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## Re-cognizing Power in the Culture of Dementia Care Knowledge

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

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Re-cognizing Power in the Culture of Dementia Care Knowledge

(Thesis format: Integrated Article)

by

Ryan Thomas DeForge

Graduate Program in Health and Rehabilitation Science

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies  
Western University  
London, Ontario, Canada

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## **Abstract**

In light of increasing system demands, system regulations, and constrained resources, those living and working with dementia in the long-term care sector are vulnerable to oppressive care practices. This is true so long as our understanding of how social power affects the ways in which dementia care knowledge is created, shared, and enacted remains limited. Based on prolonged field observations and on informal and formal interviews with care recipients, family members, and staff, the aim of this critical qualitative research was to examine the culture of dementia care knowledge in two sites: a specialized dementia care unit in a long-term care home, and an affiliated adult day program.

Three key insights arise from this study. The first is that normalizing inclusiveness in generating dementia knowledge is akin to democratizing hierarchical relationships in long-term dementia care work environments; the more that knowledge is co-constructed under ethical conditions of discourse, the more point-of-care staff can contribute to care planning and provision. Second is the temporal distinction between two prominent yet somewhat contradictory care norms: that of contextualizing a responsive behavior, and that of using force to complete daily care tasks. These co-existing care routines not only contest one another, they manifest along different timelines. Third, care providers and recipients can benefit from a three-pronged approach to generating dementia care knowledge wherein an iterative pattern of internalizing, externalizing, and socializing care knowledge yields collectively held organizational knowledge.

This study reconceptualizes “culture” in ways that consider the broader (often oppressive) social forces at play in constituting dementia care knowledge. In addition to its methodological contributions to critical qualitative health research, the study’s implications are relevant to those who espouse ethical and non-coercive dementia care practices, and to knowledge translation scholars who appreciate that as a part of context, the knowledge culture needs to be understood in terms that make clear the influence of social power among and between the culture’s constituents and the intervening knowledge translators.

Keywords: dementia, long-term care, adult day program, knowledge translation, knowledge creation, critical qualitative research

### **Co-Authorship Statement**

This dissertation was written under the co-supervision of Dr. Anita Kothari and Dr. Catherine Ward-Griffin, who will be co-authors on publications arising out of chapters four, five, and six.

## Acknowledgements

I am indebted to Dr. Anita Kothari, who, as my primary supervisor, allowed me to grow at my own pace and in my own directions while succeeding in also in curbing my appetite to absorb and integrate so many new perspectives into my work. I appreciate also the way in which she looked out for my personal wellbeing, making sure always that I thought carefully about how to strike that seemingly mythical balance between school/work and Life. I am also immeasurably indebted to my co-supervisor, Dr. Catherine Ward-Griffin, whose proclivity for digging deeper and for unpacking and orchestrating critical insights both drove and inspired me to do the same. Moreover, the training opportunities she afforded me were essential to my development and growth as a scholar. I am also grateful to Dr. Lorelei Lingard for her support and advisement. I look forward to continued relationships with all of these outstanding researchers, and will continue to be forever grateful for their mentorship.

I cannot adequately express how grateful I am for the support and understanding of my wife Janine. My doctoral studies threw our relationship and me for more than a couple loops, and yet our ‘no matter what’ love for each other continues to flourish. *That you love me for the person I am and not necessarily the scholar I am makes me ridiculously happy and fortunate.*

To my dear friend and close colleague Dr. Jay Shaw: *Thank you, thank you, thank you for your support and friendship, and for being tireless in pitting and pursuing all of our reflexive considerations. I can’t wait to find out what we’ll do together next!*

I am immensely grateful to the clients, residents, family members and staff of the care organization that participated in this study.

Finally, not every indelible moment that one experiences while *getting a PhD* actually makes it into the final dissertation. To that and those who have been erased from the text, *I forever acknowledge your everlasting presence.*

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**– Chapter One –  
Introduction**

**Four Ways to Introduce a Dissertation**

## Introduction #1 – An 8<sup>th</sup> Moment Quilt

The same material can be written for different audiences ... that's why it is called material. Like wet clay, it can be shaped and reshaped. Writing in standard ways does not prevent writing in other ways. Most important, understanding how to rhetorically stage a dissertation or journal article increases the likelihood of its acceptance. Even radical messages can be published in conservative journals, if the writer follows the rules (Agger, 1989). Consequently, deconstructing traditional writing practices is a way of making writers more conscious of writing conventions and, therefore, more competently able to meet them and to get their messages into mainstream social science (Richardson, 1997, p. 93).

I want to begin by unpacking a metaphor that I have elected to use to hold this dissertation together – that of *a quilt*. In the introductory chapter of their Handbook of Qualitative Research, Denzin and Lincoln (2005, pp. 4-5) describe the qualitative researcher as one who invariably pieces together a “set of representations that is fitted to the specifics of a complex situation” and who “uses aesthetic and material tools” in doing so. Such a quilt-maker “stitches, edits, and puts slices of reality together. This process creates and brings psychological and emotional unity – a pattern – to an interpretive experience,” allowing different voices and perspectives to “simultaneously create and enact moral meaning.” Researchers as quilt-makers “move from the personal to the political, from the local to the historical and the cultural. These are dialogic texts. They presume an active audience. They create space for give-and-take between reader and writer.”

Moreover, I elected to use quilting as a metaphor to re-present this work because I have found my data collection and analyses to have followed particular threads of thought, threads that I have had to carefully pull, follow, and weave back into a synthesized understanding of where and in which light they are prominent and visible, or more tricky, where they are hidden beneath the fabric of these participants' culture. I recognize too that in my interpretations, my own history, biography, gender, social class, race, and ethnicity are complicit in determining what insights I am privileged (or, *allowed*) to see. That is not to say that I feature myself in this quilt, but rather to point out that it is indeed a particular 'me' who has stitched together images and representations of 'dementia care knowledge.' And while I will perhaps think of a better name for this quilt later, for now I will refer to it as an 8<sup>th</sup> *Moment Quilt*. As I unpack the 8<sup>th</sup> moment, below, you will begin to see the fabric of this dissertation take shape.

Denzin and Lincoln (2000, 2005, 2012) have traced the history of qualitative research in terms of its 'moments.' In the most recent penning of these moments (2012), they list eight. It is beyond the scope of this Introduction to detail that which characterizes each, but ever so briefly: the first moment (1900-1950) is known as *the traditional*; the second (1950-1970) as *the modernist*; the third (1970-1986) as *blurred genres*; the fourth (1986-1990) as *the crisis of representation*; the fifth (1990-1995) as *the postmodern* or *experimental*; the sixth (1995-2000) as *the post-experimental*; the seventh (2000-2010) as *the methodologically contested present*; and the eighth moment (*this* moment) as *the future*, "which confronts the methodological backlash associated with the evidence-based social movement. It is concerned with moral discourse, with the development of sacred textualities. The eighth moment asks that the social sciences and

humanities become sites for critical conversations about ... freedom and community” (p. 3). These eight moments trace out the evolving focus of qualitative research – from objective, colonizing accounts that reflect the positivist scientist paradigm to an era of concern with practices of rigour, infused later with reflexivity; from doubts about if/how ‘reality’ could ever be represented in qualitative research findings, to considerations of how to evaluate and interpret – *how to make legitimate* – qualitative research. And indeed, in these ‘future and present moments’ of methodological contestation and of questioning what exactly constitutes research-based evidence, *ethics, democracy, and inclusion in moral discourse* have become the focus. As Denzin (2003) asserts, this is the “moment critical social science comes of age and becomes a force to be reckoned with in political and cultural arenas” (p. 259). It is with this moment in mind that I refer to these research findings as an 8<sup>th</sup> *Moment Quilt* – for as you will see, the topic of this dissertation, the culture of dementia care knowledge, is replete with ethical quandaries to redress; such redressing is a politically charged and performative task, made all the more complex by the subtle taken-for-grantedness of many dementia care practices.

Thus, this dissertation re-presents in a quilted fashion a critical commitment to a purposeful theory of praxis – that is, a purposeful commitment *to reflect and act upon the world in order to transform it* (Freire, 1972, p. 128). Such a commitment “involves the rejection of the historical and cultural logics and narratives that exclude those who have been previously marginalized. This is a reflexive, *performative* ethnography. It privileges multiple subject positions, questions its own authority, and doubts those narratives that privilege one set of historical processes and sequences over another” (Denzin, 2003, p. 268; McLaren, 1997). It draws strength from pedagogies of hope (McLaren, 1997; Freire,

1999) and ethnographic imagination (Willis 2000), and understands that meaning is produced and contested in the places where people live, and that all meaning-making is filtered through discursive systems of representation: media, popular, and scientific discourses, among many, filter, “shape, and give meaning to the lived experience within specific historical moments” (Denzin, 2003, p. 266). As a rhetorical device, a quilt offers the means by which to re-present the hopeful, imaginative and political aims of the 8<sup>th</sup> moment.

### **Why Four Introductions?**

To help locate the theories of knowledge and of research design that inform this study – that is, to help locate this study’s epistemological and methodological/analytic position – I have imagined myself in performative dialogue with (*you* and with) Denzin (2003) as he follows Foley (2002), Marcus (1998), and Tedlock (2000) in distinguishing at least three types of reflexive ethnography: confessional, deconstructive/postmodern, and theoretical. Introductions 2 and 3, respectfully, are instances of *deconstructive* and *confessionary* reflexive ethnography, while Introduction #4 invites the reader to engage in *theoretically* reflexive ethnography.

The deconstructive introduction (#2: *Music to our ears*), is designed to be unsettling; it deconstructs any attempt at objective ethnography that might be characterized with stable researcher and participant identities, and instead pens a space where the reader, perhaps driven by aesthetic angst, can make his/her own interpretations about *What’s going on here?* With/in such an ambiguous space, my ethnographic I/eyes forfeit my own authority (Kincheloe & McLaren, 2000; Denzin, 2003), or perhaps worse,

believe relativism. Yet in getting lost in the ruins of knowledge (Lather, 2001), I allow myself to maintain a commitment to indeterminate, evocative, poetic accounts of reality (Foley, 2002), and hold to a radical pedagogy that aims to make real a militant, utopian vision of the future (Denzin, 2003). However unconventional, or more aptly, *because postmodern reflexivity is so unconventional*, it is found right at the tip of the cutting edge of ethnographic political practices.

*Life as my CAGE* (Introduction #3), in contrast, is a for-instance of *confessional* reflexivity, characterized by the Othering of my Self, by introspection that looks through the navel to query (not if but) *how* one's Self impacts one's science (Ellis, 1995; 2004). Proponents of confessional reflexivity suggest that the genre openly invites subjectivity and a focus on caring and empathizing with research subjects rather than appropriating their lived experience in the name of generating knowledge or theory (Ellis & Bochner, 2006). Moreover, in re-cognizing the author as a "living, contradictory, vulnerable, evolving multiple self who speaks in a partial, subjective, culture-bound voice," one can "undermine grandiose authorial claims of speaking in a rational, value-free, objective, universalizing voice" (Foley, 2002, p. 474). I am trying to not be so grandiose. Rather, in offering evocative prose that might break then (perhaps) repair your heart (Ellis, 1995; Behar, 1996), the vulnerable author engenders vulnerable readers. Yet critics of confessional (auto)ethnography suggest that any such navel-gazing, even that which informs and locates and invigorates the research, is still just navel-gazing (Coffey, 1999). This reminds me to remain aware of how readily such introspection can be perceived as 'soft science,' but, as in Introduction #3, I hold fast to its values of compassion, empathy, and self-awareness.



*Tacking Between Experience and Theory* (Introduction #4) introduces the third kind of ethnographic reflexivity that Denzin (2003) writes of, *theoretical reflexivity*, and announces that this dissertation is, by and large, of that sort. Indeed, the works of the scholar whom I have followed in developing and carrying out this dissertation, Phil Carspecken (1996, 2001), are readily characterized as being theoretically reflexive. As you will see, this is because Carspecken tacks back and forth between systematically collected field data and the epistemological theory of communicative action that he has derived from Habermas (1985). Insofar that such theoretical reflexivity relates to *ways of knowing*, the related question of *what is there to know*, that is, the question of my ontological position, is answered in a similarly critical vein: I subscribe to a more constructivist ontology wherein historical cultural forms and practices (read: structures) exist beyond the consciousness of ordinary people (Foley, 2002). My epistemological stance encourages *tending to* that taken-for-grantedness with a critical value orientation that aims to illuminate, to raise consciousness, and to *emancipate*: nothing *has* to be the way it is; it *can* change; the oppressive, inequitable living and working conditions in long-term dementia care *should* change. Theoretically reflexive ethnographies, including this one, ultimately seek to offer a convincing and reasonably authoritative account of how and why things are as they are, and to re-cognize how things might be.

Thus, in order to enact this 8<sup>th</sup> Moment's politically charged, civic, democratic, introspective, confessional, performative and pedagogical ethnography, I have introduced three kinds of theoretical reflexivity. I have done so (i) to strengthen this dissertation with robust yet varied reflexivity, and (ii) to contrast theoretically reflexive ethnography with the other two kinds of reflexivity. In sum, I will and do feature theoretical reflexivity in

this dissertation, but while I do so, the threads by which I quilt together a blanket of whole understanding belie a confessional, fragmented, and poly-vocal nature. *And* a political nature – a *radical political nature* (Denzin, 2003), for indeed, current conceptions of long-term dementia care (sometimes naively) reproduce unjust, oppressive, and, resignedly, inevitable life (and work) conditions. We need to radically re-cognize the political nature of long-term dementia care.

### **Introduction #2 – Deconstructed Truth-telling: Music to our ears**

During a field visit to my research site – a long-term care home and its adjacent adult day program – I interviewed a registered practical nurse (RPN) behind the closed door of a conference room attached to the specialized care unit where 32 people with advanced dementia reside. While I interviewed the RPN, many of the residents were gathered in the common area on the other side of the door to take in the Wednesday afternoon entertainment: a man and his guitar. When I later transcribed the interview, my attention waned as I paused to listen to what song was being sung; I felt as though I was in some way able to relate to the residents listening to this music during these same moments that I sat listening to the RPN talk about providing dementia care. I was immediately and newly struck by the richness of the audio recording, replete as it is with both dialogic interview data *and* a kind of auditory conduit to what some of the people on the floor may have heard, may have been thinking, and/or may have been *feeling*. Indeed, one of the findings from my research exploring the culture of dementia care knowledge in this setting relates to the use of music as an intervention to help residents feel relaxed and to enjoy an activity that was meaningful. So, I began inserting into the transcription the

names of the songs I could hear being played as I spoke with the RPN. In reading and re-reading textual excerpts from my, her, and the residents' lived (musical) experience, I can tack back and forth between their ears and mind, and between differences of meaning.

I decided to feature this moment in the introduction of this dissertation for three reasons. One is that this RPN was very much a key informant during my research: she was full-time, experienced, trusted, and respected. What she shared with me was both candid and reflective of some of the key issues pertaining to the culture of dementia care knowledge. Although we spoke for more than an hour, there is a handful of excerpts that, in introducing this research, offer a sense of our shared rapport and of that which concerns her as a team leader. Second, I want to convey in this introduction the importance of music in dementia care (Ridder, Stige, Qvale, & Gold, 2013; Ueda, Suzukamo, Sato, & Izumi, 2013): whether it is the rhythm or the beat, the lyrics, and/or the personal history one associates with music, music does seem to have a power to connect us. And although you were not there to hear or witness either the music on the floor or my interview with the RPN, I have reassembled (in Table 1.1) seven excerpts from that interview/time, and I extend an invite to tack back and forth between the left column, where I have included data from the RPN's interview, and the column on the right, where I have listed the song title and artist and a line or two from songs being played. The intent of this invitation is for you to begin to relate to the lived experiences of staff and residents alike, perhaps imagining a circle of people living with dementia, sitting and tapping toes, or perhaps dozing, or perhaps dancing, yet all united by the music in our ears. You might begin to get a sense of how dementia care knowledge is created, shared, and enacted through social relationships. This dissertation explores

exactly that. Third, this introduction demonstrates the endless possibilities in interpreting qualitative research, wherein each reading of the data offers new connections, new insights, and new possibilities for re-thinking dementia care.

Table 1.1: Music to our ears

<b>At about the time I heard the RPN say this,</b>	<b>... the music in our ears was this:</b>
<p>RPN: Here at the home, I will say to [newly hired personal support workers], <i>We don't talk to our residents like that down here</i>. Like so many times I hear them saying to the residents, <i>Don't do that</i> [said harshly, firmly]. So I'll say, <i>We don't use those words on [here]</i>. And they'll say, <i>Well why not? She--</i> you know, whatever they're doing, and I'll say, <i>Number one, she doesn't know that she's doing anything wrong, number two, she's doing that in response to something that we've initiated within her personal space, and number three, it doesn't help one iota</i>. So they'll say <i>Oh, okay</i>, and then they're all going... rolling their eyes.</p> <p>*</p>	<p><i>(Ring of Fire – J. Cash &amp; J. Carter):</i>            Love is a burning thing            And it makes a fiery ring            Bound by wild desire            I fell into a ring of fire</p>
<p>RPN: When I have my regular staff here, it's routine, routine, routine. [She names three personal support workers – ], these people [the residents] also know them, they know their voices, they know... I'm not going to say they</p>	<p><i>(I Walk the Line – J. Cash):</i>            I keep a close watch on this heart of mine            I keep my eyes wide open all the time</p>

<p>know our expectations, but you know, I've heard the residents comment, <i>Why did she put [a particular resident] here?</i> and the other ones will say, <i>That's what they do all the time.</i> You know, they get used to us. When I have three part-timers on, it is bedlam in the morning. Really it is bedlam because they're – they're not <i>afraid</i> of you know, these new fresh faces to them, but there's no familiarity, they're demented, they don't know, you know, if you're naked and you've got say a man coming in to do your care, they have no clue about that. When we do have male [personal support workers] on the floor, I always say to them you know, take it slow and easy with these women.</p> <p style="text-align: center;">*</p> <p>RPN: And that's when I say good morning, I take a few extra minutes with them, I go eyeball to eyeball with them. And depending upon their response to me, that's when I'll check them a little bit cognitively, and I'll say, you remember me? And you know, a lot of times, no, never seen your face before and some of them look at me and say, <i>Yeah, I remember.</i> They never remember my name. Without my nametag, they wouldn't remember. But I think whether it's my routine, my voice, or being here full-time, I have a good relationship with all of them. But I</p>	<p>I keep the ends out for the tie that binds</p> <p>Because you're mine, I walk the line</p> <p><i>(When I'm 64 – P. McCartney):</i></p> <p>Send me a postcard, drop me a line, Stating point of view.</p> <p>Indicate precisely what you mean to say</p> <p>Yours sincerely, Wasting Away.</p> <p>Give me your answer, fill in a form Mine for evermore</p> <p>Will you still need me, will you still feed me,</p>
--	--

<p>also work at that relationship from day one when they come to us. I'm a pretty old-fashioned kind of nurse.</p> <p>*</p> <p>RPN: In my proactiveness, I'll say to the docs, <i>Look it, she's probably been on this for 30 years, it's an old drug, it's a harsh drug. Can we try something else?</i> and they'll say <i>Whatever you want to do, you have to deal with them, not me.</i> And we've gotten one of our residents off a very harsh drug and she's 100 times better and the family is just so grateful. She can walk easier, her gait isn't affected, her speech is clearer.</p> <p>*</p> <p>RPN: I'd also like to have me working, and it's not out of greed, I've worked every other weekend all my life, but I'd like to work Monday to Friday so I could keep things flowing smoothly. Like I do my best at leaving things so that you know, what I couldn't get done can be arranged or looked after tomorrow, but sometimes I come back, I just came back from two weeks off Ryan, everything's a mess [she says in a whisper]. Like there's appointments not booked, there's families calling in, well when you weren't there... they</p>	<p>When I'm sixty-four?</p> <p><i>(All I Have to do is Dream – the Everly Brothers):</i>  I need you so that I could die  I love you so and that is why  Whenever I want you,  All I have to do is  Drea-ea-ea-ea-eam,  dream, dream, dream,  Drea-ea-ea-ea-eam</p> <p><i>(Pretty Woman – R. Orbison):</i>  Pretty woman, won't you pardon me  Pretty woman, I couldn't help but see  Pretty woman  That you look lovely as can be  Are you lonely just like me?  Wow</p>
--	---

call on me. I think consistency – especially in that unit – is important [emphasis on especially].

\*

RPN: [One particular staff member] is very abrupt, she's very vocal, she's a nice person but you know, if it would have been me I wouldn't have picked her to have her on this floor just because of her loudness and whatnot, but in her own way, she's good to all of them in a little different way. You know, and she's so flexible, if I... she'll say they're all in the wrong spots, I'll say, what to do, so she knows where their diets go and what they eat, so that's another good thing about having a permanent staff.

\*

RPN: I don't think I'm better than anybody else, anybody else. A lot of times there's in nursing, there's a hierarchy, you have your registered nurse, you have your registered practical nurse, you have your personal support worker (PSW), and a lot of time they've said to me, *Oh I'm just an ass washer so what does it matter?* I say, *Well you're a very important ass washer*, you know. So I try to share as much of the information that time permits me to share with them and to encourage them that they're doing a good job and at that time we also talk about you

*(Love Me Tender – E. Presley):*

Love me tender,

Love me dear,

Tell me you are mine.

I'll be yours through all the years,

Till the end of time.

*(Rhinstone Cowboy – G. Campbell):*

Like a rhinestone cowboy

Riding out on a horse in a star-spangled rodeo

Rhinestone cowboy

Getting' cards and letters from people

I don't even know

And offers comin' over the phone

<p>know, when residents are displaying a behaviour, different ways of diverting their attention or you know, just even in our body language like if I go like this [a glance of her eyes to one of the full time PSWs] or something, she'll know I need help. So you know, that's a good way to develop, or to start your day off appropriately I think. Like you just... everybody comes to work, <i>Good morning, blah</i>, and gone and you're off down the wing. You're not having a pep talk at the beginning. I know when we got up in the morning with a bunch of us sitting at the table, my mom would say <i>You're doing this today, oh that's right too, you're going here and there, eat your breakfast, make sure you don't forget this or that.</i> It's unity, it's a team.</p>	
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In the found poetry (Prendergast, 2006) that follows, each line codifies the sentiment expressed in dialogue with the RPN (on the left) and in the songs heard at about the same time (on the right). Always and already, I am struck by the notion and importance of *relationships*.



What the RPN was talking about – the lyrical sounds heard in the background:

*experiential leadership – work is love is hardship*

*routine & bedlam – watchful protection*

*relational rapport – uncertainty*

*setting one free – dependency*

*consistency – loneliness*

*abrupt – tenderness*

*unity – fantasy*

\*

Suddenly, I feel sucked in.

Sucked into experiential hardship and bedlam.

Sucked into relationships replete with contradiction and uncertainty.

Will the end be abrupt, or tender?

Are we united in this?

Or is that just a fantasy?

### **Introduction #3 – Confessional Truth-telling: Life as my CAGE**

This [Introduction] is consciously self-revelatory, but my purpose in writing it is sociological, not confessional. Social scientists inherit an academic culture that holds authority over them; that culture suppresses and devalues its members' subjective experiences. For social scientists to make their lived research experience the centerpiece of an article seems Improper, bordering on Gauche and Burdensome. I have not, I hope, ventured beyond Improper (Richardson, 1997, p. 147).

### **Field Journal Excerpt**

#### **Field Visit #6 – a Tuesday morning.**

6am: I arrive on the specialized care unit (SCU). I meet with one registered nurse (RN) and three personal support workers (PSWs) in the chart room, hoping each will enroll in my study. One fully consents, and the other three consent to be interviewed and to participate in focus groups, but not to being observed. I of course feel disappointment and angst, wondering, *Did I do something not as well? Why had they not fully enrolled?*

6:15: They all disperse – I can't really observe anyone: just one PSW. By this time, "MR#1" [male resident #1] and another FR [female resident] are up and (put) in the den. I sit on a bay window ledge in the dining room, and from 6:20 till 7:20 write this *reflexive journal entry* as I find myself wondering about CAGEs (class, age, gender, ethnicity – see McMullin, 2010).

I consider first GENDER: I like and I think I tend to charm one of the evening PSWs. The two regular day/evening nurses and the life enrichment Coordinator seem to

like and welcome me and talk about being excited that I'm here ... does any of that have to do with being male? Maybe? Recall too that another PSW was enthusiastic and engaged and yet she disclosed to me that "her wife ..." ... so, I can't, don't, wouldn't in any (whole) way attribute participation/enthusiasm to just my gender. But I do think that it plays some role in engendering buy-in.

I consider next: AGE: I'm about the exact same age as the one PSW I know/like. Nursing staff are older (seemingly by 10-20 years) ... some PSWs look 5-10 years younger than me (I'm 36). I'm not attuned to if/how my age impacts my relationships with staff participants. My salt & pepper hair/beard I suppose gives me a bit of a seasoned look ... I wonder if people think I'm older than I am: they sometimes seem surprised to know that I have a 10 month old baby ... but maybe it's not age per se, maybe it's just that relatively speaking, I had my kids later in life (than who? than them? than these staff? I guess that that is what I'm supposing).

Next, I consider CLASS: Do I display indicators of my class? I tell them that : I'm a PhD student. 'I worked in a retirement home 10-15 years ago, but since then have either been in school or working in a hospital'? What about my schoolbag with a laptop in it? ... such symbolic statements might indicate a high(er) socio-economic status? If I were to somehow balance that (so as to not appear to be from some higher class), I might do so through my attire: cheap black cotton pants from Costco, a short sleeve button down from Old Navy, my Portuguese sweater (a hand-knit, grey, wool zip-up sweater), my retro, scuffed shoes from Winners. It's the PhD status I think though that creates some distance between my staff participants and me. This journal entry though is my first where I've taken time to be so introspective: I'd otherwise be busying myself trying to

capture the objective realism of daily routines, mindful though that I'm indeed altering the 'natural' conditions, especially with 2-penned note-taking [When writing by hand, I tend to separate my thoughts by color]. I see myself now writing through/out the angst and disappointment of not having fully enrolled today's participants: why didn't they agree to be observed?? Are they threatened? by me / my gender / my age / my class ? ... by what I might report? One PSW asked during consent if I'd be capturing all the 'scope' of their work: being short staffed, being so rushed, having to care for 30 people? I sense that they have concerns that they'll be sanctioned for the difficulty / conditions of their work. (OR), Today, I gave them the Letters of Information before my 'spiel' – usually I give out the Letters afterward; did that make a difference? Was it that I didn't have a leader here setting a (probably coercive) tone of engagement? (Like during my first field visit when [a senior manager] helped 'corral' the day-shift staff for me).

And finally, I critically consider ETHNICITY: And what about my ethnicity? Is it remarkable that in enrolling my night shift participants that one of them was black, another Asian, and the other two South American (I presume, given accents and skin color and facial features)? I was the only white person. Cue thoughts of white privilege? of colonialism? These are notions I don't often think about, nor do I realize how I re-produce such feelings. Many/most (but not all) of my daytime/evening participants have been white. It's a sobering, refreshing reminder to try to continue to be more reflexive about CAGE, especially ethnicity.

I conclude [this journal entry] with thoughts about where these thoughts INTERSECT: And what of these intersections? Middle-class, 30-something, white, male, PhD student ... obviously of some un-natural order, here on the SCU (What is with all

that journaling?! *What's he writing?*) Compare and contrast 'me' with the non-white, (mostly) female, usually older, perhaps poorer paid staff that aren't "knowledge makers" / researchers, and our differences become much more stark. All this reflecting makes me all the more grateful to have the buy-in that I do have: until these three tonight, it has (so far) been a very high percentage of people who consent to all three data collection methods.

6:25am: (while I journal): Housekeeping fires up the floor machine. It's loud. There are three residents sitting in the activity room with the TV on.

7:20: I've just been invited by the usual day RPN to come to report and to meet/greet/enroll via offering my spiel. Hopefully, as I seek a shared understanding of what it is that staff, residents and families do in creating, sharing, and enacting dementia care knowledge, hopefully I can be more mindful of our differences and of how these differences may shape this knowledge production and translation.

#### **Introduction #4 – Theoretical Truth-telling: Critical Tacking between Experience and Theory**

The aim of this dissertation is to critically examine knowledge, specifically dementia care knowledge, among a particular group of family members and health care providers who offer long-term dementia care. Data were collected in two settings: a specialized care unit (SCU) in a long-term care home in southwestern Ontario, Canada, and its affiliated adult day program (ADP). The ADP was physically located in the same building, had some overlapping but mostly separate staff, and was more recreation- rather than nursing-focused. In each setting, I wanted to know what dementia care knowledge seemed to be, and to critically describe its cultural nature.

It would seem that such a project requires a theoretically sound sense of what knowledge is – its nature and its derivation; that is, to have a certain amount of epistemological savviness. This while being required to recognize, record, understand, and describe the historically located and socially- and discursively-shaped care practices of a fluid group of people caring with and living as people with dementia. Moreover, by announcing this dissertation to be critical, I ascribe to being a criticalist – someone who feels concerned about social inequality and someone who wants my work to contribute in some way to positive social change. Rather than merely describing social life, critical research seeks to both understand *and refine* the nature of social structure, power, culture, and human agency (Carspecken, 1996). My job then, in studying a particular care culture critically, is to ground theoretical constructs (especially of knowing) in the everyday cultural practices of these research subjects (Foley, 2002), and to use both induction and deduction while moving “back and forth mentally between concrete field experience and abstract theoretical explanations of that experience” (Foley, 2002, p. 476). Ultimately, my job is to produce an account of the cultural other that *critiques* dominant ideologies and advocates for equitable living and working conditions (Denzin, 2003; Foley, 2002).

To that end, I have deployed in this dissertation a critical, reflexive epistemology that involves the collection of monologic and dialogic data (Carspecken, 1996). What Carspecken calls monologic data collection entailed (mostly) non-participant observation of the social routines and practices of research subjects. Dialogic data collection followed, wherein I pursued with research subjects threads of inquiry that arose from the monologic data, partly with an aim to discover systems relations so as to explain my findings (Carspecken, 1996). The theory of knowledge that I drew on in collecting and

analyzing these data purports that within a group of people, truth is judged in terms of whether or not a truth claim meets certain validity conditions to *win consensus*. As described in Chapter Three, this winning of consensus was determined, partly, by certain universal standards that are rooted in structures of human communication, *not* by what the research subjects or I *perceive* (Carspecken, 1996).

This premise – toward pre-differentiated experience and human communication rather than perception – is central to the critical epistemology employed in this research. The essential assertion is that as we encounter our lifeworld (Habermas, 1981b), our experiences are much less focused than perception *per se*; we encounter one another and recognize the situation within a culturally typified way, in a *holistic* way; our recognition of the situation in turn directs us how to act in response to the situation. And in terms of the *communicative* element of ascertaining truth, the tenet of this critical epistemology, of this way of knowing and critiquing, is that even when we do note the properties of some perceptual object, we symbolize the experience in a way that could be communicated to other people: “[t]his applies even on the low levels of self-consciousness involved when being aware that we are aware of something, so that we can record the experience in memory or otherwise get cognitive about it. Thus perception itself is structured communicatively. To construct a sound critical epistemology, then, we must understand the holistic modes of human experience and their relationships to communicative structures” (Carspecken, 1996, p. 19). Within such a way of knowing, it is possible then to reconstruct a more finely delineated understanding of the care and knowledge practices of a group of people – in this case, those living and working with dementia.

As I set out now to report my findings, I do so mindful of an obligation to be reflexive (Denzin, 2003; Davies et al., 2004; Macbeth 2001; Macphail, 2004). And while I have woven into this dissertation some of both confessional and deconstructive reflexivity, I have given primacy to Carspecken's (1996) theoretical reflexivity by deploying his "critical qualitative research" methodology.

### **Orientation to Table of Contents**

The next chapter in this dissertation, Chapter Two, details my critical review of the literature regarding *long-term care, dementia, knowledge translation, and ethnography*, and serves as the explication of the rationale for this research project. In this work, the knowledge gap I have sought to fill pertains to the culture of long-term dementia care knowledge, wherein historically located and socially- and discursively-shaped care practices are created, shared, and applied within and among a group of people living and working with dementia. It is important to know about this insofar that such an understanding can presumably shed light on what is otherwise considered a "black box" of organizational context (Rycroft-Malone, 2007), an understanding of which is presumed to factor significantly in the achievement of enhanced and sustained quality of care. Understanding the culture of dementia care knowledge is important for the purposes of "knowledge translation" and for the conceptualization and roll-out of quality improvement initiatives.

Chapter Three sets the scholarly context of this dissertation in two parts. The chapter begins by providing an overview of the critical value orientation and the key epistemological tenets that make this research 'critical.' Chapter Three also addresses the



triple crisis (Denzin & Lincoln, 2005) of representation, legitimation, and praxis. That is, I explicate how and why I chose some of the rhetorical devices that this dissertation employs, the criteria by which the rigour of this dissertation could/should be judged, and the means by which this dissertation's theoretical reflexivity can be brought to bear on actual practice.

Chapter Four is the first of three integrated manuscripts in this dissertation. Its focus is on the unpacking of the methodology that drives this research (Carspecken, 1996). Characterized by Denzin as an “elegant model for critical ethnography” (2003, p. 269), by Cook as “extremely intricate” (2005, p. 134), and by Stewart and Usher (2007, p. 998) as a “method [that] can be used to understand nursing leadership in terms of the organizational cultural factors that contribute to the way in which leaders behave,” the assumptions and practices proposed by Carspecken require delineation and explanation. To assist in the effort of conceptualizing Carspecken's theoretical methodology, I have included in this chapter a number of figurative and empirical illustrations.

Study findings are reported in Chapters Five and Six. Chapter Five features an examination of the social power that envelops caregivers as they read and interpret a person with dementia, yielding three power themes that describe the variably ethical conditions for discourse related to dementia care knowledge. Chapter Six focuses on how study participants *respond* to clients' and residents' responsive behaviors, and in particular how social power interacts with tacit and explicit knowledge in the provision of dementia care. Collectively, these findings draw attention to the need for dementia caregivers to be attuned to both the communicative capacity of a person with dementia and to how social power manifests during the enactment of dementia care. Chapter Seven

concludes this dissertation by offering implications for the fields of dementia care and knowledge translation.

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## – Chapter Two – Review of the Literature

This chapter establishes where in academic literature knowledge gaps exist with respect to efforts to improve and sustain the quality of dementia care in long-term care. To review the literature, my strategy was to focus on four broad areas: knowledge translation (KT), long-term care (LTC), Alzheimer’s disease and related dementias (ADRD), and critical ethnography. My rationale for focusing on these areas relates primarily to my targeted research setting and population (hence searching the long-term and dementia care literatures), coupled with my critical interest in the evidence-based care movement as that which is meant to drive quality care improvement (hence searching the KT literature). I entered the literature review with an *a priori* decision to search for evidence of ethnographic activity in long-term dementia care for two reasons: one is my appreciation of the importance of understanding context in KT and my presumption that an ethnographic methodology inherently lends itself to this aim. Second, my philosophical orientation is driven in large part by an intent to realize a critical epistemology, and I had known the work of Carspecken (1996) to enact such an epistemology.

To conduct a search of the literature that includes contributions from *KT, long-term care, dementia care, and ethnography*, four databases were searched, including: CINAHL, Scopus, PsychInfo, and Ovid Medline (inclusive of publications from 1948 to February 2011). The KT terms I searched for included, *knowledge translation, knowledge exchange, knowledge to action, knowledge transfer, knowledge broker, and PARIHS*, which is the acronym for a KT framework popular in health sciences, *Promoting Action on Research Implementation in Health Sciences* (see Kitson et al., 1998). While

searching the Medline and CINAHL databases, I allowed the search engine to map search terms onto subject headings, thereby expanding my search to include terms such as *evidence based medicine, health knowledge, diffusion of innovations, health policy, practice guidelines, information dissemination, and knowledge management*. To include literature related to both the overall syndrome of cognitive impairment and to its most prevalent disease, I searched for the keywords *dementia, Alzheimer's disease, Alzheimer's disease and related dementias*. Indeed, the Canadian Institute of Health Information estimates that 56% of Ontario's LTC residents have a diagnosis of Alzheimer's disease or a related dementia, which translates into an estimate of more than 64,000 people in 2015, 87,000 by 2025, and nearly 134,000 by 2035 – figures that fuel fears of the rising tide in dementia care. For 'long-term care,' I used *long-term care home, long-term care facility, nursing home, homes for the aged, and residential facilities*. Finally, I used the terms *ethnography, critical ethnography, cultural anthropology, and nursing methodology* to identify literature related to ethnography in health care.

In Medline, these four searches yielded, approximately, 1.3 million KT articles, 130 000 Alzheimer's (and related dementia) articles, nearly 850 000 long-term care articles, and 250 000 ethnographic articles. Among these 2.5 million or so articles, I then began to look for overlaps in these distinct literatures by cross-referencing the searches. For example, there were 18 articles that used both 'KT' AND 'ethnographic' keywords, six that used 'long-term care' AND 'ethnographic' keywords, two that used the Alzheimer's AND ethnographic keywords, 21 that used PARIHS as a keyword, and 285 that, according to their keywords, related to all four areas of interest. In reviewing those

285 articles, I excluded articles if they were: not in English (22), focused exclusively on LTC placement (15), only about Alzheimer's and not about Alzheimer's and KT or Alzheimer's and ethnography (46), focused on biomedical/pharmacological aspects of AD (22), related to psychiatric conditions other than Alzheimer's (1), or if they focused exclusively on non-KT tool development/psychometrics (4). Thus, after I excluded these 110 articles, I exported the remaining 185 into RefWorks (i.e., software for managing reference data) along with the other 47 articles previously identified in Medline. I then repeated the same procedures while searching the other three databases, such that I exported into my RefWorks database 95 articles from PsychInfo, 33 from Scopus, and 83 from CIHAHL, which, when added to the 232 from Medline, equaled 443 articles. I also imported 29 systematic literature reviews on/about KT I had in another RefWorks database. After subtracting 7 duplicates, my literature search ultimately yielded a total of 465 references in my database. I have organized my review of the literature into the following nine sections:

- (i) I begin by examining (facility-based) long-term care in Ontario, particularly in terms of system trends.
- (ii) I then draw attention to concerns regarding the quality of living and working conditions in long-term care, particularly in specialized care units.
- (iii) Next, I examine existing knowledge translation (KT) strategies that attempt to redress the concerns regarding living and working conditions in long-term care dementia care, and begin to problematize the notion of depositing knowledge into point-of-care caregivers' heads.



- (iv) Then I consider *relational* KT – networks, needs assessment tools, and knowledge brokering – and suggest that these strategies still do not include point-of-care providers’ views or experiential knowledge.
- (v) I then describe newer ways of thinking about best practices in dementia care research – ideas about how dementia-related KT could *or should* be conceived of in long-term care settings – and concede that these ideas are more inclusive, but maintain that they are still not *critical* in that they do not inquire about (let alone account for) the socio-political and –historical knowledge-power dynamics that shape care practices.
- (vi) Next, I focus on two regional training initiatives, PIECES and GPA, and the lessons learned from the evaluations conducted to date. And while I cannot argue with evaluations that show PIECES- and GPA-trained practitioners are *satisfied* with the training and *feel more confident* after being trained, I contend that satisfaction and confidence outcomes should not be equated to changes in practice, and, moreover, I suggest that the implementation and evaluation of these initiatives were not designed to take into account ‘critical’ considerations (of, for example, the influence of social power).
- (vii) I turn next to the literature that describes a lack of engagement with point-of-care caregivers to substantiate the notion that PSWs are often not included in care planning, and therefore neither is their tacit knowledge. I follow Kontos (who follows Merleau-Ponty) in articulating a notion of *tacit knowledge* that entails a primordial, embodied way of knowing, contending that this indeed is an important way of knowing to know about.

- (viii) Next, I look to see how others have seen long-term dementia care knowledge with (critical) ethnographic eyes, first by describing the seminal work of Diamond, then by reporting on the ethnographers who followed after him, both descriptively, and critically.
- (ix) Finally, I review the literature that expounds critical ethnographic KT, from ethnographically deriving an understanding of learning needs to a critical ethnographic exploration of knowledge work in a primary care setting. Notably, these works are rare.

In fact, to my knowledge, there has been no critical research that ethnographically examines dementia care knowledge in a long-term care residential setting. As such, I suggest that an examination of the historically located and socially- and discursively-shaped dementia care practices is justified, and that an effort to understand how dementia care knowledge is created, shared, and applied within and among a group of people living and working with dementia is useful insofar that such an understanding can presumably shed light on what is otherwise considered a ‘black box’ of organizational context (Rycroft-Malone, 2007). Ultimately, I suggest that not only can such an understanding of dementia care knowledge inform knowledge translators’ efforts to understand context, but perhaps more importantly, such an understanding of dementia care knowledge can contribute to a re-cognition of what exactly ‘knowledge’ is. I begin though by providing a sense of what system-level trends seem to exist in the long-term care sector here in Ontario.

## Long Term Care in Ontario

Comprised of 625 facilities, the long-term care sector in Ontario provides health care and accommodation services to nearly 77,000 older adults with health and personal care needs; another 24,000 people are currently on the wait list for long-term care (LTC) placement (MOHLTC, Long Term Care Homes System Report, 2010, pp. 2-9). A report by the Conference Board of Canada<sup>1</sup> (CBoC, 2011) provides a comprehensive overview of how changes to the health care system, coupled with changing socio-demographic conditions, are making affordable, accessible, high quality care more difficult to achieve. Such conditions necessitate significant innovation and transformation as multiple forces converge on the LTC sector to create this need for transformation. These converging forces include the increasing number and proportion of older adults, the increasing prevalence of chronic diseases, and, as reported by the Alzheimer's Society of Canada (2010), the "rising tide" of dementia that impairs the ability of many Ontarians to live independently. Moreover, current and future cohorts of LTC residents are expected to have higher health care needs and expectations, thus adding to the already high levels of job strain among LTC staff (Morgan, Semchuk, Stewart, & D'Arcy, 2002). The Conference Board of Canada report suggests that meeting these higher expectations will not only require additional resources, but will also require a cultural shift in LTC facilities at all staff levels.

And yet the LTC sector's financial resources and infrastructure remain highly strained: promised increases in funding to enable an increase of the number of hours of

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<sup>1</sup> The Conference Board of Canada is not-for-profit organization that provides organizational research and capacity development services to all levels of Canadian government. This particular report was developed with funding from the Ontario Long Term Care Association, and was subject to external peer review.

care per resident per day have not materialized, staff shortages continue to manifest, and unbalanced staff ratios are common (CBoC, 2011). Moreover, a need exists to ensure that there are enough professional staff in place that para-professional staff (i.e., non-registered ‘personal support workers’ – PSWs) are not being required to provide care they are not trained to provide (CBoC; Kontos, Miller, & Mitchell, 2009), and that all providers receive the support and/or training necessary to provide dementia care (Illes, Chahal, & Beattie, 2011; Stolee, Hillier, Cook, & Rockwood, 2011). Factors that negatively impact human resource recruitment/retention to the LTC sector include workload issues, inadequate staffing levels, the ubiquitous devaluation of LTC, low wages, lack of advancement and training opportunities, and a lack of autonomy (CBoC). Additionally, high or over-regulation in the LTC sector makes care harder to provide: the time needed for compliance and reporting compounds human resource challenges, i.e., reduces the availability of staff time for direct resident care (DeForge, van Wyk, Hall, & Salmoni, 2011) and hampers innovation. The CBoC report concludes, “for the LTC sector to survive and thrive in the emerging environment, it must undergo significant self-transformation and pursue improved relationships and integration with other parts of the continuum of care to ensure the most effective and efficient delivery of services to Ontarians” (p. 1).

### **Dementia Care Practices in Long-term Care**

For more than 20 years, health care organizations have been trying to establish learning cultures and to assess dementia caregivers’ needs (Bellaver, Daly, & Buckwalter, 1999; Maalouf, 1995). These caregiving activities are immensely complex

given that people with Alzheimer's disease or a related dementia, oftentimes, are dealing with comorbidities in addition to dementia (Neyens et al., 2006; Tariot, Ogden, Cox, & Williams, 1999). In geriatric nursing – where the bulk of dementia care takes place (Anderson, Ammarell, Bailey, Colon-Emeric, Corazzini, Lillie et al., 2005) – dementia is one of the main areas of knowledge where gaps have been identified (Larson et al., 2004), especially with regards to the management of behavioral disturbances both in acute (Henderson et al., 2006) and in long-term care homes settings (Draper et al., 2009; Hsu et al., 2005).

The increasing proportion of complex residents with dementia and other comorbidities has led to the emergence of specialized care units (SCU) in long-term care homes (Sidell, 1998). Such dementia care units vary in their models of care and care philosophies, physical and built environments, staff selection and training, programming, and admission and discharge criteria (Maas, Buckwalter, Swanson, & Mobily, 1994), but have in common the feature of being a unit within a long-term care home that is dedicated to caring for people with dementia (Mistretta & Kee, 1997). Despite the rapidity with which SCUs have emerged, research shows that SCU management practices across the sector are inconsistent: long-term care managers' practices vary, are often vague and process- rather than outcome-oriented, and sometimes unrealistic about the goals and criteria for success of their SCUs (Kane, Jordan, & Grant, 1998). Moreover, Phillips and colleagues (1997) showed that SCUs do little to slow the rate of cognitive decline among people with dementia. Sidell (1998) pointed too to the socio-political complexity that intertwines the historical development of SCUs and specialized programming for ADRD in LTCHs by noting the rapid emergence of special-interest

groups over the past two decades, and that despite there being limited research on the benefits and effectiveness of SCUs for the dementia population, they continue to proliferate.

In addition to calling into question the evidence base for SCUs, Sidell (1998) echoed others' (Bass, Crumpton, Griffin, Hassan, & Rustige, 1993; Sloan & Matthew, 1991) concerns regarding the segregation of people with ADRD, particularly when such segregation manifests as the isolation of especially 'troublesome' residents and/or when such segregation is offered/imposed without appropriate, positive supports. Such concerns stem, in part, from the growing body of evidence that describes the challenges long-term care home staff face in caring for residents with Alzheimer's disease and related dementias who, for instance, wander (Lucero, Hutchinson, Leger-Krall, & Wilson, 1993) or who require substantial assistance with feeding (Van Ort & Phillips, 1992) or with toileting (Hutchinson, Leger-Krall, & Skodol Wilson, 1996). These challenges, among others, increase the potential for job strain among long-term care home staff (Morgan, Semchuk, Stewart, & D'Arcy, 2002), particularly when the challenges manifest as verbal or physical assault (Gates, Fitzwater, Telintelo, Succop, & Sommers, 2002; Myers, Kriebel, Karasek, Punnett, & Wegman, 2005; Volicer, Van der Steen, & Frijters, 2009). While these challenges are not unique to SCUs, the segregation of those with dementia and with complex care needs can significantly compromise the quality of life for both those who work and live in LTC homes (Sidell, 1998) and bring about undue suffering to people with dementia and staff alike (Bourbonnais & Ducharme, 2010). These concerns begin to establish a rationale for critical research that examines how knowledge is (re)produced and exchanged in these SCU settings.

The initial response to these concerns about the living and working conditions within SCUs has been to assert that there exists a clear practice gap pertaining to the care of older adults in long-term care – especially regarding how point-of-care providers can be supported (Boström, Slaughter, Chojecki, & Estabrooks, 2012). Calls have been made for knowledge translation intervention research that focuses on organizational, financial, and regulatory elements of the health and long-term care systems (Boström et al., 2012; Moyle, 2010) and that establishes effective processes to facilitate knowledge exchange among all care providers and researchers of best care practices in this particular setting (Berta, Teare, Gilbert, Ginsburg, Lemieux-Charles, Davis, et al., 2005; Sullivan, Kessler, Le Clair, Stolee, & Berta, 2004). Such calls reflect a realization that to date, most of the existing strategies for dementia-related KT in long-term care, as shown below, have generally targeted physicians and/or have relied on a didactic teaching model that ignores and erodes existing care knowledge among point-of-care providers.

### **Existing KT Strategies in Long-term care Dementia Care**

Many of the KT research projects described in the long-term dementia care literature focus on changing physicians' medication prescription practices (Boström et al., 2012), or are premised on a single intervention, such as: the use of in-home videos (Mahoney, Tarlow, Jones, & Sandaire, 2002), the use of on-line modules (Vollmar, Butzlaff, Lefering, & Rieger, 2007; Vollmar et al., 2010), and educative interventions with volunteer caregivers (Robinson, Kiesler, & Looney, 2003) and care providers (Robinson, Bamford, Briel, Spencer, & Whitty, 2010). Each of these projects entailed expert-developed and expert-led education that subscribed to didactic teaching and

learning practices, which Grimshaw et. al (2003) have deemed limited in effectiveness. It is perhaps not unexpected then that these interventions did not yield practice changes that were shown to be sustainable; at best, they showed an improvement in ‘knowledge gain before and after’ the intervention, which again Grimshaw et al. have criticized as not being indicative of changes in knowledge *practice*.

The research by Cohen-Mansfield, Werner, Culpepper and Barkley (1997) is an exemplar of in-service training evaluation. With a goal to change knowledge, attitudes and behaviors of staff members, and to decrease agitation among LTC home residents, their in-service training program focused on understanding the causes and symptoms of dementia, and management strategies, particularly regarding dementia-residents’ wandering. While post-training measures of knowledge improved significantly, scores declined at follow-up, and only modest changes in residents’ agitation were observed. Cohen-Mansfield et al. suggest that additional mechanisms *beyond* the training sessions are needed to see knowledge changes maintained and realized in actual practice; these might include monitoring, feedback, and reinforcement by supervisors. In a Taiwanese study that addressed the risk people with dementia are at for malnutrition, Chang and Lin (2005) researched the effects of a 4-hour training session focusing on developing the skill to feed people with dementia (3 didactic hours + 1 hour of hands-on practice) and reported that by way of including elements of *experiential* learning, some knowledge and practice improvements were implemented and maintained.

Another significant development in long-term care KT is the prediction that implementation strategies are more likely to be successful when they are *multi-faceted* (Holroyd-Leduc et al., 2010). Reporting on the evaluation of an implementation



programme in improving long-term care home staff's knowledge of and adherence to an individualized music protocol for older people with dementia, Sung and colleagues (2008) described how the success of their initiative might be attributed to its multifaceted nature insofar that it included interactive education, a reminder system, a local opinion leader, and an audit mechanism. Similarly, Thomas et al. (2006) provided a review of active learning interventions that espouse the use of interactive, targeted and multifaceted techniques. An outstanding issue with multi-faceted interventions, however, relates to the difficulty in discerning which intervention had what effect and/or how the synergistic effects become integrated (Goldman, Zwarenstein, Bhattacharyya & Reeves, 2009). That said, multi-faceted approaches to realizing change are often embedded in best practice guidelines (BPGs), whose emergence, perceived usefulness, and contemporary prevalence (Edwards, Davies, Ploeg, Dobbins, Skelly, Griffin et al., 2005) has indeed reached into the field of dementia care (Lewis et al., 2005; O'Brien-Pallas, Mildon, & Murphy, 2007a, 2007b; Ploeg, Davies, Edwards, Gifford, & Miller, 2007).

