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Abstract

This paper draws from qualitative research that seeks: to provide a window into the functioning of the dynamic social environment of a publicly funded nursing home in a large Canadian urban centre: to better understand how staff contribute, beyond role definition or job description, to the environment as a home like setting: and to gain insights into the complex interaction between individuals' personal and professional commitment to caregiving. I explore 'care' and 'home', as separate concepts and map the terrain of their intersection through academic theory and everyday discourse. I consider how, in the institutional context of the nursing home, these concepts are brought to life and made real through the practices of staff. I deconstruct "homemaking" and reinvent the meaning and significance of homemaking as care. Using Reader's Theatre as a presentational format, I discuss the qualities of the form and invite the reader to experience 'home' and 'care' as psychological constructs through storied text and in-role performance.

Home is Where the Heart is: A Reader's Theatre

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Introduction

Research as Advocacy Work

My broad intention of making nursing homes and the people who live and work in them more accessible, more understandable and more inviting to family caregivers and the general public identifies my research as advocacy work. My research is specifically about staff, who they are as people, and what they can teach us about the place and people of nursing homes. In celebrating nursing home workers as people, I also promote the act of giving care, as a worthy *activity*. In order to best render the research results and to remain congruent with my commitment to accessibility, I use Reader's Theatre as a "data display strategy", and presentational form (Donmoyer & Donmoyer, 2008).

"Home is Where the Heart is: A Reader's Theatre" involves a dramatic rendering of research results, and as such, is part of the growing genre of performance ethnography (Saldana, 2008; Denzin, 1997; Conquergood,1991; McCall, 2000; Gray & Sinding, 2002).

Reader's Theatre

Within arts-informed research methodologies, reader's theatre is considered "relatively conservative" because data collection methods do not typically involve processes related to the arts, but rather rely on the traditional data gathering techniques of in-depth interviews and participant observation (Donmoyer & Donmoyer, p. 210). Reader's theatre is also relatively straightforward to present. In this case the reader's theatre performance required no props, lighting or costumes, time-consuming memorization of lines, rehearsal or preparation. The organizer invited audience members to participate on the spot and volunteers were given reading parts or a script that they held and read. A reader's theatre can also be rehearsed in advance or even performed by professional actors to enhance the quality of presentation.[1]

Despite the contrived nature of the pre-prepared script, reader's theatre is thrilling because it's live. Real people voicing the words of others maintains and enhances the human dimension of qualitative research in a way that simply gets lost when words are flattened and remain silent on the page. But while it invites an emotional response, reader's theatre also requires members of the audience to think. Instead of sitting back and riding through a story arc from beginning through the middle, to conclusions at the end, in a reader's theatre themes and ideas are presented that display a diversity of perspectives. Integrating emotion with intellect, reader's theatre energizes the audience and provokes discussion about the issues and questions raised in the content of the work.

I chose reader's theatre as a presentational form for a variety of reasons: it allowed me to remain true to the storied nature of what I had been told as a researcher and to use everyday, ordinary language. I wanted to honour the complexity and the diversity of the stories in the re-telling; and

[1] See McIntyre, 2005 for a description of a presentation of *RESPECT: A Reader's Theatre about People who Care for People in Nursing Homes* that was rehearsed and performed by professional actors.

I wanted to create, through artistic form, the type of reflective conversation so many staff said they needed to have. In so doing the Reader's Theatre format carries content and is able to render experientially, an important aspect of my research results.

1. Research Context and Method

The research is broadly qualitative and, more specifically situated within a community-centred, arts-informed, life history framework (McIntyre & Cole, 2008; Cole & McIntyre, 2001; McIntyre, 2000; Eisner, 1993). It was conducted in a publicly funded and operated 456-bed nursing home in a large Canadian urban centre. One specific objective, which is the focus of "Home is Where the Heart is", was to better understand how individual staff contribute, beyond role definition or job description, to the environment as a home like setting.

l. l Research Participants

Unit based staff that participated included personnel from: housekeeping (heavy equipment and light duty); nursing (personal care aids, nurse manager, charge nurses); recreation (recreational assistant); food service (servery staff), and social work (social worker). Home wide staff that participated included the Home Administrator, the Director of Nursing, the Manager of Programs and Services; two Complementary Care Assistants (Aromatherapy / Therapeutic Touch and Music therapy); an Occupational Therapist, the Spiritual and Religious Care Coordinator; the Supervisor of Staff Education and Development; a Psycho geriatric Consultant; and a Resident Food Service Supervisor. In total I conducted fifteen interviews.

