and that kind of thing. We have a breadmaker as well. The residents measure out all the ingredients to make the bread...they’re part of the whole thing and they get to eat the bread afterwards when it’s ready.

The human need for inclusion, to feel a part of the social group is also necessary for survival.

Often I notice people, I’m singing a song, an old familiar song, and someone with severe dementia might be breathing at the right time. They’re not actually singing, they might be vocalizing a little, but they’re breathing when I’m breathing! I’ve had some families who weren’t visiting relatives anymore because it’s too painful for them, and then its like, “Oh, you have them in a group and they’re getting all this attention.” And they get involved again almost because the facility is treating this person like a person still, you know, like a deserving, worthy, person.

For people with dementia the awareness that they are different, and the realities of the social stigma to do with their condition, can lead to feelings of profound isolation and exclusion.

We’re all required to do one evening every two weeks. I enjoy going up to the floor and seeing residents in the evening. Its quiet. The isolation that they feel is so obvious. I like being able to, kind of, you know, come into that.

Individualized care plans for people with dementia often overlook social history and the persons current needs for inclusion (Kitwood, 1997).
I think the environment has a lot to do with it, but it's really how you make the environment work for the residents, how you make them feel they’re at home, they’re not confined to certain areas, you know, don’t cross over this line. They’re free to come and go as they please, to go wherever they like to go, participate in whatever they like to participate in. They’re encouraged to participate.

On the other hand, individual care plans have helped caregivers to address the ongoing need of people with dementia to experience identity. Understanding a person’s history and the capacity for empathy are the main ways we acknowledge each other as people and confer identity.

The more we share information about who residents are, the more we share what works. The secret of long term care boils down to what works for Mary, and everybody on the team needs to know what works for Mary and what doesn’t. And if we haven’t shared that information with them, I don’t think we’re doing our job. It takes you so long to get that information. And whether you get it from direct conversation with a family member or whether you intuitively stumble across it, it’s wisdom. It helps develop a caring and empathy in caregivers.

Finally, comfort “carries meanings of tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety, [and] the feeling of security which comes from being close to another” (Kitwood, 1997, p. 81). The close association between being comforted and feeling comfortable and at home is implicit.

I’m a complimentary care assistant, which means basically I do aromatherapy, massage and therapeutic touch. One of the really good things about my job is that it’s pretty open. I have a basin of hot water and I’ll put in some essential oils like lemon or something kind of refreshing. Usually the room is small enough that the essential oil can scent the room. They always have the TV on, but I can never tell how many people are actually watching it. So I put in a video of a fish tank with just, just fish swimming around. It’s a nice soothing background in the room. So I put in that, I put on some nice relaxing music, and then I usually go around with the face cloth and I dip it in the water and give it to people. And they’re great. Like there was one man in particular he washes his whole face and scrubs his neck and when he gives it back to me, he’s all refreshed and perky.

Kitwood suggests that through “the sensitive meeting of this cluster of needs”, loving care is expressed and the personhood of an individual with dementia is maintained (p.84). He distinguishes between “person-centred care”, which foregrounds the holistic needs of a person with dementia, and “task-centred care”, which focuses less on the person, and more on particular tasks (such as bathing or changing), that need to be accomplished (Kitwood, 1997).

Not resident-focused is someone who is stuck, who thinks the most important thing is sticking to routines. “These are the absolute routines. This is what we do. Your bath day is on Tuesday because there are far too many people getting bathed on Monday. No, we bathe everybody in the morning, evening staff are far too busy to be bathing, you know that.” And you can’t be like that. You have to find out what’s important to those individuals. You have to have a unit that supports residents who want to sleep in, and if they do sleep in, how are you going to get them something to eat before lunch. You can make all of these things work, you just have to have the will to do it. Or you can stick to
Caring that is person centred requires a degree of personal presence, or in Nel Noddings terms, “engrossment” on the part of the “one caring” (Noddings, 1984, p.19). The “one caring” needs to place the person they are caring for in the centre of their sights, both literally and emotionally, in order to fully convey care. The “motivational displacement” required to accomplish this degree of presence is usually contrary to staff job descriptions that are task, rather than person centred (Noddings, 1984, p.25). Job descriptions tend to describe what the staff person must do, not how it would be helpful for them to be.