In 2005, Lewis and colleagues engaged specialized geriatric services practitioners in reviewing, summarizing and interpreting five dementia guidelines, after which they conducted two sequential workshops to develop action (implementation) plans. Evaluations of BPG tool adoption indicated that adoption was related in part to the credibility assigned to the evidence (i.e., if the BGP evidence was not of a randomized control trial standard, it was less likely to be adopted). Furthermore, the need for sustained interventions, for ongoing assessment, or for contact with extra-organizational contacts (e.g., the Alzheimer's Society) all were related to lower acceptance of BPGs among the participants. One interpretation of these largely organizational and structural

impediments was that such a lack of resources precluded practitioners' willingness to improve their practices (Lewis et al., 2005). This interpretation resonates with the findings of O'Brien-Pallas, Mildon, and Murphy (2007a, 2007b), who reported on the enablers – managerial support, point-of-care support and buy-in to the importance of evidence-informed decision-making – and barriers related to implementing BPGs in long-term care – lack of time, too many other competing priorities (including direct resident care), a lack of engagement with point-of-care staff during the *development* of the BPGs, and a lack of organizational resources to support implementation (namely staff training and backfilling). Furthermore, there were only a limited number (8) of BPG 'Coordinators' whose job was to facilitate uptake. These findings showed that the implementation of BPGs in long-term care is immensely complex, particularly in light of limited implementation resources and the heavy, complex workloads that preclude staff from engaging in either the development or uptake of BPGs.

Research such as that by Chang and Lin (2005) suggested the possibility that experiential learning may be more effective than didactic learning in dementia care. However, the literature on existing KT strategies in long-term care, including that which describes BPG implementation efforts, still fails to foster (or report) the exchange of existing know-how among point-of-care providers and instead presumes staff to be 'in need of' expert-led learning wherein knowledge is conceived of as that which can be deposited into the heads of learners. Moreover, concerns now exist that mandated practices and (over)regulation may spawn unintended dire consequences such as reduced availability of staff time for direct care of residents, and more generally, a limited ability of the LTC sector to pursue opportunities to develop and implement innovations (CBoC

2011; Kontos et al., 2009). As such, this grouping of studies reflect expert-driven education models that manifest as in-services or educational outreach programs, often failing to engage the existing knowledge of point-of-care staff or to leverage the opportunities that foster face-to-face, hands-on learning. Moreover, while these particular single-focus interventions may have shown changes in caregivers' knowledge and awareness, outcome measures typically indicate pre- and post-intervention knowledge change scores; the findings do not extend far enough to distill changes in practice. Such concerns (wherein knowledge gains are mistaken for changes in practice) have received more attention of late (Grimshaw, McAuley, Bero, Grilli, Oxman, Ramsay et al., 2003; O'Brien, Freemantle, Oxman, Davies, Wolf, Davis & Herris, 2001) and thus suggest a need for further research that extends its scope in at least four ways, in terms of: gaining localized insight into the socio-political and -historical culture of a particular setting and its care practices; integrating multiple strategies to change care practices within the KT intervention; being more inclusive of point-of-care staff in both the development and roll-out of improvement interventions; and facilitating and measuring changes in actual practice, not just knowledge or awareness. This is perhaps presupposed by the need for an alternative conception of 'knowledge' such that rather than being conceived as something that can be deposited into a learner's head, 'knowledge' is conceived as that which emerges from a collective, relational effort to solve practical (practice-based) problems within a context of not only individual learners or practitioners, but of one that also takes into consideration "reservoirs" of tool- and task-related knowledge (Argote & Ingram, 2000).

### **Relational KT: Networks, Needs Assessment, and Knowledge Brokering**

With more of an emphasis on such *relationality*, other scholars who have contributed to the long-term care KT literature focused on the impact of social networks (Sales, Estabrooks, & Valente, 2010), the development of a dementia education needs assessment (McAiney et al., 2009), and on the combination of ‘eLearning’ and knowledge brokering (Halabisky et al., 2010 Sales et al. (2010) claimed that networks can have significant influences in the innovation, adoption and behavior change processes. However, our understanding of how networks realize planned change within health care settings is limited and, as a result, our ability to design optimal interventions that employ social networks as a method of fostering planned behavior change is also limited (Sales et al., 2010). Sales and her colleagues were among the first planning to apply the techniques of social network analysis to knowledge translation in long-term care and their work promises to not only provide insights into the influences of social networks on knowledge translation, but also as a possible mechanism for knowledge translation.

In recognition of the need to take into consideration organizational and managerial support mechanisms that support dementia-focused education in long-term care, McAiney and colleagues (2009) reported on how existing evidence on adult learning principles, knowledge translation and performance improvement was used to develop an evidence-based education strategy to support care practice and improvement in long-term care homes. Four key principles framed their planning guide: use user-friendly, simple, and client-focused tools to facilitate dialogue, capacity building, access to resources, and proactive problem solving; look beyond continuing education strategies to address the

issues that point-of-care staff face; develop a well-thought-out and sustainable education plan that takes into consideration the organization's need and capacity to support education; and include both internal and external stakeholders/resources in making decisions about an education strategy. These four principals are more commensurate with KT strategies that espouse the active fostering of 'bottom up' learning and change-initiation, and inform a three-part tool designed to solicit reflection and dialogue among long-term care home staff/stakeholders about performance gaps and needs for capacity building and education. The first two parts explore the antecedents and readiness for change, while the third part consists of a menu of existing programs/initiatives that may meet a staff's needs. This 'dementia education needs assessment' (DENA) tool has been pilot-tested in 12 long-term care homes, and subsequent revisions led the finalized version of the tool; McAiney et al. (2009) concluded that the next steps for the tool include the development of sustainability strategies, assessing the feasibility of including other programs in the matrix, and testing the tool in other sectors and settings.

The research by Halabisky et al. (2010) explored if/how eLearning (i.e., online education modules) could foster the development of local opinion leaders into change leaders. The findings show that system-level organizational and technological barriers rendered face-to-face collaboration a challenge (when such collaboration was intended to be strengthened), an indication perhaps that the benefits of technology- and internet-based knowledge translation strategies may be less significant than the challenges and, therefore, that further research into the conditions and mechanisms that enable on-site, face-to-face knowledge translation and exchange are necessary.

Also interested in making use of knowledge brokers, albeit at an *inter-*organizational level, the knowledge network known as the Seniors' Health Research Transfer Network (SHRTN) further contributed to the knowledge translation – dementia literature. As a 'network of networks,' SHRTN sought to improve the flow of knowledge throughout the seniors' health-care system by "providing support to Communities of Practice (CoPs), organized around topics such as Alzheimer's disease, spiritual care, and continence care and to a network of regional libraries" (Conklin & Stolee, 2008, p. 117-8). CoPs have themselves become commonplace in a variety of health care fields, but as Li and colleagues assert in their systematic review of CoPs in business and health care sectors, the effectiveness of CoPs in the health care sector "remains unclear" (Li et al., 2009). A funded study protocol that employs qualitative methods to investigate how SHRTN CoPs function and pursue knowledge exchange has recently been published (Conklin, Kothari, Stolee, Chambers, Forbes & LeClair, 2011), but in the interim, to build capacity within its CoP, SHRTN "employs 'knowledge brokers' to support the CoPs and the librarians by facilitating communication, promoting SHRTN and extending its reach and membership, seeking useful evidence, and facilitating opportunities to move knowledge into action" (Conklin & Stolee, 2008, p. 117-8). In a subsequent evaluation of the role and impact of the SHRTN knowledge brokers (Conklin, Lusk, Harris & Stolee, 2013), the authors concluded that knowledge brokers who demonstrate competency in project management, cultural sensitivity, and interpersonal skills can respond to the unpredictable nature of knowledge flow within and across social systems, and do so by enacting multiple roles, including coach/mentor, knowledge translator (i.e., identification, appraisal, and dissemination of research evidence), and/or network developer. Moreover,

the impact a knowledge broker has on the community of practice it supports is greater when the community of practice is in its infancy; established groups, in SHRTN at least, seemed to rely less on knowledge brokers (Conklin et al., 2013).

Within the context of *public health* based knowledge brokering, Dobbins et al. (2009a) similarly conceived of knowledge brokering as a means for developing capacity for evidence-informed decision-making and as a strategy to promote interaction between researchers and end users. For Dobbins et al., knowledge brokering links knowledge users and producers by “developing a mutual understanding of goals and cultures, collaborat[ing] with end users to identify issues and problems for which solutions are required, and facilita[ing] the identification, access, assessment, interpretation, and translation of research evidence into local policy and practice” (2009a, p. 2). While knowledge brokering was not found to be as effective as tailored messaging in this particular project, it did show, similar to Conklin et al. (2013), that “knowledge brokering had a significant positive effective for public health departments that perceived their organization did not value the use of research evidence in decision making” (Dobbins et al., 2009a, p. 3). The notion that knowledge brokerage is a potentially effective means of knowledge translation in some situations is consistent with findings reported by Thompson, Estabrooks, and Degner (2006), who cautiously concluded that while scholars’ conceptualizations of knowledge brokering appear to be premised on the understanding “that interpersonal contact improves the likelihood of behavioural change when introducing new innovations into the health sector ... *considerable confusion and overlap continues to exist*” in terms of what a knowledge broker’s role could/should

entail (p. 691, emphasis added).

### **(Newer Ways of Thinking About) Best Practices in Translating Best Practices in Dementia Care Research**

Researchers interested in understanding and improving the quality of dementia care in long-term care settings have thus sought to conceive anew their KT practices. For instance, Masso and McCarthy (2009) recently completed a review of the literature to identify the factors that support the implementation of evidence-based practice in long-term care, finding that factors related to the evidence itself, the context into which the evidence was being implemented, and the way in which change was facilitated were all salient. The specific, interrelated factors Masso and McCarthy identified included: a receptive context for change; a model to conceptualize and guide the change; adequate resources, skilled staff, and stakeholder buy-in and participation; mechanisms to support the use of the evidence; and the ability to generate demonstrable benefits of the change. These contextual factors are in keeping with research that explored long-term care home staff perceptions and beliefs about evidence-based practice in long-term care (Ayalon, Arean, Bornfeld, & Beard, 2009), and are commensurable with research findings that have focused on organizational knowledge application capacity within long-term care (Berta, Teare, Gilbert, Ginsburg, Lemieux-Charles, Davis, et al., 2010).

Similarly, Draper et al.'s (2009) overview of translating dementia research into practice considered the issues of research-informed quality of care improvement strategies from a variety of perspectives (including educators, service providers, the general public, persons with dementia and their carers, and policymakers), attributing the



challenges that dementia caregivers face, in part, to the overwhelming volume of literature on dementia that is generated each year. What was different about their view of KT in long-term care settings was their assertion that the responsibility for knowledge translation needs to be shared among knowledge users and knowledge producers, a practice that requires a shift in the mindset of all key players regarding the regular flow of information between stakeholders. Moreover, this shift may require dedicated knowledge translation experts and continued provision of knowledge translation resources and research. Draper et al.'s review of the literature concluded with a summation of four key features of effective dementia knowledge translation: a simple, compelling message that is tailored to the intended audience; the use of interpersonal contact (via opinion leaders, change facilitators/champions, and change/linking agents) to improve the likelihood of the uptake of new innovations; student placements and workshops that emphasize know-how (rather than just knowledge of); and organizational structures and resources that enable a learning culture. Furthermore, such a culture ought to manifest not as a multidisciplinary culture, but rather as an interdisciplinary team capable of partnering with care recipients in care planning decisions (Orchard, Curran, & Kabene, 2005).

To date, the literature that addresses how to assess a particular long-term care context so as to determine its readiness for engagement in KT activity is premised on the development of survey tools to assess organizational context (Estabrooks, Squires, Cummings, Teare, & Norton, 2009), an approach that, within the same research program, is to be complimented by a qualitative approach to understanding context within long-term care settings (Rycroft-Malone et al., 2009). These study protocols were among the first to focus on assessing organizational context in long-term care home settings for the

purposes of informing subsequent knowledge translation strategies and do so by building on existing PARIHS conceptualizations of context. According to PARIHS, culture, leadership and evaluation are central constructs of context; Estabrooks et al. add the financial resources of the long-term care home and family caregivers, the social capital therein (manifest as care team cohesion), their formal and informal interactions, and the time for staff to engage in quality improvement / knowledge exchange activities. Estabrooks considers such notions of time to be an element of organizational slack (i.e., the cushion of time, space, and human resources). These constructs developed by Estabrooks and her colleagues constitute the Alberta Context Tool (Estabrooks, Squires, Cummings, Birdsell, & Norton, 2009); its aim (to better understand context) matches research interests from outside the long-term care sector (Cummings, Estabrooks, Midodzi, Wallin, & Hayduk, 2007; Hagedorn & Heideman, 2010; Helfrich, Li, Sharp, & Sales, 2009; Krein et al., 2010; McCormack, McCarthy, Wright, Slater, & Coffey, 2009).

Intent on broadening the scope of context beyond organizational factors, O'Connell and colleagues described a tri-focal model for care in long-term care home settings that establishes principles of partnership-centred care and positive work environment layered upon any notion of evidence-based practice (O'Connell, Ostaszkievicz, Sukkar, & Plymat, 2008). Herein, partnership entails a holistic, person-centred approach to care and research, a sharing of power and responsibility, and flexible rather than rigid parameters for service/care provision. A positive environment, meanwhile, is thought to give rise to team structures and processes that foster accountability, commitment, motivation, and social supports that reduce conflict, all of which are characteristics that depend on effective leadership. In other words, the creation

of the much-needed bridges between research and long-term care home settings can be underpinned by simple and clear implementation interventions, positive researcher-caregiver relationships, regular communication, strategic planning guided by theory and a conceptual framework, and by having optimized human and financial resources (Kaasalainen et al., 2010; O'Connell et al., 2008). When KT strategies are thus conceived, the likelihood of achieving successful implementation of change within long-term care home settings is, reportedly, enhanced.

Though these tenets of translating dementia research sound rational, and indeed more inclusive of all those involved in living and working with long-term dementia care, lacking in these newer conceptualizations of dementia care KT is a focus on understanding how care providers' values and practices interact with and are shaped by historical, socio-political / structural power(s). In order to achieve the aims of a tri-focal model of practice that supports partnerships and the living/working environment with mutually-respected evidence, we must learn how to become attuned to the distribution of social power, how to recognize the consequences of such power distributions, and how to incorporate such insights into the development of a/the emerging knowledge translation activities (Quinlan, 2009).

### **PIECES and GPA**

Two other innovative knowledge translation strategies for LTC home settings have been reported in the literature. As a consultative, train-the-trainer model, a province-wide initiative entitled "Putting the P.I.E.C.E.S. Together" (P.I.E.C.E.S. Canada, 2008), was developed to address the mental health needs of older adults. An acronym for Physical,

Intellectual, Emotional, Capabilities, Environment, Social, PIECES focuses on enhancing the wellbeing, self-determination, and quality of life for older adults. To help put the PIECES in place, the program was essentially comprised of developing “an in-house Psychogeriatric Resource Person (PRP), and in the longer term, developing an in-house Psychogeriatric Resource Team, through which a consistent resource can facilitate a cultural change and continuous integration of best practices” (McAiney et al., 2007, p. 844). This ‘train the trainer’ program involved more than 2000 health care providers. Analysis of pre- and post-training confidence, post-training satisfaction, and 3-month-post-training sustainability indicated that practitioners were generally quite satisfied with the training itself, and as newly-trained PRPs, they perceived themselves to be more confident in using the assessment tools that are part of the PIECES suite of tools. The sustained success of the PRPs in any given facility (where their ‘role in action’ was described as ‘transferring knowledge’) was largely attributed to supportive work environments and administrative support. In settings where the PRPs’ duties were incorporated into their job description, sustainability was greater. Furthermore, in homes where more than one PRP was trained, that is, where a team of resource consultants worked together, sustainability and effectiveness were even greater still. Peer mentoring and coaching were also seen as key enablers to the success of the program (McAiney et al., 2007). In a separate paper by the same group of researchers, Stolee et al. (2009) reported on the qualitatively-derived insights into the facilitators and barriers for the PIECES program that trains PRPs. Consistent with their previously reported findings, Stolee and his colleagues cited the failure of management to support the PRPs with opportunities for on-the-job application of the training as a key barrier to sustained

success, and add to that issues of limited time and staff turnover as other significant barriers.

Another recent, regional initiative has been to introduce the “Gentle Persuasive Approach” (GPA) to health care providers who care for older adults with mental health conditions that manifest as behavioral aggression and disruptiveness (Speziale, Black, Coatsworth-Puspoky, Ross, & O'Regan, 2009). Though GPA is offered in long-term care home settings, the setting for the Speziale et al. evaluation was a geriatric psychiatry program. The evaluation of the program, which targeted both nursing and allied staff, consisted of pre- and post-intervention surveys that queried participants’ satisfaction of the program and their intended and actual practice change, as well as pre- and post-intervention metrics of resident aggressiveness, staff health and safety records, and resident health status (measured to allow for analytic descriptions of resident acuity). The findings of the program evaluation indicated that care providers trained to use the GPA were generally quite satisfied with the program delivery, and that they reported having benefited from an improved understanding of the physiological determinants of the kinds of dementia that result in behavioral disruptions and how to better identify and respond to such disruptions. Moreover, the frequency of aggressive behavior decreased, although there were no changes in the health and safety metrics describing staff injury and time lost.

The evaluations of both the PIECES and GPA initiatives show that trained providers were satisfied with their training, and that they felt more confident in interacting with residents with dementia. Measures of satisfaction and confidence, however, cannot be said to reflect changes in practice outcome. In a care context where

medical and pharmaceutical decisions are shared among physicians, registered nursing staff, and families, and where decisions about how to interact with care recipients and about what interventions to try in managing their behaviors are primarily shared among registered nursing, family, and non-registered nursing staff, creating changes in practice outcome is a complex endeavor that involves more than just the provision of staff training regarding dementia. What remains unexplored, for instance, is an understanding of how inter-personal power claims manifest as/at the moments of reaching consensus about a care plan or routine. If the claims a specialized resource consultant (or any staff member) makes are deemed valid enough to establish or shape the consensus agreements that constitute the routines that in turn constitute a care culture, what inter-subjective, socio-political conditions and mechanisms are necessarily invoked in negotiating consensus for care plans and delivery? How is the knowledge of personal support workers and family members treated? How are these care decisions shaped by a culture of compliance (DeForge, van Wyk, Hall, & Salmoni, 2011) wherein long-term care staff and leaders are surveilled and held accountable by provincial ministerial legislation. Likewise in the GPA context, what kinds of individual, organizational, and legislative power, either absent or invoked, interact with knowledge (i) in arriving at a team-level decision on how to care for a particular resident with dementia, and (ii) in taking a gentle, persuasive approach to de-escalating a situation where behavioral challenges manifest? Presuming that such power-knowledge-consensus dynamics exist, our understanding of dementia care knowledge is incomplete if we cannot describe the power-laden socio-political mechanisms that influence how care recipients, family members, and paid care providers interact in planning and providing dementia care. While it is understood and

acknowledged that these evaluations of PIECES and GPA were not so ‘critically’ focused on the intersections of power and knowledge, this important nexus of dementia care remains unexplored, as are the conditions of knowledge (re)production and exchange among care providers. Each of these issues warrants further investigation if visions of partnership-centred, evidence-informed, positive workplaces (O’Connell et al., 2008) are to be realized.

### **(A lack of) Engagement of/with Point-of-care Knowledge**

A common thread in the critique of the literature reviewed so far is the notion that point-of-care providers’ experientially gained knowledge is not valued in care planning. Indeed, a growing body of literature describes how the exclusion of PSWs from dementia care planning and implementation not only precludes interdisciplinary care, but also the implementation of individualized care plans (Kontos, Miller, & Mitchell, 2010). Complicit in this exclusion are standardized care mechanisms (such as the use of the Resident Assessment Instrument mandated in all Ontario long-term care homes). Kontos asserts that as a consequence of such a reliance on computerized care planning, the *tacit* knowledge that PSWs and other point-of-care staff have accumulated is not communicated to or included in the dementia care planning process; their presumption – that tacit knowledge is important in care delivery – is congruent with a burgeoning interest in understanding tacit knowledge through knowledge ‘socialization’ and ‘externalization’ (Kontos & Naglie, 2009; Kothari, Rudman, Dobbins, Rouse, Sibbald, & Edwards, 2012; Kothari, Bickford, Edwards, Dobbins, & Meyer, 2011; McWilliam, 2007; Nonaka, 1994).

The way in which Kontos and Naglie (2009) conceived of tacit knowledge extends existing conceptualizations wherein scholars have suggested that knowledge is said to be tacit when it cannot be explicitly articulated (Polanyi, 1966), when the body knows what to do without deliberation or forethought (Benner, 1984), and, from a caregiving perspective, when caring “is assimilated as bodily knowing that becomes an extension of the learner” (Carlsson et al, in Kontos & Naglie, 2009, p. 689). While such scholarship has helped establish the “legitimacy of tacit knowledge and the creation of a new epistemic potential for understanding competence, expertise, and caring in clinical practice” (Kontos & Naglie., 2009, p. 689), Kontos contended that such conceptualizations are derived in terms of situational understanding – extensive encounters with concrete situations of clinical practice – and neglect “the primordial and socio-cultural significance of the body” (Kontos & Naglie, 2009, p. 689). Manifestations of such ‘primordial’ and ‘socio-cultural’ tacit caring are evident in ‘the power of gesture’ and the pre-reflective co-ordination of visual, tactile, and motor aspects of our body – imagine scratching an unseen itch without really thinking about it – such that “just as selfhood is tantamount to the existential expressiveness of the body, caring emanates from and is supported by the existential expressiveness of embodied selfhood” (Kontos & Naglie, 2009, p. 696). Kontos and Naglie concluded that care knowledge “that takes seriously the primordial and the socio-cultural body” is not meant to inform clinical practice alone; rather, their “exploration of the communicative capacity of the body to facilitate sympathetic care is intended to provide new insight and direction for future investigation of the body as a site for the production of tacit knowledge” (p. 700). While this would seem true in all caregiving relationships, it is especially salient in dementia



care relationships because the person with dementia cannot, often, indicate themselves how they would like to be cared for; caregivers must rely then on the 'communicative capacity of the body' to recognize and respond appropriately to people with dementia (Kontos & Naglie, 2009; Kontos, 2005).

The path toward including point-of-care long-term care home staff in care decisions is paved with research that describes and examines the socio-cultural characteristics of care provision among long-term care home staff. Hutchinson and Wilson (1998) applied the Theory of Unpleasant Symptoms to dementia care settings, thus gaining insight into the complexity and interaction of symptoms, influencing factors, and symptom consequences. Haggstrom and colleagues observed and interviewed nurses and nurses' aides (i.e., PSWs) caring for people with dementia to better understand their interactions and ways of relating with their care recipients. Their findings described how caregivers achieve understanding of care needs by way of 'affect attunement,' inductive 'puzzle solving,' having knowledge of residents' life histories, and by enacting an intrinsic philosophy of care (Haggstrom, Jansson, & Norberg, 1998). Anderson, Wendler and Congdon (1998) examined how PSWs intervene in the behaviours of elderly residents with dementia and found that caregivers could match the behaviours and activities of residents in caring and supportive ways when the care they provided was premised on having a sense of residents' familial values, respect for the elderly, teamwork, and on knowing the residents. Touhy (2004) pursued this same kind of appreciative inquiry by illustrating through a case study a focus on personhood, wherein care looks beyond the disease to the person within. The call made to long-term care home staff is to develop relationships that nurture personhood, a doubly loaded call in that the

importance of relationships is highlighted, as is the oft-overlooked notion of personhood (Touhy, 2004). With a focus on integrating tacit and explicit-instrumental knowledge, Ayalon (2009) stated that caregivers should not only be provided with ample information about the medical conditions and needs of care recipients, but that specific emphasis has to also be placed on encouraging workers' intuitive approach to dementia caregiving.

As a result of organizational/institutional dynamics that manifest in interpersonal yet often hierarchical relationships (Beard, 2008), such information-sharing practices are often absent in long-term care homes (Kontos, Miller & Mitchell, 2010). The findings of Kontos and colleagues indeed complicate our understanding of the socio-cultural climate of long-term care homes by showing how the caregiving knowledge of point-of-care staff is neither captured by standardized assessment instruments nor relayed to the interdisciplinary team. Working the intersection between experiential, tacit knowledge and inter-organizational relationships (wherein more inclusive relationships enable the privileging and sharing of previously under-valued knowledge), Kontos et al.'s recommendations included incorporating point-of-care (read: PSWs') knowledge in care planning and documentation, and, in acknowledging the occupational shifts in caregiving among registered and non-registered nursing staff (Anderson, Ammarell, Bailey, Colon-Emeric, Corazzini, Lillie et al., 2005), examining personal support workers' occupational identity and their role as interprofessional brokers in long-term care. This suggests for this present research an assumption that PSWs' knowledge is important to long-term dementia care and an interest in understanding how their knowledge claims shape the culture of dementia care delivery, or, if PSWs' knowledge is *not* incorporated into care planning, what socio-political and –historical norms (re)produce such marginalization?

### **Seeing with (Critical) Ethnographic Eyes**

In the 1980s, Diamond's fieldwork in long-term care settings drew attention to these same issues of marginalization. Diamond's research was based on lived work experiences in long-term care: he trained and then worked as a personal support worker (then called a nurse's aide) in three long-term care homes in the southwestern United States. A trained sociologist, Diamond gained his insights through ethnographic means, namely by active participant observation, meticulous journal-keeping, and, in order "to preserve the context in which things were said and done," Diamond employed a novel-like format in representing his findings "so that the reading might move along as in a story" (p. 7). Increasingly, as the chapters proceed, he interspersed sociological commentary into the conversation. What Diamond saw and experienced, he interpreted as ongoing erasure of the work, experience and knowledge of PSWs, as it is only the *physical* life of long-term care home residents that is monitored and documented. The caring (and often intimate) touch that PSWs bring to their work along with tacit-level know-how and emotional labour are all rendered invisible by virtue of the processes of care commoditization: business constructs and measures (e.g., efficiency, profit) supplant the caring discourses of long-term care homes and 'remake' the social, interpersonal elements of care into something less important. To regain and re-legitimize these elements of relational care, Diamond called for research that enables point-of-care staff and care recipients themselves to "be considered a vital voice in [long-term care] home research and political action. They know a lot about how they would like their lives to be different, and analysis of their situation can provide concrete bases for change" (1986, p. 1293).

Ethnographic research typically considers the socially and historically shaped values, beliefs and behaviors of a particular group (e.g., Spradley, 1979; Thomas, 1993). Savishinsky (1993) asserted that descriptive ethnographic research is indeed appropriate in LTC home settings, and since Diamond's (1986) work, several scholars in the field of gerontology have advocated for and conducted research designed to be sensitive to a specific population and capable of generating valid knowledge about its culture (Hirst & LeNavenec, 2007; Hutchinson & Marshall, 2000; Beuscher, 2007; Mott, 1997; Chatterji, 1998). *Critical* ethnography extends this scope by focusing specifically on the creation and hoarding of social power to reproduce oppressive conditions within a particular culture (Averill, 2005; Carspecken, 1996; Cook, 2005; Manias & Street, 2001), and a number of studies in long-term care settings have been conducted to develop theory and action that enable equitable, suitable nursing and health care (Clarke, 1997; Henderson, 1994; Rempusheski, 1999; Ward-Griffin et al., 2003).

Specific to dementia care yet closer to being descriptive rather than critical, power-focused ethnographies, the works of Mott (1997) and Chatterji (1998) are good examples of how ethnography has been used to better understand the lived experience of dementia. In exploring 'personhood,' Chatterji, for instance, used ethnographic methods of observation and in-depth, semi-structured interviews to better understand the emotions, desires, and intentions of people with dementia. The findings highlight the pervasiveness of the biomedical model wherein a long-term care home resident's "impoverishment of expressive ability must indicate diminished subjectivity" (p. 357). A methodological challenge that Chatterji takes up then is to be concerned about representing the person with dementia's experience and concludes, much as Kontos (2005) does, that as

researchers we have a responsibility to free ‘voice’ “from a restricted location in natural language [and] to embed it in other forms of embodiment” (Chatterji, 1998, p. 372). Such methodological challenges remain of salient concern not only as issues of representation (Manias & Street, 2001), but, more specifically, with respect to communicating (in the context of qualitative research) with people with dementia (Beuscher & Grando, 2009; Richter, Roberto, & Bottenberg, 1995; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997). Such concerns suggest a need to be attuned to more than just linguistic representations of values and cultural belief and to derive meaning from embodied forms of communication.

Other examples of ethnography that are not explicitly critical include the work of Hirst and LeNavenec (2007), who, similar to Chatterji, drew attention to how workplace culture often creates the conditions where the “clash of organizational objectivity and residents’ subjectivity devalues personhood” (p. 7); Hutchinson and Marshall (2000) used observation and interview techniques to explore the perceptions of a therapeutic recreational tool-kit; Beuscher’s (2007) focused ethnography featured nine people living with dementia and explored the role of spirituality in their health and wellbeing; and Beard (2008) observed care providers and recipients clinicians’ attempts at gaining trust in a specialty dementia diagnostic clinic. Others have conducted ethnographies in long-term care homes that focused less on the perceptions of care recipients and more on organizational support (Lyons, 2007), social and family support systems (Hweidi, 1999), or on nursing interventions to increase self-care among the residents with dementia in a long-term care home (Singleton, 1993). Lyons’s work, for instance, integrated findings from in-depth interviews and observation at two long-term care homes to better

understand how the built environment, features of nursing discourse, and risky continence care practices intersect to (oftentimes) violate residents' rights to privacy, dignity, and self-preservation. Conklin's ethnographic investigation into meaning-making among long-term care staff (Conklin, 2009) revealed that long-term care staff engage in meaning-making processes that create a sense of coherence and a sense of purpose while also allowing for the construction of individual and group identities, as well as the creation and maintenance of the competence needed to complete the required tasks.

By focusing on descriptions of the lived experiences of people living or working in a culture of long-term care, each of these dementia-focused ethnographies share methods that are methodologically typical for ethnography or critical ethnography (those being participant observation, in-depth interviews, focus groups, and document analysis), but they do not explicitly examine how power infiltrates knowledge (re)production. Such an aim belongs to and typifies critical ethnography, as indeed, critically oriented researchers are said to "basically begin their research with the assumption that contemporary societies have systemic inequalities complexly maintained and reproduced by culture" (Carspecken, 2001, p. 4). Moreover, Carspecken explains, critical researchers "conceptualize such inequalities as a structural feature of society, and they wish to conduct research that will support efforts to reduce it" (p. 4). As described below, only a small number of long-term care dementia research studies have adopted a critical stance that goes beyond 'thick description' by problematizing socio-political structures and/or cultural-historical patterns within the context of dementia care (Bland, 2004, 2007; Bourbonnais & Ducharme, 2010; DeForge, van Wyk, Hall & Salmoni, 2011; Jervis,

2002; Kontos, 2005; Lane, 2007, 2011; Ward-Griffin et al., 2003); none have done so with 'knowledge translation' as the primary research goal.

In New Zealand, critical ethnographic research explored the constructs of comfort and home among people with dementia living in long-term care (Bland, 2004; Bland, 2007). Over the course of 90 days of fieldwork in three long-term care homes, Bland conducted semi-structured interviews with 27 nursing home residents, and 28 staff. Additionally, and in keeping with an ethnographic methodology, Bland (2007) undertook "a range of descriptive, selective, and focused observations of nursing home life" (p. 939) with an aim to better understand daily life, care delivery practices, and underlying rationales for action. Her analysis yielded the conclusion that failing bodies, the absence of appropriate community supports, and a fear of being a burden to families renders long-term care residents as devastated, and in need of comfort. "They required individualized care to ease their discomforts, as well as support to deal with the demands of institutional living and their inevitable death. Yet promises of individualized care, provided in a home-like environment, were little more than rhetoric" (p. 942). For Bland, the techniques of critical ethnography illuminated contextual and environmental factors that "impact both positively and negatively on experiences of comfort and discomfort ... [highlighting] the unnecessary discomfort generated by nursing home life itself and the well-intentioned but destructively disempowering care delivery practices" (p. 942). Moreover, "this study also confirms that comfort cannot be 'seen' by nurses but must be verified with each resident on an individual, ongoing basis" (p. 942).

Kontos (2005) similarly focused her critical ethnographic lens on the embodied selfhood of people with dementia and, like Leibing (2008), troubled the prevalence of the

mind/body dualism that characterizes biomedical reductionism in dementia care. For Kontos (2005, p. 559), “[t]he notion of embodied selfhood speaks of a complex interrelationship between primordial and sociocultural characteristics of the body, all of which reside below the threshold of cognition, grounded in the pre-reflective level of experience, existing primarily in corporeal ways.” To achieve their critical aims and to enact innovative knowledge translation, Kontos and Naglie (2006) transformed the ethnographic text into a performative text by developing a stage-play. By making their work more accessible to their target audience (personal support workers), and by conveying through performance the embodied selfhood that could not be justified by text alone, focus group participants (i.e., health care practitioners) reported “an increased understanding gained from attending the production, and a strong endorsement of the use of drama as an educational tool for disseminating information about dementia care” (Kontos & Naglie, 2007, p. 799), evidence of achieving – at least in part – an aim to increase the critical consciousness among care providers that expressions of selfhood are not limited to verbal utterances and to stimulate dialogue about how care could thus be conceived of differently. Similar in its message, the critical ethnography by Bourbonnais and Ducharme (2010) sought to understand the meaning of LTC home residents’ screams and concluded that particular attention be paid to the care provider – recipient relationship. Where the work of Kontos (2005), Bland (2007), and Bourbonnais and Ducharme (2010) focused on the experiences of long-term care home residents, other critical ethnographers explored the relationships of family caregivers with LTC home nursing staff (Ward-Griffin et al., 2003), as well as issues of power within and among long-term care nursing staff (Jervis, 2002; DeForge et al., 2011).



Jervis (2002) found that the social stratification among nursing staff (i.e., stratification between registered nurses, registered practical nurses, and personal support workers) mirrors in many ways the stratification inherent within doctor-nurse relationships. Consequently, point-of-care staff members (i.e., PSWs) are cast as subordinates, charged with tasks deemed inferior to professional nurses' scope of practice – rejected tasks that, when carried out, project onto care recipients a sense of devaluation. Jervis's aptly titled "Working in and around the 'chain of command'" paper concludes by listing a number of resistance strategies that PSWs employed to counter the powers by which they are subjugated, including: "focusing on resident care rather than nurses' orders, refusing to make themselves 'known' to supervisory staff, limiting the scope of their involvement with higher level staff as much as possible, engaging in industrial sabotage, and leaving the job when the situation became intolerable" (p. 21).

Such strategies have elsewhere been described as 'workarounds' (Lingard, Conn, Russell, Reeves, Miller, Kenaszchuk, et al., 2007; Kontos et al., 2010). Kontos *et al.* observed that PSWs do indeed exercise their own agency "as evidenced by their abilities to perceive, negotiate, reluctantly comply with, or selectively resist provincial and institutional regulations, and thereby shape point-of-care decisions in accordance with their own deliberations concerning quality care" (2010, p. 7). Lingard *et al.*, however, caution that while workarounds are acts of resistance that may appear to offer a 'quick fix' to a problem, seldom are underlying causes addressed and problems continuously re-circulate throughout the system, resulting in 'workaround accretion' wherein workarounds ultimately complicate rather than solve problems and contribute to a kind of 'functional dysfunctionality' within the workplace culture (Lingard et al., 2007, p. 664).

Rather than jaded, resistive, covert, and ultimately dysfunctional workarounds of such power differentials, new, innovative strategies to engage point-of-care staff and to foster their empowerment are necessary (Jervis, 2002; Janes et al., 2008; Draper et al., 2009; Kontos et al., 2009).

More recently, Lane conducted critical ethnographic work to explore the assessment and treatment of patients in mental health units (2007) and, subsequently, to explore transitions from mental health units to LTC homes (2011). Findings from the former study problematize the diagnostic and placement tools common to dementia care and conclude with a call for more ‘verbal work’ among clinicians, family members and people with dementia to compensate for the short-sightedness generated from assessment metrics. Lane’s latter work (2011), which also included in-depth interviews, observations and document analysis, is re-presented through the eyes of a daughter of a woman with dementia; such a personalized narrative serves to draw attention to the need for more geriatric mental health services (and enhanced access to these services), as well as to invite consideration of the benefits of specialized care units (SCUs). Lane maintains that care provided in SCUs would enable staff to develop expertise in caring for people with dementia *so long as* the units are adapted to the unique complexities of dementia (e.g., a suitable built environment, relaxed care routines, increased freedom and autonomy among frontline staff and care recipients), and so long as staff are supported with specialized training, which should focus on increasing awareness regarding ageism and regarding how to recognize mental distress in physical symptoms. All of this, Lane suggested, ought to be premised upon an understanding that the achievement of autonomy be held in balance with institutional needs, although no concrete strategies

were offered for determining what those needs are or how to achieve such a balance. This suggests then a need to better understand how historical and socio-political factors influence how dementia care knowledge is created, shared, and enacted in such settings so that in turn SCUs can indeed become *specialized* dementia care units and not simply the manifestation of segregation. Reiterating the need to redress a propensity toward privileging institutional needs over residents' needs, DeForge et al. (2011) conducted a critical ethnography in a municipally owned long-term care home. Their findings suggest that a culture of compliance shaped by policy-driven structural mechanisms (e.g., standardized assessment protocols, accreditation processes) re-produces conditions that result in point-of-care staff being afraid and unable to care, and they conclude with a “resounding call to recognize and redress how policy-driven accountability mandates shape the caregiving/receiving experiences of long-term care staff and residents” (p. 11).

To summarize, ethnographic research that has been conducted in the context of long-term dementia care has drawn attention to: the lived, subjective experience of long-term care home residents (Bland, 2005, 2007; Bourbonnais & Ducharme, 2010); the influence of social and organizational influences on care practices (Diamond, 1986; Hweidi, 1999; Lyons, 2007); and, most critically (insofar that a focus on power exists), the socio-cultural relationships between families and long-term care home staff (Ward-Griffin et al., 2003) and among long-term care home staff (Jervis, 2002). Consistent among these works are calls for heightened awareness – ‘more attention’ to: residents’ comfort (Bland), to the meaning of screams (Bourbonnais), to the influence of the commoditization of long-term care (Diamond), to the role of social/family supports (Hweidi), to the importance of staff-family relationships (Ward-Griffin), or to the

strategies frontline long-term care home staff employ to mitigate their subjugation (Jervis). In instances where these works successfully raise the critical awareness (Cook, 2005; Freire, 1972) of readers – particularly as it relates to issues of social justice – then these works have achieved their critical goal(s). However, insofar that a goal of critical research is to catalyze change or to achieve a better, common good for residents, families and staff, these works seem to be characterized more by calls for action than by actual action. To be fair, these same studies have been driven by their methodological mandate to uncover and problematize the taken-for-granted values, practices, and socio-cultural conditions that contribute to the very issues requiring action, and this in itself is important and necessary work. The critical trick though is to enable research subjects in particular, and their professional peers generally, to access and reflect and act themselves on the findings (Freire, 1972). This would seem to require alternative conceptualizations of how research evidence is, firstly, conceived of and valued, and secondly, how it is brought to bear on the subjects for whom it matters. In other words, how transformative is critical ethnography meant to be? The following, final section of this literature review examines where/when critical ethnography and knowledge translation have been paired *at all*, then if and how such a strategy has been utilized in long-term dementia care settings.

### **Critical Ethnographic Knowledge Translation**

There is a dearth of research literature exploring the intersections of critical ethnography (CE) and knowledge translation (KT). While a small number of CE/KT studies exist in the HIV/AIDS literature (e.g., Golobof, Weine, Bahromov, & Luo, 2011; Shambley-Ebron & Boyle, 2006), the strength of these research projects is limited to their

ability to generate theory (of particular cultural norms and values) that, purportedly, *forms the basis for* intervention (i.e., prevention and treatment) strategies. The nursing education literature similarly describes a small number of studies that relied on ethnographic methods to better understand barriers to long-term care nurses' research utilization in a pediatric critical care setting and reiterated factors commonly understood to preclude the adoption of new evidence (those being hierarchical power structures, routinized and technologically-driven work, an ethos of anti-innovation, and a culture of compliance) (Scott & Pollock, 2008), or to understand nurses' learning environments (Buller & Butterworth, 2001; Cruttenden, 2006).

Focused specifically on the learning needs in long-term care settings, Cruttenden's (2006) ethnographically derived claims included valuing in leadership the ability to define "the roles for categories of staff" and to then support the capacity of each category "to identify their learning needs" (p. 347). To meet the learning needs of long-term care nurses, Cruttenden listed the following as key considerations: elements of transformational leadership, such as mentoring and consideration of others' growth; charismatic inspiration, motivation and enthusiasm; and intellectual stimulation via questioning and challenging; ultimately, nurses must take an active role in determining their own learning needs. While these findings serve well the leaders and nurses in higher, more powerful positions, they risk (re)producing subordination and stratification rather than inter- or trans-disciplinary practices that value and leverage the experiential knowledge of the 'lowly' point-of-care provider – i.e., the PSW.

While outside of the long-term care sector per se, other ethnographers have incorporated into their projects a more explicit aim to transform health care practices and

beliefs among health care providers (Lemieux-Charles, McGuire, & Blidner, 2002; Quinlan, 2009). Quinlan examined primary health care workers' knowledge work by focusing on peoples' everyday experiences to understand the influence of socio-political trends, and the insights and strategies she advocates seem applicable to the long-term care context. In attempting to trace knowledge from its creation to its being shared to its application, Quinlan offers an account of how texts (i.e., policies, procedures, legislation, etc.) coordinate team functioning. A team member citing a particular action or suggestion, for instance, activates text(s), and this can open up inter-team dialogue about tacit-level knowledge that may be pertinent. The *critical interplay*, then, between explicit and tacit knowledge is better understood in this situation as a local, particular response to the social organization of power manifest as text. Nonaka's (1994) theorizations of such dynamic knowledge creation offer a typology for conceiving such interplay: when formal, explicit knowledge is enacted by a learner it is said to be *internalized*; tacit knowledge is shared and spread throughout an organization via processes of *socialization*; and tacit knowledge, when inscribed as formalized, explicit knowledge, is said to have been *externalized* (Nonaka, 1994). While the expression of tacit knowledge is not always understood to be a response to (organizational) power (as in the example of text-activation above), insofar that knowledge *is* power, *critical* re-conceptualizations of theories of knowledge creation (like Nonaka's) should assume power to already and always be at play in processes of socialization, internalization, and/or externalization.

In terms of knowledge *creation*, Quinlan (2009, p. 626) follows Nonaka in believing that although tacit knowledge is often difficult to express, "it is precisely in its conversion into explicit knowledge through articulation that new knowledge is created."

Knowledge creation also occurs through ‘internalization,’ that is “when explicit, codified knowledge becomes part of the stock of taken-for-granted understandings” (Quinlan, 2009, p. 626). Nonaka posits that it is the conversion from tacit to explicit knowledge, and/or vice versa, that forms the conditions for the development of new knowledge. Notably, Nonaka describes how “[t]heories of organizational learning do not address the critical notion of externalization, and have paid little attention to the importance of socialization” (1994, p. 19). Quinlan’s work folds into this theoretical shortcoming two additional critiques of the evidence-based practice movement, namely that despite efforts of the KT community to highlight the importance of tacit knowledge (e.g., Greenhalgh et al., 2005; Kothari & Armstrong, 2011; Kothari et al., 2012), scholars do not know *how* to fully account for the importance of tacit, practice-based knowledge in the creation of new knowledge; moreover, knowledge processes are conceptualized as technical, cognitive processes. As such, “the social, communicative aspects of the knowledge processes are not featured; in particular, there is little consideration of the relationship between knowledge and the social organization of power” (Quinlan, 2009, p. 626). The findings of her research confirmed the importance of tacit knowledge in what she calls ‘knowledge work,’ that is, the creation, transfer, and application of knowledge. Moreover, like Nonaka, Quinlan highlighted the role of and conditions for *communication* in gaining access to such tacit know-how: “[t]he dialogical exchange that is necessary to the collective clinical decision-making of teams facilitates the articulation of tacit knowledge and thereby opens up the potential for creation of new, communicatively achieved knowledge” (Quinlan, 2009, p. 638).

Quinlan (2009) also suggested that knowledge work carried out in the context of collective decision-making involves the negotiation of knowledge claims. “Thus, knowledge creation, transfer, and application is best understood by considering the social organization of power” (p. 638), which includes textual, personal, and disciplinary particularities. Quinlan’s critical ethnographic research presents an alternative to descriptive ethnographies that might unintentionally reproduce knowledge and power hierarchies and/or miss opportunities to affect immediate change in the local setting by offering a critical, theoretical and empirical foundation and impetus for exploring knowledge work in long-term care settings. In other words, the long-term care literature that points to the marginalization of personal support workers’ tacit care knowledge (e.g., Kontos et al., 2010) might be well addressed through a systematic examination and dialogic, critical reflection of ‘dynamic knowledge creation’ processes (Nonaka, 1994) such that the patterns and unique instances of knowledge socialization, internalization, and externalization are better understood as power-laden knowledge claims that shape dementia care routines.

Indeed, among the critical ethnographic–KT projects conducted to date, little attention has been paid to how knowledge is negotiated within the social and system powers that formally or informally shape a particular context and the care decisions therein, and no such work has occurred within long-term care settings. Meanwhile, in terms of what has been asserted in the long-term care – KT literature, many of the context-assessment, best practice guideline, knowledge network / knowledge brokering / community of practice projects are exemplars of early efforts to communicate evidence to existing and potential health care service providers/users; while each shows promise, all



are in need of more robust evidence (Dadich, 2009) that similarly must attend to the socio-political relationships in specialized care units so as to more fully reflect the day-to-day realities of living and working in dementia care. This is a critical shortcoming in a literature that already suggests that a significant knowledge gap exists in terms of how to best go about generating, translating and implementing knowledge about caring for the elderly – especially those with dementia – in long-term care settings (Berta et al., 2010; Janes, Fox, Lowe, McGilton, & Schindel-Martin, 2009; Kaasalainen et al., 2010; Stolee et al., 2009).

### **Rationale for this Ethnographic LTC Project**

Evident in the above review of the long-term care, dementia care, and KT literatures, is the mounting pressure that the long-term care sector faces in light of increasing system demand, system regulation, and constrained resources. The dementia population within the long-term care sector is particularly affected by these system trends insofar that caring for people with dementia requires knowledge, skills, time, and training. Without such resources, many facilities have adopted a special care unit model of care. The risks for isolation and segregation therein leave many people concerned about the quality of life of residents with dementia in long-term care, resulting in a resounding call for knowledge translation activity in long-term care settings, particularly regarding dementia care. Through the course of KT's relatively brief disciplinary evolution, best-respected strategies have emerged – those being: the generation of organizational support, buy-in and resource provision; the utilization of local opinion leaders and/or communities of practice; and the use of theoretically-guided practices

within a cogent KT framework – and its future directions have been called for – to use and test theory, to pay attention to processes just as much as products, and to hone a better sense of how context impacts KT. Yet our understanding of KT in long-term care, especially regarding dementia care, remains far from complete. In fact, there is a dearth of evidence about what successful KT looks like in long-term care. Moreover, the existing conceptualizations of knowledge employ (what Freire, [1972] has called) a banking metaphor, wherein expert-derived knowledge is presumably deposited into the heads of needy learners without much (or any) consideration of their existing experiential/tacit/embodied knowledge, or of the socio-political and –historical mechanisms that shape their care practices. Conceiving of knowledge differently, that is as something different than that which can be deposited into learners, allows for a more creative and critical examination of the link between knowledge and practice, and perhaps contributes to the growing movement away from the tiring metaphor of knowledge *translation* (Greenhalgh & Wieringa, 2011).

Thus, what this current research seeks to understand from a critical perspective is the culture of long-term dementia care knowledge, wherein historically located and socially- and discursively-shaped care practices are iteratively created, shared, and applied within and among a group of people living and working with dementia. My contention is that it is important to know about this insofar as such an understanding can presumably shed light on what is otherwise considered a black box of organizational context (Rycroft-Malone, 2007), an understanding of which is presumed to factor significantly in the achievement of enhanced and sustained quality of care. In other words, understanding the culture of dementia care knowledge is important for the

purposes of re-cognizing knowledge translation and the re-conceptualization of quality improvement initiatives.

**Statement of aim and research questions.**

The aim of this research project is to critically examine the culture of dementia care knowledge in a long-term care home wherein a culture of dementia care knowledge is conceived as the ways in which long-term care residents, family members, and staff routinely create, share, and variably enact different forms of dementia care knowledge within a context of socio-political and –historical influence.

Given that the aim of this research project is to gain a critical understanding of the knowledge culture in which dementia care is provided in LTC, the following research questions are posed:

- (i) What are the social routines of staff and family caregivers in providing dementia care in a long-term care setting?
- (ii) What does ‘dementia care’ entail in a long-term care setting? What knowledge is necessary to provide care to people with advanced dementia?
- (iii) How and why are routine care practices (not) attuned to residents’ (embodied) selfhood?
- (iv) What knowledge claims are invoked in shaping particular care routines for residents with dementia? How are these claims related to socio-political and – historical influences?

- (v) What kinds of power are invoked in the creation, acquisition and enactment of dementia care knowledge? Who is served and who is oppressed or marginalized by such power?
- (vi) What roles do staff, family members, and people living with dementia enact in negotiating care?
- (vii) What values and norms shape care practices among those participating in dementia care?

By posing such questions and thereby aiming to gain insights into the relational and socio-political power dynamics that affect the values and norms of long-term dementia care, this dissertation is poised to offer a critical interpretation of the culture of dementia care knowledge. Such an understanding of dementia care knowledge can in turn inform knowledge translators' efforts to understand context, and, perhaps more importantly, can contribute to a re-cognition of 'knowledge.'

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**– Chapter Three –**  
**Theoretical Orientation: Establishing a Critical View and**  
**Addressing the Triple Crisis of Representation**

This chapter is comprised of two parts that collectively offer a theoretical orientation to the methodology deployed in this study. To begin, I provide in part one an overview of the critical value orientation and the key epistemological tenets that make this research ‘critical,’ then outline briefly Habermas’ influence on Carspecken, noting in particular how Habermas’ theory of communicative action plays a fundamental role in Carspecken’s theoretical methodology. In part two of the chapter, I shift the focus of this theoretical orientation toward the quality and rigour of this dissertation by describing how I addressed three inter-related questions: (i) how can I honorably re-present the lived experiences of research participants in academic prose? (ii) by what means can my account of their culture of dementia care be judged as legitimate? and (iii) how can my account of their culture trigger actual change?