1.2 Data Collection / Analysis Methods

Data collection methods included: in-depth interviews with this diversity of personnel, the examination of pertinent institutional and personal artifacts, and observations made in context while spending time on the floor as a mealtime assistance volunteer. Interview questions were open-ended. Questions were clustered around three main areas: (a) work profile (b) questions relating to beliefs about dementia[2] and long term care, and (c) questions relating to personal life and experience.

Listening to the stories staff had to tell was an emotional experience. In conversation after conversation I was moved by how much of themselves staff put into their efforts to connect with residents. Such attentive and loving care felt like it required an analytical framework where this emotional quality could be preserved. Tom Kitwood's (1997) model of person-centred care, which describes the main psychological needs of a person with dementia as attachment, identity, occupation, comfort and inclusion, with love overarching all, provided just this framework. I proceeded with data analysis guided by this model; and clustered emergent themes (such as food) according to a framing question (see below). In constructing the reader's theatre script I used

[2] Dementia is a collective name for progressive degenerative brain syndromes, which affect memory, thinking and emotion. Dementia is not a normal part of aging. It knows no social, economic, ethnic or geographical boundaries. Alzheimer's disease is the most common cause of dementia. (Alzheimer's Disease International Website, 2008).

attachment, identity, occupation, comfort and inclusion as themes within an organizing device for illumination as to how loving care was provided.

2. Institutional care and *the meaning of home*

I begin by exploring 'care' and 'home', as separate concepts and map the terrain of their intersection through academic theory and everyday discourse. Since these two words peppered each and every interview with staff, deconstructing the complexity of the various meanings associated with them provides a useful context when considering the issues staff raise. I consider how, in the institutional context of the nursing home, these concepts are brought to life and made real through the practices of staff. I touch on the points of congruence and tension between individual staff members values and beliefs about care, and the structures in which they work by exploring the general question, "How do institutional structures support or constrain staff efforts to give care and make home?"

In exploring how individual staff members make home in the institution, I deconstruct "homemaking" and reinvent the meaning and significance of homemaking as care. I invite the reader to experience 'home' and 'care' as psychological constructs through storied text and in-role performance. Direct quotations from staff and sections of storied text (taken and extrapolated from interview data) appear in italics. In the live presentation of this paper these parts are given to audience members to read aloud in a reader's theatre presentational format. (I hold numbered cards up and people chime in when it is their turn. A few readers for example #11, are given more than one segment to read aloud.) I function as the host or narrator reading the background text (non-italicized).

As audience members speak the words as staff they experience the narrative and the complexities of nursing home life. By joining in and celebrating the work of caregiving and honoring the capacity to care, we broaden and extend the community supporting people living lives with dementia. This process of deconstructing practices of homemaking through alternative forms allows my work 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.

Home Is Where The Heart is: A Reader's Theatre

3. Notions of House and Home

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 I 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 affect 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.

> **1.**
> *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).

3.1 Notions of Care and Love

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.

3.2 Person-Centred *Loving* Care

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".

> **2**.
> *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.

> **3.**
> *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.

1(a)
For a while there, like the first, I guess, 17 years…what I found really difficult about my work… was the death. The anticipation of death is constant.
I took it very personally because every resident I did care about. I started visiting people in the hospital that were sick. And so everyday I would go and visit people that were sick and go to funerals of people that died and after a while I was getting up at eight o'clock going to the hospitals, then going to funerals and then going to work. I did this for a couple of months but then I said too much, I've got to stop this. I just packed it in and I said I'll go in and do my time, listen to stories and when they're gone I'll remember the good stuff.
You know when you're there emotionally… and you're going to see death almost every week, so if you wait for it or you contemplate it or you dwell on it, it will just eat you up.

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).

4.
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.

5.
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 <u>I'm</u> breathing! I've had some families who weren't visiting relatives anymore because it's too painful for them, and then it's 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.

6.

We're all required to do one evening every two weeks. I enjoy going up to the floor and seeing residents in the evening. It's 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 person's current needs for inclusion (Kitwood, 1997).

7.

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.

8.

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 <u>wisdom</u>. It helps develop 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.