I’m lucky because it’s a part of my job to actually go in and sit down with the residents, and maybe have a little one to one interaction. Or you know just hold their hand… you know this is what I’m actually supposed to be doing. Whereas I know a lot of the personal care assistants or nurses they might not have time to do that.

For people with dementia the process of making a nursing home feel like home is not characterized by a discrete period of adjustment. Indeed Shield (1988) suggests that even cognitively intact residents never really “settle in”, because nursing home life is an “endless transition” between adult life in the community and death to come” (p.184). The very notion of “settling in” is an illusion in the “liminality” that is the reality of nursing home life (Shield, 1988).

A more hopeful vision places opportunities to make home in the hands of people who give care. For people with dementia life is an ongoing process of trying to get their psychological needs met in the face of failing mental powers. People with dementia are particularly vulnerable to feeling homeless. Simply put, feeling less sure of who you are, or of where you belong, makes the human longing for home both more pronounced and more profound. Unfortunately initiatives such as ‘wandering’ or ‘hoarding’ or ‘hovering’ that people with dementia take to express these needs, are often seen as symptoms or pathology. When individual staff persons are able to see beyond these behaviors to the human need being expressed, person centred care is provided. Care that addresses the fulfillment of the main psychological needs of people with dementia invokes the presence of home no matter where that caring occurs. Well or ill, when we feel deeply at home, our psychological needs are in some important way being met.

It starts with the nurse manager on the floor and the tone that that individual sets and the partnership that they have with the recreational staff, housekeeping staff, rehab, foodservice, everyone. All the other partners that are part of the team. It’s the texture of those relationships. If that person is really inclusive and resident-focused and has the residents best interests at heart…it will all come together.

Ultimately the people are the place, or as Bachelard (1958) poetically describes “all really inhabited space bears the essence of the notion of home” (p.5). While the sheer numbers of people at nursing homes challenge traditional notions of intimacy and of home, person centred care nurtures the closeness and connection of an ideal home.

Exploring our notions of care and of home begins to reveal the complexity of the term “nursing home”. The name itself carries the tension of conflicting expectations. A site of medical practice overlaid with images of protection, comfort and intimacy, what might that look like? And, how
should we expect that place to feel? Do we somehow equate institutionalization with homelessness? And further, in caring for a loved one with dementia at home, is the effort to resist institutionalization also an effort to resist an additional stigma—that of homelessness? Is it surprising that research shows that the sense of loss associated with placing a loved one in long term care, combined with negative preconceptions about nursing homes in general, often lead to a disjuncture between family expectations and the actual care provided (Krause, Grant & Long, 1999; Foner, 1995; Savishinsky, 1991)?

One of our biggest challenges is trying to get families engaged, to be part of the process and breaking down their initial fear and hostility. It’s a big, big, place and initially I think people are frightened and acting out of fear. They react in anger and sometimes say things that are really inappropriate to staff. I’ve been in the cafeteria and overheard people talking as though none of us are there, you know, ‘what kind of dump is this, look at the crap they’re serving’. How do you deal with that? Should I walk up and say “Hi. I’m the administrator. Do you want to come and talk to me? They don’t really want to talk, some folks just want to make a scene.

Our work has significance in its capacity to contribute to understanding and to facilitate access to the “sense of place” of long term care environments that provide care to residents suffering from dementia. By examining the social and political context in which lives with dementia are lived, the image of the “social death” usually associated with the place of nursing homes, and with dementia and Alzheimer’s disease in particular, can begin to be challenged (Sweeting & Gilhooly, 1997). In light of the current and projected need for institutional care for people with dementia, these issues are significant. Simply put, we will be needing a new generation of people who care to make home.
References