**Part 1: Carspecken’s Critical Values and Ways of Knowing, and the Influence of Habermas**

Carspecken suggests that the relationship between a researcher’s values and his or her research findings is a “complex and many-layered affair. Yes, there is a connection between findings and values. No, we cannot simply claim their fusion into being without giving contexts and clarifications” (1996, p.5). He asserts that although critical researchers value “conduct[ing] research as a way of bettering the oppressed and downtrodden,” such a value orientation “does not determine the ‘facts’ we find in the



field” (p. 6). As such, the exercise of distinguishing values from findings is important, Carspecken says, “because good critical research should not be biased” (p. 6).

Holmes and Smyth (2011, p. 151) perceive such a concern with bias as incommensurate with a critical worldview that typically accepts ‘bias’ “as an inevitable and potentially positive aspect of the research process,” but what I understand Carspecken to be saying is that one’s research findings should be empirically driven, not value-driven: yes, values play a significant role in selecting research topics, sites, and questions, but there an assumption of this research is that there still remains empirical means to generate possible answers to one’s research questions. These empirical means are a natural extension of one’s way of knowing the world, of one’s epistemological stance, yet the findings per se ought to be primarily driven by the data. Hence the distinction between values and facts: between what one feels is right or wrong, and what one can know about that being so.

In order to make this distinction clear as it pertains to this study, what follows is an explication of the value orientation and epistemological tenets that typify ‘critical’ research. Therein, I offer reflections on my own uptake of these values and tenets within the context of studying the culture of dementia care knowledge.

### **Critical values.**

Values that unite most critical researchers generally relate to a recognition that myriad forms of oppression exist in our society, and to a commitment to using research to redress such conditions (Carspecken, 1996; Kincheloe & McLaren, 1994). In listing these

values (Kincheloe and McLaren, 1994, pp. 139-140, cited in Carspecken, 1996, pp. 6-9), I situate myself and this study within this critical value orientation.

*1. As we (critical researchers) recognize society and culture as wanting in many ways, we value research that critiques social culture and supports efforts to change social injustices.*

What I recognized as ‘wanting’ in our society are the living and working conditions in long-term care settings: people living with dementia (and their families) often seem to struggle to adjust to the onset and progression of dementia, and with transitions into community and LTC services. Moreover, caregivers appear to face immense challenges in providing dementia care, ranging from physical and/or verbal aggression to being under-valued in care planning. As such, I embarked on this study in part to redress such wanting conditions by empirically examining how the value of providers’ care is conditioned by culture.

*2. As we recognize that certain groups in any society are privileged over others, we oppose all forms of inequity.*

With due respect to organizational hierarchies and their necessity, I felt concerned that the care knowledge of point-of-care providers in community and in LTC programs, namely family members and unregulated personal support workers, is not valued despite their often intimate and frequent interactions with clients/residents. Moreover, I recognized that as an arguably vulnerable population, people living with dementia are at risk of being excluded from their own care planning. Believing that important sources of knowledge might be ignored, I felt compelled to examine and redress the seemingly inequitable distributions of power and knowledge-valuations in dementia care.

*3. As we recognize that oppression and inequality are most forcibly reproduced when subordinates accept their social status as inevitable, we value research that can uncover the subtleties of oppression so that its invisibility to those affected by it might be removed, so that oppression can be challenged.*

Indeed, I value the potential to mitigate oppression that inheres in critical research and have reflected at length on how the findings from this study can be re-presented in an accessible and relevant fashion so as to achieve a re-cognition – *a seeing anew* – of the conditions that (re)produce resignation to subordination.

*4. As we recognize that oppression has many faces, we value a commitment to redress all forms of oppression, not to focus on just one form only to ignore others.*

In this regard, I recognize that oppression is ubiquitous, that people are oppressed not only by people whose actions tend to be self-serving, but also by the system or structural factors in which people are immersed. Rather than conceiving of structures as fixed, structures are conceived here as *implicated by meaningful action*; that is, a structure does not determine the action, it is rather drawn upon, reproduced, or altered by actors. As such, structures act fundamentally as claims, some of which gain stability through reproduction and some of which wane when other people refuse to affirm them. Thus, conceiving of and redressing the conditions that shape living or working with dementia cannot rely simply on examining one sub-group's experiences; rather, a variety of inter-personal and system-wide factors require critical consideration.

*5. As we recognize that mainstream sciences are generally, although most often unwittingly, part of the oppression, we value research practices that differ from*

*mainstream researchers' practices; we value a concept of truth(s) that presupposes equal power relations.*

To me, such a valuation of critical research conveys a kind of humility that seems almost counter-intuitive to the making of 'scientific' claims; by acknowledging that this study is as political as it is scientific, and by adopting a stance that questions its own authority, my aim has been to not over-power research participants with projections of what I think is truly going on in their lifeworld of dementia care, but rather to create dialogic conditions *within relationships* where participants can state or ask whatever is on their mind, even if and ideally when they contest my interpretations of the data. Such an aim reflects this notion of 'truth presupposed by equal power relations' and implies, in others words, that "[un]equal power distorts truth," hence the imperative to identify the ways in which "power corrupts knowledge. This matter goes to the very heart of critical epistemology, and it allows fundamental value orientations (for democracy, equality, and human empowerment beyond the merely democratic) to fuse with epistemological imperatives" (Carspecken, 1996, p. 21).

### **Critical ways of knowing.**

While the reflections above explicate the critical value orientation (Carspecken, 1996) that I brought to my doctoral research, I turn now to reflect on the epistemological tenets that characterize this critical research, and do so to reiterate Carspecken's (1996, p. 8) assertion that "[t]he precise nature of oppression ... is an empirical question and not a given belief." The tenets described below establish the epistemological grounds upon

which this study stands. Again, I follow Carspecken (1996, p. 9) who follows Kincheloe and McLaren (1994, p. 139) in delineating these critical tenets.

*1. Given that all thought is fundamentally mediated by power relations that are socially and historically constituted, we (critical researchers) must be extremely precise when it comes to the relationship of power and culture, power and validity claims, power and thought, and power and research claims.*

Further to the point that values do not determine findings, I take from this tenet the understanding that it is neither rigorous nor sufficient to end up making a research claim that ‘such and such a culture is imbued with power’ – that *would* simply reflect a value bias but fall short of offering any empirical findings per se. Thus, as much as possible, what must become known is: the nature of power dynamics between me and the study participants, and the extent and impact of my active and reflective efforts to mitigate power imbalance. Substantively, and in keeping with my research questions, my empirical task is to explicate the role of power in participants’ negotiations of care routines and practices.

*2. Statements of ‘fact’ are always affected by values and are thus never strictly neutral or objective. Therefore, a criticalist must make the fact/value distinction very clear and must have a precise understanding of how the two interact.*

The delineation of (my) value orientations in relation to epistemological tenets begins to take this into account, but this tenet also applies of course to the analysis of field data: my empirical task is to bring to the fore the (often remotely backgrounded) values the participants hold and/or abide by when passively or actively negotiating care

practices and norms, and to offer a sense of the nature of the relationship between that value, its source, and its manifestation in care/practice.

*3. The relationship between concept and object and signifier and signified is never stable or fixed and is often mediated by the social relations of capitalist production and consumption.*

Again, the empirical task is to go beyond making claims that relatively stable semantic significations exist and to instead list and critically contextualize the most salient symbolic cultural artifacts within a critical perspective so as to trace the evolution of such signifiers and symbols back to broader historical- and socio-political (and often capitalist) roots. These three epistemological assumptions, fueled by a critical value orientation like the one described further above, were fundamental to this study's critical worldview that examined the places where unequal power distorts truth in dementia care. But Carspecken (1996) also draws on Habermas in terms of conceiving of what there is to know, how we come to know, and what conditions should be in place in arriving at 'truth.' I turn now to discuss the influence of Habermas as it relates to the empirical nature of this critical study.

### **The influence of Habermas.**

Habermas discusses ontology in relation to the notion of "lifeworlds," referring to the (often) shared experience of physical and social worlds that constitute our everyday lives (Habermas, 1985a, 1985b). These ontologically real lifeworlds consist of objective, subjective, and inter-subjective elements that intertwine to produce practical, social knowledge about what is true and what is right. Central to this view is the inter-subjective

domain, hence the ontological primacy Habermas affords to communicative action and to discourse ethics and dialogue. Herein, Habermas establishes the concept of discursive truth, which is defined as “the idealization of the discourse conditions that make it possible to reach agreements about true statements and correct norms, and not as the reality or truth of what is idealized” (Marti, 2004, p. 327). That is, as Marti implies, rather than being concerned about whether or not a statement reached from a particular linguistic community can possibly transcend its originating context, whether truth actually exists, Habermas contends that what one should be concerned about is whether or not the statement was arrived at fairly. His idealized conditions

ensure the full inclusion as well as the equal, uncoerced participation oriented toward reaching mutual understanding on the part of all those affected so that all relevant contributions to a given topic can be voiced and so that the best arguments can carry the day. Accordingly, a proposition is true if it withstands all attempts to invalidate it under the rigorous conditions of rational discourse (Habermas, in Marti, 2004, p. 327).

Thus, in Habermas’ conception, it is inter-subjective discourse that establishes objective lifeworld claims, that is those ‘facts’ that do not depend on our attitude toward them but rather reference the objective world and shared representations thereof; similarly, normative lifeworld claims are derived from inter-subjective discourse insofar that claims about what is proper or appropriate are deemed valid when those affected by the norm “bring their experiences and background knowledge – including previously agreed normative frames – into the dialogue” (Marti, 2004, p. 327). And while objective claims are difficult to refute, normative claims are open to contestation and

(re)negotiation. Thus, Habermas' ontological weak naturalism further implies that cultures continually (naturally) learn and evolve in light of the ongoing negotiation and re-negotiation of a given lifeworld's objective claims and normative expectations. Because such a view is inherently non-reductionistic, it stands apart from *strong* naturalism, which replaces a conceptual analysis of lifeworld practices with neurological or biogenetic explanations (Habermas, 2003, p. 28). This understanding of culture as consisting in part of communicative inter-actions imbued with subjective and objective claims helps to inform the analytic frame for this doctoral study.

In terms of what can be known about any given lifeworld, Habermas contends that our understanding of that natural evolution cannot be void of participants' perspectives, but at the same time, it cannot give too much constitutive authority to the subject or to the linguistic community. It is not that reality exists only in our formulations of it, nor is it that reality exists separately from our formulations; *it's both*. As such, Habermas strives to avoid both a kind of relativism in which all claims to objective knowledge are abandoned (pragmatic contextualism) *and* reductive objectivism, which fails to do justice to participants' perspectives.

Furthermore, Habermas's (2003) explication of 'realism' considers truth in terms of its function, which is to generate unconditional acceptance of particular claims. Truth functions in terms of the normativity of validity claims, and, importantly, manifests as/during communicative action that entails a speech act and non-discursively conveyed meanings. Moreover, these communicative acts are *most* meaningful when related to solving problems of action coordination and social integration. Thus, in order to understand a particular culture, its discursive and non-discursive communicative actions



relating to social integration and action coordination must be understood in terms that do justice to the constitutive nature of language, the objectivity of claims to truth, and participants' perspectives.

Such a view of the social world and of knowing it informs Habermas's theory of communicative action (1985a, 1985b), which might be summed up by the following five assumptions:

1. A relationship exists between meaning and validity such that when a communicative act and its consequences are inter-subjectively recognizable and its validity can be criticized, it becomes meaningful.
2. As such, meaningful action occurs as discourse when the validity of claims is problematized.
3. In the argumentation that ensues, group members invoke objective and social realities as they act within an iterative, looping relationship between linguistic and empirical knowledge.
4. As group members synthesize their empirical and linguistic knowledge, their existing lifeworld is de-centered and their horizons of understanding expand.
5. As claims are backed with objective and subjective claims, language works to disclose the world to its inhabitants, and to aid in their coping with issues related to social integration and action coordination.

These five epistemological assumptions are instructive for the critical researcher, as evidenced by Carspecken's (1996) emphasis on identifying social moments that are meaningful. In this study, I was interested in *dementia care* moments that have contested

validity and that have objectively- and subjectively-referenced claims that contribute to a group's effort to establish norms regarding action coordination and social integration practices. Carspecken (1996, p. 20) states that it is "because critical epistemology takes its core imagery from common forms of communication that power must enter centrally into the theory of truth," implying that the relationships between power and knowledge are particularly salient in a consensus-based notion of truth. It is these moments that define and constitute a culture and that reveal how power, knowledge, and truth are interconnected. In other words (Carspecken, 1996, p. 21): two or more people may find themselves in disagreement regarding a particular norm, that is, regarding what they or others *should do* in a particular situation. Subsequently, they might discuss their situation and seek agreement. Their discussion would be informed by claims about what was actually going on, about how they or others seemed to feel, and again, about what should be the case. Ultimately, for any such claim to be deemed true, "*it is the consent given by a group of people, potentially universal in membership, that validates the claim*" (p. 21, emphasis in original). But in many cases, the gaining of consent (particularly regarding a practice norm) can be a product of unequal power relationships: one party might be coerced, or they might defer to another's authority at their own expense. That authority is culturally constructed, and can have the effect of silencing others "to the depths of [their] personal identity" (p. 21); it is not as though they recognize a claim as being true per se, but rather, they consent to the claim as a result of the power imbalance. Under a Habermasian influence, a critical worldview seeks to identify when and why such coercions manifest as they do, and also to attempt to create conditions where truth and

knowledge are consented to under ethical conditions of discourse, that is, by parties with equal power to speak, question, assert, and be heard.

Toward this end, Carspecken's CQR integrates into its methodological theory Habermas's 'cognitivist moral theory' – or *discourse ethics* – which examines the conditions in which social acts occur (Carspecken, 1996, p. 142; Habermas, 2003). The assertion here is that a moral claim is justified if all those affected would assent to it under the conditions of an ideal speech act, i.e., when all those affected may contribute equally to the negotiation of truth, without feeling coerced. As such, the critical empirical skill that essentially characterizes Carspecken's research methodology is understanding when and how group members (who are affected by a particular claim) do or do not have the power or authority to contribute to claim negotiations; in terms of my study, I sought to identify moments when the norms of dementia care practices were influenced by inequitable power distributions. Under the influence of such critical and Habermasian epistemological tenets, and guided by its affiliated critical value orientation, Carspecken's (1996) CQR methodology essentially seeks to examine the communicative acts that manifest as/at the negotiations of truth related to social integration and action coordination. By explicating and situating the primary tenets of the critical epistemology deployed in this research, my aim in this section has been to outline the symbolically charged, power- and value-laden lines of empirical inquiry that underpin this study. Next, I turn to address how the findings from this empirical inquiry can be deemed as representative of participants' lived experience, legitimate and valid, and as replete with the potential to catalyze change.

## Part 2: The Triple Crisis of Representation

Among the historical moments that are said to comprise the history of qualitative inquiry (Denzin & Lincoln, 2005), the fourth moment was/is the crisis of representation. Herein, recognizing that lived experience is *created* in a researcher's text creates doubts that researchers can in fact *capture* lived experience, giving rise to the assertion that issues of gender, age, class, and race therefore now all require reflexive attention as a researcher seeks to determine where and how s/he shaped the collection of data and presently shapes the re-presentation of analytics findings. Concurrently, the fourth moment called (back) into question the criteria by which qualitative research should be judged. Terms such as *validity*, *generalizability*, and *reliability*, each of which has been theorized in post-positivist, constructionist, feminist, interpretive, post-structural and critical discourses (Denzin & Lincoln, 2005), such terms in the fourth moment seem in need of re-theorization as researchers grapple with the question, How are qualitative studies to be evaluated in a time when "an embarrassment of choices now characterizes the field of qualitative research?" (Denzin & Lincoln, 2005, p. 20) – that is, how should criteria be selected and applied to qualitative research so as to deem its findings legitimate?

These two fourth-moment crises – of representation and of legitimation – shaped a third crisis, a crisis of praxis, which asks, How can change be effected in a world that is only and always a text? (Denzin & Lincoln, 2005). This crisis of praxis asserts that it is just not good enough to describe or reflect upon the world, but rather, researchers' written products must have the effect of intervening in the world so as to affect it (Denzin & Lincoln, 2005; Denzin, 2003; Freire, 1972), thereby "manipulating material and social

factors in a given context” (Greenwood & Levin, 2005, p. 53). Here then is where the so-called *triple crisis* manifests: in the real (and) discursive spaces where issues of representation and legitimation intertwine with a mandate for praxis (Denzin & Lincoln, 2005). Consequently, qualitative researchers are called to produce reflexive writing that adheres to appropriate evaluation criteria and that can pragmatically yield contextually sensitive and democratic change.

Having adopted such a pragmatic approach to inquiry in this dissertation, I have experienced my own encounter with the crises of representation, legitimation, and praxis – which is to say I have faced my own crisis and *uncertainty* with (i) a writing process that blurs the lines between field data, analytic notes, and the final text; (ii) asserting that this particular work should be judged by particular philosophical and methodological criteria; and (iii) an (in)ability to fulfill a critically-imposed mandate to not just describe the life-world I am studying, but to *affect it*. Thus, I pause here to describe the paths I followed in navigating the fourth moment’s triple crisis by situating the approaches I have taken to address issues of representation (Ellingson, 2009; Richardson, 1997), of legitimation (Holloway & Todres, 2003; Carspecken, 1996; Lather, 1986; Kincheloe & McLaren, 2005), and of praxis (Freire, 1972; Carspecken, 1996; Marx, 1977).

### **On re-presentation.**

I find myself facing two related questions: *How can I honorably represent the vast and varied experiences of the research subjects in one set of Findings? Then, how can I re-present those Findings in prose?* Rather than become paralyzed by such an arduous task, I looked to Richardson (1997) and Ellingson (2009) for guidance in *the writing of*

scientific output. To help deal with “uncertainty about what constitutes adequate depiction of social reality” (p. 13), Richardson clarifies first that part of what makes the crisis of representation a crisis at all is that scholarly conventions are themselves contested such that “politics and poetics become inseparable and neither science nor art stands above the historical and linguistic processes” (Clifford [1986], in Richardson, p. 14). Consequently, Richardson points out, the edges of the scientific enterprise have shifted to not only include epistemological assumptions, but also a re-thinking of writing processes.

In re-thinking my own writing processes, I found two of Richardson’s (1997) conceptual pairings particularly helpful: the pairing of *the collective story* and Mills’ (1959) notion of the *sociological imagination*, and the pairing of *guiding metaphor* and *narrative voice*. A ‘collective story’ is that which “tells the experiences of a sociologically constructed category of people in the context of larger socio-cultural and historical forces” (p. 14). Subjects are conceived as *a collective*, a conception that begets connection among the Subjects, empowerment, and a potential for leading them to collective action on their behalf. The promise of the ‘sociological imagination’ (Mills, 1959, in Richardson, p. 15), meanwhile, is that “knowledge of the social context leads people to understand their own experiences and to gauge their own fates,” and, when such an account also triggers for its constituents a (re)new(ed) awareness of a social context, those now-heard voices can mobilize and empower themselves to make positive social change. The telling of this collective story that sparks the sociological imagination, however, must remain accessible and appealing to its intended audience, void of

linguistic traps (Denzin, 2003). It is in this regard that Richardson's pairing of *guiding metaphor* and *narrative voice* become salient:

The final solution to the writing problem is not the extermination of jargon, redundancies, passive voice, circumlocution, and (alas) multisyllabic conceptualization referential indicators. How we choose to write raises two metawriting issues: guiding metaphor and narrative voice. Our choices are simultaneously political, poetic, methodological, and theoretical (1997, p. 17).

The guiding metaphor I employ in this dissertation is not dissimilar to Richardson's (or to many other criticalists' works): that of liberation. The collective story of the subjects I met living and working with/in dementia care is a story of disempowerment that is brought about by the context of larger social and historical forces; my metaphorical job of liberation is to story that disempowerment, to point out the oppressive conditions, and to spark the sociological imagination, to "direct energy toward changing social structures that perpetuate injustice" (Richardson, 1997, p. 19). In this text, I inscribe myself as a *liberationist*. The *voice(s)* with which I do this job, however, are more difficult to concert, to stick with, to pin down.

Like Richardson, Ellingson (2009) sees the vast array of qualitative methodologies "not as an art/science dichotomy but as existing along a continuum from positivism ... through radical interpretivism" (p. 5), i.e., from objectivist accounts of reality at one end to scholarship as art at the other, and thus encourages re-presenting (*voicing*) findings as 'crystallization,' *as multi-genred texts*, asserting that "contrasting approaches to analysis and representation, while also being self-referential to their partiality" (p. 10) offer a

single, coherent text (or a series of related texts) that builds “a rich and openly partial account of a phenomenon [and in turn] problematizes its own construction, highlights researchers’ vulnerabilities and positionality, makes claims about socially constructed meanings, and reveals the indeterminacy of knowledge claims even as it makes them” (p.

4). ‘Crystallization’ can occur most readily in research(ers) that

offer deep, thickly described, complexly rendered interpretations of meaning ...  
 represent ways of producing knowledge across multiple points on the qualitative  
 continuum [of research designs] ... utilize more than one genre of writing ...  
 include a significant degree of reflexive consideration of the researcher’s self and  
 roles ... eschew positivist claims to objectivity and a singular, discoverable Truth  
 in favor of embracing knowledge that is situated, partial, constructed, multiple,  
 embodied, and enmeshed in power relations (p. 10).

In writing and in re-presenting this research, I sought to think in terms of the study participants’ collective story so as to spark an imaginative redressing of social injustice, that is, to do so with an aim to liberate those who, in this context, are oppressed and marginalized (Richardson, 1997). And rather than confining myself to one voice that implies one way of knowing, I have begun already to form a crystallized account (Ellingson, 2009) of this lifeworld (Habermas, 1985), one that employs contrasting approaches to understanding and re-presenting ethnographic findings. These reflections helped me work through the crisis of representation by suggesting to me rhetorical means by which to render and orchestrate the research findings that appear in Chapters Five (where normalized inclusiveness is posited as a liberating means toward democratic



knowledge production) and Six (where it is shown how normative powers led to the regrettable but not uncommon use of force in providing dementia care, and where the means by which caregivers' tacit knowledge can proliferate are analyzed).

### **On legitimation.**

Holloway and Todres (2003) offer 'coherence, consistency, and flexibility' as touchstones for rigour in conducting and reporting qualitative research findings. This follows a view that the quality of qualitative inquiry is to be judged by the tenets of paradigm in which it is situated (Guba & Lincoln, 1994; Denzin & Lincoln, 2005; Holloway & Todres, 2003; Seale, 1999). To do otherwise, that is, to apply criteria from one paradigm to work conceived and carried out in another paradigm, would be akin to applying rules from one game to another, resulting in a mismatch of principles and procedural assessment and value, or what Guba and Lincoln (1994) call incommensurability. The implication is that researchers too should stay within the confines of their own paradigm, that they should avoid piecemeal approaches to designing and reporting qualitative research. That Holloway and Todres include the notion of 'flexibility' in their conception of rigour serves to create some wiggle room, some sense that, for instance, 'critical' research may convey an element of postmodernism; or, a hermeneutic analysis that focuses on meaning-making may also convey a narrative element. (Such flexibility is also in keeping with Ellingson's notion of crystallization (2009), as described above).

In any such case, the question of rigour becomes one of whether or not the tension between coherence and flexibility has been adequately addressed. For Holloway and

Todres (2003), flexibility is acknowledged as recognition that there are indeed many disparate qualitative methodologies, and yet these disparate methodologies share similar *methods* of data collection and analysis. What Holloway and Todres intend, I believe, is to encourage a more differentiated understanding of methodological requirements “in which an understanding of purposes and relative appropriateness of procedures leads to greater specificity about what can be mixed and what can not” (p. 346). But more than not, ‘coherence and consistency’ rule the day. That is to say, one should appreciate that philosophical and methodological consistency do “lead to greater clarity about the nature of the phenomenon to be explored, the questions posed and the ways researchers answer questions and communicate their findings” (p. 347). Thus, researchers should be mindful that the research question(s) they are asking, the data they have collected, the analysis they are conducting, and the re-presentation(s) of the results they produce demonstrate a ‘goodness of fit.’ “If such consistency occurs then the whole thing ‘hangs together’ as coherent; that is, the kind of knowledge generated in the results or presentation section does what it said it would do under the aims of the project” (p. 347).

And while Holloway and Todres (2003) argue that “unreflexive and undisciplined eclecticism might be avoided” (p. 356), they suggest that coherence can be achieved “not necessarily by settling on one approach as an exclusive commitment *but by applying and making explicit an epistemological position that can coherently underpin its empirical claims*” (p. 347, emphasis added). It is with this notion of flexibility in mind, perhaps aptly described as grounded flexibility – so as to convey latitude that is grounded in a single paradigm – it is this that I take as permission to think and write in reflexive ethnographic terms that are *confessional* and/or *deconstructive*, for therein I see myself

maintaining a coherent commitment to a critical worldview, to critical ways of knowing and understanding what the world really is. Moreover, the *theoretically* reflexive work that comprises the bulk of the analytic work in this dissertation is also highly consistent with a critical worldview: its core methods and analytic techniques lend themselves to aims of uncovering taken-for-granted socio-political and –historical mechanisms that fundamentally shape the lived experiences of research participants. The *alternative*, flexibly grounded re-presentations of the analyses (e.g., Introductions 2 and 3) neatly serve as alternative means to engage those reading this crystallized (Ellingson, 2009) work.

In addition to this basic premise of coherence, consistency and flexibility as the touchstones of rigour in qualitative research (Holloway & Todres, 2003), Carspecken (1996) also outlines several criteria by which a ‘critical qualitative research’ project should be judged. In specifically deploying Carspecken’s methodology, I would be remiss to not take into account his existing quality criteria, which offered guidance on specific method and methodological techniques. Table 3.1, below, summarizes Carspecken’s ‘requirements for validity’ that I followed in collecting ‘monologic’ and ‘dialogic’ data, and in conducting ‘hermeneutic reconstructive analysis,’ terms that I describe more fully in Chapter Four where I explicate the methodology that drives this work. For now, I simply note that in addition to the paradigmatic notion of coherence, consistency, and flexibility, it is these criteria by which the quality of my data collection and analysis can be judged.

Table 3.1: Carspecken's (1996) requirements for validity in the first three stages of 'critical qualitative research'

Phase:	Essence of the Phase:	'Validity requirements'
1	Collected data through 'monologic' (i.e., observational) data collection	<ul style="list-style-type: none"> <li>- used multiple data collection methods</li> <li>- used a flexible observation schedule</li> <li>- practiced prolonged engagement to reduce Hawthorne effects</li> <li>- used a low-inference vocabulary</li> <li>- used peer-debriefing to detect gaps in the data collected</li> <li>- used member-checks to democratically assess the validity of the record of observations</li> </ul>
2	Conducted 'hermeneutic reconstructive analysis' in order to delineate possible meanings and communicative structures that convey meaning, and the objective, subjective, and normative claims that people make in negotiating consent to particular routine practices	<ul style="list-style-type: none"> <li>- continued to conduct member-checks to equalize power relations and to engage participants themselves in their own hermeneutic reconstructive analysis</li> <li>- used peer debriefing to check for biases or absences in reconstructions</li> <li>- employed prolonged engagement to heighten the capacity of the researcher to assume insider perspectives</li> <li>- compared and contrast pieces or 'strips' of the primary record with reconstructions</li> <li>- use negative case analysis</li> </ul>
3	Collected data that built on the outcomes of phase 2 by conducting 'dialogic data generation' (i.e., in-depth interviews)	<ul style="list-style-type: none"> <li>- used member-checks to identify and reconcile any discrepancies found in their data</li> <li>- compared and contrasted primary record with dialogic data</li> <li>- used non-leading interview techniques</li> <li>- used peer debriefers for checks on possible leading</li> <li>- encouraged subjects to use and explain the terms they employ in naturalistic contexts</li> </ul>

One final criterion was necessary and appropriate for this research – *catalytic validity* (Lather, 1986; Kincheloe & McLaren, 2005). Whereas the principle of 'coherence, consistency, and flexibility' that Holloway and Todres call for speaks to

issues of philosophical rigour and commensurability, and whereas Carspecken's (1996) own 'critical qualitative research' criteria speak mostly to method/ological nuances (but also to power equalization among the researcher and the researched), this final criterion addresses the potential *impact* of critical research. *Catalytic validity* requires that a critical, 'openly ideological' research project be judged in terms of "the degree to which the research process re-orientes, focuses, and energizes participants" (Lather, 1986, p. 67) with respect to the "genesis, limitations, and transformative possibilities" (p. 78) of particular points of view. As Lather (1991, 1993) and Kincheloe and McLaren (2005) see it, catalytic validity is brought about by exposing the way ideology constrains the desire for self-direction, by confronting the way power reproduces itself in the construction of human consciousness, and by moving research subjects "to understand the world and the way it is shaped in order for them to transform it" (Kincheloe & McLaren, 2005, p. 324).

Thus, as the criteria by which to judge this dissertation as *legitimate*, I drew on Holloway and Todres's (2003) principle of coherence, consistency, and flexibility as well as Carspecken's (1996) criteria for critical qualitative research, and supplemented these with Lather's (1986) and Kincheloe and McLaren's (2005) notion of catalytic validity. Such a triadic set of criteria collectively invites judgment on paradigmatic, methodological, and transformative planes, and are themselves bound by a level of coherence that is in keeping with a critical paradigm. Having reflected at length on how to avoid becoming mired in the crises of re-presentation and legitimation, and having listed as a criterion for quality the notion of catalytic validity, one question remains: how am I to realize an enactment of praxis? That is, what does this dissertation *do* in order to actually trigger (catalyze) the release of the potential that presumably lies within its

culture of interest? To answer this question, and to tie-together my efforts to avoid being mired in crises of re-presentation, legitimation, and praxis, I turn first to Freire (1972) and, in particular, his practice of identifying generative themes that help illuminate *situationality*.

### **On praxis.**

Having deployed a critical epistemology and methodology that bring to the fore backgrounded values and practices, the study ultimately sought to mitigate oppression by facilitating reflection and action upon the world (Freire, 1972). For Freire, enacting praxis entails enabling subjects to re-cognize anew the ‘situation’ they are in, for often, as per a critical worldview, the oppressed and marginalized do not recognize the situation they are in, or, worse, they do but resign themselves to it (Kincheloe & McLaren, 2005). If and when research findings can be used to heighten awareness of such situatedness, those who re-cognize their situation can develop an ‘objective-problematic’ into which participants are inclined to intervene. In doing so, they step out of submersion and forward from emergence to deepen their attitude of awareness; a (r)evolution of social practices can then ensue (Freire, 1972). Thus, the liberationist’s collective story of a particular group of people serves to illuminate the situationality of group members – of both those who are served by and those who are negated by a situation – and to divide and re-integrate the whole of the situation so as to stimulate a new perception of the previous perception, and subsequently to encourage dialogic conditions where previously unperceived practical solutions come to light and where untested feasibility is considered anew (Freire, 1972). Such a conceptualization of praxis resembles the notion of

‘sociological imagination,’ described above, but is more pointed in its problem-posing and in illuminating group members’ situationality.

This Freirian conceptualization of praxis serves to supplement that of Carspecken. Carspecken’s (1996) view on praxis is derived from Marx (1977) – viewing “human life as an *expressive*, self-producing process [and thus treating research as] an *expressive* activity that takes implicitly suspected potentialities and makes them actual through the construction of some product” (Carspecken, 1996, p. 123, *emphasis added*). Constructing prose (or some other crystallized product) to ‘actualize suspected potentialities’ seems in service of both the critical criterion of catalytic validity described above (Lather 1986; Kincheloe & McLaren, 2005) and to the Freirian notion of reflecting *and acting* upon the world (1972), but fundamental to Carspecken’s praxis is the notion of *expressivism*, which asserts that

[t]he act of expression – whether it be speaking, writing, painting, composing – clarifies what is to be expressed. When acting meaningfully, we begin with a subjectively felt impetus to express something that we understand only implicitly. We cannot be sure what it is we want to express until we are actually in the process of expressing it” (Carspecken 1996, p. 123).

Expressivist insights (see also Taylor, 1979) fit well within Carspecken’s critical epistemology: just as meaning becomes more clear *as* it is expressed, Carspecken’s analytics tease apart holistic and implicit preunderstandings of meaning, yielding a more finely-differentiated and explicit understanding of a meaningful act. Moreover, the Marxist attention to capitalist influence on meaning and expression is equally critical, for

it is presumed that in a capitalist society

human work becomes alienated, cut off from the expressive impetus that is fundamental to a human being. When all the details of work have been planned and directed by someone else and when the production of products becomes fragmented into a series of trivial acts divided among a work force (as in assembly lines), workers can no longer express themselves in their labor. The need for praxis has been denied by capitalist work organization (Carspecken, 1996, p. 124).

In striving to craft and enact a pedagogy of praxis, this dissertation took from Marx a cue to be mindful of macro-sociological influences (particularly capitalism) as it examined and brought to the fore structural realities that research participants seemed to either take for granted or accept as inevitable or un-changeable. By delineating and reconstructing through Carspeckian analysis the norms expressed in the negotiation of social routines, a *Freirian* notion of praxis emerged when these critical insights were/are inscribed here for readers and research subjects alike – particularly those oppressed by unequal power distribution – *such that* they are potentially compelled by their (re)new(ed) awareness to redress their own situation.

These notions of praxis (Freire, 1972; Marx, 1977; Carspecken, 1996) each fit into a critical research paradigm wherein researchers adopt a standpoint that is critical of any status quo that (re)produces social injustices. The following chapter locates Carspecken's particular methodology within the qualitative health research literature and offers a detailed overview of how it was employed in this study.



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– Chapter Four –  
‘Critical Qualitative Research’ in Long Term Dementia Care

**Abstract**

A primary record of field data was collected by ethnographic means in two affiliated dementia care sites: a specialized dementia care unit (SCU) for long-term care, and, attached to the same building, a community-based adult day program (ADP). The aim of data collection was to gain a sense of the care practices created and shared among residents, clients, family members and staff of these two dementia care sites. Data collection methods included participant observation, in-depth interviews, focus groups, and document analysis. Data analysis focused specifically on dementia care knowledge, including how programmatically distinct historical- and socio-political factors shaped those care practices in terms of the ways in which dementia care knowledge is conceptualized, socialized, and enacted. As the observational data accumulated, selected texts from the primary record were reconstructed according to the theoretical methodology outlined by Carspecken (1996). Using Carspecken’s “critical qualitative research” (CQR) methodology in a health care context, this article reports on and critiques the use of CQR in the field of dementia care, and concludes with the contention that qualitative health researchers committed to a critical worldview should consider further extending the benefits of CQR to the field of health care – doing so can help researchers and study participants alike *re-cognize* and redress the social acts that constitute the injustices of (in this case, dementia) care.

**Keywords:** critical methods; dementia; ethnography; health care, culture of; health care, long-term; hermeneutics; reflexivity

Ethnographic research considers the socially and historically shaped values, beliefs and behaviors of a particular group (Spradley, 1979; Thomas, 1993), and a number of scholars have conducted ethnographies in long-term care (LTC) settings (Beuscher, 2007; Chatterji, 1998; Hirst & LeNavenec, 2007; Hutchinson & Marshall, 2000; Mott, 1997; Savishinsky, 1993). Critical ethnography extends beyond a descriptive scope by focusing specifically on the creation and hoarding of power that reproduces oppressive conditions within a particular culture (Averill, 2005; Cook, 2005; Manias & Street, 2001). Within the LTC sector, a number of studies have deployed this methodology to examine power-relations. Diamond (1986) was among the first when he used a sociologist's lens to chronicle and examine his experience of working as a nurses' aide. Since then critical researchers have examined family-staff relationships (Ward-Griffin, Bol, Hay, & Dashnay, 2003), social stratification among nurses (Bland, 2007), and the notion of personhood among people living with Alzheimer's disease (Kontos, 2005).

While these LTC critical ethnographies have in common an explicit value orientation toward social justice and toward mitigating oppression, the theoretical and analytic similarities are less obvious. Jervis (2002) for example, drew on grounded theory techniques (Charmaz & Miller, 2001) to examine her data, and in drawing on Lofland and Lofland (1995), Ward-Griffin et al. (2003) similarly relied on initial, secondary, and iterative coding to generate a set of emergent analytic categories. Taking a different tack, Bland (2007) cites Van Maanen (1995), Segall (2001) and Kaufman (2002) as guiding her toward 'making the familiar strange' and in "challenging ways of understanding so [care practices] are no longer seen as natural or inevitable" (p. 939). Kontos (2005),

meanwhile, drew heavily on the theoretical postulations of Bourdieu (1977, 1990) in offering a theoretical re-visioning of personhood.

Another variant of critical ethnography is Carspecken's (1996, 2001) "critical qualitative research" (CQR) methodology. Similar to other critical ethnographies, CQR uses observation, in-depth interviews, focus groups, and document analysis to collect data. The analytic procedures, however, are quite different in that they are derived specifically from Habermas' theory of communicative action and, rather than open and thematic coding, the analyses feature reconstructions of the communicative features that contribute to a group of people assenting to a particular set of normative truth claims, thus offering insight into how and why certain cultural norms come to be, or not (Carspecken, 1996). This article reports on the use of CQR in two dementia care sites: a specialized care unit in a long-term care home, and an adult day program that serves people with dementia who live at home, and offers a detailed outline of how the data were collected and analyzed according to the methodological tenets of CQR. Included are empirical illustrations of how pragmatic horizon analyses and validity reconstructions produced insights into the culture of dementia care knowledge. The aim of this article then is to contribute to the growing CQR health care literature by debunking some of its idiosyncrasies and by reflecting on how CQR might benefit health and dementia care research. I begin by reviewing the existing health care literature that has used and/or examined CQR to outline the strengths and drawbacks others have found in its use.

## **CQR in Health Care Research**

As a methodology conceived of and developed primarily in education research (Carspecken, 2001), there have only been a handful of studies in health care – and none in long-term care – that have deployed Carspecken’s (1996) critical qualitative research methodology. Stewart and Usher (2007) used CQR “to expose [nursing] leadership practice so that emancipation in the context of health care leadership becomes possible” (p. 995). In particular, they drew attention to Carspecken’s pragmatic horizon analysis, contending that the insights garnered from this kind of analysis, especially about identity claims, enables one “to recognize where dominant forms of communication are problematic [such that one] can then begin to reconceptualize leadership as being about strong and open communication as the basis for decision making” (p. 998). Similarly, Hardcastle, Usher and Holmes (2006) “were interested in the cultural conditions of [renal] nurses’ decision making during social interaction and how social structures (rules and resources) were generated and maintained during social action” and chose CQR “because it advocates for simultaneous data collection and analysis, identifies cultural structures and themes, and helps to reveal the culturally pragmatic material from which actors mutually construct their worlds” (p. 154). Hardcastle et al. make note in particular of member-checking and reflexivity strategies, noting that member-checking stimulated spontaneous responses from whoever happened to be present and so provided a quick and effective way of evaluating field notes and promoted dialogue between the nurses. When disagreements arose, these were noted for further analysis. In contrast, we assumed agreement to give credibility to the interpretations and considered it to represent a shared understanding of reality.

However, the researcher remained aware that this does not necessarily mean the view was “correct,” merely that it was the accepted view of the group (p. 158).

Vandenberg and Hall (2011) write of being concerned with such passive assumed agreement and encouraged critical researchers to “be particularly wary of their reconstructions of ‘truth’ because socially accepted ideals can be used and misused to maintain oppression” (p. 26). Vandenberg and Hall are also skeptical that two methods Carspecken suggests to use for democratizing the research process – member-checking and peer debriefs — can mitigate the inadvertent reproduction and reinforcement of dominant power relations, for peers may in fact share and reinforce a researcher’s assumptions rather than challenge them, and in member-checking, participants might lack the confidence and/or freedom to disagree with analytic interpretations. As such, Vandenberg and Hall contend that “Carspecken has neither provided clear assurances about participants’ equal opportunities to question dominant power structures through research processes nor acknowledged the difficulty of contradicting dominant discourses when careers and lives can be put at stake” (p. 26).

Other criticisms of CQR include Carspecken’s failure to “offer help with the ‘technical’ tricks of producing a text or with the reflexive literature on how persuasive texts have been produced by others” (Delamont, Coffey, & Atkinson, 2000, p. 232), something Delamont et al. take as “evidence of the lack of a rhetorical turn” in CQR. Sharing a similar concern about concretizing the abstract, Smyth and Holmes (2005) are concerned that Carspecken’s approach “may be a daunting challenge for those familiar with Habermasian and other social theories. He uses terminology rather idiosyncratically,



drawing from across paradigms and theories, and at times he seems unnecessarily verbose and occasionally obscure, and this tends to compound the challenge” (p. 73).

In an article that outlines CQR’s neo-Marxist, American pragmatic, and expressivist influences, Holmes and Smyth (2011) pair their critique of CQR’s idiosyncrasies with notions of incommensurability by suggesting that Carspecken’s rather confusing use of terminology sometimes extends to descriptions of his theoretical concepts ... [e.g., the notion of ‘pragmatic horizon analysis,’ such that] Carspecken would have us put aside our existing beliefs about these and other concepts and issues that he describes, so that we may – as it were – adopt and develop a new discourse, but this can prove problematic if only because his concepts draw on familiar and respected formulations” (p. 150).

The concern Holmes and Smyth have is two-fold: on one hand, “these elements have been established and articulated within the context of the complex theories in which they originate, and only a superficial understanding can be obtained if that theoretical context is ignored” (p. 150-1); and on another,

there is the problem associated with the grounds on which the rest of that theory is ignored. Carspecken’s eclecticism is not based on a reasoned rejection, nor even problematisation, of those bodies of work, but entirely on the usefulness, to his purpose, of salvaging certain specific elements, a strategy rooted in his deep-seated philosophical pragmatism (p. 151).

That said, the criticisms of Holmes and Smyth (2011) and of Vandenberg and Hall (2011) are few, and are couched in “the obvious virtues” (Holmes & Smyth, p. 153) of CQR, namely its “clear step-by-step approach, the powerfully argued and well-theorized measures to increase rigour and demonstrate validity, and the flexibility of data collection and analysis are [all] especially appealing to a novice researcher” (p. 153). Smyth and Holmes’s earlier article (2005) characterizes CQR as a methodology “to which most nurses will be sympathetic, since they have as their aim the enhancement of individual wellbeing and a general increase in human welfare” (p. 73).

Further support for CQR comes from Kincheloe and McLaren (2005), who state “Carspecken rehabilitates critical ethnography from many of the misperceptions of its critics who believe that it ignores questions of validity” (p. 327-8). They add that among the strengths of CQR is its conception of “meaning as embodiment and understanding as intersubjective, not objective or subjective. ... [Hence, Carspecken] recommends that critical ethnographers record body language carefully because the meaning of an action is not in the language, it is rather in the action and the actor’s bodily states” (p. 328). According to Denzin (2003) however, the challenge in writing up such theoretically reflexive scholarship is to avoid re-presenting findings in terms so abstract that the study is no longer accessible or relevant to the participants and stakeholders for whom the study is relevant.

What follows is an explication of how CQR was deployed in a dementia care study that sought to examine how dementia care knowledge was created, shared, and applied in practice. Both figurative and empirical illustrations serve to debunk CQR’s somewhat idiosyncratic procedures. Ultimately, the intent is to demonstrate that CQR is

capable of generating critical insight into how power and knowledge intertwine, thus suggesting that Carspecken's CQR methodology has significant utility in qualitative health research.

### **Data Collection**

The study took place in Ontario, Canada, in an urban, not-for-profit, 160-bed, provincially-funded long-term care (LTC) home, attached to which is an affiliated community-based adult day program (ADP). Governed by a Board of Directors that is accountable to various provincial legislative mandates, and administered by a chief executive officer and senior leadership team that includes staff from both the LTC home and the ADP, the two sites were otherwise separately staffed, although some part-time nursing and recreation staff worked in both sites. Aside from interactions with the organization's senior leadership team, data collection was confined to the two care areas where dementia care is the primary focus: the special care unit (SCU) within the LTC facility, and the client and staff spaces within the adult day program (ADP).

#### **Description of the two sites.**

##### ***The specialized care unit.***

Located on the ground floor and comprised of two perpendicular wings that were joined by a common area and dining room, the SCU was a 32-bed "resident home area" for people living with advanced dementia. All residents had a dementia-related primary diagnosis at admission. About half were living with Alzheimer's disease or a related dementia, many had a secondary dementia-related diagnosis, and most had a non-

dementia-related secondary diagnosis. As indicated by internationally established aggregate Resident Assessment Instrument – Minimum Data Set (RAI-MDS) Scores, more than half the SCU residents experienced severe or very severe cognitive impairment, half exhibited verbal or physical aggression or socially disruptive or inappropriate behavior, three-quarters of the residents exhibited a potential or acute problem with depression, and more than half of the residents required at least some assistance with many or most of their activities of daily living (see Table 4.1).

#### INSERT TABLE 4.1

The SCU is staffed by either a Registered Nurse (RN) or a Registered Practical Nurse (RPN), one – four unregulated personal support workers (PSW), as well as one full-time ‘Life Enrichment’ recreational therapist. Housekeeping, cleaning, maintenance, and kitchen staff members work on the floor as regularly scheduled or as needed. A social worker supports residents and families, particularly with respect to admission processes. Three physicians share responsibility for residents’ medical directives; they typically visited one or two half-days per week, and relied on the nursing staff to direct their attention to residents’ health care needs.

#### *The adult day program.*

The ADP was staffed by recreation specialists who led programming throughout the day, while PSWs assisted with meals, toileting, portering, and some recreation programming. A RN and/or a RPN oversaw nursing assessments and treatments. Social

workers offered individual and group counseling and education to families, and participated in team meetings designed to prevent and/or mitigate clients' responsive behaviors. Extended evening hours were available Monday through Friday. Weekend services were also available, albeit limited to 15 clients, five of whom could be scheduled to stay overnight so as to afford a family respite. On weekdays, the ADP has a daily maximum capacity of approximately 60 clients. Clients typically arrived by bus, were welcomed into an atrium, then shown to one of three program rooms – one room each for high-, medium-, and low-functioning clients.

Similar to the SCU residents, approximately half of the ADP clients had been diagnosed with Alzheimer's disease or an Alzheimer-related dementia; the other half had been diagnosed with Schizophrenia, vascular dementia, Pick's, Creutzfeldt-Jakob disease, Wernicke-Korsakoff Syndrome, or an unspecified dementia. Often a client would commence in the high-functioning group, but over time be moved to the other groups, depending on his or her particular disease progression. When a client could no longer function in the low-functioning group, or when a client could no longer remain living at home in the community, the social workers assisted family caregivers in making the necessary arrangements to be admitted to the SCU in the affiliated LTC home or another preferred LTC home.

### **Creating the Primary Record**

Prior to commencing the study, the Western University Office of Research Ethics approved this study and its recruitment and data collection strategies. Most of the SCU and ADP staff members were enrolled during the first four field visits to their respective

site, often in a group setting where several staff members could be addressed at once; thereafter, staff members who had not yet been invited to enroll were notified of the research in progress and invited to enroll. ADP clients and families were invited to participate by mail. The registered nursing staff approached SCU residents and families on my behalf; if they expressed interest, they were provided with the relevant information and consent forms. A total of 139 participants enrolled in the study, including 71 point-of-care staff, 12 members of the senior organizational leadership team, and 56 non-staff (i.e., clients, residents, and family members).

The observation period was comprised of 34 field visits, which started in the LTC home's SCU, and then continued in the ADP. I was careful to schedule field visits such that I was able to observe during all hours of operation, seven days a week. While I stayed late into the evening on several occasions, I did not record any overnight observations, in part because all but one or two residents/clients were asleep by midnight, but also because within the SCU, the night-shift staff had only consented to being interviewed, not observed. I then left the field for two weeks to engage in preliminary analyses before returning to the field for eight more field visits to conduct in-depth interviews. Then, after a lengthy continuation of analysis, I returned to the site for three more field visits to conduct one focus group (with the SLT) and 12 member-checking interviews to share and refine preliminary findings and to fill gaps in the data by speaking with participant-groups about whom (or regarding topics about which) I had insufficient data. Table 4.2 presents details about when and how data were collected from these various data sources.

INSERT TABLE 4.2 HERE

Figures 4.1 and 4.2 show the basic floor plan of the site areas where I collected data. In the SCU, I spent most of my observation time standing at or behind the nursing station, sitting in the chart room while staff went about their work, or, ‘on the floor’ in the den, activity room, or dining room. I also attended a team care meeting in the adjacent conference room, which is where I later conducted stage three and member-checking interviews. On occasion, I went into residents’ rooms, either with the resident or with a family member. In the ADP, I conducted my observations in the team room, the atrium, or one of the three program rooms. I observed two team meetings in the conference room down the hall, which is where I later conducted stage three and member-checking interviews.

INSERT FIGURES 4.1 & 4.2

During the observation stage, I strove to balance cordiality with a mandate to be a non-participant observer so as “to reduce the effects of researcher presence on routine activities” (Carspecken, 1996, p. 51) as much as possible. My mindset as the researcher was to “take the stance of a student who has little to contribute and much to learn” and to “[b]e conversant and get accepted to the group, but let them lead the action in every way” (Carspecken, 1996, p. 52). Thus, this observation period did not involve any “penetrating dialogue” with participants but rather took a third person position in relation to them: “describing them from the perspective of an uninvolved observer” (p. 42) by producing

“a thick record of social routines in as naturalistic a form as possible to reduce analytic complications brought about by Hawthorne effects” (Carspecken, 1996, p. 52). Such ‘social routines’ included both the care practices that staff and family members engaged in as well as patterns of inter-personal interactions among the participants. I took extensive hand-written field notes that served as an audit trail of where I was when doing what, and as a place where single, fleeting moments were described in immense detail: what I saw, felt, smelled and heard; body postures and movements, eye contact; and frequently, the time of day. I kept my notes void of any theorizations or opinion and instead used a low inference vocabulary replete with *as if*, *seemingly*, and *as though* qualifiers (Carspecken, 1996).

While making field notes, I would often use the ‘primary objective method’ described by Carspecken (1996) wherein for approximately five minutes, the primary object of my observation would be one particular person; observations might secondarily include people with whom the primary person speaks or interacts, and/or, thirdly, particular features of the room or setting, but the primary focus was always on one person. After five or so minutes, I would shift the focus of my observations to another person. Data thus derived helped me to understand particular care routines from a particular vantage point and served to systematize, focus, and vary my observations.

On occasion, I asked a staff member to clarify for me key contextual information such as the nature of computerized documents that shape care practices, or about the nature and history of a particular client, resident, familial, or professional relationship. When I could tell that a participant was about to share with me a few minutes of their time to talk about living or working at this site, on 11 occasions, I received permission to



record our conversation for subsequent transcription; doing so allowed me to be a more active listener rather than scribbling as much information as possible, although it was not uncommon for me to be speaking intermittently with a participant while making a field note. On seven occasions, team meetings were audio-recorded and later transcribed for inclusion in the primary record. During such meetings, I sat quietly on the periphery of the team interactions taking notes. On two occasions, I conducted in-depth interviews during the observation phase, both scheduled and conducted sooner rather than later for the participants' convenience. Therefore, the largely monologic primary observation record consisted of 34 transcribed field notes, 20 transcribed audio recordings, and several discursive artifacts (including admission forms, assessment tools, reference manuals, communication logs, and whiteboard messages).