9.

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).

> **10.**
> *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 the rules. Sticking to the rules means you may run a very efficient unit but it's a cold unit where the residents are a product, not people.*

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.

> **9(a)**
> *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 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.

11.
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, <u>everyone</u>. 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.

12.
Some of them don't know me by name but they'll call me "the food lady". I'm "the food lady" or "the food nurse". Officially I'm one of three resident food service supervisors in this home. I'm responsible for two hundred residents.

I like trying to do things that make the day a little easier for the resident. A cheese sandwich with jam instead of tuna or ham—it's a small thing, but if Mr. Sanchez likes cheese and jam, it means something.
I try and keep it simple. I say: "Let's eat!"
I <u>show</u> them the chicken. I <u>show</u> them the cannelloni. It's all presentation…even people who still know, they want to see what food they're choosing.

The social dynamics of eating, they're just as important as the actual meal itself. Because if they're not happy with who they're sitting with, they're not eating. We have two ladies that sit together and they don't really want anyone to sit with anyone else, and let me tell you they make that clear. Another lady, who's over 100, she wants a conversation. Anybody who can't feed themselves or speak up for themselves, she doesn't want to sit with. I think she's 106 now.

11(a)
How can you feed thirteen residents with four staff in half and hour? It's very difficult for staff, especially since they want to do a good job. Paperwork is different. You can put it aside, or take it home and do it. But with resident care, you can't. Generally staff want to provide the quality of care that they're expected to, and they find that they just can't keep up… That brings up lots of hard feelings.

12(a).
These days people are coming in sicker…more progressed with disease.

You see them in a later stage of life than when they were baking the cakes and doing the birthday parties and dancing in the dining room.
It's important to find out what the individual needs and what the group at each table wants. Do they prefer to have tea before the meal or afterwards? Are there other rituals around eating—like prayer that we can help with? Are there couples who want to sit, the two together, off to the side, alone?

Sometimes family members have ideas about what we can do…Their father will only eat their mother's cooking. Well we can't cook the same way your mother did in this kitchen. And even if I wanted to cook in my own kitchen I couldn't cook like your mother did. But if you want to bring the food in…we can accommodate that. We'll store it, we'll heat it up, and we'll serve it the best we can.

I grew up in a small town, about 6000 people, on a dairy farm. I did a lot of manual work when I was young. It was a real family farm, we worked together, my parents were always home. I'm no city slicker.
I don't like to cook or anything. I can cook a decent meal but I'm not going to make an elaborate meal for anybody, right?

13.
I just have to tell you this story. On the sixth floor there are a large number of Portuguese residents and I have Portuguese recreation staff and there are Portuguese housekeeping staff—in fact <u>they</u> are the ones that actually point out certain needs of the residents. For example, my rec staff said to me, "You know the Portuguese observe this Portuguese day of grace and I'd really like to do something with it." So I said, "Well, tell me what it is". She replied, "It's almost a special religious type celebration, once a year." And I said, "So what would we be doing? I need the visual."
And she said, "We can do a service in the worship centre. There would be a Portuguese priest that could come in and do the service and then we'll have this dinner in the auditorium." I said, "Okay, so who is providing this dinner? How are we doing this dinner?" And it was just really classic, but at first I thought, oh gosh, I don't know that I can do this. She said, "Don't worry, just leave it to me and I'm going to go out in the community and I'm going to get donations for this, that, and the other and you don't have to worry". And I'm thinking, oh, this sounds <u>huge</u>, like how can you do this? Anyway, I trust my staff and I know she does an excellent job and she went out into the community and she had this whole entourage of church volunteers come in from a particular church. They brought all their huge pans from the church kitchen. Out here I had, I can't tell you, <u>how</u> many chickens and <u>how</u> many bags of carrots and potatoes, and the chopping and everything that was going on. I just sat here saying,"I don't know how this is going to end up."

But they cooked up all this stuff, and the auditorium when I went in there was absolutely amazing. They had transformed it into the Azores. They had the video going. They had all their lace. They had traditional costumes. They had…the entire auditorium was Portuguese. It was just <u>amazing</u>. The room was packed. We had a hundred, and I don't know, twenty people and I said, how do we have 120 people, we only <u>have</u> I don't know,

40 Portuguese residents or whatever, but we had 120 people in this room. All there for dinner, the auction was going on, they raised money for the floor. Everybody had a great time. And then it became an annual event.