Following Carspecken's suggestion (1996, p. 49), I ended the observation phase when I found myself recording the same basic routines over and over again. I believe I had "allowed time for the subjects to become accustomed to [my] presence" and that I had "solid information on body movements, vocal tones, and facial expressions in addition to verbatim speech acts." I moved to stage two.

### ***Preliminary analysis.***

I imported the primary record into qualitative analysis software (NVivo Version 9, 2010), then applied a list of 'CQR codes' I had derived from Carspecken (1996) – 16 code-categories to index notions such as *shared time*, *bids to shift a conversation setting*, *power at play*, and *roles and identities*; under each were more finely detailed sub-codes

(54 in total). See Table 4.3 for a list of the most prominent CQR code-categories, sub-codes, and empirical samples.

INSERT TABLES 4.3 & 4.4 HERE

Concurrently, I developed a list of 17 emergent code-categories and 56 sub-codes therein – see Table 4.4. These codes were useful for organizing and retrieving data describing participants’ care practices, and were ‘low-level’ in that they remained grounded in the primary record. These emergent codes reflected what, in an ideal situation, multiple observers would have understood as the routine care practices and the embodied enactment of arriving at and carrying out those routines. Subsequent meaning field reconstructions yielded assertions of what subjective and normative data coincided within the context of these objectively referenced accounts.

***Initial meaning field reconstructions.***

While coding the observation data with both the *a priori* CQR codes and the *in vivo* emergent codes, I also flagged (coded) data strips to subject to ‘initial meaning field reconstruction.’ Meaning field reconstruction is a hermeneutic process that entails adding “discursive articulations of tacit modes of meaning” (Carspecken, 1996, p. 95): my observations, which were initially intuitive and undifferentiated, were further delineated and refined as I literally made note of the possible unarticulated meanings that seemed to underpin participants’ dementia care knowledge. As my familiarity of the participants

and the research site grew, I felt that the meaning fields I articulated grew closer to be what the actors themselves would report (Carspecken, 1996, p. 96).

Initially, 116 strips of data were identified as being worthy of meaning field reconstruction. With an abundance of data that was arguably about dementia care, I wanted to focus on dementia care *knowledge*. Thus, data from a family member about speaking to one PSW about another PSW were not reconstructed, nor were observations of staff members who spent time texting or Internet surfing with their smart phone. Similarly, data about stocking the medication cart and about clicking in the computerized daily care sheets were not reconstructed. While each of these examples arguably relate to dementia care, the analysis focused on *how dementia care knowledge works* (Quinlan, 2009). Thus, reconstructions featured data regarding how someone “reads” a person with dementia who cannot speak, about how and why certain recreation activities are deemed appropriate, or about the interactive care negotiations between family members and staff. The analytic aim was to reconstruct meaningful moments related to participants generating, sharing, and enacting dementia care knowledge. Ultimately, 90 strips of data were selected to reconstruct. (See Table 4.5 for sample meaning field reconstructions). This seemed to be a substantial and adequate amount of data to submit to this kind of analysis, and the excerpts seemed to reflect the entirety of the data collected up to that point regarding dementia care knowledge. The initial meaning field reconstructions were useful in helping conceive of a range of possible meanings that might inhere in a particular claim, and began to illuminate a range of possible feelings and norms that coincided with the ‘objective’ data I had recorded. Pairing these meaning field reconstructions with an emergent (and codified) sense of how routine care practices were

enacted was useful in generating topics worthy of further investigation in subsequent stage three interviews.

INSERT TABLE 4.5 HERE.

*Generating interview topics.*

As the preliminary analysis progressed, I began to recognize a number of actions that seemed fundamentally related to dementia care knowledge, such as approaching people living with dementia, admitting new residents (SCU) and meeting new clients (ADP), brainstorming about what clients or residents might like to do, negotiating changes in care plans, staff and family members mentoring and educating one another and assisting with activities of daily living (such as bathing, dressing, feeding). While I had begun theorizing about if or how these actions contributed to system-level reproductions of social inequity, I was careful not to let such theoretical and critical jargon slide into my interviews; had I done so, I might have “distort[ed] the communicative context and ... [made] subjects feel incompetent to comment on their lives and experiences” (Carspecken, 1996, p. 155). Instead, I rendered the actions into topic domains about which participants would be able to speak about with confidence and familiarity; I hoped they would “explore issues with their own vocabulary, with their own metaphors, and their own ideas” (p. 155). See Table 4.6 for a list of topics covered during the interview phases.

INSERT TABLE 4.6 HERE

As indicated by the list of member-checking topics in the middle of Table 4.6, I often invited interview participants to comment on one or more of the initial meaning reconstructions; choosing which one depended on a judgment about the fit between topic and participant. Typically, this entailed reviewing actual text. With the excerpt from the primary record printed on the top half of a piece of paper, I covered the bottom half the paper where I had reconstructed the meaning field. Participants could then read the primary record excerpt on their own or, if willing, listen to me read it – this was my preference because it clarified in the subsequent transcription of our discussion the context of what I had originally observed and was now being commented on. After reading the excerpt, interview participants then commented on it without provocation from me, then read and/or heard from me my reconstruction of the excerpt before commenting on those interpretations. Alternatively and as the interview phase progressed, I conducted member-checks dialogically: I would convey to an interviewee an event I had observed, seek their interpretation of that event, indicate what my initial interpretation entailed, then invite their comments on my interpretation. As such, I was able to member-check various snippets of data in each interview such that the quality and richness of my primary record of dialogic data grew while also becoming increasingly democratic.

Characteristic of the reconstructions I chose to member-check were high-level inferences: I inferred for instance that the data about ‘staying seated’ and about (non)gentle care seemed indicative of provider- rather than client-centred care; the data about ‘tone setting’ and about (a lack of) inter-disciplinary respect seemed indicative of

socially- and historically-located interpersonal dynamics; I was interested in member-checking about the impact of occasionally working with a male PSW because I wanted to mitigate the risk of my own gender biasing my interpretations on the impact of gender.

An additional strategy I used to generate interview topics was to track specific questions for specific people. For example, I observed an ADP RN comment that working in the ADP is a *constant learning and teaching experience for [PSWs and] for [her] too to make them think outside of their box*. While I had noted her comment in my field note, I did not at the time have a chance to hear more about this ‘constant learning’ and ‘getting outside the box;’ the interview though afforded me this opportunity. I was thus prepared to begin the interview phase with a master list of topics (that subsequently evolved) as well as individual-specific topics, and a set of meaning field reconstructions I had deemed worthy of member-checking.

### ***In-depth interviews.***

This phase of data collection included 10 interviews that ranged from 60 to 100 minutes in length. Selecting participants to interview was determined in part by a sense of who seemed well suited to respond to the topics generated in the preliminary analysis, in part by who was available to be interviewed, and also by an aim to speak with seasoned, mid-career, and new care professionals from among registered and non-registered nursing staff, recreational therapists, and senior management. Throughout the interview phase, I continued to make field notes about where I was when and with whom I spoke. I also inserted into each field visit entry the most recent copy of the master topic list so that I could track the topics I had not raised or that we had not the time to discuss; I also added

in another font color three or four bulleted notes under each topic about the interviewee's responses. This aided the process of developing updated, prospective interview protocols and facilitated the quick review of the most remarkable interview content. As the interview data accumulated, certain topics became adequately addressed, which allowed me to stop raising that topic (e.g., table mates at meal time) and to cover other less adequately addressed and/or newly emerged topics.

Carspecken's (1996) direction on interviewers' response work (cf. raising a topic) is noteworthy. I had prepared for each topic a list of probes or "covert categories" (p. 157), that is, topic elements to keep in mind without leading the interviewee. For example, in discussions about trans-disciplinary care, I was prepared to covertly integrate the following probes: *What might the pros and cons of trans-disciplinarity be? Can you tell me about a time when you saw a need or an opportunity for trans-disciplinarity? What about a time when someone seemed to be practicing beyond their disciplinary scope?* Within any given topic, I encouraged both verbally and non-verbally the interviewee to speak from their own familiar position in their own words. Concurrently, I was opportunistic in leveraging segues to covert categories, and/or I worked the probe into the end of our discussion about the topic, sometimes as though I was simply seeking clarification about something the interviewee had said.

Another important methods-related protocol had to do with monitoring my own innocuous responses, which Carspecken (1996, p. 158-162) sees as including *bland encouragements, low-inference paraphrasing, non-leading leads, active listening, medium-inference paraphrasing, and high-inference paraphrasing*. In terms of the frequency and appropriateness of the above list of response-types, the former-most

responses should be used most frequently so as to establish rapport and encourage the interviewee to keep talking, whereas the latter-most responses should be used least often as they might “lead the subject being interviewed into agreeing to things she does not really believe or denying things she really does believe” (p. 161). Thus, I tended to limit my interview responses to bland encouragements, low-inference paraphrasing, and to covertly probing deeper into each topic so that I could slowly solicit background beliefs, values, and feelings involved in the descriptive depiction of the participant (Carspecken, 1996). I permitted myself to ask medium- and higher-inference questions at the times when I asked member-checking questions.

### **Creating the Reconstructed Record**

With a set of 10 cleaned (de-identified) interview transcripts to add to the primary observation record, I was now ready to resume analysis so that I could transform my ‘primary record’ into a ‘reconstructed record.’ I continued to apply the previously developed *a priori* and *in vivo* codes to enable retrieval and cross-referencing within and between the two sub-sets of data. I also continued to reconstruct meaning fields, but rather than having an aim to generate interview topics, my aim at this point was to identify data to subject to ‘pragmatic horizon analysis’ and ‘validity reconstructions.’ Derived by Carspecken from Habermas, these analytic techniques deliver higher-level inferences about subjectively-located feelings and about enacted norms of practice. As such, these analytic concepts both constitute and explain key elements of a social act; reconstructions in these terms served to illuminate the (sometimes contradictory) values and norms that underpin dementia care practices.



To assist my own up-take and practice of these techniques, I developed empirical and figurative illustrations. In fact, the cover of Carspecken's (1996) book on critical qualitative research features a simple line drawing that includes a horizontal line intersected by a vertical one, centred on top of which are a circle and a triangle, and extending from the top left quadrant to the bottom right is a diagonal line. A close reading of Carspecken's methodological theory will likely lead one to see that the figure is a heuristic for his approach to hermeneutic reconstructive analysis. In the course of this study, I have both internalized and adapted this heuristic, as follows.

#### **Analyzing a social act with/in CQR.**

Carspecken's (1996) conceptual and analytic elements of a social act analyzed within a CQR project might be conceived as having six elements (see Figure 4.3):

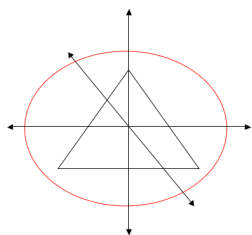
INSERT FIGURE 4.3 HERE.

The two lines that encapsulate the figure and that are interconnected by gray fill-in (element #6) depict the notion of hermeneutic circling, wherein I, as an interpretive researcher, circle among holistic, undifferentiated understandings of a social act and more finely detailed delineations of that meaningful act. Moreover, and as reason for the two layers of hermeneutic circling, I acknowledge that not only must I hermeneutically reconstruct and re-cognize a given meaningful act, but so must the reader: you must read and make sense of my interpretation of the act, circling as it were between (a) the differentiations I make in saying what others mean and (b) a more holistic impression of

said act. It is in this grey area where we the writer and reader meet. This outer-most element is perhaps extraneous to the substantive content of this study, but it marks an important epistemological element of critical qualitative research insofar that it acknowledges the multiple layers of interpretive rendering that occurs in any such project. Substantively, it is the first five elements of a social act that serve as Carspecken's (1996) apparatus upon which meaning may be conceived and analyzed.

***(1) The pragmatic horizon.***

'Pragmatic horizon analysis' is a term that Carspecken (1996) uses to refer to the

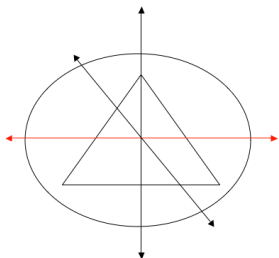


contextualization of a meaningful social act. The pragmatic horizon is constituted by temporally-specific and communicatively-conveyed structures that are “grasped at once, tacitly, each moment one human being understands

another” (Carspecken, 1996, p. 110). The reconstruction of how an act is understood involves explicating its temporal location, its linguistic/symbolic and embodied elements, its references to objective, subjective, and normative claims, and the power-laden identity- and role-claims. These structures are ‘pragmatic’ insofar that they contribute to a meaningful communicative act by being action-oriented, that is, oriented toward the establishment of a consensual truth. Although the horizon appears two-dimensional in this figure, it is more apt to conceive of the pragmatic horizon as having depth: when we notice an object or social phenomenon, “we notice it against many other objects [and social phenomena] that are out of focus” (Carspecken, 1996, p. 103) but that nevertheless interact with and (re)produce that which we notice.

**(2) *The temporal axis.***

Locating a meaningful social act along its temporal axis involves noting how

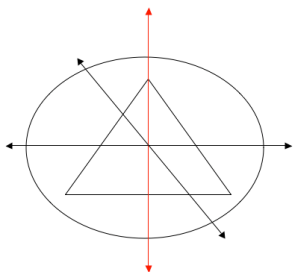


actors construe the appropriateness of their acts vis-à-vis their inter-subjectively shared awareness of prior events, about their expectations of events to come. The rhythm of communicative exchange is also noteworthy and productive of critical insights. While these temporal

elements are essential to the context of a social act, they might be “construed differently by different actors” (p. 106) such that the axis essentially carries on it both objectively- and consciously-referenced time. An example from this study is a shared awareness among many staff about how they *used to* be able to “do more” for the residents, such as assist with keeping their wardrobes and clothes in order; in contrast, “nowadays” staff did not have time to do so (and as a consequence, many residents’ dresser drawers were in disarray). The temporality in this comment helps contextualize the common reference to a greater proportion of client/resident populations having severe dementia.

**(3) *The paradigmatic axis.***

This set of communicative structures includes semantic (linguistic and symbolic)



elements as well as non-discursive elements, namely social power, and pragmatic structures that enable inter-subjective recognition and understanding. Most literally, it was useful to make note of the semantic units that

were common to the study participants. “Semantic units have relatively stable meanings

across a variety of interactive contexts but are always employed in relation to other structures of meaning to bring off the sense of a particular act” (Carspecken, 1996, p. 108). Semantic units that were common to the participants in this study included: the invitation/instruction to *come sit down*; asking a fellow PSW, *Who’d you just do? Who do you got?*; referring to clients or residents as *a new admission, a feeder, a two-person assist, a wanderer, a vascular, an Alzheimer’s type, a wetter*. Such terms “appear to codify many complicated features of a general cultural view” (Carspecken, 2001, p. 18); by coding these terms, I could retrieve and compare the observed social/care acts that incorporated these seemingly loaded terms and subsequently begin to reconstruct the claim(s) being conveyed therein.

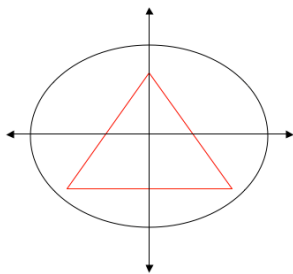
The non-discursive elements of the paradigmatic axis further assist in conveying meaning. Useful structures to analyze include implied contrast (softness of voice, for example, is more fully grasped when one tacitly invokes its contrast, harshness) and identity and role claims. Explicating participants’ claims (that they are such and such kind of person, e.g., a clever person, a competent person, a righteous person, and so on) “is often a very effective way to find core themes within a culture or personality” (Carspecken, 2001, p. 16). Similarly, noting what roles were being enacted served to bring to the fore what was otherwise recognized by the study participants themselves in a tacit, holistic manner.

Vital to a critical research study is an understanding of power claims, also a feature of the paradigmatic axis. Following Carspecken’s (1996, p.130) adaptation of Weber’s (1978) conceptualizations of power, my task was to discern whether the invocation of power was *normative* (wherein cultural norms are invoked to achieve

subordination); *coercive* (wherein the avoidance of sanctions leads to subordination); *an interactively established contract* (wherein the promise or reciprocation of favors or rewards leads to subordination); or *charming* (wherein a subordinate acts out of loyalty to the superordinate because of the latter's personality). Such discerning analysis yielded a sense of what norms were typically invoked (e.g., the organization should meet or exceed government and family expectations), what sanctions were typically used to coerce subordination (e.g., being written up / a blemish on a personal and/or public relations record), what charming characteristics engendered a subordinate's loyalty and conformation (e.g., congeniality, the appearance of genuine interest and concern, the giving of time), and what goods or services were traded or reciprocated (e.g., a caregiver offering a client or resident validation in exchange for that person's cooperation with activities of daily living). Being thus oriented to the x- and y-axes of the pragmatic horizon, I could then turn my reconstructive attention from communicative elements of a social act to the specific objective, subjective, and normative references that intertwine with one another to give a social claim its validity.

**(4) *Validity reconstructions.***

In conjunction with meaning field reconstructions and pragmatic horizon analysis,



the third technique that comprises hermeneutic reconstructive analysis is validity reconstructions. An epistemological tenet of CQR is that 'truth' is defined by its function, which is to generate unconditional acceptance

to a claim (Carspecken, 1996). In order for a particular claim or practice to win consensus

among a group of caregivers, to be deemed valid, the claimant must convince fellow group members with a set of reasons for that claim. Validity reconstructions are efforts to articulate “the reasons an actor could provide to explain expressions. The reasons will generally fall into the three categories of objective, subjective, and normative-evaluative truth claims” (Carspecken, 1996, p. 111), depicted in Figure 4.3 as the triangle. These ontological categories can be characterized as follows.

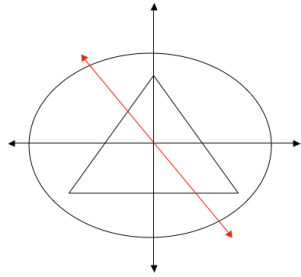
First, objectively referenced claims derive validity from a principle of multiple access because they “are made against the presupposition that other people could observe in the same way as the observer and arrive at agreement with the statement” (Carspecken, 1996, p. 64). Carspecken explains further that such a presupposition is an ontological one insofar that “sense objects *exist* in such a way as to be open to multiple observers who will agree on their existence if they share certain features of a language and a culture” (p. 64, emphasis in original). Thus, counting people or objects, noting movements, or hearing utterances can all generate objectively referenced claims – claims that others would agree to were they there to observe as well. Subjectively referenced claims, secondly and conversely, derive validity from a principle of privileged access. The true nature of a subjective state (such as emotions, desires, intentions, levels of awareness, etc.) can be known only by that particular participant and is not accessible to an observer. “The act of disclosure is not the subjective state disclosed; it is a representation of it. All actors have a certain amount of control over what they reveal of their realm of privileged access and what they conceal” (p. 69). Subjectively referenced claims factor significantly in relational care practices, and accounting for participants’ subjective perceptions is a quality that a Habermasian approach to inquiry would espouse (Habermas, 2003).

The third category of reasons a person might offer in convincing others to consent to a particular practice is that of ‘normative-evaluative’ claims. Normatively referenced claims refer to “what behavior is proper, appropriate, and conventional; they can be articulated as ‘should claims’” that generate an inter-subjective recognition that “people should act in such and such ways at such and such times” (Carspecken, 1996, p. 83). These claims “impose on others by tacitly insisting that the other should conform to a certain convention” (p. 83). Understanding what normative claims shaped the care cultures provided me with the means to attend to the nexus of power and truth insofar that “[c]ultural power cannot be observed objectively but must be found within the normative-evaluative horizons of the culture being studied” (p. 145). Hence, I was interested in discerning whether a claim was consented to for strategic, material, or psycho-social reasons, or if “one would only consent to this norm or value because of the play of power” (p. 145). If a claim is not being consented to freely, it is either disputed (and care routines are (re)negotiated) or *imposed* through acts of intersubjective-power (such that care routines are enacted according to the claim of the superordinate). In such cases, subordinates’ resistance, however active or passive, will involve values, which by definition concern ideas about what is right, wrong, good, bad; “thus norms and values are distinct but internally connected” (p. 83) because values provide support for norms and, conversely, “disputes over norms will soon move into value arguments” (p. 83). Once resolved (or at least, after the dispute is settled), norms provide the conventions people need to communicate with each other (Carspecken, 1996). While norms take on a rule-like form when explicated (e.g., people should take turns during a social activity; we should assist people living with dementia maintain a certain level of physical

cleanliness), it is important to remember that norms are not rules; rather, norms are characteristic of a particular culture (Carspecken, 1996).

***(5) Fore- and back-grounded claims.***

The diagonal line depicts the relative fore- and back-groundedness of a validity



claim. (It is akin to a z-axis that gives the pragmatic horizon its depth). The phenomenological presumption here is that an “object takes on a distinctive form within perceptual experience only against a background horizon

... We only understand an idea against a horizon from which that idea is brought forth” (Carspecken, 1996, p. 103). Thus, any of the elements inside the pragmatic horizon can be re-cognized somewhere between an immediate foreground and a remote background. It is especially useful to locate validity claims on this fore-to-background continuum, for we “learn a lot about people and cultures when we are able to articulate, or reconstruct, frequently employed horizon backgrounds” (p. 121). I coded reconstructions as foregrounded or backgrounded objective claims, as foregrounded or backgrounded subjective claims, and as foregrounded or backgrounded normative claims. The sorting into claim types was a discreet exercise – with practice, I improved my skill (speed, certainty) in categorizing claims as objective, subjective, or normative – I populated the figurative triangle, so to speak. Conversely, claims are not so easily sorted into fore- and background categories, for claims sit on more of a continuous rather than discreetly differentiated continuum. For coding purposes, I dichotomized the claim as being either fore- or backgrounded, but in the full reconstructions and in writing up my findings, I



tried to be more discerning in qualitatively labeling a claim somewhere along a continuum from immediately foregrounded to remotely backgrounded.

### **Hermeneutic Reconstructive Analysis Applied to a Sample Data Strip**

To illustrate how meaning field reconstructions, pragmatic horizon analyses, and back- and fore-grounded validity reconstructions inform and complement one another, I provide here a full reconstruction of one strip of data. For this particular illustration, I have selected a strip of data from an interview with a full-time SCU PSW.

We met in the conference room adjacent to the SCU after her shift was over. The interview lasted 100 minutes, allowing us to cover several topics, including member-checking meaning field reconstructions. In describing one such occasion here, my intent is two-fold: (i) to describe a for-instance of how the member-checking was facilitated and unfolded in this study; and (ii) to ‘show and tell’ how hermeneutic reconstructive analysis works by applying the techniques described above within the context of the member-checked data.

#### **Context of member-checking query.**

Part way through the interview with this particular PSW, I raised the notion of ‘remaining seated.’ The PSW listened while in 200 or so words I paraphrased an excerpt from the stage one primary record (see the first two parts of section A in Table 4.5). As I spoke, she murmured “Mmhmmm” several times, and said “Yeah” or “Oh yeah” thrice. As I concluded sharing the original excerpt by mentioning that I had observed the PSW’s hand on a resident’s shoulder, I said to her, “So you’re nodding your head and, like I

wonder like, do you think that that PSW is getting that from [the RPN] and other...”--

She interjected: “That’s what we’re told to do.” I re-stated: “Keep them seated.” She then said,

Keep them seated. They're not to get up. They're not to stand. Not to switch seats even. And you know [a particular female resident] will get up and want to switch to another seat, but I just-- I hate having them sitting there all the time. I feel terrible. I don't like it. But that's [the RPN]'s rule, and [the RPN]'s my supervisor so I have to listen.

At this point then, I was already anticipating that my meaning field reconstruction was slightly off-base – while I had accurately surmised that fall prevention is indeed at play in PSWs’ practice of keeping residents seated, I had misattributed the practice to the PSWs when it seemed, at least from this member-check, that some PSWs do not condone the ‘stay seated’ practice. Nonetheless, I continued, moving from the original excerpt to my meaning field reconstruction (the third part of section A in Table 4.4). I started reading, saying *Sitting rather than moving or dancing is the PSW's preferred state for the residents*-- the member-checking PSW interjected:

It's not PSWs at all. Like you... you haven't been here in a while. [The other full-time PSW] has been ... after dinner when we bring them in the other room, putting on music, because we can't change anybody till 6. Sometimes we're out of the dining room by 20 to 6. What do we do, sit there for 20 minutes? She'll put music on and we'll dance with them you know. There's a couple of them that love to dance, and it entertains others ... they clap or they're—you can just see

them smiling and that's what makes it all worth it, right? It's not the PSWs. [OC: emphasis on not]. Stroke, stroke, stroke...

And with that, she mimicked stroking out that part of my meaning field reconstruction, which in hindsight, I see as an indication that at least with this PSW, the researcher-interviewee relationship had been more or less democratized: she, with perhaps a vested interest in speaking on behalf of her fellow PSWs, had felt empowered enough to right my wrong.

After thus acknowledging her correction, I continued with member-checking this particular meaning field reconstruction. Again, the PSW offered nods and utterances that seemed to convey agreement with my reconstructions (restless residents do not tend to stay seated ... sitting is a fall prevention strategy ... seating someone over and over can be exasperating), but when I reached the end, indicating that a PSW's exasperation can manifest as an altered tone of voice AND/OR as physical restraint, the PSW quickly added her own all-caps addition: ***AND [she says with emphasis], the residents get annoyed. They get frustrated with us – they don't want to be told sit down all the time, just as much as we don't want to tell them to sit down.*** Struck by her sense of understanding those to whom she provides care, it is this quote that I fully reconstruct here to illustrate what the products of a CQR analysis might be; each of Carspecken's (1996) three primary techniques of hermeneutic reconstructive analysis described above is illustrated below.

### **Initial meaning field reconstruction.**

Constantly seating people who live with dementia and who are feeling restless is exasperating AND that exasperation can manifest as an altered tone of voice OR as physical restraint AND/OR as an alteration in the caregiver–care recipient relationship AND the people living with dementia can sense the caregiver’s exasperation AND the exasperation triggers AND/OR exacerbates frustration AND/OR responsive behaviors. Moreover, the residents either tell caregivers AND/OR non-discursively convey their preference to not be seated, a preference PSWs cannot OR do not respect because they accommodate their supervisors’ preferences instead.

### **Pragmatic horizon analysis.**

(The constituents of the pragmatic horizon are underlined). The quote confirms that the phrase ‘sit down’ is indeed a semantic unit in this culture, that is, a relatively stable term that’s use confers a complex, multi-faceted practice. The roles implied to be at play here include:

- the fall preventer (a role everyone shares and values, but one that registered staff in particular enact with fervor because a fall triggers an immense amount of paper work, assessment, and monitoring that generally, registered staff wish to avoid);
- the friendly usher (a role imposed upon PSWs but shared also by registered staff when they engage in the act of persuading a client or resident to be seated);
- the compliant subordinate (the PSW who follows registered staff members’ instructions to enact a norm, i.e., seating residents or clients, a norm that one PSW said she ‘hates’ doing and that makes her feel ‘terrible’);

- the exasperated trigger (the caregiver whose frustration with trying to keep residents seated transfers to the residents, who, as an unintended consequence to an effort to prevent a fall, become agitated and perhaps responsive);
- the happy wanderer (the residents who appear content to pace or to move from one chair to the next, at least until s/he meets the exasperated trigger).

Temporal effects include a shared past and on-going exposure to fall prevention discourse and to the regular tracking of fall statistics. More immediately, there is a shared understanding that falls in this setting trigger a whole set of administrative and nursing processes, from documentation and notification of family to on-going monitoring. One PSW indicated that yes, *we should try to prevent falls, but they need to live too* – an apparent reference to valuing a decent quality of life in the relatively limited time that someone living with dementia has left. Power at play is evident in the normative power of the fall prevention discourse; in the coercive power of the public image sanctions that accompany high fall rates and that presumably serve to motivate and re-produce fall prevention discourse, right up to the moment of the RPN herself keeping someone seated and/or directing the PSW staff to do so too; in the seemingly finite amount of charm-as-power that is needed to seat residents who want to wander; and in the coercive power of physical restraint.

### **Validity reconstructions.**

In stating that the residents *get frustrated with us – they don't want to be told sit down all the time, just as much as we don't want to tell them to sit down*, the following claims seem particularly situated within this PSW's pragmatic horizon:

#### Possible Objective Claims:

##### Foregrounded:

- Constantly seating a person living with dementia can cause them to become frustrated.

##### Backgrounded:

- Residents resist or resent constantly being seated.

##### More backgrounded:

- Keeping someone seated all the time deprives him or her of the opportunity to live freely.

#### Possible Subjective Claims:

##### Foregrounded:

- Being engaged in 'please sit down' negotiations – for either party – is not a desired practice.

##### Backgrounded:

- I despise having to constantly seat residents.

##### More backgrounded:

- Among some staff, and perhaps especially registered staff, the prospect of fall follow-ups provides a motivation to keep residents seated.

- Other staff just wish residents could be allowed to walk / risk falling.

Possible Normative Claims:

Barely foregrounded:

- Our care practices should not have the effect of frustrating residents.

Backgrounded:

- Residents should be able to stand or pace as they please.
- We should do as instructed by our supervisor.

Examining this single instance of hermeneutic reconstructive analysis

(Carspecken, 1996) in reference to other parts of the primary and reconstructed records offers much in answer to the research questions that drive this study. To the question of *what social routines do caregivers engage in*, we see that seating restless residents or clients is a common activity. Moreover, to the question of *what knowledge is necessary to enact this practice*, we learn that caregivers have to know which residents are ‘a fall risk’ and/or are at risk of triggering other residents’ responsive behaviors; caregivers also have to know how to persuade residents or clients to be seated, be that through charm (*Come here and give your bones a rest – you’ve had such a busy day*), through coercion (*restraining a seated resident from standing*), through contractual power (*Sit there a minute and I’ll bring you a nice cold drink*), or through normative suggestion (*It’s time for a rest now*). These forms of persuasion each contribute to answering the research question that asks *how power is invoked in dementia care*. Further to this point, this analysis also acknowledges the normative power inherent in disciplinary hierarchies and suggests who seems well served by this power and who seems oppressed. In this instance,

the person with the highest status is served best – the registered nurse mitigates the risk that she will have to do fall follow-up – while the people with less status, the PSWs and the persons living with dementia, are denied the opportunity to act freely or in accordance with their values and preferences.

The analysis has also offered a sense of *the roles that are being enacted in this situation*, and the interaction among these roles illuminates how caregivers in this case are indeed quite attuned to residents' embodied selfhood – it is just that the disparate values along the caring/nursing hierarchy ultimately create an inequitable norm that negates what the subordinate knows. That these findings stemmed from my analysis of a democratized and dialogic member-check demonstrates a consistency with the values and epistemological tenets that underpin this study: what was an initial reconstruction of a field observation led to a more refined and critical understanding of the cultural nuances of dementia care knowledge that manifest as the practiced norm of keeping people with dementia seated.

### **Reflecting on Reconstructive Sense Making en route to Study Findings**

Further to the practice of member-checking, it cannot be said that all the reconstructions in this study's analysis were member-checked, nor were all the data presented as quotes in this thesis, nor the final write-up. That is, while I contend that the member-checking I did do enriched the data quality and analysis, and perhaps too my relationships with those participants, I concede that it was not possible to member-check all the interpretations. That which was member-checked was selected to mitigate interpretive error in high inference abstractions, and/or to clarify my sense-making of



what Hardcastle et al. (2006, p. 154) described as the “culturally pragmatic material from which actors construct their world.” Enabling research participants more opportunities to question researchers’ interpretations as well as dominant power structures should remain a priority of critical qualitative researchers (Vandenberg & Hall, 2011). Moreover and as a continuation of this program of research, these study participants should be afforded an opportunity to read and respond to the inscribed representation of their lived experiences.

And while the empirical illustration of CQR analysis in the previous section hopefully diminishes some of its idiosyncratic, Habermasian mystique (Smyth & Holmes, 2005; Holmes & Smyth, 2011), the analysis above also speaks to a concern Vandenberg and Hall (2011) raised: that critical qualitative researchers may unintentionally *reinforce* dominant and oppressive power structures, both in their interpretive analyses and in collecting and member-checking data. My reflections on my own performance as interviewer lead me to re-cognize that I was perhaps complicit in such unintentional reinforcement insofar that I led the interviewee when I asked if she thought the other PSW had been directed by the RPN to keep residents seated. I feel comforted in this case at least that my lead was based not on an naïve reproduction of hierarchical structures, but rather on stage one data wherein I had observed, frequently, the RPN herself asking residents to be seated: it was premised on an objectively-referenced claim. Moreover, I was encouraged by the member-checking interviewee’s good-hearted candidness in stroking out my apparent misinterpretation that attributed the ‘stay seated’ norm to the PSW; it did not seem as though she nor I were reinforcing oppressive structures.

On the other hand, the interviewee did make seem inevitable her own subordination by suggesting that *that’s [the RPN]’s rule, and [the RPN]’s my supervisor*

*so I have to listen*, thus giving credence to Vandenberg and Hall's (2011) concerns about *unintentional* reification of dominant structures in critical qualitative research studies that, ironically, aim to reveal and redress the power relations that condition oppression. Moreover, I cannot be certain that all member-checking participants were so inclined to openly contest my interpretations; perhaps perceived power differentials and/or a mismatch of interests precluded a mutual commitment to co-constructing interpretations. The espousal of reflexivity and reciprocity, and of addressing power and trust relationships (Hall & Callery, 2001; Vandenberg & Hall, 2011) in critical research practice nurtures a critical researcher's effort to not undermine him- or herself, and I see myself in this study as having enacted such reflexive practices: I strove in my fieldwork to foster trusting and supportive (reciprocal) relationships with study participants, and to share analytic and interpretive power with them by way of creating member-checking conditions that invited and encouraged participants' input (relationality). All that said, I still need(ed) to (and did) convey to the PSW that perhaps subordinate norms that 'feel terrible' to perform do not have to continue to exist; perhaps her supervisor's 'rule' can be re-negotiated? And while conveying such a notion and thereby contradicting a dominant discourse might put careers and lives at stake (Vandenberg & Hall, 2011), the critical epistemology and axiology (value base) of Carspecken's methodology beckons such critical reflection and *action* – such action is this project's praxis, which brings about the possibility of emancipation that Stewart and Usher (2007) felt CQR capable of producing.

Related to this notion of praxis is a rhetorical reflection on the assertion that CQR has yet to take its rhetorical turn in that the methodology has yet to sort out its technical

tricks of persuasion (Delamont et al., 2000). The reflection is premised on discernment between this study's analysis and its write-up. The *analysis* in this study focused on meaningful moments of relational care, moments where care providers felt, often with a kind of embodied, holistic recognition (Kincheloe & McLaren, 2005) an impetus to act, then negotiate with one another to address that impetus, to deliver and receive care. The *write up* that conveys the critical findings of this study aims to narrate the collective story (Richardson, 1997) of the study participants in such a way that they would not only recognize themselves, but such that they would *re-cognize* themselves, that is, see themselves anew and become critically aware of how often the negotiation of care norms is not premised on equal power relationships. Such re-cognition is intentionally fostered so as to catalyze change (Freire, 1972; Kincheloe & McLaren, 1994): if the collective narrative can become one of equalizing power and creating ethical conditions for care discourse, the inequities of dementia care may be mitigated. It is noteworthy how helpful this critical "pedagogy of praxis" (Freire, 1972; Gadotti, 1996) was in elevating my analysis from a groundcover of completed reconstructions to a set of generative themes that organize themselves around orienting the study participants to their own situation of injustice, to the conditions therein, and to the possibility of change. Carspecken (1996) says little about the thematic organization of findings, a shortcoming critics have not overlooked (Delamont et al., 2000); I found that in storying these study findings in terms of a collective story narrated by a liberating imagination (Richardson, 1997), I come closer to bringing about re-cognition of unjust situations and to compelling those who are a part of the knowledge culture of dementia care to create less oppressive conditions. Furthermore, this rhetorical turn helped to ground Carspecken's pragmatic but arguably

eclectic and sometimes “confusing” theoretical concepts (Holmes & Smyth, 2011): infusing the critical re-presentations of this culture of dementia care knowledge with praxis remains coherent with CQR’s critical epistemology, which itself binds together the concepts that collectively constitute hermeneutic reconstructive analysis.

## **Conclusion**

The intent of this article has been to provide an overview of Carspecken’s (1996) critical qualitative research methodology and to describe how it was deployed in the context of this study. The approach was founded upon a discerning appreciation of both the critical values and critical epistemological assumptions that underpin CQR, and marks an effort to understand where and how power relationships (among participants and between myself and participants) can be equalized. In detailing my conceptualization and experience of CQR data collection and analysis, I convey my contention that qualitative health researchers should extend the benefits CQR brings to the field of education (Carspecken, 2001) to the field of health care. Doing so can help researchers and study participants alike *re-cognize* and redress the social acts that constitute the injustices of dementia and health care.

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– Chapter Five –

**Re-cognizing Social Power in Reading and Interpreting**

**People with Dementia in Long-term Dementia Care**

**Abstract**

Set in two dementia care sites, this critical qualitative research study examined a key element of organizational context – its knowledge culture. Data were collected during ethnographic fieldwork in the specialized dementia care unit and in an affiliated, but separately staffed, adult day program of a non-profit long-term care organization in Ontario, Canada. This article focuses on the social power that inheres in the inter-subjective and socio-political relations that envelop reading and interpreting the responsive behaviors of persons with dementia. Data analysis entailed reconstructing the communicative and non-discursive meanings that were conveyed during moments when dementia care knowledge was created, resulting in three power-related themes. The *democratic co-construction of dementia knowledge* represents instances of knowledge creation when the reading and interpretation of a person with dementia occurred under what I considered to be ideal conditions of ethical discourse; the *unjust distortion and exclusion of dementia knowledge*, conversely, describes moments of knowledge creation where coercion and hierarchical exclusion ultimately de-centre one or more of the (many) people affected by the care knowledge (including staff, family members, and the person with dementia). Between these, a third theme of *normalized inclusiveness in knowledge generation* represents those efforts to democratize unjust conditions of dementia knowledge discourse. This article contributes both to the field of dementia care by showing how social and organizational power affect the reading of someone with

dementia, and to the field of knowledge translation and its concern for being able to understand and assess the culture and the context in which change strategies will be developed.

**Keywords:**

dementia, long-term care, context, culture, critical qualitative research, knowledge translation

A variety of demographic trends have contributed to an increased number and proportion of older adults living with dementia (Alzheimer Society of Canada, 2010; Hebert, Weuve, Scherr & Evans, 2013), many of whom manage comorbid diagnoses (Neyens et al., 2006; Tariot, Ogden, Cox, & Williams, 1999). Furthermore, a growing body of evidence describes the challenges long-term care home staff face in caring for people who, for instance, wander (Lucero, Hutchinson, Leger-Krall, & Wilson, 1993) or require substantial assistance with feeding (Van Ort & Phillips, 1992) or with toileting (Hutchinson, Leger-Krall, & Skodol Wilson, 1996). These challenges, among others, increase the potential for stress among long-term care home staff (Morgan, Semchuk, Stewart, & D'Arcy, 2002), particularly when the challenges manifest as verbal or physical assault (Gates, Fitzwater, Telintelo, Succop, & Sommers, 2002; Myers, Kriebel, Karasek, Punnett, & Wegman, 2005; Volicer, Van der Steen, & Frijters, 2009). Dementia is thus one of the main areas of knowledge where gaps have been identified in geriatric nursing, where the bulk of dementia care takes place (Larson, Chernoff, & Sweet-Holp, 2004; Anderson, Ammarell, Bailey, Colon-Emeric, Corazzini, Lillie et al., 2005), especially

with regards to the management of behavioral disturbances both in acute (Henderson, Winch, Holzhauser, de Vries, 2006) and in long-term care homes settings (Hsu, Moyle, Creedy, & Venturato, 2005; Draper, Low Withall, Vickland, & Ward, 2009).

In response to calls to support dementia care providers (Boström, Slaughter, Chojecki, & Estabrooks, 2012) and to better understand how organizational elements enhance or impede the processes of knowledge exchange (Berta, Teare, Gilbert, Ginsburg, Lemieux-Charles, Davis, et al., 2005; Bostrom et al., 2012; Moyle, 2010; Sullivan, Kessler, Le Clair, Stolee, & Berta, 2004), the aim of this study was to understand how the influence of social power manifests in the culture of dementia care knowledge. As the object of this inquiry, a/the ‘culture of dementia care knowledge’ is conceived as the ways in which long-term care residents, family members, and staff routinely create, share, and variably enact different forms of dementia care knowledge within a context of socio-political and –historical influence. Herein, discursive and non-discursive communicative actions relating to social integration and action coordination must be understood in terms that do justice to the constitutive nature of language, participants’ own perspectives, and the relationships between power and knowledge. This interest in how power and knowledge are interconnected follows Quinlan’s (2009) examination of how social and institutional forces shape the knowledge work of nurse practitioners and other health care providers in and across multi-disciplinary primary health care teams. Her study suggests that in the course of their collective clinical decision-making, “teams’ dialogical exchange facilitates the articulation of tacit knowledge and opens up the communicative space for the creation of new knowledge” (p. 625); one might presume, conversely, that teams’ dialogical exchanges might also

impede the articulation of tacit knowledge and perhaps close, rather than open, communicative space for the creation of new knowledge. The concern Quinlan raises is that in trying to understand an organization's culture of knowledge, not enough attention has been paid to the communicative elements of culture, nor to "the dialogical exchange that facilitates the articulation of tacit knowledge" (p. 626); knowledge translation researchers have overlooked "the relationship between knowledge and the social organization of power" (p. 626). This study addressed this concern by critically examining knowledge culture in dementia care.

### **The Context and Culture of Exchanging Dementia Care Knowledge**

A number of theoretically informed frameworks have been developed to help knowledge translation researchers and practitioners conceptualize their work (Estabrooks, Thompson, Lovely, & Hofmeyer, 2006), including the PARIHS framework (for Promoting Action on Research Implementation in Health Sciences) developed by Kitson and colleagues (Kitson, Harvey, & McCormack, 1998; Kitson, Rycroft-Malone, Harvey, McCormack, Seers, & Titchen, 2008). PARIHS stipulates that the successful implementation of knowledge into practice depends on three inter-related dimensions: organizational context, the nature of the evidence to be implemented, and the means by which change is facilitated. In 2008, Kitson *et al.* suggested that PARIHS be used in two stages – a diagnostic and an evaluative stage – such that facilitation strategies should be "shaped and molded" (p.2) once the strength of the evidence has been established and in the light of an assessment of context. The prominence of this interplay between context and evidence has since been extended to KT methodology in population health along

with a call for researchers and knowledge users to collaboratively engage in phases of knowledge creation, refinement, implementation, and evaluation (Kitson, Powell, Hoon, Newbury, Wilson, & Beilby, 2013; Powell, Kitson, Hoon, Newbury, Wilson, & Beilby, 2013).

Given the importance then of context, researchers have examined its myriad domains (Jacobson, Butterill, & Goering, 2003) and knowledge producing environments (Kitto, Sargeant, Reeves, & Silver, 2012), the means by which to assess social mechanisms (French, Thomas, Baker, Burton, Pennington, & Roddam, 2009) and individuals' interplay with evidence and context (Rycroft-Malone, Seers, Chandler, Hawkes, Crichton, Allen, et al., 2013) that facilitate knowledge exchange, and how internal and external contexts each has its own influence on the identification, interpretation, and application of evidence (Dobrow, Goel, Lemieux-Charles, & Black, 2006). Kitson et al. themselves define context as “the environment or setting in which the proposed change is to be implemented” (1998, p. 150), or as “the forces at work which give the physical environment a character and a feel” (p. 152). They sub-divide the dimension of context into three core elements – culture, leadership, and measurement – and note that an organization is highly amenable to change when its culture values people, is patient-centred, and, as a learning organization, includes continuing education (Kitson et al., 1998). Building on these PARIHS dimensions of context, the Alberta Context Tool (ACT – Estabrooks, Squires, Cummings, Birdsell, & Norton, 2009; Squires, Kong, Brooker, Mitchell, Sales & Estabrooks, 2009; Estabrooks, Squires, Hayduk, Cummings, & Norton, 2011) includes an assessment of culture premised on survey respondents indicating the extent to which they agree that: they receive

recognition from others; they have control over how they do their work; the organization strikes a balance between best practices and productivity; they are supported to undertake professional development; they work to provide what clients need; they are part of a supportive work group (C. Estabrooks, personal communication). These items are said to indicate “the way we do things” in a given organization or health care culture (Squires et al., 2009).

Quinlan’s (2009) work suggested that the operationalization of culture (and more broadly, context) might be expanded to bring more attention to social power and its relation to clinical decision-making and to knowledge translation. Moreover, further development of the construct of culture (as conceived in the ACT – Estabrooks et al., 2009; Squires et al., 2009) might consider what contributes to a lack of recognition from others, or to the absence of control over one’s work. How much control *should* one have in their own work, and how might this vary across disciplines and/or across different classes of nursing (e.g., registered compared with non-registered staff)? The purpose of this study then was to critically examine the knowledge culture in two dementia care sites: a specialized care unit (SCU) for residents living with advanced dementia in a long-term care home, and an affiliated adult day program (ADP) designed for clients with less-advanced dementia who were still living at home. In so doing, this study may contribute to re-conceptualizing and operationalizing “culture” and “context” in ways that consider the broader (potentially oppressive) social forces at play in constituting dementia care knowledge. Conceiving of advanced dementia care knowledge as knowing how to read and interpret a person with dementia and how to prevent and respond to responsive behaviors – often while assisting with activities of daily living – this article focuses on

the social power in the inter-subjective and socio-political relations that envelop *reading and interpreting the responsive behaviors of persons with dementia*.

## **Methodology**

‘Critical qualitative research’ (CQR) (Carspecken, 1996) shares with critical ethnography an aim to understand the routines and taken-for-granted values and assumptions that shape a particular culture (Manias & Street, 2001; Thomas, 1993), and aims to redress the social inequities and injustices that are (re)produced by both those in powerful social positions and by their subordinates (Kincheloe & McLaren, 2005). It was assumed in this CQR study that a given lifeworld (Habermas, 1985) – that is a particular cultural group and the system(s) in which it is embedded – is comprised of objective, subjective, and inter-subjective elements that intertwine to produce practical, social knowledge about what is true and what is right (Habermas, 2003). In this view, truth is not conceived of as Truth in a transcendent sense; rather, truth is instead conceived of in terms of its function, which is to generate unconditional acceptance of particular claims in meaningful moments of communicative action, moments that entail a speech act and non-discursively conveyed meanings. The primacy of inter-subjectivity in this worldview draws attention to communicative action and dialogue, and to discourse ethics by assessing whether or not cultural practices are arrived at fairly. By reconstructing such communicative acts in terms that explicate both foregrounded and backgrounded (implicit and/or non-discursive) claims, the objective, subjective, and normative claims of a particular culture can be examined so as to better appreciate how social power influences truth (Carspecken, 1996) about dementia care.

### ***Ethical Considerations***

Data were collected in a single, non-profit long-term care home and its affiliated adult day program located at the same site. The Research Ethics Board at Western University approved the study. Participants provided informed consent to be observed and/or to participate in audio-recorded interviews, and to allow use of anonymous data for analysis and dissemination. Because many of the clients and residents were living with advanced dementia, proxy decision-makers were included in the recruitment process for both groups. On days when data were collected, a notice was posted on the door(s) into the research site to inform anyone entering about the study, its aims, and who to contact for further information.

### ***Participant Recruitment***

Most staff members were recruited during the first four visits to the research site. A member of the senior leadership team helped facilitate this by asking staff members to gather at the beginning or end of their shift to consider enrolling. Subsequently, any non-enrolled staff members who were encountered were notified by the researcher about the study, offered a letter of information, and invited to participate. As indicated in Table 5.1, aside from the senior leadership team, staff participants represented a variety of disciplines. Participants included full- and part-time staff from day and evening shifts.

INSERT TABLE 5.1



To recruit residents and families from the SCU, registered nursing staff approached residents/families on my behalf; if they expressed interest, I subsequently met with them to provide the relevant information, and, where applicable, the appropriate consent form. As indicated in Table 5.2, the majority of SCU residents' primary dementia-related diagnoses were of the Alzheimer's type (16 of 32 residents); others' primary diagnoses included Pick's disease and vascular dementia; seven residents had been diagnosed with an unspecified dementia.

#### INSERT TABLE 5.2

In the ADP, clients and families were invited to participate by mail. Clients' powers of attorney received a letter of information, a consent form, and the researchers' contact information. The ADP clients had a distribution of diagnoses similar to the SCU residents, but were at an earlier stage of disease progression. Each day, clients were divided into high-, mid-, and low-level functioning groups, each with its own program space and recreational therapist. One to three personal support workers (PSWs) and one registered nursing staff provided interdisciplinary support to the clients and recreational therapists by assisting with ADL and other health care needs and by monitoring the clients when the recreational therapists were on break.

#### ***Data Collection***

Data were collected in three phases. The first phase entailed non-participant observation whereby I would make hand-written field notes in a journal, which were later

transcribed. Noting participants' routines and interactions as well as body language and other contextual information, observations were conducted primarily in the common areas of the SCU and in some instances within enrolled residents' rooms. In the ADP, observations were conducted in the three activity rooms and in two staff workrooms. Although the observations were largely non-participant in that I avoided asking any deep, penetrating questions, some interactions did occur, mostly in terms of seeking clarification about routine care practices, that is the care practices that staff and family members engaged in as well as patterns of inter-personal interactions among the participants. On eleven occasions, dialogic exchanges between care providers were audio-recorded with permission.

As data accumulated and in preparation for the subsequent interview phase, analysis of the observation data began with a focus on generating topics that addressed actions fundamentally related to dementia care knowledge. The intent of the interview phase was to invite participants to describe and explore topics related to dementia care with their own vocabulary, metaphors, and ideas. Thus, participants were invited to share their views on topics such as, *the notion of appropriateness in dementia care, coming to know new residents, flexibility in work rules and routines*. Additionally, a number of the phase two interviews included member-checking, wherein the participant would be invited to listen to or read and respond to the initial reconstruction of what seemed to be going on in a particular moment. Phase three, conducted after the interview data had been analyzed (approximately two months later), focused solely on member-checking the interpretations that arose during this most intensive phase of analysis: participants were invited to comment on an emergent sense of what dementia care entails, and on the

various forms and sources of knowledge that drive that care. This additional data collection and discussion resulted in refinements to how dementia care knowledge was conceived, and provided opportunities for participants to reflect on the salience of the findings with respect to their own work and caregiving roles.

In total, data collection spanned over nine months and included 45 field visits, 146 hours of observation spread across both day and evening shifts and across all weekdays, 11 informal and 24 formal audio-recorded interviews, 10 observed and audio-recorded team meetings, and one focus group with the senior leadership team composed of 12 individuals.

### ***Data Analysis***

Hermeneutic reconstructive analysis in CQR (Carspecken, 1996) seeks to delineate possible meanings, communicative structures that convey meaning, and the objective, subjective, and normative claims that people make in negotiating consent to particular routine practices. It is hermeneutic in that it focuses on the making and interpretation of meaning in the negotiations and events that participants engage in together; it is reconstructive in that it “reconstructs, into explicit discourse, cultural and subjective factors that are largely tacit in nature” (p. 93).

The first of the three elements of HRA conducted was initial meaning field reconstruction, in which tacit modes of meaning that underlie the recorded interactions were identified. These initial reconstructions are prone to error, hence the importance of engaging participants in member-checking; that said, it is presumed that over the course of data collection and as familiarity with the participants and the research sites grew, the

reconstructed meaning fields grew closer to what the actors themselves would report (Carspecken, 1996).

The second phase of Carspecken's (1996) analytic approach is called pragmatic horizon analysis. This entailed making note of how participants' meaning-making was affected by inter-subjectively shared awareness of prior events and of expectations of events to come. To complement this temporal contextualization of meaningful events, noted also were the participants' identity claims (e.g., *I'm a hard worker*) and social roles (e.g., *instructor, tone-setter*), the semantic units they used to convey meanings unique to their culture (e.g., *feeders, wanderers, behaviors, interventions*), and the kinds of power wielded in persuading others to consent or conform to particular care practices. This focus on power was central to the analysis of reading and interpreting a person with dementia, and entailed noting: (i) whether acts of reaching consensus were based on coercive, charming, contractual, or normative power, and (ii) whether or not the participants engaged in the negotiation of the care act were afforded the conditions of ethical discourse – that is, were they permitted to speak freely, to be heard, to consent to the care practice without coercion?

The third phase of hermeneutic reconstructive analysis is what Carspecken (1996) calls validity reconstruction. Herein, the explicit and implied claims being made during the negotiation of a care act were delineated into objective claims (about what multiple observers would agree *exists*), subjective claims (about how one feels), and normative claims (about what should happen, what is appropriate). Normative claims are value-laden: a participant's sense of what is good or bad or right or wrong manifest as conveying what should be. While each of these three kinds of claims can be made

explicit, each are also conveyed (in meaningful moments) in a more implied fashion, or what Carspecken refers to as backgrounded claims. Hints of sarcasm, a raised eyebrow, an implied contrast, or even a particular identity claim (as such 'n'such a person) can all convey in a very subtle fashion the objective, subjective, and normative claims that are being communicated in the negotiation of a care act. Hermeneutic reconstructive analysis *brings to the fore* these backgrounded claims so as to illuminate the social power at play within a particular culture.

### ***Rigour***

Strategies used to ensure a high quality of data collected included the use of multiple data collection methods (non-participant observation, informal interviews, planned in-depth topic-driven interviews, focus groups), prolonged immersion in the research site, a flexible observation schedule, and non-leading interview question (Carspecken, 1996). Analytic rigour was established by the use of negative case analysis, peer debriefing to check for biases or absences in the reconstructions, member-checks, and by comparing and contrasting strips of observation data with strips of interview data. Finally, to maintain its epistemological-methodological coherence (Holloway & Todres, 2003), researcher-participant interactions and the write up of the study findings presented the opportunity for participants to re-cognize their own collusion in the (re)production of any such social inequities and to feel compelled to redress their own situation (Freire, 1972), thus generating a kind of catalytic validity (Lather, 1986; Kincheloe & McLaren, 2005) that re-orient participants to the transformative possibilities within their own culture.

## **Findings**

Manifesting in inter-subjective and socio-political realms, knowing how to provide care for someone with advanced dementia is conceived in this study as knowing (i) how to read and interpret a person with dementia, often while assisting with activities of daily living (ADL), and (ii) how to prevent and respond to responsive behaviors. The findings reported here focus on the first of these two practices by examining how staff went about reading and interpreting a person with dementia on a day-to-day basis. As far as ADL care is concerned, this responsibility belonged largely to the PSWs who assisted with dressing, toileting, personal hygiene (including oral care and bathing), feeding, and the provision of meaningful social engagement and activities. Significant or total assistance was needed by most of the SCU residents and for some of the ADP clients. At various times, nursing, personal support, and recreation staff were all observed engaging clients/residents in 1:1 conversations, typically by invoking something from the client/resident's personal history or from current events as a topic of conversation. Recreation staff featured prominently in the provision of meaningful activities by facilitating large group activities such as exercises, games, and music programs, and by enabling clients/residents to engage in individual activities, such as arts and crafts, puzzles, and reading.

### **Reading and interpreting a person with dementia.**

Knowing how to read and interpret a person with advanced dementia was premised on both an inter-subjective realm wherein caregivers observed or engaged directly with a person with dementia and with one another, and a literal realm wherein

caregivers referred to existing electronic records about the care recipient. Moreover, such reading and interpretation was not only a caregiving behavior, or skill, that rested with the care provider; rather, it was enveloped in relational and socio-political aspects of the care settings, conceived here as three ‘power themes’: (i) the democratic co-construction of knowledge; (ii) the unjust distortion and exclusion of knowledge; and (iii) normalized inclusiveness in knowledge generation. Described first though are the realms in which these power themes manifest.

*Inter-subjective and digital realms.*

Caregivers needed to know how to read the person they were caring for not just in an objective, observant kind of way, but inter-subjectively, that is in approaching and interacting with a person with dementia. The staff in both the SCU and the ADP were observed, and later described, paying attention to body language, particularly as conveyed by one’s eyes. Here is one SCU registered practical nurse (RPN) describing how establishing eye contact with the residents at the beginning of each day is an important part of her care routine:

I do my paperwork in the morning, get myself set up for what has to happen during the day, get my cart ready and then I’m out on the floor, I start the morning medication pass, and that’s when I say good morning: I take a few extra minutes with them, I go eyeball to eyeball with them, and depending upon their response to me, that’s when I’ll check them a little bit cognitively, and I’ll say, You remember me? And you know, a lot of times, No, never seen your face before, and some of them look at me and say, Yeah, I remember. They never remember

my name. Without my nametag, they wouldn't remember. But I think whether it's my routine, my voice, or being here full-time, I have a good relationship with all of them. But I also work at that relationship from day one when they come to us. I'm a pretty old-fashioned kind of nurse.

In the presence of impaired verbal communication, the body's capacity to communicate one's emotional status (mood, anxiety) was fundamental to a person with dementia's participation in any such inter-subjective interaction. Being attuned to this communicative capacity helped the care provider understand the client/resident's readiness to accept care, and to gauge whether or not the client/resident could comfortably and safely interact with others and/or engage in the recreation programs being offered. This also entailed appreciating daily, and perhaps expected, fluctuations in one's mood and level of engagement with others (often attributed to sundowning – the period at the end of the day when clients/residents often experienced heightened anxiety). Furthermore, knowing how to read a person with dementia's emotional status and cognitive skill level was important in terms of ongoing assessment of disease progression or of intervention/treatment success. As such, care providers (and full-time registered nursing staff in particular) typically sought to establish a baseline of a person's psychosocial functioning such that deviations from that baseline – *She's a little off today* – could be taken as an indication of a need to investigate more thoroughly, and possibly to revise the client/resident's care plan.

Indeed, a client or resident's care plan was an additional and vital source of information for (some) care providers in reading a person with dementia. The electronic



documentation of one's psycho-social functioning and medical and social history, often contributed to by family members during initial admission assessments, helped staff care providers prepare for and further contextualize their own inter-subjective experiences with a given client or resident. Staff working in the ADP frequently interacted with clients' electronic records by both reviewing and adding chart notes, and the recreational therapists in particular often reviewed clients' records to reacquaint themselves with the family and social history of the clients attending the program on that particular day. One ADP recreational therapist explained,

I love charts. I love knowing about the person because I feel I can give them way more – I'm kind of, not obsessed, but to me, it's a really important part. I feel like I could be their friend and get to know them if I know anything about them. If I know – if they were a sailor. If they were, like anything. Anything I can have about them ... just because they're low functioning doesn't mean I can't get anything out of them. So if I have any little– or if I'm doing a program and I know they have a dog, you know, 'You have a big dog.' You know? If I can know some of that information, then all of a sudden they'll wake up and they'll actually participate for me. Now I can't know everything about everybody, but I feel the more I get to know, the more I can get from them and the more pleasure I get from my job making them happy too. So that's kind of my thing.

Not all staff had equal opportunity to access and read this electronic information, however. In both the SCU and the ADP, PSWs rarely accessed these records, thus limiting their reading of residents/clients to an inter-subjective realm. That said, the

PSWs in both sites contributed significantly, albeit indirectly, to the addition of new information to electronic records, as evidenced by the mantra *always tell the registered*, which is to say, whenever a PSW recognized a change in a client/resident's behavior or mood (or, of course, health care needs), s/he was expected to let the registered nursing staff know so that the change could be investigated, monitored, and/or documented. At least in an inter-subjective sense, the reading and interpretation of a person with dementia was something that all dementia care providers needed to know how to do. As described next, the social power that enveloped this reading and interpretation could, at times, render the dialogic exchanges of this knowledge as democratic and inclusive.

### **Power theme 1: Democratic co-construction of knowledge**

This theme is exemplified by the reconstruction of an interactive sequence among ADP recreational therapists making decisions about which clients should attend which afternoon program; see Appendix 5.1: *Do you know who gets along?* The reconstructed validity claims from this interaction include backgrounded objective claims that a client's mood can be observed and that that knowledge contributes to a shared decision about which program a client might attend (the 'sorting' of clients into afternoon programs always involved at least two recreational therapists, and sometimes as many as five). This interaction contributed to the recreational therapists constructing a shared sense of who gets along and who does not. These objective claims were supported by the subjectively held inclination to problem solve as well as backgrounded normative claims that this decision-making should be democratically shared among the recreational therapists, and that this decision-making should take into consideration past reading and interpretations

of the person with dementia. Care providers were free to share their own perspective and experience, and together, they co-constructed new knowledge about the person with dementia: others' opinions were solicited; pros, cons, and alternatives were considered; and the proposed plan was consented to without any sign of coercion. The social dynamic among these recreational therapists thus (re)produced a culture of democratic co-construction of knowledge.

This democratic co-construction was evidenced by roles the recreational therapists enacted, including: *shared decision-makers* – the three recreational therapists considered together which activity clients should attend that day and which clients could/should be seated together or introduced; *strategic match-makers* – the pairing of particular clients yielded opportunities for socialization and mitigated pacing; *strategic risk managers* – the recreational therapists strategized together about how to mitigate the risks that inhere in constant pacing. In these roles, the disciplinary practice of being a recreational therapist and a dementia care provider was democratized insofar that each of these roles entailed co-constructions of how to read the clients and interpret their socialization needs, the risk(s) they might pose to themselves or others, and/or the activities they are likely to enjoy. Moreover, two potential barriers to such democratization were absent in this scenario: the care was not being negotiated among two different disciplines, nor among providers with clearly demarcated hierarchical placement; that is, these roles were taking place among providers with arguably equal power and within a single discipline. This should not be taken though as requisite for democratic co-construction of dementia care knowledge; the following example of this power theme features an inter-disciplinary interaction.

As a second illustration of *democratic co-construction of knowledge*, consider the appended scenario wherein a RPN from the SCU invited a recreational therapist to complete a standardized assessment of depression for a particular female resident – see Appendix 5.2: *You spend more time with her than I do*. At the beginning of this interaction, the RPN acknowledged that she had invited the recreational therapist to complete this assessment with her because she “wanted to make sure it was fair” to this female resident that the RPN was “not over judging or under judging her.” This acknowledgment might be taken as an implied normative claim about what such assessments should entail, i.e. that the assessment should benefit from multiple perspectives, and/or that those with the most experience caring for the resident be involved in making the assessment. Thus, because the recreational therapist spends more time with the female resident than does the RPN, the recreational therapist should have input into the scoring of the resident’s depression. Concurrently, further backgrounded normative claims stipulated that nursing and recreation staff should collaborate to co-construct an assessment of a resident, and that standardized assessment tools such as this depression scale should contribute to the establishment of knowledge constructions.

This theme of *democratic co-construction of knowledge* was present in both the ADP and the SCU, and manifested both within and across disciplines. The theme might be said to represent the ideal conditions for generating dementia care knowledge in that the ideal conditions for ethical discourse (Habermas, 2003) were met: in co-constructing dementia care knowledge, participants were free to share their own views and could contribute to the negotiation of practice norms without feeling coerced. The normative power at play in such interactions (re)produced collaboration and shared decision-

making, which in turn served well the actors involved – their own psychological-social interests appeared to be met insofar that their professional identities were validated as astute, competent, and valued, and they were afforded collectively-conceived strategic insights into how best to care for the person with dementia. Arguably absent from these democratic and co-constructive negotiations, however, is the person with dementia who is subjected to the providers' care decisions, and/or their family members. In this study, this absence reflected a backgrounded, implied care norm that suggests that a person with advanced dementia often cannot communicate verbally his or her care preferences, and so providers must themselves take the position of their clients/residents in the decision-making processes and continue to be aware of the impact of their decisions. Family members were sometimes involved in this process when new dilemmas arose (e.g., a newly observed or difficult to manage responsive behavior; a change in health status), but by design, both the ADP and the SCU offered family members respite from this day-to-day decision-making – family members did not attend or participate in any ADP activities, and only a few were regular visitors to the SCU. Thus and in the absence of family members, a feature of this theme is the shared effort of the staff care team to validate the clients/residents – the providers all seem to be serving the client/residents' best interests: which program would they enjoy the most? Who would be good to pair together for a chance to socialize? Is an adjustment to their prescribed medications required? This benevolence is characteristic of *democratic co-construction of knowledge*, and contributes to the ideal conditions for reading a person with dementia. This theme stands in contrast to the second theme of power-laden reading and interpretation, *coercive distortion and exclusion of knowledge*, which is described next.

## **Power theme 2: Unjust distortion and exclusion of knowledge**

The theme of *unjust distortion and exclusion of knowledge* is explored in relation to an exemplar reconstruction that features a PSW's encounter with a female resident whom she was about to help bathe – see Appendix 5.3: *Normally I would have left her, but down here*. Charged with the responsibility of assisting a female resident with a bath, and despite having sensed agitation *and* despite the resident's stated preference to not have a bath, the PSW was arguably overpowered by the organizational norm to complete the care task anyway, and, in doing so, she herself was harmed in a physical altercation with the female resident. (She was scratched on the arm). In contrast to the normative power that (re)produced democratic knowledge creation in the previous theme, this theme is characterized by coercive power that (re)produced practices that contradicted individual providers' care values and knowledge (as well as the purported organization values). The coercive power is evidenced by the PSW's backgrounded indication that she had internalized an expectation to do the bath, (almost) no matter what; if she did not do the bath, she presumably had to face her colleagues, supervisors, and/or the resident's family members and explain that she could not entice or persuade the resident to take her bath. This would also have the effect of putting into motion a need to reorganize the week's bath schedule. Thus, it seems, the PSW was highly motivated to complete the task and to avoid the psycho-social sanctions she would otherwise face, even if it meant encountering, creating, and/or working through the resident's agitation/aggression. Such motivation essentially trumps her own intuitive reading of the resident as well as the resident's own stated preference to not have a bath. Consequently, we can see that the female resident invoked her own kind of coercive power in being physically aggressive,

as if to convey, *If you do this to me against my will, the sanction you will face will be aggressive resistance.* Study data showed, however, that *when care had to be done*, staff overcame such resistance by way of persistence, insistence, teamwork, and physical strength, all in service of the internalized practice norm of task completion that contests and distorts care providers' initial and intuitive sense of what they read in a person with dementia.

In terms of whom this distortion of knowledge serves and impacts, the organization as a whole benefited insofar that it could report to government inspectors and/or family that adequate care had been provided, and indeed, in asserting her power over the resident, the PSW avoided having to account for an uncompleted task. On the other hand, as the less powerful actors affected in this scenario, the PSW and the resident experienced unethical conditions of discourse insofar that they consented to the care act only under subtle and backgrounded coercion: the PSW had to complete the task or face psycho-social and identity sanctions from her peers and/or supervisors, while the resident acquiesced to the persistent persuasion of a care provider determined to complete her task. A consequence of this unjust distortion then *is* the exclusion of both the subordinate care provider's knowledge and the resident's care preferences.

As demonstrated by Appendix 5.4: *I don't believe that*, coercive distortion and exclusion were at times further (re)produced by hierarchical differences between registered and non-registered staff. Typical of PSWs' reports that their knowledge of residents was ignored and/or deemed illegitimate by some registered nursing staff, the reconstruction of this quote indicated that the subjective state of those who experienced such subordination was one of feeling offended and devalued. Such a scenario typically

included the adoption of the following roles: the PSW *as a want-to-be knowledge sharer*; the one kind of registered staff *who solicits and values PSWs' knowledge*; the other kind of registered nursing staff (featured in this appended reconstruction) *who reproduces a hierarchical scheme that invalidates the PSW's knowledge*, resulting in *the demoralized PSW who feels there is nothing she can do* about the way she is treated. Registered staff enacting the exclusionary role and who were recently unfamiliar with the SCU residents were prone to misjudge residents' psycho-social functioning, a problem that was compounded when that registered staff neither solicited nor valued the knowledge of the full-time PSW with whom she was working. In other words, a part-time RPNs' ability to judge residents' wellbeing and functioning would be enhanced were s/he not to exclude sub-ordinates' knowledge.

In such cases of exclusion, social power can be seen to manifest primarily as two contesting forms of normative power: on one hand, the presumably desirable norm is that knowledge of residents is exchanged freely and that all staff on any given shift, regardless of their disciplinary status, function as a team. On the other hand, and seemingly more problematic, the reification among (some) registered staff of the normative subordination of PSWs ultimately manifests as coercive power insofar that the PSW experiences her own psycho-social sanction: she is discredited and left feeling devalued. This exclusion amounted to an unethical condition for discourse (Habermas, 2003), and serves (along with the bath scenario above) as a second example of injustice and oppression within the culture of dementia care knowledge.

The two power themes presented so far essentially reflect polar opposites in terms of their conditions for ethical discourse (Habermas, 2003). Democratic ideals of



inclusiveness and a lack of coercion characterize theme one, whereas theme two is characterized by exclusion and by the presence of coercive power such that those affected by the care knowledge being generated are either not included in the negotiation, and/or they are somehow coerced into agreeing and complying with the care decision. The third theme related to reading a person with dementia falls somewhere between these first two extremes.

**Power theme 3: Normalizing inclusiveness in generating knowledge.**

In *normalizing inclusiveness in generating knowledge*, those who are affected by the care decisions *are* included in the care planning process, but the conditions surrounding their participation border on being coercive; only when re-framed as strong leadership does coercive power become normalizing power. Two reconstructions, one from each site, illustrate this theme. The reconstruction in Appendix 5.5: *Nursing is only as holistic as you make it*, features an ADP RN chairing a short, daily, midday meeting with the PSWs. Sitting together around one large table, an RN would bring to the meeting a binder into which she would write notes to later be transcribed, and with pen poised, would often commence the meeting by wielding normative-authoritative power, saying to the PSWs, “Okay ladies. Talk to me. What’cha got?” Any silence that followed soon felt unbearably loud, and typically, the PSWs would report on who did or did not eat, or on who was resisting care, or on emotional status and behavioral manifestations of their dementia. Probing about trends, the RN would seek clarification about whether the PSWs’ observations were new, recent, or a continuing trend, and about what strategies the PSWs and the team might employ to help meet the clients’ care needs. In a

subsequent interview with the RN, she highlighted the significance of these daily meetings, noting the opportunity to “not just get stuck in the tasks” and to instead “see them [the clients] as a person;” these meetings provided the opportunity to PSWs and the RN alike to “share the knowledge of who [the clients] are.”

In contrast to the reconstructed *I don't believe that* quote (in Appendix 5.4) where the hierarchical nature of the registered – non-registered staff relationship is reproduced in a divisive fashion, here the norm is one of bridging the PSWs' knowledge with the RN's in an inclusive fashion. A significant role that the RN adopts in this context is that of 'educator-as-facilitator of knowledge exchange.' Inherent in this role is the RN's identity claim of herself being a holistic nurse as well as a team leader capable of empowering her subordinates. Social power can again be seen to manifest primarily as (*becoming*) normative: the attainment of this more democratic and inclusive norm is enabled through the reproduction of normative authority that creates an expectation among the PSWs that they will participate in the meetings. This normative power is aided by the power of charm: rather than foster participation in a coercive fashion, it was clear from the RN's reflections that she strove to make the PSWs feel valued, saying in another segment of the same interview, “I have to be very careful to not make [any of the PSWs] feel that I think what [one person] thinks is more important – it's just as important as what everybody else is saying; if they don't think they're being heard, they're not going to talk to me, so they have to know that they're being heard.” The RN's apparent sensitivity to group dynamics indicates that she understood that if her sub-ordinates do not feel equally valued, the more historically (re)produced norm of registered—non-registered divisiveness will take hold, and even then, that coercive edge of her

authoritative power would not likely bring about the desired quality of dialogic knowledge exchange. Hence, her efforts normalized inclusiveness, not just with one but with all the PSWs with whom she worked.

Normalizing inclusiveness in generating dementia knowledge also occurred in the SCU setting. In Appendix 5.6: *We're working on developing a relationship with him*, the enactment of inclusiveness bridged both the disciplinary/expertise gap between a RPN and a physician, as well as the relational and communicative gap between a resident and the staff. The reconstruction features a RPN reviewing with a physician a list of residents' names and care needs; the RPN raised concerns about one particular male client and her efforts to establish a rapport with him. Ultimately, the RPN persuaded the physician to increase the daily dosage of the resident's anti-depressant. The physical absence of the resident in question in this passage illustrates how, in the culture of dementia care knowledge, the social power in clinical decision-making lies not with the resident but with professional caregivers. Deemed as a consequence of impaired verbal communication and cognitive functioning, this practice norm seems both obvious and taken-for-granted. The reconstructive analysis though brings to the fore important claims that the RPN backgrounded in her exchange with the physician: the objective claim that maintaining an established relationship with a resident – especially a newly admitted resident – provides a sense of the resident's care needs; the subjective claim that the RPN feels frustrated and concerned that she could not (yet) relate to this particular man; and the normative claim that physicians should consider seriously the judgments of the registered nursing staff. In the clinical decision-making interaction with the physician,

these claims combined to enable the RPN to speak on behalf of and advocate for the resident.

The reconstruction thus illustrates how important it is to a physician that the nurses are able to read and to contextualize the residents' dementia and wellbeing. Thus, even though the normative authoritative hierarchy was maintained between the RPN and the physician (the physician maintained decision-making authority), at the moment when the RPN's knowledge of the resident was articulated, the physician read the resident through the eyes of the RPN; the conditions of dialogic exchange fostered inclusiveness, approximating the democratic co-construction of knowledge described in theme one. What discerns this *normalized inclusion* from that *democratic co-construction of knowledge*, however, is that continued existence, however backgrounded, of a hierarchical divide. In the examples provided in theme one (*Do you know who gets along?* and, *You spend more time with her than I do*) – in each of these cases, no significant hierarchical difference separated the recreational therapists from one another or from the RPN. In these last two examples though, the RPN and the physician respectively maintain and re-produce their authoritative stance *while* normalizing inclusiveness.

*Normalizing inclusiveness in generating knowledge* is a theme that fits between the *democratic co-construction of knowledge* and the *unjust distortion and exclusion of knowledge* as an alternative means by which to generate shared knowledge about the people for whom care is being provided. Indeed, *normalizing inclusiveness* might be taken as a strategy for providers finding themselves *in distorting and exclusionary* conditions and wanting to move toward *democratic co-construction of knowledge*. The

discussion that follows considers how these power-laden themes regarding the reading and interpretation of a person with dementia relate to one another.

## **Discussion**

Because people with dementia in this study frequently experienced an impaired ability to communicate verbally, and because of the cognitive impairment in dementia, reading and interpreting a person with dementia required one to be attuned to the person's non-verbal communicative capacity, be that by eye contact and body language, by the mood and emotional status the person conveyed, and/or by the electronic record of his/her social and medical history. As reading and interpreting a person with dementia occurred, social and organizational powers variably took form as normative, coercive, and charming power, often in a complementary way, to shape the dialogic conditions that manifested at the moment that the reading of a person with dementia became shared knowledge. The findings presented in this article discerned three power themes that enveloped and conditioned the practice of reading and interpreting a person with dementia: (i) the democratic co-construction of knowledge; (ii) the unjust distortion and exclusion of knowledge; and (iii) normalized inclusiveness in knowledge generation. These findings are relevant both to anyone living or working in long-term dementia care who is affected by care planning, and to knowledge translation (KT) scholars and practitioners who appreciate that as a part of context, the knowledge culture being studied and/or targeted (for a KT intervention) needs to be understood in terms that make clear the influence of social power among and between the culture's constituents and the intervening knowledge translators. Accordingly, the ensuing discussion invites

consideration of how these findings contribute to the existing literature pertaining to attunement, power in dialogic exchange, and to assessing culture as part of context.

### **Attunement.**

Based on reconstructive analysis (Carspecken, 1996), these findings have shown that when knowledge of one's life history is assembled together with embodied, intersubjective recognition, caregivers read and breathe life into what Kontos called *embodied selfhood*: "a complex interrelationship between primordial and sociocultural characteristics of the body" (2005, p. 559). Ultimately, being so attuned to the person being cared for demonstrated that the body *is* a site of knowledge production (Kontos & Naglie, 2009). It was also evident that a subjective state of inquisitiveness flourished most when the ideal conditions of knowledge creation were in place – the democratic co-construction of knowledge was characterized by inclusiveness and by the absence of coercion, and engendered a more holistic reading of the person with dementia so as to nurture personhood in a way that looks beyond the disease (Dupuis, Wiersma, Loiselle, 2012; Kitwood, 1997; Kontos, 2005; Touhy, 2004). Thus, the findings reported here resonate with previous research that found that caregivers achieve understanding of care needs by way of affect attunement, inductive puzzle solving, and having knowledge of residents' life histories (Haggstrom, Jansson & Norberg, 1998; Anderson et al., 2005) such that caregivers 'figure it out in the moment' (Janes, Sidani, Cott & Rappolt, 2008).

Importantly, these findings extend our understanding of the social power relations that envelop this 'figuring out,' this reading and interpretation. For instance and as in power theme two, when social power manifests unjustly as the distortion and exclusion of

knowledge – brought about either by existing hierarchical rifts among staff members (such as those described by Jervis, 2002) and/or by normative organizational powers that subtly displace caregivers' intuitive sense of clients'/residents' care needs (such as those described by Kontos et al., 2010) – the inquisitive, solution-oriented character of a caregiver is replaced by subjective states of feeling offended and devalued. Rather than discussing what might have contributed to a resident's agitation or aggressive behavior, the PSW facing a divisive registered nursing staff member instead turned her attention to her own exclusion and subsequent frustration. If a caregiver's subjective experience is dominated by such diminished emotions, if the psychosocial interests of the caregiver are threatened by the social power being wielded by others, space for compassionate curiosity and client- or resident-focused care cannot flourish; instead, caregivers' actions begin to be in service of their own threatened interests rather than in service of their client or resident.

These study findings also extend our understanding of how a care team can optimize its collective attunement. While such normalized inclusiveness was maintained within hierarchical relationships, the efforts by those in higher positions of power to solicit and value their sub-ordinate's knowledge and experience reflected an empowering dynamic similar to what Rycroft-Malone (2004) and colleagues (Kitson et al., 1998, 2008) see as qualities of leadership. As such, one of the benefits derived from normalized inclusiveness is that multiple perspectives contribute to a shared sense of being better attuned to each person with dementia.

This study contributes an understanding that social power plays a significant role in the production of dementia knowledge, and that normative and coercive power

especially mix at organizational and individual practice levels to enhance or impede quality care. This then begs for dementia caregivers to not only be attuned to the people they help care for, but also to be attuned to power in dialogic exchange.

### **Power in dialogic exchange.**

Of central importance in this study's analysis has been the dialogic conditions at the moment when a single caregiver's observation becomes shared knowledge, or at the moment when the privately-known preference of the person with dementia becomes known to the caregiver. Quinlan (2009) found in her examination of collective decision-making among nurse practitioners in primary care settings that although tacit knowledge is difficult to express, "it is precisely in its conversion into explicit knowledge through articulation that new knowledge is created" (p. 626). For Quinlan, tacit knowledge was conceived of as knowledge that is taken-for-granted, and like Nonaka and Takeuchi (1995), Quinlan believes that "discussion is an effective mechanism for the articulation of taken-for-granted, tacit knowledge" (p. 626).

This study's findings are similar, but rather than limit the definition of knowledge creation to the conversion of tacit knowledge, knowledge creation here included also the articulation of privately-held observations and preferences. At the moment of articulation, the observation or preference becomes meaningful in an inter-subjective sense (Carspecken, 1996; Habermas, 2003), and the dialoging participants either have already, or begin to work toward, a shared understanding of what should be done about this newly shared and now co-constructed knowledge. If there exists no shared understanding of what should be done, the participants explicitly invoke and otherwise convey subjective



and objective claims in persuading the others to consent to his or her preferred way forward. These negotiations entail both subtle and obvious exercises of power, and as long as everyone affected by the negotiation is included in the dialogue, and as long as no one is coerced into consenting to the final outcome, the negotiation meets the ideal conditions for ethical discourse (Habermas, 2003). These power-laden criteria – of inclusion and the lack of coercion – are what differentiate the three themes presented in these findings, demarcating the conditions under which dialogic knowledge creation occurs. What is helpful then is to consider how normative, coercive, and even charming power shapes the dialogic exchanges that create knowledge among dementia caregivers.

Charming, normative, and coercive power can each contribute to both ethical and unethical conditions of discourse. Normative power, for instance, can (re)produce exclusion, such as the case when the registered nurse negated and devalued a PSW's articulation of knowledge. This confirms and helps explain the assertion made by Kontos, Miller and Mitchell (2010) that information-sharing practices are often absent in long-term care homes, and illustrates what most people probably think of when they read of organizational and institutional dynamics that manifest in interpersonal, yet often hierarchical, relationships (Beard, 2008). In these divisive encounters, normative power often colludes with coercive power to (re)produce the invalidation and devaluing of others and/or their knowledge. Moreover, PSWs sometimes contributed themselves to the reification of this divisive norm by maintaining a belief that such conditions were inevitable and unchangeable. But normative power can also foster inclusiveness, as when the RPN shared with the physician her reading of a resident. In this case, normative and charming power complemented one another in the interaction to enable the sub-ordinate

(RPN) to enact her valued role as nurse and to enable the physician to have access to her observations-now-turned-knowledge. It is not that hierarchy or sub-ordination are themselves problematic – when a hierarchical relationship fosters and maintains inclusiveness and the freedom to share one’s input and questions, and when the relationship is free of coercion, both the super- and the sub-ordinate can thrive by having psycho-social and strategic goals met. The RPN was highly valued, her roles and identity claims validated, and, strategically, she was afforded the opportunity to persuade the physician to adjust the care plan of a particular resident for whom she felt concern. Similarly, the physician was valued for his authority and ability to prescribe – his role was validated – and strategically, he was able to care for the resident without having exerted much time or effort; he was instead able to rely on his relationship with and the judgment of the RPN.

This notion of validating identity claims and having a strategic purpose supports the findings recently reported by Conklin (2009), who suggested that long-term care staff members engage in meaning-making processes that create a sense of coherence and purpose while allowing for the construction of individual and group identities; the findings presented here show how social power is implicated in this creation of coherence, purpose, and identity. Given that people generally use power for material, strategic, or psycho-social interests (Carspecken, 1996, p. 143), it is plausible to suggest from these findings that divisive and exclusionary knowledge creation practices stem from positions of power that serve the super-ordinate’s own psycho-social interests (e.g., if their ego thrived on the control of others and/or the reinforcement of a higher social standing) and/or strategic interests (e.g., if they were not inclined or able to find time to

acknowledge, investigate, and/or document newly created knowledge about a particular person with dementia). Likewise, it is equally plausible that in more inclusive and democratic conditions, the co-constructors of the new dementia care knowledge serve their shared strategic interests by advancing their collective understanding of a client or resident and by subsequently revising their care plan. In a care culture that does not de-centre the person with dementia, such strategic advancements presumably serve the client/resident's interests as well, not just the providers'. Thus, the ways in which one wields social power might provide an indication of which of their own interests they are serving.

Conklin (2009) also suggested that meaning-making among long-term care providers serves to create and maintain the competence needed to complete tasks. The findings presented here extend and further delineate this idea by showing that being competent does not always equate to providing person-centred care. On one hand, democratic and inclusive conditions for knowledge creation (such as when the RPN worked through an assessment of depression with a recreational therapist) might indeed be construed as a scenario where the competence of both care providers was enhanced to subsequently benefit the resident. On the other hand, the development of competence to bathe a resident was fueled by coercive expectations that matched neither the provider's own values nor the resident's stated preferences – *but the competent PSW gets the bath done anyway*. In this case, the creation of task competence is in service of the organizational culture rather than the person with dementia, and the person with dementia is de-centred as cultural norms for efficiency and routine override the espousal of person-centred values. As a response to the call made by Kontos *et al.* (2009) to examine the

occupational identities of PSWs (and perhaps all LTC workers), this analysis shows that social power manifests at the precise moments when occupational identities are (re)formed – evidenced by the power-laden discourses that condition competence.

A final point of discussion regarding power in dialogic exchange points to the significance of those formal mechanisms that create opportunities for knowledge creation and sharing. Citing evidence that PSWs do indeed have the knowledge and interpretive abilities (Kontos & Naglie, 2009; Anderson, Wendler, & Congdon, 1998) to influence registered nurses (Anderson et al., 2005), Kontos *et al.* (2010) advocate that PSWs be provided with a formal mechanism to enact a role of interprofessional knowledge broker. Herein, *interprofessional* means to *bridge* PSWs' knowledge of the clients and residents they care for with the knowledge of registered nursing staff. As much as the conditioning of professional identities and competence occurs in informal and sometimes in invisible situations, this study also showed how social power might manifest within formal mechanisms (such as the daily *Talk to me* meetings that the registered nursing staff conducted with PSWs in the adult day program). Although fueled by a kind of normative power that borders on coercive power, these daily nursing-PSW check-ins, scheduled for a particular time and always following a similar format, seem to approximate what Kontos and others seem to envision, especially as coercion dissipates and is replaced by a normative power that both the nursing and personal support staff members (re)produce. It should be noted though that despite caring for similar client/resident populations, the SCU did not have a similar mechanism – these formalized check-ins were a part of the ADP practice only. This difference was attributed primarily to human resources (a system-level norm) – the SCU residents would be left unattended or with just one

recreational therapist if all the nursing staff met at once. That is not to say the SCU was void of communication: reports between shifts allowed registered staff to share updates on the residents' well being, and the RN or RPN would then pass on pertinent information to the PSWs, but often in a much more fluid and unstructured way, sometimes even as the PSW was walking away, about to begin his or her duties. In contrast, the sit-down check-in meetings in the ADP were focused, void of distractions, and offered a daily opportunity to re-frame task competence as more holistic care, as person-centred care.

### **Implications**

This critical examination of how different forms of social power envelop the reading and interpretation of a person with dementia in long-term care and adult day care settings forms a response to calls to better understand how organizational elements enhance or impede the processes of knowledge exchange (Berta et al., 2005; Bostrom et al., 2012; Moyle, 2010; Sullivan et al., 2004). Relevant to practice, education, and policy, the following critical reflections are intended to spur critical reflection about dementia care practices for those living or working in similar organizations.

First, providers and educators should be encouraged to (continue to) practice enacting the notion of attunement – that is, reading and interpreting the embodied, primordial, socio-cultural (Kontos, 2005) and familial elements of a person's communicative capacity *as well as* remaining aware of how one's own affect (tone, body language, pace of interaction) influences a person with dementia. A second insight to leverage is re-cognition that among those caring for a particular person with dementia,

the knowledge they gain from experience and from being so well attuned needs to be shared and exchanged such that other care givers can benefit too from this knowledge. This is especially important as the dementia progresses and as a greater number of caregivers become involved, and particularly as new relationships emerge between unpaid, family caregivers and paid, program- and/or facility-based providers. Thirdly, given the importance of developing and fostering a subjective state of inquisitiveness among dementia caregivers, and given the negative impact coercive power has on caregivers' subjective state, care providers (super- and sub-ordinates alike) should critically reflect on *then discuss* when, how, why, and with what effect coercive power is deployed in dementia care planning. This would involve identifying situations where one or more of the people affected by the care plan forces obedience through the threat of a sanction and the care plan is subsequently carried out not because the sub-ordinate consents to it but because s/he wants to avoid sanction (Carspecken, 1996, p. 130).

Lastly, with respect to fostering conditions of dialogic exchange that are conducive to democratic co-construction of knowledge, family caregivers and paid care planners alike should encourage the inclusion of all those who provide care and who are affected by the care decisions, and allow for those affected to share their perspectives and experiences as well as questions and concerns. This would require fostering in leaders and in family caregivers an aptitude for soliciting and valuing others' person-specific dementia care knowledge, an aptitude that might be facilitated through the creation of mechanisms for informal, on-the-floor knowledge exchange between and within staff groups (i.e., both intra- and inter-disciplinary knowledge exchange), and by the development of easily accessible reports that summarize familial history, likes and

dislikes, and socio-cultural information that can help caregivers contextualize their interpretations of persons living with dementia.

The notion of fostering co-constructed knowledge among dementia care providers points to a second set of study implications, ones that pertain to the field of dementia-focused knowledge translation and exchange. In re-conceiving the best possible ways in which to implement selected evidence, Kitson *et al.* (2008) suggested that KT strategies be deployed such that the diagnoses of an organizational context precedes the development of a facilitation strategy; the KT intervention should be shaped and molded by the information gathered during the assessment of context and, specifically, during the assessment of the knowledge culture for which the evidence is relevant. Indeed, the very constructs that Kitson *et al.* (1998) deem as central to culture – its capacity to learn, its patient-centredness, its values – each of these, arguably, is moderated by the ways in which social power manifests as normative, coercive, and/or charming power. Part of any assessment of context should thus be attuned to power and its affect on how dementia care knowledge is or is not freely solicited, shared, and valued. Subsequently, the development of a (presumably more) context-sensitive facilitation strategy could then target and recognize participants' psychosocial interests, leverage existing charm and normative powers (that are not coercive), and foster and leverage the ideal conditions for ethical discourse (Habermas, 2003). Those developing and coordinating training and education initiatives could enhance the impact of their work by integrating into dementia curricula the means by which caregivers can both identify and discuss the ways in which power is distributed across the local, cultural milieu.

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– Chapter Six –

**Reconstructing (Responses to Responsive) Behaviors in Dementia Care  
by Re-cognizing how Social Power Interacts with Tacit & Explicit Knowledge**

**Abstract**

This critical ethnographic research study took place in two dementia care sites: a specialized care unit (SCU) in a long-term care home, and, attached to the same building, an affiliated adult day program (ADP) designed for people living in the community with dementia. This article focuses on how SCU and ADP staff *respond* to clients' and residents' responsive behaviors, and in particular how social power interacts with tacit and explicit knowledge in the provision of dementia care. By examining routine care practices that caregivers used to respond to responsive behaviors and the justification of those practices, the analysis showed (i) that normative powers within the care site led to the use of force being a regrettable but not uncommon care practice, and (ii) that caregivers' tacit knowledge proliferated through processes of knowledge externalization and socialization. These findings suggest that when a dementia care organization can uncover and leverage existing tacit knowledge and elevate that knowledge from an individual to a team level – and make it accessible to care workers – discourses of responsive behavior and personhood can flourish and the need to use force can be mitigated.

**Keywords:** dementia, long-term care, context, culture, tacit knowledge, critical qualitative research



In accounting for the behaviors a person with dementia might exhibit – such as pacing, verbal and/or physical aggression, repetitiveness, or resisting care (Gates, Fitzwater, Telintelo, Succop, & Sommers, 2002; Myers, Kriebel, Karasek, Punnett, & Wegman, 2005; Volicer, Van der Steen, & Frijters, 2009) – the dominant discourse has been of a micro-level, biomedical realm (Dupuis, Weirsmas & Loiselle, 2012). In this view, “dysfunctional” or “compromised” behaviors act as a communicative device (Innes & Jacques, 1998; Sabat & Harre, 1992) to convey an inability to cope with excessive stress (Hall & Buckwalter, 1987) or to convey unmet, difficult to express needs (Algase et al., 1996; Colling, 1999; Kovach et al., 2005; Stokes, 2000). Dupuis *et al.* point out that although the impact of the built environment is recognized by some such conceptualizations of dementia-related behavior, “broader social and political contexts that shape human actions and serve to either enable or disable persons with dementia are rarely considered” (p. 163). Instead, behaviors come to act as the means by which people with dementia are labeled (as resisters, as wanderers, as aggressive) and, ultimately, dehumanized insofar that they also objectified and categorized into stages of disease progression; rather than be seen as people within their own right, such dehumanization “results in the devaluing of the person, which wears down and damages self-esteem and self-efficacy of those labeled” (Dupuis et al., 2012, p. 164), ultimately leading to withdrawal from the social world as the deterioration of one’s well being is exacerbated (Dupuis et al., 2012; Kitwood, 1997; Kontos, 2005).

An alternative discourse is the responsive behavior discourse, which “views all actions as meaningful and moves us away from judging behaviors to *understanding meaning in actions* and responses” (Dupuis et al., 2012, p. 170, emphasis in original).

Herein, as Dupuis *et al.* explain it, notions of compromised dysfunction and decline are replaced by a belief

in the continued abilities of persons with dementia to express their experiences and act in purposeful, meaningful and even intentional ways [... yielding the] opportunity to find new ways of connecting with persons with dementia in understanding meaning in actions by being truly present, actively listening, and recognizing that there are many ways for persons with dementia to communicate their experiences, to *be*” (p. 170-171, emphasis in original).

For Dupuis *et al.*, responsive dementia care is more about understanding actions beyond the individual than it is about pathologizing, predicting and controlling behavior.

A number of scholars have examined the frequency and severity of the most challenging responsive behaviors (Dupuis et al., 2012; Moore, Ozanne, Ames, & Dow, 2013; Morgan, Cammer, Stewart, Crossley, D’Arcy, Forbes, et al., 2012). Dupis *et al.* reported that particular characteristics of the behavior(s) a person with dementia exhibits determines “the level of challenge associated with specific behaviors. These characteristics included the intentionality, predictability (or unpredictability), and persistence of the behavior, how threatening the behavior was perceived, the social appropriateness of the behavior, and the degree of impact on others of the behavior” (p. 168). At worst then, and regardless of whether it is perceived as symptomatic and/or as communicative, caregivers might well feel affronted by persistent and intentional yet unpredictable, threatening, inappropriate and harmful behavior.

If the preferred discourse is that of responding sensitively to responsive behaviors (Dupis et al., 2012, Kitwood, 1997; Kontos, 2005), what would empower caregivers to maintain a therapeutic relationship with their clients in the face of such challenging conditions, to understand actions beyond the individual? How and where does caregivers' tacit and explicit knowledge function in responding to responsive behaviors? How does social power interact with this knowledge to affect routine dementia care practices? This article addresses these questions in order to gain a better understanding of how the culture of dementia care knowledge shapes advanced dementia care practices.

### **On tacit and explicit knowledge translation.**

Knowledge is said to be tacit when it cannot be explicitly articulated (Polanyi, 1966), when the body knows what to do without deliberation or forethought (Benner, 1984), and, from a caregiving perspective, when care knowledge "is assimilated as bodily knowing" (Carlsson et al, in Kontos & Naglie, 2009, p. 689). Kontos and Naglie contend that such conceptualizations of tacit knowledge should not neglect "the primordial and socio-cultural significance of the body" (2009, p. 689) and suggest that such tacit knowledge is evident in the power of gesture and the pre-reflective co-ordination of visual, tactile, and motor aspects of our body. This was shown by Kontos (2005) to resemble a key element of a person with dementia's communicative capacity, or what Carspecken (1996) and Habermas (2003) might otherwise call the non-discursive communicative action that enables inter-subjective recognition of meaning.

Indeed, the relationship between tacit knowledge and communication is significant (Nonaka, 1994; Quinlan 2009). Following Nonaka, Quinlan highlighted the

role of communication in gaining access to tacit know-how by showing that the dialogic exchange that comprises a care team's collective clinical decision-making facilitates the articulation of tacit knowledge "and thereby opens up the potential for creation of new, communicatively achieved knowledge" (Quinlan, 2009, p. 638). Nonaka described such a process as the 'externalization' of tacit knowledge, enabled by team members' attempts to articulate their lived work experiences. Communicative action also drives the process of 'internalization,' which entails the conversion of explicit and codified knowledge (often print and curricula) into one's knowledge base; in this case, the communicative action relates the learning processes and inter-subjective interactions that occur in educational settings to relevance – the internalization of information as knowledge occurs when the information can be related to the action(s) required to perform the job. As a third form of knowledge generation driven by communicative action, socialization is said to occur when tacit knowledge is shared and spread *as tacit knowledge* throughout an organization, often without language per se – rather, tacit knowledge is socialized much as an apprentice learns through shared experience (Nonaka, 1994).

While Nonaka (1994) posited that these processes are among those that condition the development of new knowledge among individuals, his aim was to conceive of a theory that conceives of these "patterns of interaction" as inter-related and as resulting in the creation of organizational learning. At an individual level, Nonaka understood that people are driven by a commitment to recreate the world in accordance with their own perspectives and by an intention to acquire knowledge for their own betterment (which necessarily introduces into knowledge creation the notion of value judgment – knowing and understanding occur in the context of purposeful activity). Moreover, individuals

enjoy a certain amount of autonomy to absorb knowledge, and can take into account the ambiguity and randomness of their own context as they create, impart, and absorb knowledge. But as they engage in these knowledge creation processes within a social ontology, wherein organizational beliefs and practices become collectively justified as normative, socialization, internalization, and externalization become involved in a spiral of *organizational* knowledge creation. So while individuals develop new knowledge, organizations play a significant role in articulating and “amplifying” that knowledge (Nonaka, 1994, p. 14). Thus, Nonaka cautions that we must not over-emphasize the processes of internalization (the conversion of explicit to tacit knowledge) at the expense of understanding how tacit knowledge is externalized and spread through socialization; rather, to understand organizational knowledge creation, the interplay of each pattern of knowledge interaction needs to be understood so that the knowledge can become concerted in redressing the particular problems to be solved in a given context.

For the purpose of building upon and applying this theory of knowledge creation (Nonaka, 1994) to the field of advanced dementia care and in particular to caregivers seeking to understand (rather than control) responsive behaviors, two assertions are warranted. The first is that we have available an evolved, four-pronged conceptualization of what tacit knowledge is insofar that: tacit knowledge is indeed difficult to articulate (Polanyi, 1966); as it precedes conscious effort, it is pre-reflexive even while it drives the body’s actions and movements (Benner, 1984), thus entailing a primordial and embodied (rather than cognitive) consciousness that is shaped by socio-cultural inclinations over which an individual has no conscious mastery (Kontos & Naglie, 2009); and, as Nonaka sees it, tacit knowledge includes a realm of mental models, schema and beliefs upon

which we structure our cognition as well as more technical know-how and craft-skill, even if that remains difficult to articulate and pre-reflexive. The second assertion that relates knowledge creation to caring for someone with responsive behaviors is that we ought to strive to give renewed primacy to tacit knowledge first by understanding how it works at an individual level within the context of dementia care, then by examining those processes of knowledge conversion and knowledge sharing within the power-laden organizational culture where dementia care occurs. As such, this study endeavored to contribute to understanding (in Nonakian terms) how the externalization, internalization and socialization of tacitly held dementia care knowledge interacts with social and organizational power.

### **Methodology**

A critical qualitative research design (Carspecken, 1996) guided and infused this study with insights derived from a Habermasian worldview. In the analysis of ethnographic data that featured ADP and SCU staff and family members interacting and caring with clients and residents, primacy was given to participants' inter-subjective, communicative action, and to examining the conditions under which truth claims are generated. In this view, rather than being understood in a transcendent sense, truth is understood in terms of its function: to generate unconditional acceptance of particular claims (Carspecken, 1996; Habermas, 2003), an epistemological view that resonates with Nonaka's view (1994, p. 15) that knowledge is a "dynamic human process of justifying personal beliefs as part of an aspiration for the 'truth.'" In this view, truth is seen to entail communicative negotiation – both verbal and non-discursive – the aim of the analysis

was to reconstruct the communicative actions that inhere in meaningful social interactions so as to bring to the fore implicitly conveyed objective, subjective, and normative claims. Normative claims were of particular interest as these are the claims that govern what *should* occur and what behavior is *appropriate* within a particular situation, and are thus highly representative of a given culture (Carspecken, 1996). By reconstructing the objective, subjective, and normative claims of a meaningful interaction, and by reconstructing the social power(s) invoked to justify those claims, one can come to understand how a particular culture produces social, practical knowledge about what is true and what is right (Habermas, 2003). Nonaka's theory of knowledge creation serves to hone this analysis by tracing the iterative 'spiraling' that occurs between tacit and explicit knowledge.

### **Ethical considerations.**

The Research Ethics Board at Western University approved this study. Organization leaders circulated their own internal memo to let potential participants (staff members, families, residents of the long-term care home, and clients of the adult day program) know that the study was being conducted. On days when data were being collected, notices were posted on the doors into the research site and the care areas to inform anyone entering about the study, its aims, and who to contact for further information. Those who enrolled in the study provided written consent to be observed and/or to participate in audio-recorded interviews, and to allow use of anonymous data for analysis, interpretation, and dissemination. Accordingly, all re-presentations of the data preserve participants' anonymity and privacy. Residents and clients who enrolled did

so with the written consent of their substitute decision makers, a procedure deemed necessary given their diagnoses of dementia, which in many cases was quite advanced.

### **Participant recruitment.**

The majority of staff members were recruited in small groups during the first four field visits. Thereafter, when I encountered any staff members who had not been recruited, I notified them about the study, offered a letter of invitation, and invited their participation. Residents of the long-term care home and their family members were recruited with the assistance of a registered nursing staff member, who approached potential recruits on my behalf to offer them a brief overview of the study and to invite them to consent to receiving a letter of information and to consider enrolling. Clients of the adult day program and their family members, meanwhile, received a letter of information and a consent form via mail; those willing to enroll subsequently returned their signed consent form to the program secretary. All participants were assured that participation was voluntary, and that declining to enroll would have no consequence on the care they received or their status as an employee.

### **Data collection.**

This critical qualitative research study took place in two dementia care sites: a specialized care unit (SCU) in a long-term care home, and affiliated adult day program (ADP) designed for people living in the community with dementia. Data were collected over a period of nine months that included 34 field visits for the purpose of observing participants (146 hours in total), plus an additional 11 field visits for the purpose of



conducting 12 in-depth and 12 member-checking interviews and a focus group. Data collection began with a period of non-participant observation conducted in the common areas of the SCU and, in some cases, in residents' rooms, and in the three activity rooms and two staff workrooms of the ADP. Any verbal interactions that occurred with study participants during this stage were usually just cordial, although I did occasionally seek clarification about the provision, receipt, and/or negotiation of routine care practices; on 11 such occasions, my informal conversation with a care provider was audio-recorded with permission. On 10 separate occasions, dialogic exchanges between care providers were recorded with permission. The observation phase also included collecting documents and other discursive tools or information sharing mechanisms (e.g., admission forms, communication books, notices posted in staff work areas).