12(b)

That is quite a story.
Anyhow, you know how I said I'm no city slicker? Well, sometimes I do go to Starbucks for a treat. I'm no regular. But every few months it's Saturday and I've been shopping and I do enjoy a warm beverage around four o'clock. Maybe a little sweet too. So I step into Starbucks and I'm immediately overtaken with all the delicious smells, and the colours of the walls, so I just sort of stand there staring at the menu for a while.
Toffee Nut Late, Vanilla Latte, Caramel Machiato, White Chocolate Mocha…I just roll the names around in my mouth...they all sound so plumped up and fluffy.
After a while I realize that I'm still just sort of standing there my eyes slightly closed, head tilted back, loving the smells…and the chipper server guy behind the counter has looked at me again and this time his eyebrow is a bit raised.
So I figure I better bear down on the menu. Scanning the board I'm looking for one of those new sweet black teas that's cooked up with spices. Chai. It's called chai. But is it tazo hot tea, or tazo chai that I like?
Further down I notice another whole tea section with tazo citrus, tazo berry and tazo chai crème. A line is starting to form so I don't take the time to ask the server guy the difference between tazo and tea, chai and tazo chai. I order a grande tazo chai creme…which I know from experience is the medium size, and start rummaging around in my wallet, trying to quickly produce the $4.15, oh, but with tax it will be what? $4.50 or so.

Off to the side now I watch the server gal artfully construct my beverage. I get mesmerized again by all the pouring and measuring, and testing of temperatures.
And I start to think about all the things we do to try and keep the residents' food hot, coming all that way from the kitchen in the basement to the floors. The new steam tables we got on the units, the meetings we had trying to tighten up the system between the elevator porter and the servery staff, the hot holding carts...and still it's not perfect.
Three meals a day, with a choice between two entrees at each meal in five different textures: regular, mince, purees, dental soft, and chopped. Do people have any idea how complex it is, providing food for older people—people who are losing their teeth and their capacity to swallow? The special diets for health—lactose intolerant, low sodium, high calorie, and low spice. Snacks three times a day—a sandwich or some digestive cookies, tea or juice or maybe a glass of milk. The different tastes and preferences, the religious restrictions like pork and special foods for holidays. Suddenly Starbucks seems simple.

I laugh out loud when I realize that what I've paid--$4.65 with tax, for my grande tazo chai crème—my Saturday after shopping treat, is 16 cents more than our per day resident food budget. Yeah, that's right—three meals a day, with a choice between two entrees at each meal in five different textures: regular, mince, puree, dental soft, and chopped. Plus snacks with a beverage at 10:00, at 2:00 and before bed at 8:00. Plus tea and cookies

during the night for the wanderers. All that for $4.49 per resident per day. It's gone up 23 cents since 1993. Ten years and an increase in 23 cents per day per person. How much do you figure Starbucks has put up their prices in ten years?

1(b)
A few years back during one of those restructurings, it looked like the place was going to go private, sold off…bought up…And that's pretty scary because you think these people are going to come in and they want to make a profit so they don't want all the stuff you do, basically they don't care what your philosophy is, just do the work, cut costs, don't use too many linens. Lots of paperwork with being public, but trust me, it's a whole lot better than care for profit.

3.3 Caring to Make Home

Exploring our notions of care and 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)

14.
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.

Epilogue

Each time I present my research as a Reader's Theatre (in public libraries, at academic conferences and at forums of health care workers) a space is provided to recognize and honour the people who care for people living with dementia, and to consider the realities and possibilities of nursing home life. I always name and make explicit the tribute aspect of my work--in academic presentations and public venues alike. No one ever balks. People are always respectful of my intentions. Indeed they are quick to volunteer as readers. Reading aloud in a group brings out the very best in people. They speak well, with spirit, from the heart. When people honour my research participants and my writing with their voices, and speak from the

position of nursing home workers, they make audible voices that don't often get widely heard. Joining together in what could be described as a political act, by the time the last voice is heard the atmosphere reverberates with a feeling of communion. A palette of tones resonates through the room. The experience begins to feel like more than the sum of its parts. Hope emerges. In light of the current and projected need for institutional care opportunities to create hope and inspiration to give care are critical. Simply put, we will be needing a new generation of people who care to make home.

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