Subsequently, these observation data were subjected to preliminary analysis so as to generate interview topics that addressed actions that seemed fundamentally related to dementia care knowledge. Topics included the notion of appropriateness in dementia care, flexibility in work rules and routines, meal time routines, having to sometimes use force to provide care, and the notion of educating families and/or managing their expectations. Ultimately, the intent of the interview phase was to have participants describe in their own words issues related to dementia care and its related actions and routines. A more detailed description of how interview topics evolved and of the data analysis techniques is provided elsewhere – see Chapter Four; briefly though, the primary techniques for data analysis are described next.

**Data analysis.**

Carspecken (1996) broadly conceives of his critical qualitative analysis as hermeneutic reconstructive analysis. *Hermeneutic* analysis refers to meaning making and specifically to the cyclic process of circling between partial and whole understanding such that data that were initially perceived in a holistic and undifferentiated fashion were delineated into the elements that together comprise the making and interpretation of meaning in social events. *Reconstructive* analysis refers to the articulation of implied meanings and implied claims, which is presupposed by the assumption that meaningful social interactions include a range of backgrounded and foregrounded claims. Moreover and following Habermas (2003), the kinds of claims people make were categorized into three ontological categories: objective claims that are defined by a principle of multiple access – two or more observers would agree on how an observed event transpired; subjective claims that are defined by a principle of single access – only the person in question can know for sure what his or her own feelings, desires, and intentions are; and normative claims that serve as an indication of how people *should* act in a given situation. By reconstructing these three kinds of claims, as well as the non-discursive communicative context in which the claims are made, hermeneutic reconstructive analysis yields insight into the culture of a particular group of people (Carspecken, 1996) – in this case, those living and working in a long-term dementia care environment.

**Rigour.**

The rigour of this study was established in terms of epistemological coherence (Holloway & Todres, 2003), and, following the theoretical methodology set out by

Carspecken (1996). Regarding coherence, Holloway and Todres suggest that a study's methodology, methods, analysis, and knowledge claims all ought to align or "hang together" with its underlying worldview and, accordingly, its aims. As a critical qualitative research project (Carspecken, 1996), this study aimed to better understand the culture of dementia care knowledge and specifically the influence of social power in terms of knowledge creation, sharing, and application.

In addition to striving for coherence (Holloway & Todres, 2003), a variety of strategies were used to ensure methodological rigour (Carspecken, 1996). First, prolonged immersion in the research sites and a period of non-participant observation preceded dialogic data collection – 34 field visits for observation were conducted before the 12 topic-driven and 12 member-checking interviews were conducted. This allowed me to gain a sense of what the social and care routines entailed and to begin to generate topics for subsequent interviews. Second, a flexible data collection schedule allowed for observation and exploration of all care routines related to dementia care – field visits took place during day and evening shifts and across all seven days of the week. Third, I used multiple data collection methods: observation of clients and residents, visiting family members, and program/unit staff; formal and informal in-depth interviews; member-checking; and analysis of organizational documents. This enabled me to compare data from various data sources, particularly interview data with observation data. Fourth, member-checking helped to democratize the interpretive analysis by giving participants an opportunity to validate and/or refine analysis, and to share new insights. Fifth, the use of non-leading questions during interviews and a tendency toward limiting responses to low-level inferences were strategies intended to mitigate the risk of a social response bias

and to facilitate participants' use of their own words and ideas to discuss particular topics. Sixth, the examination of apparent abnormalities to routine care practices (i.e., negative case analysis) provided a means by which to validate or refine reconstructions. Finally, peer debriefing with other researchers (advisors and colleagues) helped to check for biases or absences in the data reconstructions. I kept a diary-style record of 15 such debriefings, held with four different researchers throughout the data collection and analysis periods. As a result of these debriefings bringing to my attention new or alternative analytic angles, I was better able to consider fully, and, in turn, to justify my analytic decisions.

### **Sample.**

Between the two affiliated sites, a total of 139 participants enrolled in the study, including 71 point-of-care staff, 12 members of the senior leadership team, and 56 non-staff participants. Among these 56 were six SCU residents and seven of their family members, as well as 42 ADP clients and one additional family member. Most of the point-of-care participants were female, and most were personal support workers (PSWs;  $n = 39$ ) or recreational therapists ( $n = 9$ ). Also included were registered nurses (RN;  $n = 4$ ) and registered practical nurses (RPN;  $n = 7$ ), a nurse practitioner, two physicians, dietitians, physiotherapists, and housekeepers, and three social workers. Aside from three of the RPNs and about half of the PSWs, the enrolled staff members worked full-time.

## **Findings**

The findings that follow are organized into two broad sections, the first of which describes what responsive behaviors were observed and how staff members responded to these responsive behaviors. It should be noted that while staff members often looked to family members for advice or to notify them about changes in psycho-social function, family members were rarely present when responsive behaviors manifested, hence the focus on staff members' responses. As one of these responses entailed the use of force in assisting with activities of daily living, the first section concludes with an account of how and why the staff members justified the use of force and how family members made sense of this practice. The second section sorts staff members' other, non-forceful responses to responsive behaviors into categories that illustrate how knowledge is internalized, externalized, and socialized (Nonaka, 1994), and how these individually-located knowledge creation processes interact with social power to create organizational dementia care knowledge.

### **Observed responsive behaviors.**

During the observation phase of this study, it was common to observe clients in the ADP and residents in the SCU pacing, seeming anxious or agitated, and sometimes becoming verbally or physically aggressive. One PSW remarked that physical aggression was not at all uncommon:

... it happens a lot, like I've been hit, scratched, gone home with black eyes. [That male resident] right there, he's one that you have to be careful with – like he won't just swing at you, he'll get you in a head lock and beat on you, yeah.

During another field visit, I witnessed a female resident punch another female resident in the chest, and later push an RPN hard enough to cause her to lose her balance and fall to the ground. Such physical aggression was described by PSWs as something “you just take,” a notion returned to further below. Other instances of responsive behaviors observed during the initial field visits include:

A male SCU resident leaned against the desk at the nurses’ station, stooped over with his head on the counter, sobbing quietly, straightening slightly only to hit himself in the head several times with open palms. He did this for extended periods of time, for days in a row.

Several different SCU residents and ADP clients often walked to a locked door and tried to open it and/or to figure out the keypad code beside the door, a behavior staff often referred to as “exit-seeking.”

A male ADP client infringed on others’ space, standing within inches, smiling and seeming to hope for some form of social engagement, but he usually had the effect of affronting the other client(s) and seeming to thus trigger agitation and sometimes aggression.

More frequently in the SCU than the ADP, residents resisted care providers’ efforts to assist with ADLs, resistance that variably manifested as verbal refusal, pulling away from the caregiver (usually a PSW), lashing out verbally or physically.

Several ADP clients had to be reassured and convinced that they were supposed to be there that day, and that they would be going home.

A female resident asked a caregiver about every minute to speak with her own (known to be deceased) mother; another asked just as often why she had not been fed supper (when she had just recently eaten).

A male ADP client disrupted large group programs by dominating the conversation and/or belittling others' participation.

While some residents/clients were inclined to pace (in circles around an atrium or up and down hallways), others wandered into others' rooms to fiddle with or collect others' belongings; such behavior was often referred to as "hoarding," sometimes as "collecting."

*Collecting. Dominating. Needing. Seeking. Refusing. Engaging. Exiting. Sobbing. Striking.* Viewed through a lens of responsive behavior (Dupuis et al., 2012), the behaviors I observed can be (re)cast as actions and as purposeful and meaningful expressions that deserve (or perhaps command) the opportunity for interaction. And indeed, staff caregivers met such behaviors with myriad forms of interaction, the range of which is described next.

**Staff members' responses to responsive behaviors.**

Staff members employed a variety of care practices in responding to these responsive behaviors. An initial response was to approach the person in an appropriately gentle way so as to not exacerbate or trigger any further responsive behavior. While this was not presumed to be a guaranteed way of preventing responsive behavior, it was understood that approaching clients/residents in a rushed, gruff, or insensitive way was likely to trigger or exacerbate responsive behaviors. A gentle approach, in contrast, was presumed to afford opportunity to try to understand what was causing the behavior. While this was sometimes confined to a pathological, disease-based investigation or query, thus resulting, perhaps, in an adjustment to the person's medication, it often also included more holistic and socio-cultural investigation, particularly among the full-time registered nursing staff, and within the ADP. Such investigations often included an element of trying to find meaningful activities with which to engage the person with dementia – music, books or magazines, arts or crafts – something of interest that was specific to the person's past. By providing staff members with insight into the client or resident's preferences and personal and/or professional past, family members often played a significant role in such investigations when they were able, willing, and available.

The provision of meaningful social engagement and activities was close in nature to what was otherwise referred to as a re-direct: re-directing the person with dementia's attention away from anything that might have been causing a responsive behavior, or cueing their attention toward a more therapeutic activity. Such practices (cueing, re-directing) were better resourced in the ADP than in the SCU – the ADP was considered a



recreation program and, accordingly, was staffed with at least five recreational therapists per day to serve its 60 or so clients, whereas the SCU featured only one recreational therapist to serve its 32 residents.

Another response to responsive behaviors, oftentimes, was for staff members to let the person be, thereby passively validating (or perhaps, sometimes, ignoring) the person with dementia in his or her own present moment. At other times, albeit less frequently on account of having limited time, staff members engaged in “validation therapy” to dialogically validate the person in his or her present moment. Reassuring in nature, this entailed saying or doing something that was quite often unrealistic – a reflection of validation therapy being conceived of as a practice opposite to “reality orientation” – and thus included responses such as writing a fake bus ticket for someone, giving someone a phone book so they could look for their family (often a parent’s) phone number, cordially repeating oneself in light of a resident or client’s impaired short-term memory, or simply asking questions and talking about whatever issue seemed to be upsetting or interesting the client or resident.

As with any inter-subjective negotiation of a meaningful moment, common in these staff members’ responses was the presence of power, which typically manifested as persuasion, and sometimes as force. To persuade, caregivers used charm (i.e., endearing oneself to another with terms of endearment, humor, compliments), invoked norms about (in)appropriateness (*It’s time for ...; That’s not how we treat one another here*) and/or negotiated with contractual power (*If you ... then I’ll ...*). In cases when efforts to persuade failed, the use of physical force was not an uncommon response to responsive behaviors. This coercive power served to restrain or isolate a person, either to complete

ADL tasks and/or to mitigate the risk of others being harmed. Together, these approaches, treatments, investigations, validations, persuasions and coercions formed a repertoire of “whatever works.”

Struck by the remarkable ethical dilemma that seems to inhere in using force, I describe next how and why force was so readily justified in the provision of care. Thereafter, the focus of the findings and the subsequent discussion turns to how knowledge about responding to responsive behaviors manifested in these dementia care sites, thereby disclosing caregivers’ variable (in)ability to interpret and contextualize the behaviors to which they were responding while also shedding light on knowledge conversion processes and the manifestation of a care team’s collective knowledge.

#### **On the use of force.**

Regarding the use of force, PSWs often expressed concern about this, fearing reprimand either from family members or from a government official. One PSW’s comment seemed to imply that rather than be accused of being abusive, PSWs might, sometimes, just not provide the care.

Yeah, with [a particular female resident], if we tried to clean her mouth out and take her teeth out, it's going to take 2 or 3 people, so when the Ministry stands there and sees us they'll just think that we're being abusive.

Upon asking one of the PSWs’ managers about this concern, she acknowledged the worrisome nature of the practice and that one of the quality improvement initiatives under way in the home was about oral care. She also indicated that with advanced

dementia, sometimes using force is necessary, and families understand and condone the practice:

I find that as long as you have family on board - because the thing is, families know. Families on [the SCU] are very well - most of them - well educated. And all I find is you have to say to them, you know, we're having difficulty on bath days and if you can come, great. If you can't, he hasn't had a bath in a week and we really need to get him in the tub. And this is what we're going to do. And families will say do whatever you have to. They know we're not hurting them. He's just standing in the shower yelling. We're not hurting him. But you need to have the families understand and I think as long as the families understand that we're not abusing them, then I think we're okay. You can't just ignore [residents' ADL needs] - I mean if you want to have no force, then don't bother bringing them into long-term care because we can't provide the care that you're wanting.

Attributed to objectively referenced claims (that the SCU residents had a diminished capacity to complete their own ADLs and that without such forceful care, the residents would languish), this manager's *normative* claim was that the ADL care should get done, even if by force, so long as the residents were not physically hurt during the encounter. In the day-to-day provision of ADL care, this 'getting it done' norm was more prominent and more relevant to the work of the PSWs than the other norm at play to understand and contextualize the responsive behaviors so as to prevent them in the first place. Consequently, using force in response to responsive behaviors was a norm unto itself. A PSW described her encounters with a particular male resident,

... he's changing, he is a two person, one person could do him before, but he is so strong, he is a two person most of the time. I'm mean you've seen us pushing him down the hall like this [she held her arms out in front of her, locked straight; I had indeed seen her pushing this male resident just so, his rigid body leaning back heavily against her open palms] ... how horribly degrading is that for a person? But sometimes it is the only way we can get him down there, otherwise you wait half an hour. Sorry, we don't have half an hour to wait for you to get from that end of the hall to get down to the lunchroom to eat.

In characterizing this encounter as degrading, the PSW subtly conveyed a subjective claim that she did not like having to literally push this resident, as well as a backgrounded normative claim that indicates that under ideal conditions, the resident should be allowed to take all the time he needs to come to lunch, and any persuasion needed to bring him along should not involve the use of force. The backgrounded objective claim, though, seemed to convey that *these current work conditions were not ideal*.

While that particular resident's resistance was not aggressive, others' resistance was and it seemed as though staff should expect and tolerate residents' physical aggression; a member of the senior leadership team commented,

... the staff take a lot here as you probably noticed – it's when aggression goes resident to resident that a person is "Formed" and discharged to an acute psychiatric unit, and on not just a mishap, but regular basis.

This manager's point was that resident-to-staff aggression does not warrant discharging a resident to a mental health facility. Rather, the aggression is documented and flagged for further investigation, but meanwhile, when "you have to get the care done," the cultural norm was for staff to do whatever it takes, including tolerate physical aggression and to engage themselves in aggressive behaviour.

When the topic of physical altercations between residents and staff was raised with another higher-ranking member of the senior leadership team, her response reiterated a protocol to "document and discuss," and for staff to re-approach rather than use force, "to continue to go back." But when that sentiment was subsequently raised with a PSW and the notion of "re-approach re-approach re-approach" was offered for consideration, the PSW responded by saying,

Yeah and we do [re-approach], but I can't leave them with poop all the way up the back, I can't do that, you know? And this has happened, that they've had poop running down their legs, so what are you supposed to do, just say Oh, you know-- you approach them and they'll fight, yeah like [one particular female resident], she'll fight like a man, like she takes three people. So you're going to have residents' families around and poop's coming out down their leg and it's up her back too-- you just ask her and she says no and she's very strong-- so you're going to say okay we'll re-approach her? Like I can't do that.

***Reconstructed power in the justification of using force.***

Examining this sequence of quotes on the use of force in terms of the objective, subjective, and normative claims being made illuminated the various roles enacted in this

kind of response to responsive behavior, and how staff members justified the use of force. Backgrounded and objectively referenced claims indicate that despite gently and calmly re-approaching a person with advanced dementia one or two or sometimes several times, there are some who will still refuse and resist care, hence the foregrounded claim that in order to complete the care, sometimes two or three caregivers must work together to force (without harm) the person to allow for care to be provided. The subjectively held concern though is that such care can appear abusive. As such, and given the power of family and government inspectors alike to put into motion disciplinary measures to mitigate abusive care, staff members conveyed a backgrounded preference to not *want* to use force.

Intertwined with these objective and subjective claims are the normative claims that characterize the use of force in dementia care: the forefronted claims that staff should not harm care recipients, who themselves should not be left to languish unkempt or dirty (or unfed), and the related yet backgrounded normative claims that yes, staff members should re-approach those who resist care, but after a reasonable amount of time or when someone is really dirty, and rather than leaving the care work for someone on the next shift, the staff should do *whatever it takes* to assist with ADLs. Moreover, the claim is made that families should be “on board” with this practice, and as long as they understand that no harm is intended and that the care is necessary, families should expect this care practice to occur. Staff members (and PSWs in particular) thus enacted two particular roles in these moments when force entered into care practices: the paternalistic caregiver who was doing this for the good of the person with dementia, and s/he who prevents harm. When charming persuasion failed, these roles were fueled by normative

powers that stipulate that a person's hygiene care (and other ADLs) should be completed, and that it is the work of PSWs – and of long-term care homes – to perform such care, even if the performance ultimately manifests as coercively overpowering and physically restraining the person with dementia.

Data from the SCU participants offer a sense of family members' sense-making of this practice and suggest that family members were usually of one of two minds: either they found such a practice abhorrent and non-condonable, or they were in agreement with what the senior manager conveyed in the quote above – that is, they understand that despite the resident's protests and resistance, he or she is not being harmed and the care must be provided. These categorizations, if you will, of family members' sense-making were further sub-divided by a split in how frequently family members visited. Some were frequent visitors, that is, daily or almost daily visitors, sometimes referred to by staff as the “20-80s” – *20% of families are here 80% of the time*; other family members visited weekly; others still hardly at all. The intersection between family members' frequency of visits and their view of the use of force shaped staff members' care practices insofar that frequent visitors who did not condone the use of force attributed their continued presence to a need to mitigate the risk that staff would use force on their loved one. A spouse of a male resident with Pick's disease described her sense of what would go on were she not there to provide her husband's care herself:

If I'm not here and on it all the time, then he's not been changed. He doesn't get the right product on. They feed him in like 10 seconds flat. You know, like a machine. [She mimics rapid spoon-feeding]. He's just left on his own to walk wherever. Because of his disease, he needs a one on one. He won't sit in that

circle. And he won't sit in and have to do a puzzle by himself too much. He wants somebody to be with him all the time.

This family member dealt with her concern about neglect and about forceful, machine-like care by being a '20-80.' The corollary of such a mitigating practice is that the majority of residents did not have such frequently visiting family members; they were thus subject to staff members' routine care practices, including the use of force.

Despite the apparent frequency and normalcy of interactions involving the use of force, it was also clear in this study that using physical force was not a default practice; rather, staff members did endeavor to contextualize and interpret responsive behaviors, and to leverage their dementia care knowledge – be that general or person-specific – to respond to responsive behaviors in a more therapeutic, less forceful way. To examine how such practices are conceived and justified, what follows is an explication of how social power manifested in the externalization, internalization, and especially in the socialization of dementia care knowledge.

### **Externalizing knowledge to contextualize responsive behaviors.**

Family members' knowledge of their loved ones played a significant role in enabling staff members to better contextualize any responsive behaviors. To externalize this knowledge, various intake and assessment forms solicited from family members their tacitly held knowledge about dementia care. For example, the ADP developed a four page form for families to complete and send in with clients staying for their first weekend stay (in which case the client would attend the Friday and Monday programs, but also



stay the entire weekend; the activity rooms were fitted with Murphy beds and temporary walls so as to create separate ‘bedrooms’). The first two pages of the form offered a number of strategies that family members could use “to ease our guests into the process,” including encouragement to send in a brief, hand-written “comfort letter” to reassure the client that they will be returning home after their short visit. Pages three and four though were designed to solicit from family members care knowledge that staff members could use during the stay, including descriptions of morning and bedtime routines, indications of what the person’s usual mood was at different times of the day, and what “comfort measures and other helpful suggestions” family members might have to address, for instance, “night time wakefulness.” As this knowledge derived from family members was of a personal nature, deeply rooted in their own specific context of cultural particularities, it was of a tacit nature (Kontos & Naglie, 2009; Nonaka, 1994). By filling out this form and by otherwise participating in the admission process, family members began to engage in externalizing tacitly held knowledge about dementia care in terms of the know-how and caregiving skills they had learned to apply within their own particular context, that is in caring for their loved one.

Moreover, the family members who shared their knowledge – either in an intake form such as this or verbally – shared knowledge that they expected to be shared and used; in Nonakian terms, family members expected the knowledge they shared to be first internalized by one or more staff members, then, as that knowledge became assimilated and tacitly held, to be spread among the staff through processes of knowledge socialization. While the intake form from this particular example provided a mechanism that had the potential to work well, an RPN who described the form qualified its benefits:

It is very helpful in that it's the first thing I read when I come in, but, on subsequent weekends, if the RPN who's on hasn't cared for the client before, they might not easily find or read this info – then things can get missed. And of course, families vary in how much info they provide: some will write a book, others, not so much.

This RPN's quote offers three insights. First, that the information collected on the form was relevant enough to be “helpful” such that, presumably, it was internalized as actionable knowledge that could help the RPN support the client during his/her weekend stay. Second, that family members' externalization of dementia care knowledge was sometimes not fully achieved via an assessment or intake form – some family members provide sufficiently useful, relevant, and particular information, others “not so much.” A third insight from this quote relates to *if and how* the knowledge was subsequently internalized by other team members, a point I return to below in the section on internalization.

Another example of externalized knowledge included staff members' completion of standardized assessment forms that required a judgment of psychosocial functioning. An item querying social engagement, for example, required the nurse or recreational therapist to render a tacitly held account of the person with dementia's social engagement – gained by experience and observation – into an explicit account or, more often, a quantification. In cases where these externalized data were entered into the suite of Resident Assessment Instrument (RAI) tools, the data contributed to the formulation of RAI-generated RAPs (resident assessment protocols), which cued the registered nursing

staff to further assess the person with dementia and to update their care plan accordingly. As such, the RAI tools were an actor of sorts in the dementia knowledge work – the RAI algorithms transformed, coordinated, and processed the externalized knowledge as information such that when a particular threshold was reached, staff were triggered to act. The RAI tools thus served as a mechanism by which knowledge derived from an individual level was transformed into a different form of codified, explicit knowledge, then made available at a team level.

***Reconstructed power in the justification of externalization dementia care knowledge.***

In soliciting knowledge relevant to the care of a person with dementia, intake and assessment processes and forms played a significant role in externalizing tacitly held dementia care knowledge. And despite the variable quality and quantity of data, and despite the barriers to accessing the knowledge after it was externalized, these forms (re)produced a cultural norm to solicit and make available to others care knowledge that was relevant to formulating therapeutic responses to responsive behavior. Backgrounded behind this norm was a second set of norms, which stipulated that standardized intake and assessment procedures should serve this function of solicitation of family members' tacitly held knowledge, and that families should comply in providing this information. In tandem, these norms (to use standardized intake and assessment forms, to solicit/explicate and share tacitly-held knowledge) were driven by a normative discourse that espouses standardized assessment, and by a kind of coercive power that stipulated non-compliance with the completion of such standardized assessment would result in

sanctions: a point-of-care provider could be ‘written up’ for poor job performance, and/or the organization could face reduced funding for not adequately assessing and documenting care needs. That said, and insofar that these normative and coercive powers “worked” in justifying the externalization of knowledge, the now-externalized knowledge needed to subsequently become internalized.

### **Internalizing knowledge to contextualize responsive behaviors.**

As indicated above, among the dementia knowledge to be internalized was that which had been externalized either at admission or when the person with dementia was at an earlier stage of his/her journey through dementia care services. (Several of the SCU residents had formerly been clients in the affiliated ADP). Thus, the explicit and codified knowledge to be internalized typically related to diagnoses, medical and social histories, likes and dislikes, and strategies to comfort and care for the person. Some family members also prepared for the staff a photo album or a scrapbook filled with memorabilia signifying the person with dementia’s familial and socio-historical past. While this knowledge was available to be reviewed and, ideally, internalized by staff members who were enacting an intentional commitment to enhance their knowledge and understanding of the person(s) they cared for, heavy workloads and time constraints often precluded this from happening. Recognizing this problem, a recreational therapist from the SCU explained how even a short summary of the client- or resident-specific knowledge would be helpful, especially for the PSWs who do so much of the hands-on care:

It would be nice to have like a little– like a short, point form information on each resident. We’re working on doing like a scrapbook and I would put that page in

each resident room and it would just say like you know, where they were born, the names of their kids, what they did for an occupation, just so that you know, when the PSWs are in there – cause realistically time is a major factor of course, we all use our time differently too, and organize our time – but that way they would at least have some key words and again, if we had consistent staff, that could be really, really helpful. But we'll see. [One of the RPNs] and I are working on it.

In lieu of having a family-prepared summary or scrapbook about a particular resident or client, staff members relied instead on pre-existing documentation as a source of person-specific knowledge to internalize. Job responsibilities and positional status meant that registered nursing staff and recreational therapists had more opportunity to access and internalize such pre-existing knowledge, whereas PSWs had significantly less opportunity to do so. And even among the nursing and recreation staff, time constraints and a heavy workload often resulted in the under-utilization of this pre-existing knowledge, thus precluding the possibility of individually derived knowledge from becoming team-level knowledge. As in the example above regarding the intake form for weekend stays – recall the RPN indicated that “on subsequent weekends, if the RPN who’s on hasn’t cared for the client before, they might not easily find or read this info, then things can get missed” – this shows that whatever knowledge was externalized was sometimes difficult to access and review, in which case the person-specific knowledge could not be internalized by staff. This points to the interface between individual and team-level knowledge: unless sufficient mechanisms and relationships are in place to

facilitate the sharing of family members' newly externalized dementia care knowledge, that knowledge becomes relegated to information on a piece of paper, not care knowledge.

While family members and intake forms generated and availed a significant amount of person-specific dementia care knowledge to the care teams, the organization that the SCU and ADP were a part of also supported and enabled its staff to participate in two regional dementia training programs – Putting the P.I.E.C.E.S. Together (P.I.E.C.E.S. Canada, 2008), and the Gentle Persuasive Approach (Schindel-Martin & Dupuis, 2005). These training sessions provided additional opportunity to staff members to internalize dementia care knowledge as it relates to personhood. In both the SCU and the ADP, registered nursing and recreation staff members were nearly all “PIECES trained,” the majority of PSWs were “GPA trained,” and plans were afoot to ensure all staff received this training and regular refresher courses. It was evident that the codified and explicit dementia care knowledge of these curricula had been internalized by some as routine dementia care knowledge and practice (i.e., as tacit knowledge). Reflecting on what it was like to try to care for physically aggressive clients 10+ years ago when she started working in the ADP, one recreational therapist said,

At the beginning when we were really new and way back, if they started hitting, it was like, okay, they've got to get out of here [i.e., be discharged from the program]. But now we've come up with way more interventions, way more understanding. We understand PIECES. We look at, “Are they in pain?” Like we look at our whole thing and that person would already go to a behaviour team, so [our Director] would be involved, the social workers would be involved. [The

person] would have been discussed a number of times at that behaviour meeting and the interventions would be then typed on here [an electronic record] for everybody to read. If it's a really big deal, they'd even write it in the main communication book so that everybody's on the same page. And we go way out of our way to not get them to that point [of having to be discharged].

This quote (and in particular, her use of the pronoun *we*) indicates that the internalization of the PIECES and GPA philosophies occurred at a team level, such that team members collectively enacted practices that contextualized responsive behaviors and utilized communication mechanisms to share with other caregivers details regarding the resultant interventions. Also evident in these findings, moreover, is that staff experimented, learned by doing and through trial and error; such processes served to trigger and/or enhance this interactive pattern of internalizing knowledge.

***Reconstructed power in the justification of internalizing dementia care knowledge.***

Relative to the internalization of pre-existing dementia care knowledge, staff typically enacted one of three roles: student learner (in a GPA and PIECES classroom), detective/historian (in reviewing and committing to internalize client- or resident-specific information gathered and documented during prior assessments), and/or, the busy worker who did not have time to review electronic records of clients'/residents' medical, familial and social histories. The discrepancy between those who did and did not have the authority or privilege to access electronic records closely mirrored the hierarchical divide

between professional staff (recreational therapists and registered nursing staff) and the unregulated PSWs – without access to the charted client- or resident-specific knowledge, PSWs could only internalize knowledge provided in the formal education initiatives. Conversely, the positional power that professional staff members were granted carried with it a normative expectation to internalize the knowledge available to them and to enact the role of detective/historian.

The student learner faced a similar normative expectation, coupled with some degree of coercive power that mandated participation in the GPA and PIECES classrooms. The other form of normative power at play in these initiatives stipulated that any and all such internalized knowledge should contribute to charm-infused efforts to respond to responsive behaviors without force or without the undue administering of psychotropic drugs. Observed practices of developing non-forceful “interventions” to use in response to responsive behaviors can thus be taken as evidence of the internalization of the care philosophy and practices outlined in both the PIECES and GPA frameworks: inquisitive problem solving (“putting the pieces together”), an appreciation that “all behavior has meaning,” and approaching clients/residents in a gentle, calm fashion are all evidence of such internalization. For this internalized knowledge to be *most* useful, it needed to reach and influence the care practices of as many caregivers as possible, including the family members struggling to maintain an active and effective role in providing care. For this, processes of socialization were essential within the culture of dementia care knowledge.



### **Socializing knowledge to contextualize responsive behaviors.**

Mentorship, modeling care, and small team meetings were all means by which tacitly held dementia care knowledge was shared with, or socialized, among staff caregivers. By way of these mechanisms, dementia knowledge that had been internalized from dementia training curricula (such as PIECES or GPA), from family members' knowledge of a person with dementia, or that had been gained at an individual level experientially, could be combined and spread as tacit knowledge among the care team. One RPN on the SCU, leveraging her authoritative power and enacting a role of leader and educator, described how she addressed PSWs who spoke harshly with residents:

Like so many times I hear them saying to the residents: 'Don't do that!' [said harshly, firmly]. So I'll say, 'We don't use those words here.' And they'll say 'Well why not, she--' you know, whatever they're doing, and I'll say, 'Number one, she doesn't know that she's doing anything wrong; number two, she's doing that in response to something that we've initiated within her personal space; and number three, it doesn't help one iota.'

But the RPN's redressing of (socialization of) the PSWs' approach was not limited to admonishing them; rather, the RPN would often model the gentle, persuasive approach. She explained that she would say to a PSW,

'Call me if you need help to get them into the tub room.' Like for some of [the residents], it's like walking the walk of doom towards that tub room, like they're just resistive as anything. So I say, 'Don't pull them along so roughly. Just come and get me before--' and I'll say, 'These are the ones that might give us

problems.’ So they come and get me and I’ll say, ‘Oh hi, come on, we’re going to go for a walk--’ and before they know it, the resident, they’re sitting in a tub chair ready to be dunked in the water.

While that might be taken as evidence of inter-disciplinary socialization – between registered and non-registered nursing staff – there were also accounts of intra-disciplinary socialization among the PSWs. This became evident, for example, in speaking with a PSW about what it is like to have to work with another PSW who is not familiar with the SCU residents and routines; the PSW said,

You know they've got to learn just like I learned but if I can guide them along or if I, you know, work as doubles with them, at least I know the residents are still getting the proper care and maybe they're kind of picking up on some tips. I mean if somebody does something I don't have a problem saying you know, ‘Next time try this,’ or you know, ‘They don't like if you do this or the family doesn't like if you do this.’

The PSW’s comment confirms that a significant portion of what one needs to know to care for someone with dementia is learned experientially, on the job, which indicates that the person with dementia plays a significant role in socialization the care practices bestowed upon him or her. Moreover, this experiential knowledge can be shared, or socialized, inter-subjectively. The PSW’s interest in ensuring ‘proper care,’ meanwhile, can be reconstructed as an indication that she values gentle, compassionate care, and that she feels concern for residents who might be treated otherwise, hence the practice of

working “as doubles,” a practice that afforded opportunities to show and/or model for the other PSW some caregiving tips *and* to ensure that proper care was provided.

As such, that PSW (re)produced a cultural norm that gives primacy to humane care practices, a norm that, as illustrated in the following quote, was supported and fostered by senior leadership members and by team leaders (i.e., the full-time registered nursing staff). Speculating on the differences between nursing and recreation staff, one registered nursing staff member said,

I think for nurses – as opposed to recreational therapists, their focus is recreation, so I think that they naturally think creatively – [yet] for PSWs, they can become very trapped in just being task oriented. And it takes a lot of pulling at them and stretching their mind and making them look at stuff to not just get stuck in the tasks. You know, toileting, transferring, feeding, stuff like that. And you’ll hear it. Like people will say, oh, she’s – he’s a toileter or he’s a feed, you know? No, he’s a human who needs to be fed. And I think that really is – I think that’s something that we work very hard at here and I poke at them about because it’s – that’s very, very important.

This overt effort to not objectify residents/clients was further supported by a clinical perspective that translated disease-related symptoms into behaviors. The purpose of this re-framing was to help staff members understand that the persons with dementia for whom they were caring were not vindictive or intentionally making caregivers’ jobs more difficult. In speaking with members of the senior leadership team, the discussion turned to consideration of how much medicalized knowledge PSWs need to do their job well,

and the suggestion was made that more so than knowledge about different kinds of dementia, PSWs needed support in learning how to socialize effectively with their clients/residents. Hearing this, another senior leader remarked,

I think the danger in totally ignoring that [medical, diagnostic] part or minimizing it is that you might take a particular behaviour as purposeful if you don't recognize it as a symptom, and I am particularly talking about frontal lobe dementias where behaviours are really sometimes bizarre and contrary, and if people don't understand that this is just as much a symptom as memory loss, they will look upon that person as contrary or making my life miserable on purpose. So that purposefulness, that translation of symptoms into behaviours is still a very important step as far as I can see.

The social power that inhered within the senior leadership team – a normative authoritarian power – was itself an effective means of socializing tacitly-held knowledge about dementia care. Moreover, leaders recognized that asking staff members to internalize explicitly *written* knowledge was unlikely simply because there was already literally so much paper on the walls, desks, and memo books in each unit. One member of the senior leadership team thus preferred regular face-to-face meetings for strategizing on how to care for particularly difficult SCU residents:

I think word of mouth is better than the written word. People– there's too many pieces of paper. Look at it. [She gestured to her own paper-covered desk]. People stopped reading it. Seriously. They stopped reading it. I mean if I have something really important I want to convey, I use a different colored piece of

paper. Because if I hand out a white piece of paper like that, it just gets put with all the other white pieces of paper. And I mean it's not that we don't try to keep up, but if you look at— go to any of these nursing stations and there's paper everywhere. Like it's difficult. That's why I think that a weekly word of mouth is far better— for your difficult situations, or if you have a family that's difficult. How are we going to tell— let's have the same united front — how are we going to answer them? What are the answers you're going to give them? Don't tell them this because we can't promise them that.

Ultimately, enacting socialized dementia care knowledge seemed to be determined not just by what care providers knew about dementia care as much as by social power and who was present to observe, mentor, audit, or report the care. As one PSW put it,

If management's around, you're going to do what management wants, whether it's right or wrong, whether you feel it's right or wrong. If family's around, you're going to do what that family asks, even if it is forceful to change those clothes. You know, that's what I mean: it's not an easy job mentally because what I might think is right might be completely wrong to someone else, right?

This comment perhaps suggests that rather than the care mantra being *do whatever works*, the social power at play within a dementia care site re-shapes the mantra as, *do whatever works, depending on who's around*.

***Reconstructed power in the justification of socialization of dementia care knowledge.***

An assumption in the analysis of the socialization of dementia care knowledge was that the socialization was akin to a transference of knowledge back and forth between two caregivers, and/or from an astute, capable caregiver *to or toward* a caregiver who either lacked dementia caregiving experience, or who did not abide with shared understandings of what was the appropriate way to care for someone with dementia. While there was evidence of other care acts being socialized – such as one PSW socializing another about completing their documentation tasks – the focus here is on the socialization of dementia care knowledge that was intended to benefit the person with dementia.

Such socialization was justified by intertwining objective, subjective, and normative claims. Three objectively referenced claims included the notion that staff members' own care practices can easily and unknowingly trigger or exacerbate responsive behaviors, the more backgrounded claim that such triggering is preventable, and the remotely backgrounded claim that what one might think is a rational and acceptable way to provide ADL and/or nursing care is often not perceived as such among people living with dementia. Related to these objective claims were subjectively referenced claims that subtly conveyed the compassion and concern that caregivers have for care recipients, especially if/when they are being cared for by someone who does not actively endeavor to preserve personhood. Thus, the related normative claims can be reconstructed as follows: caregivers should avoid harming a person with dementia by being rushed or impatient, and, furthermore, should avoid objectifying and dehumanizing the person. In other words, staff members should enact care practices that maintain personhood. In part, the socialization of this norm was fueled by charm, wherein

engendered loyalty and respect commanded compliance. Beyond that though, this norm was (re)produced by normative-authoritative relationships wherein the status conferred upon the super-ordinate garnered and enabled the socialization of care practices (as when a PSW does as instructed by a mentoring registered nursing staff member).

## **Discussion**

Both the observational and dialogic data in this study clearly indicated that staff members in both the SCU and the ADP sites encountered an assortment of responsive behaviors, ranging from physical and verbal aggression and resistance to exit seeking and wandering and collecting, from repetitive questioning to seemingly inappropriate social interactions. In delineating and accounting for how staff members responded to these responsive behaviors, the hermeneutic reconstructive analysis (Carspecken, 1996) showed that the use of force was, usually as a last resort, one way in which staff responded. This was justified by staff members in light of the organizational norm that gives day-to-day primacy to the completion of ADL tasks and that de-centres another (*the other*) prominent norm in the culture of dementia care knowledge, that of contextualizing the responsive behaviors. These findings contribute to the literature on violence in long-term care (Banerjee, Daly, Armstrong, Armstrong, Lafrance, & Szebehely, 2008; Levin, Beauchamp, Misner, & Reynolds, 2003) that has shown that the physical violence that is very nearly an everyday occurrence in most long-term care homes is attributed to the way in which work is organized and funded: there is not enough time or human resources to do so much work, a phenomenon Banerjee et al. describe as “structural violence” (p. iv). The findings presented here bring to the fore backgrounded organizational norms –

adhered to and (re)produced by upper management and point-of-care workers alike – that essentially condone the use of force in completing the ADL care, even in a culture that understood and had integrated into its care practices person-centred approaches such as GPA and PIECES. Despite subjective claims that staff did not like or want to use force, and were even afraid of being reprimanded, and despite the valuing of person-centred care, the concurrent perceptions that (i) residents with dementia would languish as their personal hygiene deteriorated and (ii) that the care work had to be done so as to not inconvenience others nor risk non-compliance, ultimately justified the use of force.

In examining these contesting norms and to find the meaning in a behavior so as to prevent it; and to, if necessary, use force to complete ADLs, distinct temporal elements in each norm emerged as significant. While staff did attempt and often succeed in contextualizing behaviors, it took time to do so – to document, assess, document, investigate, strategize, try an intervention, document, re-assess, etc. – and in the hours and days that passed as this investigative contextualization was taking place, there were care duties and ADLs that “had to get done.” When responsive behaviors manifested *before* they could be investigated and resolved or prevented, this was a culture that both tolerated the clients’ and residents’ physical aggression and, sometimes, met such aggression with physical force of its own.

This temporal rift perhaps reframes what Dupuis et al. (2012) described as the “inability to contextualize behavior” (p. 170) as being more than an issue of one received discourse dominating another; rather, the scenario might be more aptly described as two co-existing discourses wherein the more immediate needs and norms surrounding ADL care provision de-centre the slower-to-emerge products of the gentle, persuasive, ‘all



behavior has meaning' discourse. This raises implications for dementia care organizations trying to integrate into their workforces person-centred discourses by pointing out that usual care practices will likely continue to coincide with the "best practices" that unfold along a slower moving timeline than the activities of daily living. In re-cognizing that these two sets of practice coincide, managers and leaders might acknowledge that the more highly trained staff – registered nursing staff and recreational therapists – need to continue and perhaps redouble their efforts to contextualize and subsequently prevent the responsive behaviors rather than blaming point-of-care providers for an inappropriate approach when in fact that day-to-day care is being provided by staff who have not sufficient training, resources and support (Ersek, Kraybill, & Hansberry, 1999; Grabowski et al., 2010). Moreover and so as to provide the necessary resources and support, managers and leaders should remain cognizant that as the 'get care done' and the 'understand all behaviors' practices continue to coincide, so too should the propagation of dementia care knowledge that mitigates and prevents responsive behaviors.

***Implications for empowering therapeutic relationships with dementia care knowledge.***

Despite the normalization of the use of force during care provision, a number of coinciding knowledge generation processes provided staff members with the knowledge needed to *avoid* having to use force or restraint when responding to responsive behaviors. Following Nonaka (1994), such efforts could be seen to manifest in three different patterns of knowledge interaction: the *externalization* of tacit knowledge – shown here to

occur during intake and admission assessments and to have involved soliciting from family members their knowledge of ‘what works’ in caring for their loved one, as well as medical, social, and familial history; the *internalization* of explicit knowledge – this manifested within the context of specialized dementia training programs such as PIECES and GPA, as well as in making use of the person-specific knowledge previously externalized from family members; and the *socialization* of tacitly held dementia care knowledge, which manifested within a variety of intra- and inter-disciplinary roles that staff enacted, including mentor, coach, care partner, and strategist.

These findings lend support to the PIECES (P.I.E.C.E.S. Canada, 2008) and GPA (Schindel-Martin & Dupuis, 2005) initiatives that have attempted to integrate into long-term dementia care discourses of person-centeredness and responsive (rather than *dysfunctional*) behaviors. That informal mechanisms enabled socialization to occur is in keeping with previous research that showed that the sustained implementation of PIECES was greatest when, along with a supportive work environment and leadership, multiple staff members were trained and could engage in the mentoring and coaching of others (McAiney, Stolee, Hillier, Harris, Hamilton, Kessler, et al., 2007). This study’s findings also serve as a case in point of how the processes of internalization and socialization supplement one another, thus lending support to Nonaka’s (1994) assertion that an organization’s efforts should not be limited to internalization (education and learning events) only. Given also the significance of externalizing family members’ knowledge and of the subsequent internalization and socialization thereof among staff members committed to enhancing their own care practices, this study has shown that these three knowledge conversion processes sometimes occurred in an inter-related fashion such that

individually derived knowledge was elevated to team-level knowledge. In other words, these findings lend support to Nonaka's theoretical framework of the constituent dimensions of knowledge creation.

These findings also support previously stated assertions that (i) tacit knowledge is a "crucial component" of a team's ability to create new knowledge (Quinlan, 2009, p. 638; see also Greenhalgh et al., 2005), and (ii) that the externalization of tacit knowledge can be enabled by not only dialogue (Nonaka, 1994), but also by text-activated dialogue: standardized intake and assessment forms act "as constituents of the co-ordination of social relations within the institutional order of health care delivery" (Quinlan, 2009, p. 638). Indeed, the significance of tacit knowledge in dementia care should not be understated: as part of that which was externalized from caregivers already in the know, tacit knowledge was central to clinical judgment, and to appreciating individuals' "dispositions and generative schemes for being and perceiving" (Kontos & Naglie, 2009, p. 690).

Together these findings suggest that just as in public health research (Kothari & Wathen, 2012; Kothari et al., 2012), dementia care researchers and practitioners might be encouraged to uncover and leverage tacit knowledge in establishing collaborative health relationships. Indeed and in keeping with Nonaka's (1994) terminology, dementia care leaders and trainers might re-cognize their interactions with family caregivers as the opportunity to uncover and externalize tacit knowledge, just as they might re-cognize the inter-subjective relationships between and among caregivers and persons with dementia as space in which that tacit dementia care knowledge is socialized. Recalling Nonaka's warning that organizations must not over-emphasize the processes of internalization at

the expense of understanding how tacit knowledge is externalized and spread through socialization, such re-cognition of where and how tacit knowledge can be brought to bear on dementia care would supplement the more formal curriculum-based efforts to have care providers internalize dementia care knowledge. Consequently, a three-pronged approach to generating dementia care knowledge can contribute to establishing and maintaining a person-centred approach to dementia care. This can help advance the movement away from dominant medicalized discourses toward discourses and practices that preserve humanized and inter-subjective care.

### **In Closing**

The socialization of a person-centred norm in responding to dementia-related responsive behaviors was (re)produced by both normative-authoritative relationships that commanded compliance, and by the loyalty and respect that inhered in collegial and hierarchical relationships alike. Ultimately, this study has drawn attention to the need for dementia caregivers to be attuned to the communicative capacity of a person with dementia – a sensitivity that itself demands the re-cognition of their tacitly held but not easily communicated knowledge – *and* to be attuned to where and how tacit knowledge flows from and among clients and residents, staff, and family caregivers. In light of research that points out a need to re-conceptualize long-term and dementia care as knowledge work (Berta, Laporte, Deber, Baumann, & Gamble, 2013), such ‘dual attunement’ would contribute to the critically reflexive practice environment that Dupuis et al. (2012, p. 171) suggest is necessary for dementia care; rather than resorting to the use of force, care practices that are attuned to tacit knowledge can lead to “caring in

humane and relational ways, and in ways that allow [caregivers] the time they need to be truly present, [and to] understand the meaning in actions.”

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## – Chapter Seven – Discussion

This study took place in two dementia care sites: a specialized care unit (SCU) for residents living with advanced dementia in a long-term care home, and an affiliated adult day program (ADP) designed for clients with less-advanced dementia who were still living at home. The SCU was home to 32 residents living with advanced dementia, mostly of the Alzheimer's type, but also related to Schizophrenia, vascular dementia, Pick's, Creutzfeldt-Jakob disease, and Wernicke-Korsakoff Syndrome. The ADP was attended by up to 60 people per day living with a similar range of primary dementia diagnoses, albeit less advanced than those in the SCU.

The overall aim of this study was to understand how the influence of social power manifests in the culture of dementia care knowledge. In order to do so, a critical qualitative research (CQR) methodology was selected to guide the data collection and analysis (Carspecken, 1996). Ethnographic in nature, this study thus entailed a period of observation, followed by an interview phase. Additionally, a number of iterative member-checks were conducted throughout and toward the end of data collection as preliminary findings were shared with and refined by study participants. The defining feature of the CQR methodology (Carspecken, 1996) is its *hermeneutic reconstructive analysis*, constituted chiefly by three analytic techniques that serve to operationalize the theory of communicative action (Habermas 1985a, 1985b, 2003). The premise of hermeneutic reconstructive analysis has much in common with Quinlan (2009) and Nonaka's (1994) assertion that dialogic exchange among two or more people facilitates the articulation of observed and tacit knowledge, and that it is this shared experience through discussion that creates new knowledge. The delineation and reconstruction of these communicative

elements yielded a deep understanding of how dementia care knowledge is shaped by historical and socio-political influences.

Conceived and analyzed as CQR (Carspecken, 1996), the focus in this study was not just on what was said or on what knowledge emerged in these discussions; rather, the focus also included the non-discursive realm of communication, which Carspecken describes as the pragmatic horizon of a communicative act. Additionally, one of the analytic tacks taken in this study was to assess whether or not cultural practices were arrived at fairly and without coercion (Habermas, 2003). The analysis of social power in this study yielded insight into where and how coercive power was at play, thus pointing out cultural practices that were more or less oppressive in nature, in turn yielding a better appreciation of how social power influences the locally contained truth about dementia care. By re-cognizing cultural practices and beliefs in this light, a critically lit path toward less oppressive and more equitable care and work conditions became visible. A summary of study findings, insights, and implications follows further below; first though, this discussion turns to some methodological reflections.

### **Methodological Limitations and Reflections**

In Chapter Three, I outlined the triple crisis of representation (Denzin & Lincoln, 2005) in terms of crises of representation, legitimation, and praxis. I return to that framework now to consider the strengths and limitations of this study and to reflect on the utility of Carspecken's "CQR" methodology.

## **Strengths**

I identify three key strengths in this study: the overall coherence of the study, the democratizing intent and effect of the member-checking, and the legitimacy of the findings. First, a goal was to achieve ‘coherence and consistency’ in terms of the epistemological-methodological-knowledge claim linkages in this study (Holloway & Todres, 2003). While this might be taken as fundamental to all research, I believe my rhetorical treatment of a theoretically dense analysis has helped render such coherence: the critical values and ways of knowing described in Chapter Three provided both a foundation and a point of departure for this study as I was able to remain grounded therein while critically exploring and re-presenting study participants’ knowledge and lived experiences of dementia care knowledge. The claims this work makes – that oppression can be mitigated by normalized inclusiveness and by uncovering and leveraging tacit dementia care knowledge – are similarly critical. Bolstered by the merits of the methodology itself, I feel as though this dissertation does achieve ‘coherence.’

Second, the member-checks I conducted during the interview phase of data collection strengthened this study immensely. While I acknowledge that member-checking has its shortcomings (i.e., the possibility that participants chose not to or felt unable to contest my interpretations; the impossibility of member-checking all interpretations; and the risk that member-checking might (re)produce existing dominant and oppressive structures), I feel that the sequencing of field observations followed by initial meaning field reconstructions, followed in turn by in-depth interviewing and member-checking helped to both refine the data analysis and to fold into the analysis its subjects. That meaning field reconstructions were framed in the member-checks as a

range of possible meanings seemed to enable participants to confidently assist in honing the interpretations, and this frequently led to even richer dialogic data collection.

Third and as indicated in Chapters Five and Six, I believe I was successful in rendering a *legitimate* account of the knowledge culture under study. This was aided by being mindful of a number of criteria, including prolonged immersion, observations preceding interviews, interview topics derived from those observations, comparing interview data with observation data, and iterative member-checking of the reconstructive analysis. I thus believe the study findings reflect the participants' experiences of creating, sharing, and enacting dementia care knowledge in this one dementia care organization. While not generalizable, such an in-depth understanding, particularly of the normative and coercive powers that shape those experiences, will be relevant and applicable for other similar organizations where formal caregivers are providing dementia care. While I may have avoided a crisis of legitimation, I do wish to acknowledge the limitations in dealing with the crises of representation and praxis.

### **Limitations**

Regarding the crisis of representation, the imperative to reflexively consider how my gender, class, and race shaped the collection and re-presentation of the study findings stems from the recognition that study participants' lived experience is *re-created* in a researcher's text and that this in turn *creates doubt* about a researcher's ability to in fact capture participants' lived experience (Denzin & Lincoln, 2005). On this account, I feel as though my choice to use CQR limited my opportunity to demonstrate such reflexivity. Instead, CQR seems to generate findings and claims that, despite their interpretive-

reconstructive nature, reflect authoritative all-knowingness. Including Introduction #3 (Life as my CAGE) was meant to humanize this view from above, to show that certainly during data collection, I tried to be aware of how my presence, my way of being, might have affected the study participants. But Chapters Four, Five, and Six were essentially void of any such reflexivity, hence I count this as a limitation to the way in which this study was re-presented.

A second limitation has to do with the under-representation of family members' voices in this work. This study has indicated that family members do indeed play a significant role in the culture of dementia care knowledge insofar that they are a key source of knowledge related to staff members' sense of care recipients' personal and unique history, and of knowledge related to that which provides meaning in care recipients' lives. That said, the study data and the findings presented here focused on staff members' interactions and on the nature of the mechanisms by which their dementia care knowledge was created, shared, and enacted. This focus on staff reflects a claim that during the periods of observation, family members were often not present; moreover, since CQR stipulates that interview data be derived from and compared to observation data, the bulk of the interview data focused on staff members. That is not to say though that family members were not included in the observation and interview phases of data collection, they were, but the generative themes that emerged from the data – and subsequently their presentation in these findings – was limited to staff members' experiences of and within the culture of dementia care knowledge. A more thorough integration of family members' perspectives and experiences of creating, sharing, and

enacting dementia care knowledge is likely to have yielded an even deeper understanding of the culture of dementia care knowledge.

A third limitation of this study has to do with praxis. I indicated in Chapter Three that my efforts to enact a pedagogy of praxis draw largely on Freire (1972). I attempted to render accounts of this knowledge culture that may help most individuals living or working in dementia care to not just recognize, but to *re-cognize* situations that they commonly find themselves in. And in seeing the situation anew, in seeing how various actors in this knowledge culture – and perhaps even they themselves – are complicit in negating and oppressing others, the intent has been to divide and reconstruct the whole of the situation so as to stimulate a new perception of problematic living and working conditions, and subsequently to encourage dialogic conditions where previously unperceived practical solutions come to light (Freire, 1972). Partly because my strategy for exiting the research field was open-ended and carried with it a ‘to be continued’ tone, and partly because these study findings are just now (potentially) reaching the study participants and other dementia care stakeholders, I am unable to judge the extent to which the study findings are catalytic. This is a limitation I return to further below in considering the future directions of this project.

### **The Utility of CQR**

Regarding Carspecken’s (1996) CQR methodology itself, the time and effort required to understand, employ and orchestrate its myriad elements and idiosyncrasies posed a significant challenge, and the concerted efforts that resulted in Chapters Five and Six were in effect bound and somewhat constrained by the novelty and complexity of



Carspecken's hermeneutic reconstructive analysis. That said, I believe that my deep engagement with hermeneutic reconstructive analysis is what contributed to my success in rendering a legitimate account of this knowledge culture: I was afforded a set of critical values, tenets, and schema that yielded me deeper insights than I could otherwise have imagined. This was aided (i) by the internalization of the figurative heuristic that helped me to conceptualize the pragmatic horizon of hermeneutic interpretation (recall Figure 4.3), and (ii) by the use of both *a priori* and *in vivo* coding, the former of which helped with the orchestration and retrieval of CQR's constitutive elements, while the latter framed the development of an emerging sense of how dementia care knowledge was created, shared, and enacted. I believe also that my deployment of CQR benefited from the attention paid to the triple crisis of representation (Denzin & Lincoln, 2005): while the legitimation of the study findings is in part a function of adequate and valid hermeneutic reconstructive analysis, the potential achievement of praxis is, additionally, a function of how those legitimate findings are re-presented. While a writer's craftwork might always feel imperfect, I feel that the fore-fronting of the crises of praxis and representation has assisted in rendering this legitimate account of this culture of dementia care knowledge and in achieving its critical aims.

Moreover, my immersion into and deployment of CQR has forever changed me: I have experienced tremendous growth in my ability to find my bearings in the variably deep and choppy waters of critical epistemology, and I have internalized what *hermeneutics* is and what hermeneutic reconstruction entails *and feels like*. It feels like I am doing it all the time, constantly delineating the meaningful and inter-subjective moments in my own life into normative and subjective realms, peering around the back

of language to grasp and bring to the fore that which is backgrounded, spotting power. Such critical growth is akin to insights that cannot be unseen, and I expect now to encounter and build upon this growth as I continue to develop a critical program of research.

### **Summary of Study Findings**

The findings presented in this study were based on a conceptualization that dementia care knowledge means knowing how to read and interpret a person with dementia and how to prevent and respond to responsive behaviors, often while assisting with activities of daily living (ADL). Thus, in addition to assisting with personal care, the routine care practices that inhered in providing advanced dementia care focused on providing opportunities for meaningful social engagement and/or meaningful leisure activities, and, in doing so, on mitigating the frequency and severity of responsive behaviors. This latter practice was enabled by collective efforts among staff members to ‘read’ or ‘become attuned to’ the person with dementia, to contextualize and understand the unique personal history of care recipients, and to share this knowledge through a variety of mechanisms, both verbal and written, formal and informal. As reading and interpreting a person with dementia occurred, social and organizational powers variably took form as normative, coercive, and charming power, often in a complementary way, to shape the dialogic conditions that manifested at the moment that the reading of a person with dementia became shared knowledge.

Insofar that a culture can be understood largely in terms of the norms that govern it (Carspecken, 1996), the normative aspects of the culture of dementia care knowledge in

this study can be characterized by the following five statements of what is (or is not) appropriate: (i) Caregivers should ‘take the position of’ and advocate for the person with dementia for whom they are caring so as to ensure that that person remains included – even if by proxy – in the care planning process; (ii) In planning and providing care, caregivers should seek to establish and maintain an authentic, inter-subjective relationship with the care recipient(s) – even if non-verbal – so as to re-cognize the body as a site of knowledge production (Kontos & Naglie, 2009) and to in turn re-cognize care needs and/or changes in care recipients’ psycho-social status; (iii) The planning and provision of care should be informed by the judgment and experience of those who have been or are most familiar with the care recipient – and should thus include family members’ and personal support workers’ knowledge – and, moreover, this planning and provision of care should be shared and democratic in nature; (iv) Caregivers should respect care recipients’ choices and preferences; and (but), (v) If/when clients’/residents’ choices and preferences need to be reconciled with an organizational mandate (norm) to assist with personal care and to keep clients/residents safe, caregivers should use a variety of (ideally, non-coercive) strategies to persuade care recipients to accept care. These cultural norms manifested in a variety of sometimes contradicting social roles (e.g., mentor, educator, tone-setter; advocate, shared decision-maker, provider of contextual knowledge; compliant sub-ordinate, want-to-be knowledge sharer, the too-busy worker). Ultimately, these cultural norms permeate the study findings and bear directly on the recognition of social power described in Chapters Five and Six.

Chapter Five – *Re-cognizing Social Power in Reading and Interpreting People with Dementia in Long-term Dementia Care* – asserts that the reading and interpreting of

a person with dementia occurs in both inter-subjective and digital/electronic realms, and the analysis in Chapter Five resulted in three power themes by which to conceive of the conditions of discourse in this situation: (i) the democratic co-construction of knowledge; (ii) the unjust distortion and exclusion of knowledge; and (iii) normalized inclusiveness in knowledge generation. It was suggested that democratic conditions for the co-construction of knowledge are an ideal for dementia care organizations to strive toward wherein inclusiveness and the freedom to speak and ask questions are all maintained so as to benefit, in particular, the care recipients, but also the caregivers who take the position of and advocate for those for whom they care. Moreover, for organizations or for groups of caregivers that find themselves in converse conditions – those that lead to the unjust distortion and exclusion of either the people affected by a care decision and/or their knowledge – emulating the third power theme of normalized inclusiveness in knowledge generation can help a group of caregivers become more democratic and to come closer to achieving the ideal conditions for ethical (dementia) discourse, thereby mitigating the marginalization of those whose knowledge is excluded. As the conditions for the democratic co-construction of knowledge are achieved, caregivers, ideally, become attuned to both the communicative capacity of the persons with dementia for whom they care, while also becoming attuned to social and organizational power in dialogic exchange.

Chapter Six – *Reconstructing (Responses to Responsive) Behaviors in Dementia Care by Re-cognizing how Social Power Interacts with Tacit & Explicit Knowledge* – focused on the manifestation of power in staff members' actual responses to responsive behavior. Grossly dividing such responses into therapeutic and forceful responses, a

critical examination of the latter type showed how and why the use of force was justified within this culture of dementia care knowledge. This justification centred around the assertion that without forcefully intervening to overcome clients' and (especially) residents' resistance to ADL care, a person with dementia would languish, perhaps unfed and unclean, or be left for the next caregiver on the next shift. Staff did not like to have to use force, but, despite their reticence, the cultural norm that dominated care practices was to use force if necessary to complete the tasks of assisting with ADL care. This is something that individual caregivers and organizations alike need to explicitly come to terms with as they form and maintain relationships with the people for whom dementia progresses and affects.

What made this finding about the justification of using force all the more remarkable is that this occurred even though a person-centred philosophy of care had more or less become integrated into the organization. This was apparent in all the *other* ways that staff responded to responsive behaviors, be that an effort to contextualize and understand the behavior so as to prevent it; using a calm, gentle approach; both passive and explicit validation of a person's interests or concerns; and/or the provision of therapeutic activities and social engagement. Person-centred attitudes and practices were also evident in tracing the generation, conversion, and spread of tacit dementia care knowledge.

### **Summary of Key Insights**

The findings of this study give rise to a number of key insights and related points of significance. The first is that normalizing inclusiveness in generating dementia care

knowledge is akin to democratizing the hierarchical and classist relationships in long-term dementia care work environments. This is important because the more that dementia care knowledge is co-constructed under ethical conditions of discourse (where people are free from coercion, free to share their perspectives, free to ask questions or critique, and where *all* those affected by a care decision are involved in making it) – under these conditions, I contend that the subjective state of caregivers can better flourish in a way that is conducive to dementia care. That is, rather than be consumed with the resentment and frustration that spawns from being devalued and disrespected by super-ordinates, the respected and included sub-ordinates can focus their time and energy on being present with the persons for whom they are caring (while presumably enjoying greater job satisfaction). The conditions that enabled such normalized inclusiveness centred around leadership that embodied a role of *educator-as-facilitator of knowledge exchange*; such strong leadership, rather than coercively deploying authoritative status, created space for the inclusion of others' knowledge, and for the empowerment of sub-ordinates wherein they felt equally valued.

The second insight relates to the temporal distinction between two prominent and somewhat contradictory care norms in the SCU setting – that of understanding and contextualizing the meaning bestowed in a responsive behavior, and that of using force when necessary to complete ADL-related tasks. These co-existing care routines not only contest one another, they manifest or *unfold* along very different timelines. The care work that goes into understanding a responsive behavior is often very slow to evolve: observations lead to discussions, postulations, assessments and investigations; finally, an intervention is trialed, and it may or may not work, or it may work but not for long so the

cycle begins again, and all the while, each step is documented. *And meanwhile*, the so-called less-skilled and definitely less-paid care workers continue to provide the hands on, day-to-day ADL care, often for eight or nine or more residents, some of whom continue to exhibit responsive behaviors every day, sometimes every hour or half hour, sometimes seemingly every minute. These distinct and starkly contrasting timelines of investigating a responsive behavior and of caring for someone exhibiting a responsive behavior seems to reflect and further reproduce the hierarchical relationships between professional and unregulated staff, and warrants either that less blame be placed on point-of-care care providers (PSWs), that the ratio of PSWs to persons with dementia be increased, and/or that professionally trained and regulated workers develop and integrate new mechanisms to better contextualize responsive behaviors in a more timely manner.

The third insight is that in order to better contextualize responsive behaviors in a timelier manner, organizational managers and leaders need a three-pronged approach to generate the requisite dementia care knowledge, wherein the three prongs iteratively include (i) the internalization of known best practices (i.e., successful education events); (ii) the externalization of family members' knowledge *followed by the subsequent internalization thereof*, and (iii), the socialization of all this now-tacitly-held knowledge. Rather than relying on the haphazard and disjointed outcomes of any one of these knowledge generation processes, the suggestion is that a concerted effort be made to optimize and integrate *and make available and accessible* the collective knowledge that is produced by all three processes together (Brown & Duguid, 1991; Nonaka, 1994).

### **Implications of Key Insights**

In keeping with CQR, each of the following implications is stated as a normative claim, that is, as what *should be done* in a dementia care setting that (i) espouses and upholds the conditions for ethical discourse, (ii) acknowledges the temporal rift between investigating and responding to responsive behaviors, and (iii) that takes a concerted, three-pronged approach to generating dementia care knowledge.

### **Implications for Dementia Care Practice**

As family members and staff establish and maintain relationships in their efforts to create, share, and enact dementia care knowledge, and as they collectively strive toward enacting and normalizing inclusive care planning (Hennings, Froggatt, & Keady, 2010; Petriwskyi, Robinson, Parker, Banks, & Andrews, 2012), they would do well to recognize coercion and to flag it to be redressed. This might entail folding into and nurturing within the culture of dementia care knowledge the practice of re-cognizing the vulnerability of sub-ordinates' subjective state when coercion does manifest and how this can potentially affect care recipients negatively. This kind of reflective practice should entail an understanding of which communication strategies disable and enable triadic communication among family members, staff, and residents/clients (Adams & Gardiner, 2005).

A second practice implication relates to making an active effort to eliminate blaming practices by re-cognizing the temporal distinction between contextualizing responsive behaviors and having to care for someone who continues to exhibit responsive



behaviors, that is by acknowledging that while the responsive behavior is being ‘figured out,’ daily care must carry on. It should not be presumed that the manifestation of responsive behaviors during the provision of ADL care is the fault of care providers (Morgan, Cammer, Stewart, Crossley, D’Arcy, Forbes, et al., 2012); instead, regardless of being paid or unpaid, regulated or unregulated, all care providers should focus on exchanging their particular knowledge of a client/resident so that the behavior can be contextualized and mitigated in a more expedient fashion (Dupuis, Wiersma, & Loiselle, 2012).

Moreover, during such investigative care planning, if the person with dementia is not or cannot be present, staff leaders and/or family members should have someone take the position of the care recipient and imagine, exhaustively, what the person with dementia might want, need, or be interested in, and have that person assume a role of advocate during the care planning. Such ‘position taking’ runs a risk of misrepresenting the person with dementia’s true preferences or intentions, but this risk might be mitigated by promoting the equal participation among all those affected by the care planning, by providing the resident or client with opportunities to talk, and by being sensitive to non-verbal cues (Adams & Gardiner, 2005; Kontos, 2005).

### **Implications for Dementia Care Education**

As an extension of the practice implications stated above, those who develop and offer specialized dementia care education might consider explicitly acknowledging and discussing in their training sessions the temporal distinction that separates investigating a responsive behavior (Egede-Nissen, Jakobsen, Sellevold, & Sørli, 2013; Keady & Jones,

2010) and (in the meantime) responding to it. Furthermore, in service of establishing inclusiveness, educators might consider modeling in their education events the conditions for ethical discourse (Adams & Gardiner, 2005), perhaps as a set of new, institutional ground rules. Educators might also orient learners – including family members – to varied patterns of knowledge generation (Nonaka, 1994) and orient and encourage the targeted learning group to engage in the externalization and socialization of others' tacit knowledge so as to enhance their ability to contribute to care planning. Doing so might contribute to broadening the vision of 'personhood' in dementia care (O'Connor, Phinney, Smith, Small, Purves, & Berry, 2007) by instilling in learners the value of and a commitment to become knowledge brokers, thus creating a positive feedback loop between being valued and being able to grasp and leverage tacitly-held dementia care knowledge.

### **Implications for Dementia Care Policy**

In terms of policy implications for organizations that are interested in establishing a more ethical, practical, and astute culture of dementia care knowledge, organizational leaders and managers might make it a policy to plan and deliver care within the conditions of ethical discourse (Dupuis, Gillies, Carson, Whyte, Genoe, Loiselle, et al., 2013; Habermas, 2003; Mitchell, Dupuis, & Kontos, 2013; Sellevold, Egede-Nissen, Jakobsen, & Sørli, 2013). Toward this end, Dupuis et al. have developed a concept of 'authentic relationships,' while Mitchell et al. have suggested that the notions of 'embodied selfhood' and 'knowing other-wise' can transform the nature of dementia care relationships from suffering to affirming. The power analysis in this study further

suggests that organizations might enact this policy by leveraging a combination of authoritative-normative and charming power to eliminate hierarchical divisiveness, coercion, and exclusion. These leaders might suppose further that those who do not or cannot abide by these conditions need to be shown compassion and concern about whatever else is going on in their lives. Similarly, consideration might be given to developing mechanisms to orient and involve family members in long-term dementia care (rather than *process* them through LTC) and to externalize their tacitly held knowledge about caring for their loved one. Olsson and colleagues (2012), for instance, found that the use of information and communication technology was useful in meeting the needs of family caregivers, while another study showed that long-term relationships that included a multidimensional assessment were found to help coordinate care among family members and persons living with dementia (Judge, Bass, Snow, Wilson, Morgan, Looman, et al., 2011). These studies thus suggest that policies should be considered to develop mechanisms – formal and informal, relational and electronic – to make the person-specific knowledge that is available *accessible*.

A separate policy implication relates to the status of PSWs: given the emerging recognition of PSWs as caregivers with invaluable knowledge about the status of and ways to relate to dementia care recipients (Berta, Laporte, Deber, Baumann, & Gamble, 2013), organizational leaders and managers should endeavor to elevate the status of PSWs by way of enhancing and regulating the dementia-focused education they receive and by explicitly acknowledging – on an individual, one-by-one basis – the knowledge work PSWs perform. In the home care sector, research toward this end has focused on understanding what drives recruitment and retention of unregulated home care workers

(Sims-Gould, Byrne, Craven, Martin-Matthews, & Keefe, 2010) and what factors contribute to the provision of effective, efficient, and respectful care (Sims-Gould & Martin-Matthews, 2010); similar efforts are warranted in long-term dementia care (Berta et al., 2013). Additionally, an organization might further acknowledge the value of its PSWs by developing the means to increase the ratio of PSWs to clients/residents with dementia (Karantzas, Mellor, McCabe, Davison, Beaton, & Mrkic, 2012).

### **Implications for Knowledge Translation and Dementia Care**

This study also carries with it a number of implications for KT and dementia care, the first of which is a re-cognition that the “best practices” in dementia care are (only) principles, and that the knowledge one needs to *do* dementia care is extremely particular and requires the externalization and socialization of *person-specific* knowledge. As such, in deciding what constitutes the “evidence” to be translated to and among care providers (Bluhm, 2005; Rycroft-Malone, Seers, Titchen, Harvey, Kitson, & McCormack, 2004; Staus & Haynes, 2009), KT practitioners should re-cognize the ubiquity and salience of tacit knowledge in dementia care (Kontos & Naglie, 2009) and ensure that KT efforts in dementia care take into full account the genesis and conversion of tacit- and explicit-knowledge (Kothari, Rudman, Dobbins, Rouse, Sibbald, & Edwards, 2012). Doing so might further substantiate efforts to foster bottom-up KT practices (rather than top-down, authoritatively driven KT practices) that include family members and point-of-care workers and that are grounded in the tenets of ethical discourse: inclusion of all those affected by the practices, freedom from coercion, freedom to speak, ask, and critique.

Methodologically, this study has demonstrated the potential of Carspecken's (1996) CQR methodology to discern and reconstruct the power that inheres in and constitutes a particular knowledge culture. This was achieved by reconstructing a sense of what contributes to a lack of recognition of one person's care knowledge by others, and of why and how one might experience an absence of control over one's work. The nature of these insights is relevant to KT scholars and practitioners who appreciate that as a part of context, the knowledge culture being studied or targeted for a KT intervention needs to be understood in terms that make clear the influence of social power among and between the culture's constituents and the intervening knowledge translators (Quinlan, 2009). As such, this study has contributed to re-conceptualizing and operationalizing "culture" and "context" in ways that consider the broader (often oppressive) social forces at play in constituting dementia care knowledge, thus offering deeper insights into the 'hidden complexities' of the long-term care context (Cammer, Morgan, Stewart, McGilton, Rycroft-Malone, Dopson, et al., 2013) and, specifically, its knowledge culture. This critical methodological contribution can potentially be applied to care settings beyond dementia care where efforts to enhance inter-disciplinary and person-/family-centred care are underway.

### **Future Research**

A number of potential research questions arise out of this study, the first two of which relate directly to ethical considerations. First, in terms of implementing a culture change, how feasible is it to introduce the conditions for ethical discourse (Habermas, 2003) in long-term and dementia care? And related to this, how would one ever know of

(or possibly police) violations of a presumed commitment to non-coercive relations? In other words, while the conditions for ethical discourse are arguably sound and indeed *ethical*, to what extent can one expect dementia care organizations' staff, family members and clients/residents to adopt and enforce among themselves these conditions as a kind of *way of being*, or as a performance expectation? Might other, more entrenched organizational and/or political discourses preclude the conditions for ethical discourse from taking hold? How could entrenched hierarchies and attitudes among staff (Stolee, Esbaugh, Aylward, Cathers, Harvey, Hillier, et al., 2005) be displaced so that the rhetoric of inclusive and ethical care can be realized?

A second future research question related to ethics asks, what else can be learned about the use of force in dementia care? Is the use of force to be attributed to the 'structural violence' that inheres in the way long-term care work is structured and organized (Banerjee, Daly, Armstrong, Armstrong, Lafrance, & Szebehely, 2008)? What would happen if staff abstained from using force in completing ADLs and instead just re-approached, re-approached, re-approached? How do families – at various stages of dementia – come to expect, condone, or detest the use of force? And, how would the addition of more human resources (more PSWs) affect the rate of occurrence of the use of force? The concerning normalization and justification of using force found in this study confirms the findings of Daly and colleagues (2011), and research that aims to better understand and change this care norm seems warranted.

Third and related to the professional identities of PSWs, future research might pose the question, what would serve to elevate the status of PSWs within the knowledge culture of dementia care? What innovative strategies can an organization deploy to

generate and pay respect to this sector of the health care workforce? A place to start, perhaps, might be to follow the call of Berta and colleagues (2013) who suggest that PSWs' work be re-recognized as *knowledge work* (a claim supported by this present study) and that PSWs' attitudes, motivations, and decision-making abilities be further explored. While this is arguably an important step toward understanding the needs and attributes of this group of caregivers, such investigations should not de-centre the concurrent need to enhance the social status bestowed upon this group of unregulated albeit invaluable care workers. Researchers can and should focus their enquiries to this end.

Related to gaining a better understanding of knowledge cultures and knowledge work, a fourth area of future research might ask, how can a dementia care organization optimize the solicitation and garnering of care recipients' existing tacit knowledge about their own care needs? What innovative mechanisms can improve this externalization? Subsequently, how can this just-externalized knowledge be made accessible – not just available, but accessible – to other caregivers? While this question might well be examined through a CQR lens, it might be examined too through alternative critical methodologies, ones that perhaps give more primacy to understanding how texts and/or other non-human actors shape the culture of dementia care knowledge (e.g., institutional ethnography – see Smith, 2005, or actor network theory – see Law, 2009).

Such postulations relate to a fifth area for future research stemming from this study, a methodological one, which is to explore further the utility of using 'critical qualitative research' methodologies – be that of Carspecken (1996) or other critical, power-focused methodologies – in assessing different knowledge cultures within and beyond the field of long-term dementia care. Following the suggestion that skillfully

facilitated reflective nursing practice can yield valued and significant change to clinical practice (Paget, 2001), warranted specifically is an exploration of the extent to which findings from this critical, qualitative examination of the culture of dementia care knowledge can be used as a fulcrum to leverage deeper reflection en route to mitigating oppression and marginalization in care sites where similar services are offered.

## **Conclusion**

This dissertation opened by invoking the metaphor of a quilt to describe the product(s) of the qualitative researcher who pieces together a “set of representations” to fit “the specifics of a complex situation” so as to create “psychological and emotional unity – a pattern – to an interpretive experience” (Denzin & Lincoln, 2005, pp. 4-5). While my threads bear the markings of Carspecken (1996), they have been woven together in a way that I think Denzin and Lincoln would approve of – that is, to create and enact moral meaning. The unifying pattern that holds this particular quilt together is one of a critically expanding horizon that brings to bear on our understanding of dementia care knowledge backgrounded norms and subjectivities, taken-for-granted roles and significations, and unseen temporal distinctions. The intent has been to expand and illuminate our horizon of meaning-making as it relates to dementia care knowledge such that those who have been marginalized and oppressed can be re-centred.

To this end, this study of the culture of dementia care knowledge has critically examined the ways in which dementia care knowledge is created, shared, and enacted. Its findings about the how and why particular norms govern the knowledge culture have given rise to the claims that oppression can be mitigated by normalized inclusiveness and



by uncovering and leveraging tacit dementia care knowledge. Moreover, its findings point to a number of practice, education, and policy implications, which collectively espouse the conditions for ethical discourse, acknowledge the temporal rift between investigating and responding to responsive behaviors, and advocate for a concerted, three-pronged approach to generating dementia care knowledge.

The findings, claims, and implications of this study are theoretically derived. That is, the epistemological and axiological tenets that inform this study's methodology have been drawn upon extensively in rendering this presentation of its findings. It has been suggested that such theoretical scholarship can inform both the field of dementia care by identifying its unethical and oppressive aspects, and the broader field of KT where scholars' attention continues to concentrate on how social power manifests within and affects a particular culture, and on how different forms of knowledge – including tacit knowledge – can be re-cognized and integrated into the planning and implementation of KT initiatives. An even more reflexive deployment of the CQR methodology in/as KT science might entail turning the methodological lens upon researcher-knowledge user relationships: henceforth, efforts to establish and maintain collaborative and integrated relationships through iterative cycles of creating, refining, implementing, and evaluating knowledge can benefit from data collection and analysis strategies that both illuminate and democratize the power disparities that inhibit successful integration.

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Appendix 6: Letter of Information & Consent Form

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<b>Table 4.1: Four RAI-MDS Outcome Scales – SCU residents</b>		
<b>Outcome Scale</b>	<b>Score Range</b>	<b>No. of SCU Residents in that Range</b>
<b>Cognitive Performance Scale (CPS)</b> A five-item scale that ranges from 0 (intact) to 6 (very severe impairment). Note that a CPS score of 3 is equivalent to a 15 (out of 30) on the Mini Mental State Exam.	5 – 6	19
	3 – 4	13
	0 – 2	0
<b>Aggressive Behavior Scale (ABS)</b> A 4-item scale that ranges from 0 (no aggression) to 12 (verbally and physically aggressive and/or socially inappropriate or disruptive).	0 – 3	16
	4 – 8	8
	9 – 12	8
<b>Depression Rating Scale (DRS)</b> A seven-item scale that ranges from 0 to 14; a score of 3 or more may indicate a potential or acute problem with depression.	0 – 2	8
	3 – 7	17
	8 – 14	7
<b>Activities of Daily Living – long form (ADL long)</b> A seven-item scale ranges from 0 to 28; higher scores indicate more impairment of self-sufficiency in ADL performance.	< 10	1
	10 – 14	6
	15 – 19	9
	20 – 24	10
	25 – 28	6

<b>Table 4.2: Data Collection</b>			
<b>Data Source:</b>		<b>Specialized Care Unit</b>	<b>Adult Day Program</b>
Stage 1 (Apr 12 – Jul 31 2012)	field visits	25	9
	observation	81 hours — average 3.25 hours / visit — range 2.5 – 7 hours — all days of the week, including five weekend visits — observations started as early as 6 am and ended as late as 1130 pm) — included the collection of discursive artifacts (i.e., documents) used in providing dementia care	65 hours — average 7.25 hours / visit — range 2.5 – 8 hours — all days of the week, including two weekend field visits — observations started as early as 730 am and ended as late as 7 pm) — included the collection of discursive artifacts (i.e., documents) used in providing dementia care
	informal interviews	8 — a male resident’s spouse; another male resident’s daughter; six with staff (1 physician, 2 RPNs, 4 PSWs)	3 — Recreation, RN, RPN
	observed & recorded team meetings	1 — ‘Team Care Meeting’ that included a male resident’s daughter and six staff	6 — Team ‘check-ins:’ 3 among nursing staff, 3 among recreation staff
	in-depth interviews	1 — Someone from the SLT who was about to retire)	1 — male client’s spouse
Stage 2 – Preliminary Reconstructive Analysis (July 25 – Aug 7 2012)			
Stage 3 (Aug 7 – Sept 12 2012)	field visits	4	4
	observed & recorded team meetings	0	3 — Rec team check-in; a Team Care meeting; a Behavioral Committee meeting)
	in-depth interview	7 — A.DoC, 1 RN, 2 RPNs, 2 PSWs, LE	3 — Recreation, RN, RPN
Return to Stage 2 – Continued Reconstructive Analysis (Sep 12 – Dec 11 2012)			

member-checking interviews (conducted over 3 field visits, mid-Dec 2012)		SLT focus group (n = 10)	
		7 — LE, RPN, 5 PSWs	5 — 4 PSWs, 1 RPN
TOTALS	# of months in the field	9 (*footnote: 9 includes the 3 month analytic hiatus. Stages 1-3 essentially lasted 6 months; I then returned approx. 3 months later to conduct 3 days worth of member-checking interviews)	
	field visits	45	
	hours of observation	146	
	informal interviews	11 (2 with family caregivers)	
	observed & recorded meetings (in-depth & member-checking)	10 (12 & 12 =)	
	interviews	24 (1 with family caregiver)	
	focus groups	1	
Legend: SLT = senior leadership team; A.DoC = assistant director of long-term care home; RN = registered nurse; RPN = registered practical nurse; PSW = personal support worker; LE = life enrichment staff			

<b>Table 4.3: Ten most prominent CQR Code-Categories &amp; their respective Sub-codes (developed <i>a priori</i>)</b>		
<b>Code-category</b> ○ Sub-code(s):	<b>Description / Comment</b>	<b>Sample(s)</b>
<b>99.01 – bid to shift the setting</b> ○ 99.01.1 – successful attempt ○ 99.01.2 – failed attempt	Indicative of power dynamics: a successful bid shows that the person has power to shift the setting; a failed attempt can indicate that a person is overpowered by another participant.	○ A physician shifts the conversation setting from small talk to starting the task at hand - chart reviews (successful bid). ○ A family member during a team care meeting shifts the setting from her father's evening care to her father's issues with weight loss and gain (successful bid). ○ One resident succeeds in engaging another resident in polite conversation, but fails to clearly articulate a question about finding something she is looking for (failed bid). ○ A PSW who is charting overhears the RPN and physician talking about a particular resident, offers input in the form of a comment, but her comment is not acknowledged (failed bid).
<b>99.02 – consenting to a claim or decision</b> ○ 99.02.1 – coercive conditions ○ 99.02.2 – non-coercive conditions ○ 99.02.3.1 – consenting for psychosocial reasons ○ 99.02.3.2 – ... for strategic reasons ○ 99.02.3.3 – ... for material reasons ○ 99.02.4 – not-consenting	Used to discern seemingly coercive from non-coercive situations; in cases of the latter, the reason why someone seemed to consent was coded (i.e., what was in it for them).	○ A resident remains seated because a PSW's hand on her shoulder prevents her from standing (coercive). ○ An RPN from one shift explains to me that she gave up struggling with the staff from another shift regarding the seating plan in the dining room (psychosocial rationale for consenting). ○ While administering medications during lunch, an RPN allows a resident to stand and leave the dining area despite not being done her meal yet; the RPN appears too busy with her task at hand to be able to redirect the resident back to her meal (strategic consent).
<b>99.03 – Observed embodiment</b>	I came to this study with an interest in knowing when and how caregivers seemed attuned to clients'/residents'	○ A family member explains that even though some of the SCU residents do not respond to her words, <i>some do with their eyes</i>

	<p>embodied selfhood – i.e., when and how did was body language interpreted? Moreover, a Carspeckian (1996) analysis understands that communicative acts are “initially entirely holistic, tacit, and embodied” (p. 125).</p>	<p>... <i>I just like to humor them a bit, and tease them. Some of them respond.</i></p> <ul style="list-style-type: none"> <li>○ A field note excerpt: a particular female resident seems intrigued by some other residents’ behaviors (singing aloud, hollering loudly); it is as if she wants to but cannot engage the other residents; rather, she seems to spend her time paying close attention to what these others are doing, often following from a distance.</li> </ul>
<p><b>99.05 – Tracking the Interviewer</b></p> <ul style="list-style-type: none"> <li>○ 99.05.1.1 – asking a question</li> <li>○ 99.05.1.2 – seeking clarification</li> <li>○ 99.05.2.1 – active listening</li> <li>○ 99.05.2.2 – bland response</li> <li>○ 99.05.2.3 – non-leading leads</li> <li>○ 99.05.2.4 – low inference paraphrasing</li> <li>○ 99.05.2.5 – medium inference paraphrasing</li> <li>○ 99.05.2.6 – high inference paraphrasing</li> <li>○ 99.05.03 – member-checking</li> </ul>	<p>This is a reflective practice that serves to monitor not only my own question-asking, which should be concrete, non-leading, an ‘domain opening,’ but these codes also allow me to monitor my ‘response work,’ which Carspecken (p. 158-161) describes as “much more important than the wording of [my] questions.” A reflective exercise to conduct is to consider the extent to which I used the appropriate kind of response at the appropriate time.</p>	<ul style="list-style-type: none"> <li>○ The questions I asked (in the context of either an informal or in-depth interview) were usually topic-based. E.g., <i>Something I’ve heard people talk about is ‘appropriateness’ – can you talk about that for a minute?</i> (asking a question)</li> <li>○ I might encourage the respondent with <i>Uh-huhs and Mm-hmmms</i>, by saying, <i>I see ... or, Tell me more about that.</i> (active listening; non-leading leads)</li> <li>○ I paraphrase a family member’s sentiment when I infer from her statement that the PSW she has hired privately seems to be welcomed and accepted and appreciated by the SCU staff (low inference).</li> <li>○ In a member-checking interview, I solicited input and reactions to a high-level inference regarding the seemingly blurry line between ‘going with a resident’ wherever their current state of mind takes them, and using therapeutic lies to keep a resident calm (member-checking, high inference).</li> </ul>
<p><b>99.07 – Paradigmatic axis</b></p> <ul style="list-style-type: none"> <li>○ 99.07.1 – contrast or opposition</li> <li>○ 99.07.2 – hierarchical inclusion</li> <li>○ 99.07.3 – reference to</li> </ul>	<p>As part of the pragmatic horizon of communication, the paradigmatic axis includes communicative structures (such as specific words and expressions, metaphors, implied</p>	<ul style="list-style-type: none"> <li>○ A PSW comments that caring for residents in a SCU <i>is not like they teach you at school</i> (contrast).</li> <li>○ Examples of semantic units that are particular to the SCU include:</li> </ul>

<ul style="list-style-type: none"> <li>○ something virtual</li> <li>○ 99.07.4 – semantic unit</li> <li>○ 99.07.5 – similarity or complementarity</li> <li>○ 99.07.6 – use of metaphor</li> </ul>	<p>contrasts, implied similarities) that constitute meaning. Additionally, tone of voice, specifically placed emphasis, and facial expressions are all to be taken into account in reconstructing the meaning intended with/in a communicative act. (p. 106-110).</p>	<ul style="list-style-type: none"> <li>○ <i>appropriate care</i></li> <li>○ <i>transitional unit</i></li> <li>○ <i>counting the barbs [meds],</i></li> <li>○ a PSW asking another PSW <i>Who do you have today?</i></li> <li>○ Staff saying to residents, <i>Sit down.</i></li> <li>○ Staff referring to residents who require assistance eating as <i>feeders.</i></li> <li>○ <i>All behavior has meaning.</i></li> <li>○ Staff frequently compared working in a SCU to parenting, often citing the similarities among the two care domains.</li> </ul>
<p><b>99.08 – Power at play</b></p> <ul style="list-style-type: none"> <li>○ 99.08.1 – coercive persuasion</li> <li>○ 99.08.2 – charming persuasion</li> <li>○ 99.08.3 – contractual persuasion</li> <li>○ 99.08.4 – normative persuasion</li> </ul>	<p>Carspecken (p. 129-130) follows “Weber’s famous typology of power relations [that] divides interactive power into coercion and three types of authority: charismatic, legal-rational, and traditional.” Carspecken’s adaptation of this typology reconceives ‘traditional’ power as ‘normative-evaluative’ power. Coercion usually involves the threat of sanction or the use of physical or psychological force; charm begets loyalty; and contractual power entails (often tacit) obligations to reciprocity (e.g. You did that for me, I’ll do this for you).</p>	<ul style="list-style-type: none"> <li>○ A PSW is reprimanded by [a manager] about not completing her computerized flow sheets (coercive power – implied threat of sanction);</li> <li>○ ... henceforth, the PSW is to leave the floor at a particular time (before the end of her shift) to do her charting (normative power).</li> <li>○ A recreationist asks a resident into joining her on the dance floor during a music activity (charm).</li> <li>○ A PSW suggests to a resident that if she gets dressed and comes to breakfast, she will be able to see her daughter later (contractual).</li> </ul>
<p><b>99.12 – roles and identities</b></p> <ul style="list-style-type: none"> <li>○ 99.12.1 – identity claim</li> <li>○ 99.12.2 – reference group</li> <li>○ 99.12.3 – roles</li> </ul>	<p>Since, in a Carspeckian analysis, “all communicative acts take place within social relations ... actors must adopt roles ... [and] must share understandings about the social context of the act for the act to be communicative” (p. 104).</p>	<ul style="list-style-type: none"> <li>○ A PSW describes her laid back approach and propensity for telling jokes (identity claim)</li> <li>○ A recreationist describes how on some shifts, there are some staff who are just <i>here for the paycheck</i>, whereas others are here because they like and are good at caring for people living with dementia (reference group)</li> </ul>

	Identity claims, and claims to belonging to a particular group are indicative of that social context. Moreover, roles, as “a complex mode of activity that actors recognize as having some unity” (p. 136), are useful in helping understand and predict “what basic form actions will take as long as this player is acting out the same role” (p. 136).	<ul style="list-style-type: none"> <li>○ An RPN explains that when she hears other staff speaking gruffly to a resident, her role is to step in and to explain to that staff that such behavior will not help and, more likely, it will exacerbate the situation (role claim).</li> </ul>
<p><b>99.15 – interactive syntax</b></p> <ul style="list-style-type: none"> <li>○ 99.15.1 – reference to shared past</li> <li>○ 99.15.2 – ... shared present</li> <li>○ 99.15.3 – ... shared future</li> </ul> <p>Note that the ‘interactive syntax’ is described in more detail at the end of section three in this article.</p>	As the temporal axis within the pragmatic horizon, an interactive syntax refers to “the location of [a communicative] act within the participants’ awareness of prior events and within their shared expectations of events about to come. ... As all acts of meaning are contextual” (p. 105-106), this temporal element helps define that intersubjective context by illuminating the assumptions and expectations of the interacting participants.	<ul style="list-style-type: none"> <li>○ Two PSWs reflect aloud on what it was like some months ago when another particular PSW worked with them (and how hard that was because this other PSW did not ‘fit well’).</li> <li>○ An RPN comments on the physical/built environment, particularly the enclosed patio area outside, suggesting that since [the organization] moved to this new building, SCU residents are afforded more opportunity to go outside (shared present)</li> <li>○ On several occasions, staff wondered aloud in anticipation of ministry inspections that were bound to occur (shared future).</li> </ul>
<b>99.16 – reference to ‘the system’</b>	In anticipation of stages four and five (system relations), I began immediately to code data that made reference to the broader system factors that participants invoked when contextualizing their situations or claims.	<ul style="list-style-type: none"> <li>○ A [manager] contextualized the term ‘transitional unit’ within broader system pressures to deal with the long list of people waiting to be admitted to the SCU.</li> <li>○ An RPN says that <i>the Ministry says we’re supposed to mix feeders with non-feeders, but it’s not always very practical.</i></li> </ul>
<p><b>99.17 – knowledge exchange</b></p> <ul style="list-style-type: none"> <li>○ 99.17.1 – socialization</li> <li>○ 99.17.2 – externalization</li> <li>○ 99.17.3 – internalization</li> <li>○ 99.17.4 – combination</li> </ul>	As my research aim focused on the creation, exchange, and application of ‘dementia care knowledge,’ I began immediately to code data that seemed to indicate when and how was shared. These codes are not Carspeckian; rather, they reflect Nonaka’s (1994)	<ul style="list-style-type: none"> <li>○ A family member has an exchange with a privately hired PSW about the best ways to help her husband up out of his chair: <i>I coax him up by holding his blanket out in front of him, then back up as he reaches for it</i> (socialization).</li> <li>○ An RPN confers with a recreationist about how to codify</li> </ul>

	<p>typology wherein socialization refers to tacit knowledge being modeled by one participant and taken up by another; externalization refers to the explication of seemingly tacit knowledge; internalization refers to the process of converting explicit and/or formal knowledge into tacit know-how; combination refers to formal knowledge being re-explicated and re-inscribed as new explicit knowledge.</p>	<p>a particular resident's anxiety (externalization)</p> <ul style="list-style-type: none"> <li>○ Referring to an instruction manual, an RPN mentors/instructs a PSW about how to do the computerized charting (internalization / socialization).</li> <li>○ A family member expresses to me her observation that during a team care meeting, she was provided with lots of information verbally, but no one (except she herself) took any notes; she thought that the home/organization should provide some sort of meeting summary/report (combination).</li> </ul>
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<b>Table 4.4: Ten most prominent Emergent Code-categories and their respective Sub-codes (developed <i>in vivo</i>)</b>		
<b>Code-category</b> ○ Sub-code(s):	<b>Description / Comment</b>	<b>Sample(s)</b>
<b>01.0 – human resources</b> ○ 01.1 – workarounds	These data reference HR issues. Often, staff and families would comment about there not being enough staff/HR to provide adequate care; union issues were included here as well. The code ‘workarounds’ refers to caregivers’ efforts to work around existing rules and regulations (and subsequent HR shortcomings), i.e., ‘rule bending.’	<ul style="list-style-type: none"> <li>○ staffing compliment; a quality improvement initiative that piloted the addition of an additional five hours of PSW care on day shift; flexible break times (HR considerations)</li> <li>○ An RPN asked me to monitor the common area while she left the floor for a couple minutes to attend to some paper work; PSWs leaving their computerized charting incomplete because their shift is technically over; staff allowing a male and female resident to hold hands if/when there were no family members around to see/complain about it (workarounds).</li> </ul>
<b>03.0 – public relations</b>	The ADP and the SCU staff, and indeed the organization as a whole, often focused on maintaining positive public relations and a favorable reputation.	<ul style="list-style-type: none"> <li>○ A PSW comments that after the annual inspection, <i>things will go back to the way they were – they [management] just wants to get it so it looks like things are perfect when it’s not.</i></li> <li>○ PSWs expressed concern that the care they provide might be perceived by others as abusive, as forceful.</li> <li>○ Management and staff struggled with having to ‘grandfather in’ some families/residents regarding the relatively new rule that the SCU is a transitional unit – some families were adamant about not wanting to be transitioned off the SCU when the person living with dementia was technically no longer eligible to stay on the SCU, but rather than upset the family, the staff acquiesced.</li> </ul>
<b>04.0 – responsive behaviors</b> ○ 04.1 – trigger of a responsive behavior	I was interested in trying to catalog what responsive behaviors manifest, what seemed to trigger what kind of	<ul style="list-style-type: none"> <li>○ Staff had several stories of being punched, kicked, pinched; of residents resisting care, especially baths, of heightened sexuality, and of socially inappropriate behavior</li> </ul>

<ul style="list-style-type: none"> <li>○ 04.2 – intervention to a responsive behavior</li> </ul>	<p>responsive behavior, and also how staff and/or family subsequently intervened to mitigate the responsive behavior and prevent it from reoccurring.</p>	<p>such as hollering at other residents and/or swearing (responsive behaviors)</p> <ul style="list-style-type: none"> <li>○ (triggers include) the time of day – i.e., ‘sun downing;’ a misunderstanding between residents; an inappropriate approach by a staff caregiver; medical and/or physical discomfort</li> <li>○ (responses include) redirecting residents, re-approaching at a later time, having someone else approach the client or resident; anticipating and removing the trigger (e.g., knowing that someone gets very upset when she thinks she has not yet eaten a meal, staff can either bring her some food or reassure her that a meal is about to be served.</li> </ul>
<p><b>06.0 – personal care</b></p> <ul style="list-style-type: none"> <li>○ 06.1 – feeding</li> <li>○ 06.2 – toileting</li> <li>○ 06.3 – dressing</li> <li>○ 06.4 - grooming</li> </ul> <p><b>09.0 – non-dementia-related nursing care</b></p> <ul style="list-style-type: none"> <li>○ 09.1 – med administration</li> <li>○ 09.2 – RAPs</li> <li>○ 09.3 – documentation</li> <li>○ 09.4 – skin or wound care</li> <li>○ 09.5 – other</li> </ul>	<ul style="list-style-type: none"> <li>○ Many of the registered nursing staffs’ and PSWs’ daily care routines focused respectively on basic nursing care and on the provision of personal care; these codes helped isolate those data.</li> <li>○ ‘RAPs’ are ‘resident assessment protocols,’ which are ‘triggered’ by data inputted into the computerized documentation system (RAI – resident assessment instrument); ‘doing a RAP’ entails creating and monitoring care plan goals to mitigate or treat whatever what triggered by the daily documentation.</li> </ul>	
<p><b>11.0 – reference to dementia care training or education</b></p> <ul style="list-style-type: none"> <li>○ 11.1 – Gentle Persuasive Approach</li> <li>○ 11.2 – P.I.E.C.E.S.</li> <li>○ 11.3 – U-first!</li> </ul>	<p>These provincial initiatives had, prior to this study, been introduced to the SCU and ADP staff. To assist in understanding what kind of impact this training had, I coded any mention of these initiatives.</p>	<ul style="list-style-type: none"> <li>○ Although there were both positive and negative valuations of these programs, they were more often than not characterized as a waste of time.</li> <li>○ An RPN stated that for some who attend such education workshops, <i>the information goes in one ear and right out the other.</i></li> <li>○ There were several documents / flyers posted in staff areas listing the tenets of these programs.</li> </ul>
<p><b>12.0 – twenty-eighties</b></p>	<p>This is a semantic unit (i.e., an expression particular to the SCU and perhaps to LTC) that characterizes a small proportion of family</p>	<ul style="list-style-type: none"> <li>○ Such family members were compared favorably in contrast to families who hardly ever visit, but conversely, PSWs sometimes spoke of having to favor particular residents over others so as to not</li> </ul>

	members (about 20%) who visit the SCU often (about 80% of the time). I.e., 20% of family members are here 80% of the time.	<p>upset the frequently visiting family members.</p> <ul style="list-style-type: none"> <li>○ On another hand, recreation staff spoke of the benefits of such frequent interactions with these '20-80s.'</li> </ul>
<b>15.0 – fall prevention</b>	A number of care practices seemed to be premised on fall prevention.	<ul style="list-style-type: none"> <li>○ Notes were often posted in the SCU chart room about keeping bed rails up at night.</li> <li>○ A common semantic unit – asking a resident to <i>Sit down</i> – was consistently attributed to fall prevention.</li> <li>○ The paperwork and medical monitoring that is mandated after a fall is characterized as onerous and as time-consuming, and thus as added incentive to prevent falls.</li> </ul>
<b>19.0 – person-centred care</b> <ul style="list-style-type: none"> <li>○ 19.1 – what seems to not be PCC</li> </ul>	While I appreciated that data thus coded would require some 'normative reflection' on my part to tease out how/why I saw some practices as 'person-centred' or not, I tried also to code participants' sentiments about what was / was not person centred.	<ul style="list-style-type: none"> <li>○ An RPN explains to me the profound effect the staff has on residents <i>as humans</i>, thus conveying a sense that relating to residents is a fundamental element of dementia care work.</li> <li>○ A PSW heard me humming a song, asked what I was humming, then showed me to a resident who is a great singer. The PSW then charmed the resident into singing a song for me; the resident did so, and her spirits subsequently seemed elevated.</li> <li>○ What seemed to not be person-centred care: assertions that some PSWs rush residents through activities of daily living, especially getting dressed.</li> <li>○ An example of a care practice that is not clearly right or wrong is joking with residents – on one hand, the use of humor and levity indeed seemed person-centred, but on the other hand, the jokes were funny to the PSWs seemingly because the jokes went over the heads of the residents to whom the jokes were directed.</li> </ul>
<b>25.0 – dementia care knowledge</b>	This was a somewhat generic code used to identify data that I felt in some way reflected the	<ul style="list-style-type: none"> <li>○ A physician described to me that dementia care simply entails two complex objectives: providing assistance with the activities of</li> </ul>

	<p>generation or application of dementia care knowledge. There were times too during informal interviews that I raised the topic of 'dementia care knowledge' (as a central interest of the study) so as to invite participants to share whatever came to mind in that regard.</p>	<p>daily living, including the provision of meaningful activities, while also preventing and responding to responsive behaviors.</p> <ul style="list-style-type: none"> <li>○ A nurse practitioner refers to an iPad <i>to check certain drugs</i>.</li> <li>○ Two PSWs name for me a handful of residents who they can tell <i>just aren't there</i>, but maintain that it is not terribly difficult to care for them <i>if you know what they need and what they like</i>.</li> </ul>
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**Table 4.5: Sample ‘Meaning Field Reconstructions’ from the Stage One Primary Record**

A: Reconstructing possible meanings about the practice of keeping clients and residents seated.

Context:

It’s 8:10pm and I am standing at the SCU nursing station, observing the activity room that is within my purview. Several residents are seated in the activity room; one PSW is present too, seemingly with the task of monitoring and/or engaging residents. One male resident who had just been standing at the nursing station now mills about the activity room. He seems both restless and depressed, as indicated by his body language (frowning, tearful; putting his head down on the counter, hitting his own head; pacing). Note that ‘MR’ denotes ‘male resident;’ ‘OC’ denotes ‘observer’s comment.’

Field note excerpt:

PSW is rotating from MR to MR, trying to keep them seated. He dances with one of the MRs. Then seats him. Then asks the other one to sit. He grabs a reader’s digest to give to a MR (OC: seeming to hope that it’ll keep him occupied and seated for a moment). The MR tosses the digest aside. The PSW is now intercepting the other MR. He seats him this time at a table, in a chair with arms, pushed quite in. The MR goes to stand. The PSW’s hands are on his shoulder to seat him again. *So’n’so, please. Please. What do you want?* (OC: kind voice in that it’s gentle, not angry, but clearly a hint of being exasperated, as if I hear a tone of exasperation when the PSW says the MR’s name). The MR goes to stand again; the PSW seats him again: he’s standing behind and off his right shoulder, his right right hand under the MR’s arm, his left hand on MR’s shoulder. He seats him.

Meaning Field Reconstruction:

Sitting rather than moving or dancing about is the PSW’s preferred state for the residents AND such residents who’re restless don’t stay seated for long AND/OR having them sit rather than walk/dance about is a fall-prevention strategy AND such a practice of constantly trying to seat someone can make a PSW feel exasperated AND such exasperation manifests as an altered tone of voice AND/OR as physical restraint (hand on shoulder; chair pushed quite far in).

B: Reconstructing possible meaning about what makes someone a good worker.

Context:

As she sat in the SCU chart room on her meal break, a full-time PSW agreed to participate in an informal interview. In seeking some clarification about a remark I had heard her make earlier, I said to her: *You commented earlier that [a particular male PSW] is a good worker and I just wondered, what strikes you as a good worker?* Her response:

Quote:

PSW: He’s gentle. He’s organized. He doesn’t just stand around and you have to say go do this one or whatever – some of them you have to tell them, or they’ll just stand there, even though they’ve been down here hundreds of times, so you have to say to them while you can do this one here, they’ll go…… but [that PSW] he’s just, he’s gentle with the residents, he is so gentle.

Meaning Field Reconstruction:

Being gentle during care provision is a preferred/ideal characteristic AND there are, as an implied contrast, staff who aren't gentle AND with respect to the organization, there's an expectation that a PSW knows what s/he is supposed to do, what the care routines are, what the residents' needs/preferences are AND yet some part-time staff don't know this AND if part-timers don't know the routines (for legitimate reasons) they should only have to be told once or twice what to do AND there are some staff who must be told OR monitored OR tolerated over and over again.

C: Reconstructing possible meanings about how PSWs recognize dementia.

Context:

In the SCU chart room, I was speaking with two PSWs about whether or not it is ever appropriate or necessary to not be honest with a resident. I explained that an RPN had recently said to me that I might think it's mean that she would remind [a resident] that his wife's dead, but he's someone who can handle it. At once, both PSWs said, *Yeah*, and I subsequently sought an explanation.

Quote:

PSW: *Well, because we know who can handle it and we know who's just like not here. At all. [A particular female resident] is not here. There's no way – like there's things that come out of her mouth and we kind of just ask – like we take her back to that time and we ask her, like what happened and everything's okay. And sometimes she can give you an answer. Sometimes she doesn't. [Another female resident], she is up and down. I go by how she responds to me. If she's back to when she was like 10 years old, then I'll take her back there. I don't mind. [Another female resident] is usually never here. Very rare.*

Meaning Field Reconstruction:

One way of categorizing residents is a judgment of whether or not the resident “is here” or not AND the criterion for ‘being here or not’ is that what someone says makes sense AND that (being here or not) can change from day to day OR moment to moment AND the demeanor / state-of-mind of residents is something that the PSW(s) can perceive AND/OR such states of mind can change quickly depending on how someone approaches them.

Table 4.6: Interview Topics

<p>Initial set of topics:</p> <ol style="list-style-type: none"> <li>1. the notion of ‘appropriateness’ – i.e., what makes someone (in)appropriate for providing dementia care?</li> <li>2. what ‘dementia care knowledge’ entails;</li> <li>3. residents’/clients’ table mates at meal time;</li> <li>4. new residents; different dementias;</li> <li>5. force cf. neglect;</li> <li>6. there being (or not) enough for residents/clients to do;</li> <li>7. ‘reality orientation’ cf. ‘validation therapy;’</li> <li>8. mentorship;</li> </ol>
<p>Interviews often included an instance or two of member-checking; topics ‘checked’ included:</p> <ol style="list-style-type: none"> <li>9. a ‘for instance’ I had observed where staff were trying to keep residents seated;</li> <li>10. a comment made about particular staff members ‘setting the tone’ for a particular shift;</li> <li>11. a comment about PSWs not being respected by registered staff;</li> <li>12. a comment I had heard about some PSWs not being gentle; and</li> <li>13. a comment to me about the benefits of having male PSWs.</li> </ol>
<p>Additional topics that emerged during the interview phase:</p> <ul style="list-style-type: none"> <li>• impressions of an on-going quality improvement initiative (i.e., the addition of a 0.5 full-time equivalent PSW to the day shift in the SCU);</li> <li>• the impact of a specialized consult team to whom a referral is occasionally made to</li> </ul>

problem-solve particularly difficult resident behaviors;

- the notion of educating families and/or managing their expectations;
- flexibility in work rules and routines;
- the extent to which care practices should be *trans*-disciplinary.



<b>Table 5.1: Participants Enrolled</b>		LTC SCU Site:	Community ADP Site:	Senior Leadership Team	Total
Care Recipients (i.e., non-staff)	Residents	6 (4 male)	n/a	n/a	6
	Clients	n/a	42 (20 male)		42
	Family Members	7 (1 male)	1		8
sub-total: non-staff		13 SCU	43 ADP		56 non-staff <sup>1</sup>
Staff	PSW	31 (2 male)	8		39
	RPN	4	3		7
	RN <sup>2</sup>	3 (1 male)	1		4
	Nurse Practitioner	1	n/a		1
	Physician	2 (both male)	n/a		2
	Life Enrichment Staff	1	8		9
	Social Worker	1	2	3	
	Dietitian	2	n/a	2	
	Physiotherapist	2 (1 male)	n/a	2	
	Housekeeping	2	0	2	
sub-total: point of care staff		49 SCU staff	22 ADP staff	71 point-of-care staff <sup>3</sup>	
Senior Leadership Team (SLT)	CEO	n/a	n/a	1 (male)	1
	Administrators <sup>4</sup>			2	2
	DOC LTC			1	1
	Assistant DOC LTC			1	1
	Director ADP			1	1
	Directors of			4	4

	Operations <sup>5</sup>				
	Receptionist			2	2
	sub-total – SLT			12	12 SLT
<b>Total number of Participants:</b>					<b>139</b>
<p>Acronyms: n/a – not applicable; LTC – long-term care; SCU – special care unit in LTC site; ADP – adult day program in community site; PSW – personal support worker; RPN – registered practical nurse; RN – registered nurse; CEO – chief executive officer; DOC – Director of Care; SLT – Organization’s Senior Leadership Team</p>					
<p>Notes: 1 – Family members of two of the residents from SCU and eight of the clients from the ADP only consented to the resident/client being observed, not interviewed.</p> <p>2 – Of the 3 SCU RNs, 1 worked part-time as the education facilitator and another worked full-time as the RAI coordinator.</p> <p>3 - All but three staff members agreed to be observed and/or interviewed; one agreed to be observed but not interviewed; 2 agreed to be interviewed but not to be observed.</p> <p>4 – Two Administrators were enrolled as the first retired during the first phase of data collection.</p> <p>5 – Included directors of Finance, Communication, and Volunteer Services, and a Liaison to the [Organizational Foundation]</p>					

<b>Table 5.2: SCU residents' age, gender, time since admission, and diagnoses</b>		
	<b>Women:</b>	<b>Men:</b>
<b>Gender:</b>	n = 21	n=11
<b>Age:</b>	mean: 81.5 years old standard deviation: 9.2 range: 62-95	mean: 81.4 years old standard deviation: 8.2 range: 66-91
<b>No. of months since admission to SCU:</b>	mean: 24.7 months standard deviation: 21.5 range: 3-84	mean: 27.2 months standard deviation: 11.5 range: 15-45
<p>Primary dementia-related diagnoses included:</p> <ul style="list-style-type: none"> <li>• Alzheimer's disease with early onset (n=1)</li> <li>• Alzheimer's disease (n=14)</li> <li>• Dementia in Alzheimer's disease, unspecified (n=1)</li> <li>• Dementia in Pick's disease (n=5)</li> <li>• Mixed cortical and subcortical vascular dementia (n=1)</li> <li>• Other specified degenerative disorders of the nervous system (n=1)</li> <li>• Other vascular dementia (n=1)</li> <li>• Stroke, not specified as hemorrhage or infarction (n=1)</li> <li>• Unspecified dementia (n=7)</li> </ul>		
<p>Secondary dementia-related diagnoses included:</p> <ul style="list-style-type: none"> <li>• Anxiety disorder (n=1)</li> <li>• Depressive episodes (n=4)</li> </ul>		

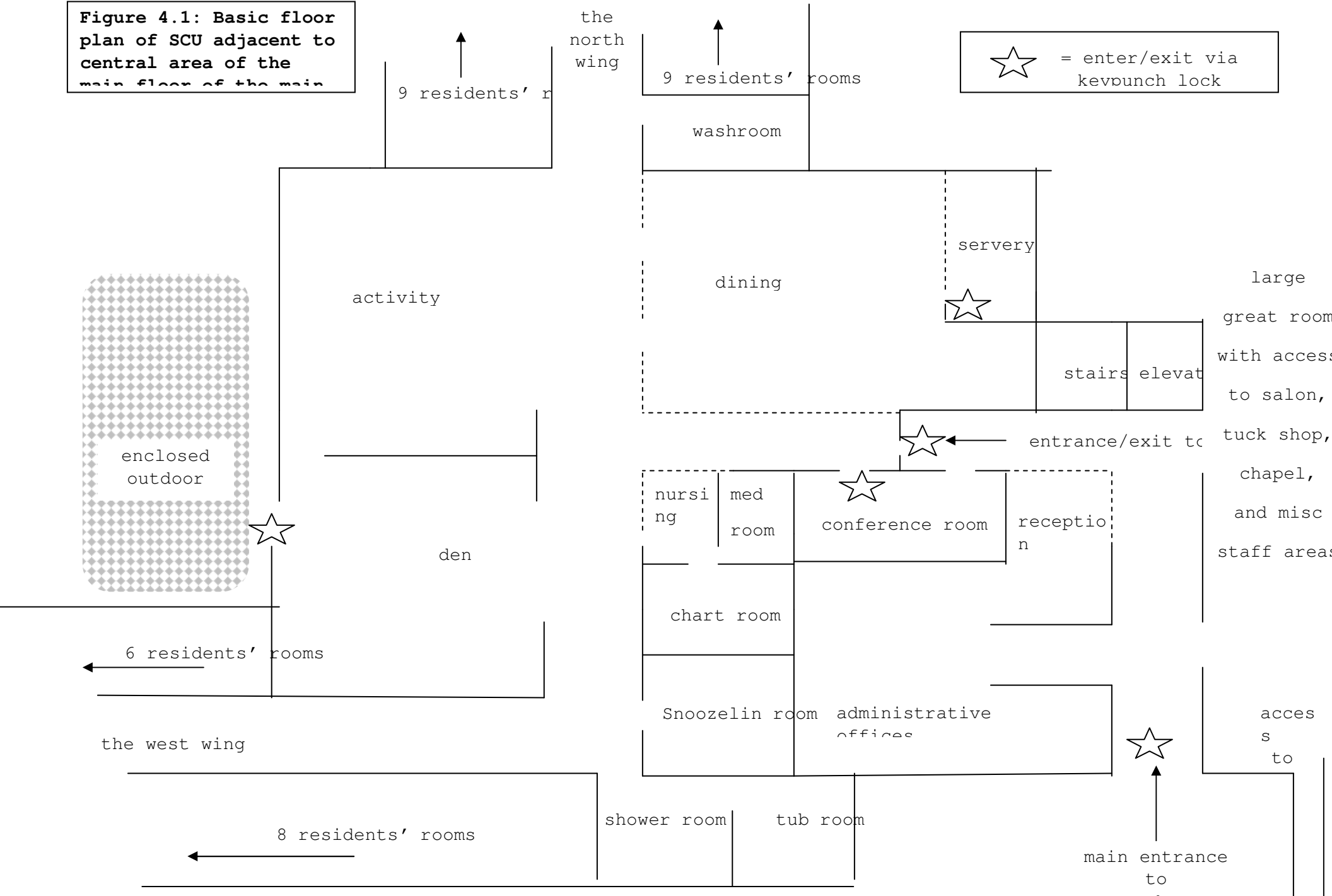
- Dysphasia and aphasia (n=4)
- Parkinson's disease (n=1)
- Peripheral vascular disease, unspecified (n=2)
- Recurrent depressive disorder, unspecified (n=5)
- Schizophrenia, unspecified (n=1)
- Stroke, not specified as hemorrhage or infarction (n=4)

Most prevalent secondary diagnoses included:

- Arthrosis (n=5)
- Atherosclerotic heart disease (n=6)
- Benign hypertension (n=19)
- Cataract (n=6)
- Hyperlipidaemia (n=6)

Figure 4.1: Basic floor plan of SCU adjacent to central area of the main floor of the main

☆ = enter/exit via keypunch lock



**Figure 4.2: Basic floor plan of ADP adjacent to central area of the main floor of the main building**

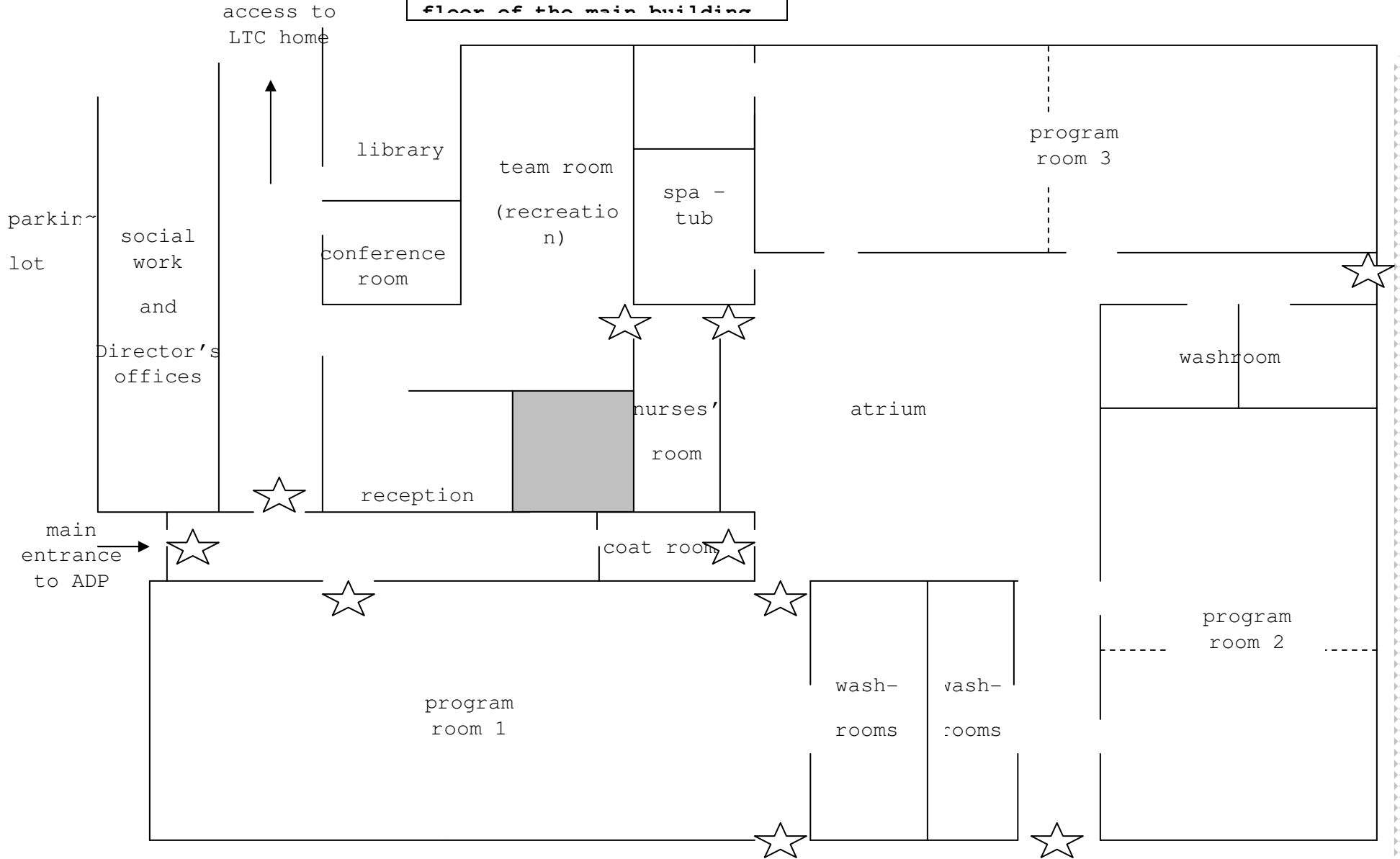
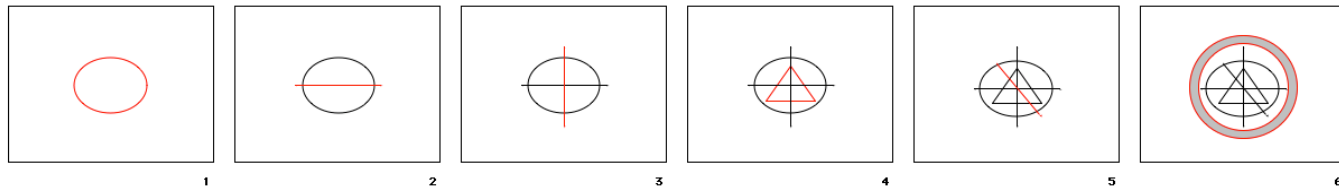


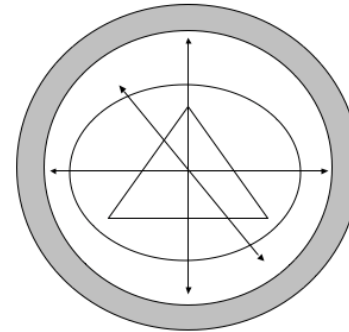
Figure 4.3: Carspecken’s (1996) conceptual and analytic elements of a social act in CQR.



**LEGEND:**

1. Pragmatic horizon
2. Interactive temporal syntax
3. Paradigmatic (communicative) axis
4. Objective, subjective, and normative claims
5. A claim’s relative degree of being back- or fore-grounded
6. The hermeneutic circling processes involved in analyzing and re-presenting then reading and recognizing a critically interpreted social act.

**Representing a Social Act with/in CQR**



Adapted from the cover of Carspecken’s 1996 book, *Critical Ethnography in Educational Research – A Theoretical and Practical Guide*. Routledge: New York, NY. (Book design by Charles B. Hames).

**Appendix 5.1: Do you know who gets along? – a reconstruction of *democratic validation of co-constructing knowledge***

*Context.* Four recreationists are holding their 12:45 p.m. check-in meeting in preparation for the afternoon activities. They are sorting the day's clients into three groups, and here, specifically, they are determining which relatively high-functioning clients could/should attend the music program. In the following quote, MC and FC respectfully signify a male and female client.

Rec1: MC would be good. He's quite alert today. FC, I think would like [the live entertainment booked for the afternoon]. Will she sit though? I don't know her. She's new to me.

Rec5: Depends on her mood.

Rec6: Sometimes –

Rec5: It depends.

Rec1: She's in a good mood.

Rec6: Yesterday she sat for a while and then all of a sudden she got up and she was going and she was heading to the bathroom. She didn't have her walker and I was chasing her and – but

Rec1: She was really good this morning. **Do you know who gets along** is her and [another FC].

Rec4: [Repeats the latter FC's name], yep.

Rec6: Let's try her.

Rec1: Put [the two FCs] together. Put them side-by-side because then they'll just chatter. They talk the whole morning.



Rec4: Do you know who was really good with [a particular MC] in the afternoon is [a different FC].

Rec1: Really?

Rec4: Because she talks – yeah. Because she talks talks talks talks talks and [the MC] doesn't get up. He listens. He sits there while she's talking.

Rec1: Oh really.

Rec4: It's a wonderful combination. So you don't get the pacing going on in the afternoon.

Rec1: Because he paced all morning.

Rec4: I know.

The following validity reconstructions delineate how the recreationists justify co-constructing strategic knowledge to inform decisions to try pairing particular clients:

Possible Objective Claims:

Foregrounded:

- Strategically seating clients in particular pairs can result in their becoming engaged in socialization.

Backgrounded:

- A client's mood can be observed, and can predict whether or not s/he will tolerate or enjoy a particular program.
- The recreationists, collectively, construct a shared sense of who gets along and who does not get along.

More backgrounded:

- Pairing clients who do not get along is likely to result in at least one client becoming agitated.
- The recreationists are / will be busy (during the program) and thus having many clients to monitor and/or keep seated can be difficult.

Possible Subjective Claims:

Foregrounded:

- It is a relief to observe someone who paces a lot socializing with another client instead.

Backgrounded:

- It is stressful to have to “chase” down a pacing client, especially if s/he is at high risk of falling.

More backgrounded:

- Pacing is presumed to indicate that the client is agitated.

Possible Normative Claims:

Somewhat foregrounded:

- Recreationists should make an initial decision regarding which activity a client should attend that afternoon (i.e., on behalf of the clients).
- The recreationist should base their decision, in part, on the mood of the client; that is, if the activity might further agitate the client, the client should be assigned to another activity that will not exacerbate agitation or a bad mood.

Backgrounded:

- Pacing is a symptom of dementia that should be addressed.

- The recreationists should base their decision on past experience of what the client does or does not enjoy.
- The decisions about which programs particular clients should attend should be shared among the recreationists and should be democratic in nature.

**Appendix 5.2: You spend more time with her than I do – a reconstruction of  
*democratic validation of co-constructing knowledge***

*Context.* A RPN and a recreationist (Rec, in the excerpt below) from the SCU were sitting together in the SCU chart room. The RPN invited the recreationist to help her complete a standardized depression assessment form for one particular female client.

RPN: ... you know the background here for [this female resident]. It's just that we want her to have more quality of life. I was kind of concerned about drugs and whatnot, you know, what she's on, so this is a Cornell scale for depression, so have you every heard of it, seen it?

Rec: I've heard of it.

RPN: Yeah. So between the two of us I just wanted to make sure it was fair to [this female resident] that I'm not over judging or under judging her. So her anxiety... does she have anxious expression, ruminations and worrying. I felt she does.

Rec: Yes, definitely.

RPN: One is mild or intermittent. I wouldn't say it's severe. You know, if you disagree, just tell me, because you spend more time with her than I do.

Rec: No, I would say that's right. I was thinking it, at times, might be a little bit more severe.

RPN: I'll put one to two...one to two.

Rec: When she's feeling really anxious she's pretty difficult to...

RPN: Oh, yes. Sadness, I myself thought sad expression, sad voice and tearfulness, at times she's looks extremely sad to me. Lack of reactivity to pleasant events. Has that changed?

Rec: Lack of... I have to think about that... Lack of... I'm not following it.

RPN: Does she react to, if you say to her, Come on, we're going to bake...

Rec: Oh yeah, oh yeah.

RPN: She still onboard for that?

Rec: Yes, yes.

RPN: OK, so I would say that's absent. Her irritability, easily annoyed and shorttempered.

Rec: Definitely.

RPN: I think she's a severe.

Rec: Yes.

RPN: I think the other residents get to her...

Rec: Very low tolerance.

RPN: So the behavioral disturbance: her agitation, restlessness, hand-wringing, hair pulling, I'm assuming this is on herself, but I know that she gets restless.

Rec: Gets restless for sure.

RPN: Yeah. I would say it's mild at this point ... but just say no if you don't agree--

Rec: Yeah, no, no, for sure.

Focused in particular on the line, *if you disagree, just tell me, because you spend more time with her than I do*, the validity reconstructions below delineate how the RPN justified soliciting the recreationist's input.

Possible Objective Claims:

Foregrounded:

- The recreationist spends more time with the female resident in question than does the RPN.

Backgrounded:

- The RPN supposes that the recreationist may have a different perception about the resident than she.

Possible Subjective Claims:

Foregrounded:

- The RPN is concerned that an assessment of this resident's dementia based on her judgment alone might not be accurate or fair.
- The recreationist feels safe enough in this dialogue to acknowledge that she does not understand what one of the assessment items means.

Backgrounded:

- The RPN wishes for the recreationist to feel included, valued, and free to disagree in co-constructing this assessment.

Possible Normative Claims:

Foregrounded:

- The assessment of a resident's depression should be fair – i.e., made by one or more staff members who can confidently judge depression based on familiarity of and experience with the resident.
- Because the recreationist spends more time with the female resident than does the RPN, the recreationist should have input into the scoring of the resident's depression.

Backgrounded:

- Nursing and recreation staff should collaborate to co-construct an assessment of a resident.
- Standardized assessment tools such as this depression scale should contribute to – and perhaps form the basis for – the establishment of knowledge constructions.

**Appendix 5.3: Normally I would have left her, but down here, – a reconstruction of *distortion and exclusion of knowledge***

*Context.* In speaking with a younger, less experienced, part-time PSW who works on other floors in the home as well as in the SCU, I (RTD in the dialogue below) raised the topic of validating a person with dementia’s current state of mind even when that state of mind reflects, by our standards, a distorted reality. I had spoken with the same PSW and an RPN two days prior about “validation therapy” (i.e., going along with the resident’s frame of mind, whatever that might be) versus “reality orientation” (i.e., rationalizing with the resident and cuing him/her back to “our” reality). In speaking with the PSW on this occasion, I asked if she had any more thoughts on that topic. In response she reflected on her experience of trying to bath a female resident earlier that day; the encounter did not go well – it resulted in the female resident being resistive and physically aggressive. The PSW bore three scratches on her arm from the encounter.

*RTD: What happened this morning? [I motion to her arm].*

*PSW1: [A FR] was not impressed with having a bath so she attacked me and grabbed my arm–*

*RTD: Tell me – if you can go back a minute. Tell me like a movie. Like I was a movie camera over your shoulder, what happened?*

*PSW1: What happened? Okay. So I brought her into the tub room and she was already agitated because I saw this look in her eyes in the hallway. I asked her if everything was okay and she just stared at me. So I’m like Okay, we’re going to go have a bath. And we came in and the water was running and I always like to point to that because sometimes when they see things they understand better. And*



*I said [to her], We're going to have a bath. And she just stared at me and I'm like, okay, I'm going to help you get undressed. You're going to sit on this blue chair and it was just from then on, like just trying to help her, take her nightgown off: she refused. Like, [Name] you need to have a bath. She's like, No! Get off me! Blah bla blah, screaming and stuff and I'm like, [Name] you have to have a bath and she's like Why?! And then that's when I told her, [Your daughter] says she's going to come. Sometimes it helps that she like sees my nametag. She thinks I'm her daughter because we have the same name. I'm like [Your daughter is] going to come and she wants you to have your bubble bath like you have every Friday morning. And she's like No. I'm like, Oh my God. So normally I would have left her, but down here we're very, like, you know, everyone just has their baths and stuff. Whereas upstairs we know that if they say no, then it's no. But because down here we have to do everything for them, it's better they have their baths every week, twice a week. So I just – I – she grabbed my arm and I'm like [Name]. Please don't hit me. And she's just like, You're hitting me. And I'm like, I'm not hitting you. Like look what you did to my arm and she just kind of stared at it and she's like, Well, I don't want to. I'm like – so I just let her calm down a little bit. She was eventually okay, but yeah. And then she was like after she grabbed it she was ready to bite me and I'm like, Don't bite me. She is very up and down too. She was pretty aggressive, but she – it's very rare. It's not like every day but usually when she comes out, it's like, yeah, it's a little scary but then she'll be fine for the rest of the day. I can go up to her right now and she'd be like Oh, honey. I love you.*

The following validity reconstructions demonstrate how caregivers' values and knowledge can be overpowered by organizational powers that coercively distort care practices and exclude both PSWs and people with dementia from clinical decision-making.

Possible objective claims:

Foregrounded:

- By the look in her eyes, one could tell that this resident was agitated.
- Residents are scheduled to have two baths each week.

Backgrounded:

- Having dementia can result in someone needing assistance with ADLs, including with bathing.
- Memory deficits and cognitive impairment may result in residents not recognizing that they need to take a bath to maintain an acceptable level of hygiene.
- If SCU residents do skip a bath because a PSW could not persuade them to cooperate in taking the bath, residents' personal hygiene can deteriorate.

Possible Subjective Claims:

Foregrounded:

- It can feel frustrating, even scary, when working with an agitated and/or aggressive resident.
- The PSW feels affection for this resident.

Remotely backgrounded:

- PSWs want to be perceived by colleagues and supervisors as being capable of providing ADL care, including the bathing of residents.

Possible Normative Claims:

Foregrounded:

- When a resident without dementia objects to taking a bath, a PSW should respect that viewpoint and not force or even negotiate further with that resident.
- Residents in the SCU should have their scheduled baths each week even if they object to doing so.

Backgrounded:

- PSWs should be able to reduce agitation and calm a resident enough so as to be able to complete the task of bathing the resident.
- PSWs should employ a variety of strategies to persuade residents with dementia to cooperate in receiving their bath care.

**Appendix 5.4: I don't believe that – a reconstruction of *distortion and exclusion of knowledge***

*Context.* The quote below comes from an interview with an experienced, full-time SCU PSW. During the interview, I sought her opinion on the accuracy of my preliminary interpretations (i.e., I conducted a member-check) regarding data that indicate cliques, if not disparate sub-cultures exist between registered and non-registered staff. While her response acknowledges that there certainly were some registered staff members who do respect PSWs and their knowledge, her focus was on those who do not.

PSW: I find with the young registered staff, they're very, they're good. The ones that I work with I have no problem with them, they'll come to me and *say I haven't been here for a while, what's going on?* or whatever. They'll come to one of us and ask or whatever but then you get those ones that they know it all. Like I remember with [one particular FR], she got really aggressive one night, her and [another FR], they were fighting like men and the registered staff were upstairs and we [the two PSWs] were doing rounds so we had to drop what we were doing and go in to separate them. So when we told her what had happened she said, [That resident? (As in, Really??)], and she hadn't been down here for like I don't even, like for months and months and months, didn't even know this woman; "*Her? Oh that's hard to believe. I can't believe that.* I said, *Yes she can, you can walk past her and she'll punch you.* -- *Oh no I don't believe that.* So then when one of the registered staff from nights came in she was saying *Oh they were saying to me that [that FR] is aggressive.* And the registered staff says *Oh yes*

*she is, just the other day she punched so and so in the back. -- Oh I didn't know that, like...* [she pauses to imply her point].

Validity reconstructions that account for the PSWs' experience of her knowledge being negated include the following:

Possible Objective Claims:

Foregrounded:

- Some registered nursing staff do and some do not seem to respect PSWs and their knowledge of residents.

Backgrounded:

- In addition to full-time and regular part-time staff, the SCU is sometimes staffed by care providers who have not been on the SCU for quite some time.
- Staff who are scheduled to work on the SCU infrequently lack familiarity with the status of residents' psycho-social functioning.

Possible Subjective Claims:

Foregrounded:

- The PSW is pleased to work with registered staff who acknowledge their own lack of familiarity with the residents and who solicit PSWs' knowledge about residents.

Backgrounded:

- The PSW feels offended and devalued by registered staff who appear to simply not believe what she shares about a resident.

Remotely backgrounded:

- Such devaluation diminishes morale among the PSWs.

Possible Normative Claims:

Foregrounded:

- Registered nursing staff who are (newly or recently) unfamiliar with the residents should solicit and value the knowledge PSWs have about those residents.

Remotely backgrounded:

- Generally speaking, the SCU should only be staffed with people who work regularly enough on the unit to maintain familiarity with the residents.

**Appendix 5.5: Nursing is only as holistic as you make it – a reconstruction of  
*normalized inclusion in knowledge exchange***

*Context.* At 1:30 p.m. in the ADP, once the recreationists had resumed their programming, the three PSWs who had been monitoring, feeding, and caring for the clients during lunch left the floor and joined a registered nurse (RN or RPN) in the staff team room for a brief (15 minute) meeting. This was a long-established practice that afforded the registered nursing staff an opportunity learn from the PSWs about how the clients are that particular day. Historically, these meetings have focused on the PSWs' tasks (toileting, dietary intake, mobility and transfers), but these meetings had evolved as an opportunity for the nursing staff to “do some education” about holistic dementia care practices.

In speaking with an RN after one such nursing meeting, she described how PSWs can

*become very trapped in just being task oriented, and it takes a lot of pulling at them and stretching their mind and making them look at stuff to not just get stuck in the tasks. ... that's something that we work very hard at here and I poke at them about because that's very, very important.*

I then asked if it was these particular 1:30 meetings that provided the opportunity for that “pulling and stretching” of the PSWs; the RN replied,

*Yeah. Because then as a group of peers, you know, someone may be brave enough to step up and say something. And another one will come in and protect them but we all know what we're talking about. You know, let's not get wrapped up in the task. And see them as a person. Not as – not as someone to dress. Not*

*as someone to feed. Not as someone to toilet. But, you know, she was volunteer of the year ... She speaks seven languages. See this person as a person. And then when you're toileting her, doing stuff with her, you've now humanized her and as long as you have humanized that person, and put some kind of a personality to it, it's much easier not to get wrapped up in task.*

This quote shows that the RN tried to develop and foster a new care norm, one that (re)humanized people with dementia, one that she thought all staff recognized: that the stay should be “seeing them as a person”. Evident here is the RN’s sensitivity to group dynamics, including her own authoritative and normative power, as well as her valuing of holistic care. A comment the RN made a moment later demonstrates the importance of being able to read a person with dementia, to gain and share knowledge of the *person* with dementia:

*I think that if everyone took the time to have these type of meetings, and then if the whole environment was rich like ours where we're – we have this knowledge of who they are and we have people who share the knowledge of who they are.*

*When I get PSW students in here, we work very hard to give them that type of a picture because it's very easy to just become, you know, a task oriented person.*

*And nursing is such a holistic practice but it's only as holistic as you make it.*

Based on the comment that nursing is only as holistic as you make it, the following validity reconstructions stand as justification for the RN’s normalized inclusion of the PSWs’ knowledge and experience.

Possible objective claims:

Foregrounded:



- Without a mechanism that reframes the PSWs' care practices as (needing to be) holistic, PSWs' practices can become task oriented.
- The culture of dementia care knowledge in the ADP features giving primacy to knowing not only each client's case history, but their personal, familial, and professional history as well. Moreover, the culture is one that actively seeks to share and spread this knowledge among the care providers.
- Getting to know the personal history of a client with dementia serves to humanize that client, to make the client someone that providers can relate to.

Backgrounded:

- Other teams within the organization do not have such a formal, regularly scheduled mechanism to enable this kind of knowledge exchange.

Possible Subjective Claims:

Foregrounded:

- PSWs can sometimes feel uncomfortable and perhaps even threatened by these check-in meetings.

Backgrounded:

- The RN feels confident that she can mitigate PSWs' discomfort and that she can in fact make the PSWs feel valued for what they know and for what they do.
- The RN is proud of her and her team's care practices and their focus on holistic and humane care provision.

Possible Normative Claims:

Foregrounded:

- All dementia nursing care, including the practices of PSWs, should be holistic; that is, care providers should see a client not as a body but as a person that requires assistance.
- The PSW's knowledge and experience of the clients should be taken into account when care planning.

**Backgrounded:**

- Dementia care providers should be interested in knowing about their clients' personal history.

**Appendix 5.6: We're working on developing a relationship with him – a reconstruction of *normalized inclusion in knowledge exchange***

*Context.* A full-time RPN was reviewing with a SCU physician a list of residents. There were about a dozen names on the list, i.e., almost half of the SCU residents. The RPN and the physician had known one another for more than four years, and had expressed their high regards for one another both to each other and privately to me. The two of them were seated in the SCU chart room around a small round table, along with myself. In another corner of the room, a PSW sat at a computer documenting the provision of daily care. The dialogic sequence begins as the RPN begins sharing with the physician (MD) her knowledge of a recently admitted male resident.

RPN: [MR] is the first person in many, many years that I feel I cannot make any form of a connection with, he's so blank. Somebody said to me this morning, could he be depressed? He's on, I think it's 10 mg of cipralex [an anti-depressant], or maybe a little bit more.

MD: Yeah.

RPN: But he's very, his affect...

MD: Flat.

RPN: Very flat [emphasis on *very*]. He's strong in his-- but whether he allows us to take care or not, and we're, 'course we never force, but the man needs care sometimes, so we have to do it.

MD: Is he resistant?

RPN: Yep. Like, when he says no...

PSW [who is sitting nearby, charting]: [MR?]

RPN: [MR].

PSW: When he says no, it's no.

RPN: It's no.

PSW: The only person that can get through to him ever, is his wife.

RPN: Yeah, his wife is so good with him.

MD: Yeah.

RPN: I just feel bad for the man, cause he always looks so lost...

PSW: He is.

RPN: ...and blank.

MD: What I'll do is, I think I agree with you, the cipralex is at 10, we could go to 15...

RPN: Okay.

MD: ...with monitors, so, I'll increase the dose to 15.

RPN: I'm, you know, when I say I'm trying to develop a relationship, I know it's not going to be like, you and I, or you and Ryan talking, but for the first couple of weeks, he wouldn't even look at me, he wouldn't make eye contact. I get right in their faces, with the pills. Now he's, if I say his name and Good morning -- this morning I tried to talk to him about his kids, and I said, *You've got a daughter, I just met her yesterday*, and I said, *What's her name?* And he looked at me, and he said, *I don't know*. So we're working on developing a relationship with him.

There are a number of things that make this exchange remarkable. One is the interjecting contribution of the PSW that served to corroborate the RPN's account of the resident – despite this important role in this exchange, neither the RPN nor

the physician explicitly acknowledge her comment. Another remarkable aspect of this exchange is the ambiguous reference to (not) using force when providing care - *'course we never force, but the man needs care sometimes, so we have to do it.*

For the present purpose of further illustrating the theme of *normalizing inclusiveness*, the following reconstructed validity claims demonstrate how and why the RPN justifies the importance of building a relationship with residents.

Possible Objective Claims:

Foregrounded:

- The RPN claims that her practices include developing rapport and building a relationship with residents by interacting with them each and every morning while administering medications
- Building relationships with a person with dementia is quite different than building a relationship with someone who does not have dementia

Backgrounded:

- Invoking a resident's family history is (usually) an effective technique for opening up a meaningful conversation with residents.

Possible Subjective Claims:

Foregrounded:

- The RPN feels badly for the resident, manifest as compassion and sympathy

Backgrounded:

- It is frustrating or concerning that she cannot establish such a rapport with this resident (as it stands in contrast to her success in doing so with other residents over her career)

Possible Normative Claims:

Foregrounded:

- As a full-time RPN, she should establish and maintain a relationship with all residents, even if that relationship is non-verbal, so as to enable ongoing opportunities to be able to read/assess residents' wellbeing / change of psycho-social status

Backgrounded:

- Depression should be treated.
- Registered nursing staff should convey to physicians observed symptoms of depression and the how these symptoms affect care provision.

Remotely backgrounded:

- Physicians should rely on, or at least consider seriously, the observations and judgments of the registered nursing staff.

**Appendix A: Letter of Information & Consent Form (staff version)****Letter of Information and Consent Form****Understanding the Culture of Dementia Care Knowledge****Study Investigators:**

Ryan DeForge, PhD (c)

Health & Rehabilitation Sciences Graduate Research Program

Faculty of Health Sciences

The University of Western Ontario, London, ON

Dr. Anita Kothari, PhD

School of Health Studies

Faculty of Health Sciences

The University of Western Ontario, London, ON

Dr. Catherine Ward-Griffin, RN, PhD

Arthur Labatt Family School of Nursing

Faculty of Health Sciences

The University of Western Ontario, London, ON

## **Introduction**

As someone who works in a long-term care home, you are being invited to participate in a research study that will explore your perspectives on providing care to residents with dementia.

The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this research. It is important for you to understand why the study is being conducted and what it will involve. Please take the time to read this carefully and feel free to ask questions if anything is unclear or if there are words or phrases you do not understand.

## **Purpose of this Study**

The purpose of this research project is to examine the ways in which long-term care residents, family members, and staff create, share, and apply different forms of practice knowledge about dementia care. We are asking you to participate in this study because you provide care to those who live in long-term care.

## **Summary of Research Project**

This research project proposes to critically examine the ‘culture of dementia care knowledge’ within a long-term care setting. Of particular interest is how care routines are negotiated, shared as they are among staff and, at times, family members. The objective of the data collection and analysis is to better understand what taken-for-granted values, beliefs and behaviors shape the interactive, power-laden discussions that in turn shape care routines.

To collect the project data, a student researcher from The University of Western Ontario, Ryan DeForge, will begin by observing interactions among/between residents, staff, and family members. Then residents, staff, and family members will be interviewed to discuss further issues related to dementia care. Finally, residents, staff and family will be invited to participate in small group discussions to exchange interpretations of the study findings.

## **Who can participate in this study?**

We invite all residents of this long-term care home and their family members to participate. Additionally, all healthcare providers (i.e., anyone providing direct care to residents, education to long-term care home staff, as well long-term care home management) are invited to participate. Your participation in this study will not affect your participation in any other concurrent or future studies.

## **What will I have to do if I choose to take part?**



There are three components to the data collection strategy. Initially, the researcher will be observing interactions among residents, staff, and family members in an effort to understand how dementia care knowledge is created, shared, and applied. Although no personally identifying information will be recorded, these observations will be recorded as field notes in a journal. When such observations are being conducted, a “Notice of Research in Progress” will be posted at entryways to the home and to the specific unit being observed to ensure you are aware that a researcher is present.

You may subsequently be asked to participate in an interview to reflect on and share your perceptions of dementia care. The interview component of the study is designed to extend and deepen the researcher’s understanding of dementia care knowledge.

Finally, you may also be asked to participate in a small group discussion that facilitates the exchange of your and the researcher’s interpretations of the data. These focus groups are designed to spark conversation about the culture of dementia care knowledge and to generate and share ideas about how dementia care practices can be improved.

In total we will need approximately 1-2 hours of your time. It is expected that an interview will take about 60 minutes of your time, and/or, if you participate in a focus group discussion, it is also expected to take about 60 minutes of your time. The research interviews and focus group discussions will be conducted within the long-term care home, and will be tape-recorded and transcribed. Your questions, comments or stories will remain confidential as no personal identifiers (such as your name) will be collected or retained for research purposes.

### **Will I be paid to participate in this study?**

You will not be paid to take part in this research study.

### **Are there any risks or benefits of taking part?**

*Risks:* There are no known risks associated with participating in this study aside from those that may arise in reflecting on and discussing your personal care-giving experiences. When the study results are published or presented, your name will not be used. No information that discloses your identify will be released or published without your explicit consent to the disclosure. You do not waive any legal rights by signing the consent form.

*Benefits:* Many people who participate in research-based interviews about their job find some benefit in reflecting on the challenges and rewards of their work, and we hope this is the case for you. In more general terms, while you may or may not benefit *personally* from participating in this study, the knowledge gained from this study may be useful in

designing effective educational resources/tools/information for health care providers caring for long-term care home residents who have dementia.

**Do I have to take part?**

No. Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. Refusal to participate will not result in any punitive action: while the leadership team of McCormick Home supports this study, it is understood that your right to participate in this study voluntarily must be preserved.

**What happens to the information I provide?**

We will not retain any information that could be used to identify you. The information you share in an interview or in a small group discussion will first be transcribed verbatim, then “cleaned” so as to remove any names or other personal identifiers. The information you provide will be stored on a password-protected computer and/or in a locked cabinet in a secure office accessible to only the research team. Your name will not appear in any verbal or written reports of the study findings.

As we are not able to link your name to the information you give us, once you have provided a response to our answers we are unable to retract your information.

If you would like to receive a copy of the overall results of the study, please put your name and address on a blank piece of paper and give it to the person conducting the interview or focus group.

This letter of information is yours to keep for your own records. If you have any questions about your rights as a research participant or the conduct of the study you may contact The Office of Research Ethics at (519) 661-3036 or by email at [ethics@uwo.ca](mailto:ethics@uwo.ca). Please note, representatives of The University of Western Ontario may contact you or require access to your study-related records to monitor the conduct of the research.

## Consent to Participate

**Understanding the Culture of Dementia Care Knowledge****Study Investigators:**

Ryan DeForge, PhD (c)

Health & Rehabilitation Sciences Graduate Research Program

Faculty of Health Sciences

The University of Western Ontario, London, ON

Dr. Anita Kothari, PhD

School of Health Studies

Faculty of Health Sciences

The University of Western Ontario, London, ON

Dr. Catherine Ward-Griffin, RN, PhD

Arthur Labatt Family School of Nursing

Faculty of Health Sciences

The University of Western Ontario, London, ON

I have read the Letter of Information, have had the nature of the study explained to me, and all questions have been answered to my satisfaction. I agree to (please check all that apply):

\_\_\_ allow observations of my interactions with other staff and with residents and residents' families to be recorded

\_\_\_ participate in an interview that explores my perceptions of dementia care knowledge

\_\_\_ participate in a focus group that discusses the preliminary findings from this study

Name of Participant:

Date:

Name of Study Investigator/ Person Obtaining Consent:

Date:

## Appendix B: Curriculum Vitae – Ryan DeForge (November 2013)

### EDUCATION

#### i) Degrees

*Doctoral Candidate* in Health & Rehabilitation Sciences Graduate Research Program (Health Promotion stream), Faculty of Health Sciences, Western University, London ON. (September 2007 start; defense date: November 4<sup>th</sup> 2013).

M.Sc., Family Relations & Applied Nutrition (Gerontology)  
University of Guelph, Guelph, ON, (2000 - 2002).

B.A.Sc., Gerontology, University of Guelph, Guelph, ON, (1994 - 1999).

### EMPLOYMENT HISTORY

#### i) Current Positions

- a) Research Associate. Research and Evaluation, Specialized Geriatric Services of St. Joseph's Health Care, London, under the direction of Dr. Iris Gutmanis and as a member of the Care of Older Adults team within the Aging, Rehabilitation and Geriatric Care Research Centre at Parkwood Hospital (2004 – present).

#### ii) Previous Positions

- a) Policy Consultant, Nursing Policy Unit, Health Canada (2013).
- b) Project Coordinator. *Building Partnerships in Community Dementia Care*. Principal Investigator: Dr. C. Ward-Griffin (2010 – 2012).
- c) Project Coordinator. *Double Duty Caregiving and Health Human Resources: A Knowledge Translation Initiative*. Principal Investigator: Dr. C. Ward-Griffin (2012).
- d) Editorial Assistant. Social Policy & Practice Section, Canadian Journal on Aging (2008 – 2011).
- e) Graduate Research Assistant. *The negotiation of care in home-based dementia care: A critical ethnographic exploration*. Principal Investigator: Dr. C. Ward-Griffin (2007 – 2010).

- f) Research Assistant, City of London/The University of Western Ontario. 'Examining the readiness of London's long-term care homes to serve seniors with dementia.' Principal Investigator: Dr. A. Salmoni (School of Kinesiology, Western), (2009 – 2010).

## AWARDED FUNDING

1. Frederick Banting – Charles Best Canadian Graduate Scholarship – Doctoral Award. Canadian Institutes of Health Research. 2009 – 2012. (\$105,000).
2. Ontario Graduate Scholarship, 2008. (\$15000).
3. Accepted to the Canadian Institutes of Health Research – Institute of Aging "Summer Program on Aging." Honey Harbour ON, June 2008.
4. Accepted to the Canadian Institutes of Health Research – Institute of Health Services and Policy Research / Institute of Population and Public Health Summer Institute "2008 Innovation in Knowledge Translation Research and Knowledge Translation." Cornwall ON, June 2008.
5. National Initiative for the Care of the Elderly (NICE) Student Mentorship program 2007-08 and 2008-09. (\$1000).

## PUBLICATIONS

### (i) Peer Reviewed

#### a) Journal Articles:

1. St-Amant, O., Ward-Griffin, C., **DeForge**, R., Oudshoorn, A., McWilliam, C., Forbes, D., Kloseck, M., & Hall, J. (2012). Making care decisions in home-based dementia care: Why context matters. *Canadian Journal on Aging*, 31(4), 423-434.
2. Shaw, J. & **DeForge**, R. (2012). Physiotherapy as bricolage: Theorizing expert practice. *Physiotherapy Theory and Practice*, 28 (6), 420-427.
3. Stolee, P., Byrne, K., Awad, M., **DeForge**, R., Clements, S., & Glenney, G. (2012). A multi-site study of the feasibility and clinical utility of Goal Attainment Scaling in geriatric day hospitals. *Disability & Rehabilitation*, 34 (20), 1706-1715.
4. **DeForge**, R. & Shaw, J. (2012). Back- and fore-grounding ontology: exploring the linkages between critical realism, pragmatism, and methodologies in health and rehabilitation sciences. *Nursing Inquiry*, 19(1), 83-95.

5. Ward-Griffin, C., Hall, J., **DeForge**, R., St-Amant, O., McWilliam, C., Oudshoorn, A., Forbes, D., & Klosek, M. (2011). Dementia home care services: How are we managing? *Journal of Aging Research, Volume 2012*.
6. **DeForge**, R., Van Wyk, P., Hall, J., & Salmoni, A. (2011). Afraid to care; unable to care: A critical ethnography within a long-term care home. *Journal of Aging Studies, 25*, 415-426. [**Listed as a 'New and notable' ethnographic research article** in The Weekly Qualitative Report, [Vol. 4, No. 46](#), November 14, 2011].
7. Cornelissen, E., Urquhart, R., Chan, V., **DeForge**, R., Colquhoun, H., Sibbald, S., & Witteman, H. (2011). Creating a knowledge translation trainee collaborative: From conceptualization to lessons learned in the first year. *Implementation Science, 6*:98. ("**Highly accessed**" article).
8. Forbes, D., Ward-Griffin, C., Klosek, M., Mendelsohn, M., St-Amant, O., **DeForge**, R., & Clark, K. (2011). "My world gets smaller and smaller with nothing to look forward to": Dimensions of social inclusion and exclusion among rural dementia care networks. *Online Journal of Rural Nursing and Health Care, 11*(2). <http://rnojournl.binghamton.edu/index.php/RNO/article/view/18>
9. Kho, M., Estey, E., **DeForge**, R., Mak, L., & Bell, B. (2009). Riding the knowledge translation roundabout: Lessons learned from the Canadian Institutes of Health Research Summer Institute in Knowledge Translation. *Implementation Science, 4*:33 (12 June 2009). ("**Highly accessed**" article).
10. **DeForge** R., Cormack C., Byrne K., Hillier, L.M., Mackenzie R., & Gutmanis, I. (2008). Facilitators and barriers to recommendation adherence following discharge from geriatric rehabilitation. *Topics in Geriatric Rehabilitation, 24*(4), 345-353.
11. **DeForge** R., Regan B., & Gutmanis, I. (2008). Lean on Me: Building volunteer capacity to support frail seniors' participation in community seniors' centre programs. *Therapeutic Recreation Journal, 40*(2), 170-179.

#### b) Journal Abstracts

1. Van Bussel, L., Gutmanis, I., Jarvie, A., Speechley, M., & **DeForge** R. Using theatre to explore long-term care home healthcare provider needs. (2012). *Research Insights, 9*, 10.
2. **DeForge**, R. (2011). Modelling critically and ethnographically derived transformative knowledge exchange. International Institute of Qualitative Methods – Qualitative Health Research conference, Vancouver, BC, October 2011. *International Journal of Qualitative Methods, 10* (4), 488.

3. **DeForge, R.,** Ward-Griffin, C., Speechley, M., & Gutmanis, I. (2011). Research-based theatre as a catalyst for transformation. International Institute of Qualitative Methods – Qualitative Health Research conference, Vancouver, BC, October 2011. *International Journal of Qualitative Methods, 10* (4), 499.
4. Ward-Griffin, C., McWilliam, C., Orange, J.B., Klosek, M., Wong, C., & **DeForge, R.** (2011). Building partnerships in community-based dementia care: A critical constructivist grounded theory. International Institute of Qualitative Methods – Qualitative Health Research conference, Vancouver, BC, October 2011. *International Journal of Qualitative Methods, 10* (4), 460.
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Notes







END.