CO-CREATING PERSON-CENTRED CARE IN ACUTE CARE

by

Lillian Mei Hung

B.N., University of Manitoba, 1993

M.A., Simon Fraser University, 2008

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Abstract

Patients with dementia in acute care often experience poor outcomes, as nurses and other staff in hospitals are not equipped to provide good dementia care. Person-centred care has been recognized as the best practice for dementia care, but its application in hospital environments remains unclear. This action research involved patients with dementia, a team of staff members, and public advisors to co-create changes in a medical unit.

The objectives of the project were to: (a) develop person-centred care in a medical unit, (b) explore ways to support the involvement of patients with dementia in research, (c) examine the processes of staff engagement for bringing together staff from different disciplines to co-inquire, and (d) evaluate the impact of research on the process of change and identify the lessons learnt to inform practice, education, policy, and research. Various methods were used such as: interviewing patients with dementia, focus group sessions with a team of inter-disciplinary staff, and participant observations.

In this thesis, I argue for a new positive and collaborative approach that views change as a continuous process. In the past, the problem-focused model that sees change as fixing people has largely failed with regards to advancing practice developments in dementia care. An important outcome of this research is the heuristic guide *'Team Engagement Action Making'* (TEAM), which can be used to support teams to engage staff in co-creating positive change. The results of this study indicate that appreciative inquiry is a useful strategy for engaging people on a team to learn together and to co-create a better future of care. The findings also suggest that more attention should be paid to the dynamic inter-connection of research and practice, rather than just one or the other. The results demonstrate that action research can affect the process of change by generating positive energy, attitude change, and

a momentum for action activities in the unit and beyond. Future research should further explore strategies that would maximize the potential of bringing patients, families, researchers, and practitioners to work together for positive change.

Lay Summary

Older people with dementia going into hospitals often have poor experiences. This research is aimed to make changes to improve patient experiences by working with patients and a team of staff across disciplines to develop person-centred care in a medical unit. I interviewed patients with dementia, had group discussions with staff, and carefully watched activities happening in the unit. One important research result is the creation of the guide *Team Engagement Action Making* (TEAM), which describes how to bring people together to make change. The study calls for learning and working together to grow knowledge and skills in dementia care. More attention should be paid to bring research and practice closer together. Future research should find ways to maximize the benefits of bringing patients, families, researchers, and practitioners to work together for positive change.

Preface

This thesis was written by L. Hung, the author of this original work. The research was approved by the UBC Behavioral Research Ethics Board and the Vancouver Coastal Health Research Institute: certificate numbers: UBC H15-03036 and VCHRI V15-03036, respectively.

Mrs. Jenifer Tabamo, clinical nurse specialist, and Mrs. Doris Bohl, nurse educator at the Vancouver General Hospital are practitioner collaborators who actively contributed to the planning and carrying out of action activities in this project. Mr. Jim Mann, a public advisor, provided advice on the design of research activities from the perspective of a person living with dementia. Ms. Gerlise Matz and Ms. Sheila Lamb, family advisors from the Community Engagement Advocacy Network of Vancouver Coastal Health, contributed to the environmental assessments and advised about the research development.

I conducted all interviews and observations, and wrote the initial drafts of all manuscripts. JT and DB were involved in the data analysis. The supervisory committee provided guidance on research development, data analysis, and critical review of the writing.

List of Papers

Three papers derived from Chapters 5 to 7 have been prepared for publication with the following authors: Hung L., Phinney A., Rodney P., Chaudhury, H., Tabamo J., and Bohl, D. One article on critical reflection from Chapter 8 has been published as a single author article by Hung L.

Paper A

Hung, L., Phinney, A., Rodney, P., Chaudhury, H., Tabamo, J., & Bohl, D. Little things matter. Exploring the perspective of patients with dementia about the hospital environment. *International Journal of Older People Nursing,* published in open access, http://onlinelibrary.wiley.com/doi/10.1111/opn.12153/full

Paper B

Hung, L., Phinney, A., Rodney, P., Chaudhury, H., Tabamo, J., & Bohl, D. Using videos reflexive groups to develop practice in a hospital.

Paper C

Hung, L., Phinney, A., Rodney, P., Chaudhury, H., Tabamo, J., & Bohl, D. Bridging research and practice: Buiding a TEAM.

Paper D

Hung, L. (2017). A critical reflection: Using appreciative inquiry to research practice development. *International Practice Development Journal*, 7(1), published in open access, https://www.fons.org/library/journal/volume7-issue1

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List of Abbreviations

ADL   Activities of Daily Living

BPSD   Behavioral and Psychological Symptoms of Dementia

CEAN   Community Engagement Advisory Network

GNABC   Gerontological Nurses Association of British Columbia

GPA   Gentle Persuasive Approaches

HEAP   Hospital Environment Assessment Protocol

KT   Knowledge Translation

MMSE   Mini-Mental State Examination

TEAM   Team Engagement Action Making Guide

TESS   Therapeutic Environment Screening Survey

Glossary

Becoming	The dynamics of the continuous unfolding of an individual or social group towards growth (Gergen, 2014)
Dialogue	Any exchange between two or more people, as opposed to monologue being delivered as one-sided (Bakhtin, 1981)
Discourse	A set of interrelated words, graphic images, or symbolic expressions and related practices of their production and dissemination, cultivating a way of thinking into being (Bushe & Marshak, 2015)
Generative capacity	The ability of a social group to engage in a process that leads to new ideas, opportunities, and positive changes (Bushe, 2013)
Narrative	Written or verbal accounts that focus on certain themes that link a set of ideas into a storyline (Frank, 2011)
Relational approach	An approach that seeks to understand and attend to people in context (e.g., social conditions, organizational resources, and political climate). From an interpretive worldview, meanings are not privately held, but are always shaped by communal discourse and historical background (Doane & Varcoe, 2011).
Transformation	Transformation happens when there is new ideas, new ways of thinking, as well as new capacities and processes that can generate new knowledge and action (Bushe, 2005).
Video Reflexive Ethnography	It involves filming videos in the clinical units and playing the video segments to a team of practitioners. The purpose is to facilitate shared learning through team reflection (Carroll, Iedema & Kerridge, 2008).
Story	Story is an account of events. In the lens of social constructionism, story is always open to interpretation and re-interpretation. Meta narratives constructed by stories can influence how people think and act in social groups (Frank, 2011).

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I am grateful for the invaluable support that I received from my primary supervisor, Dr. Alison Phinney. Thank you for your faith in my ability. Your intellectual rigor and critical questions improved my work and set high academic standards that elevated the quality of my thesis. Thank you for guiding me to become a scholar in the field of dementia care. Your commitment to involve people with dementia in research deeply inspired me. I also want to send my heartfelt gratitude to Dr. Habib Chaudhury who is dedicated to the success of each student. I have learned so much from you. Dr. Chaudhury is an exceptional teacher and mentor. He gave me the courage to reach my dream of completing the PhD. He taught me to focus on the positives in the first course I took from him in environmental design. Dr. Paddy Rodney is also an exceptional teacher and a great resource for any questions that arose. Thank you for giving feedback in supportive and challenging ways. You challenged me to think deeper and be clearer and you made me feel that I could totally do it. I feel extremely privileged to have an amazing supervisory committee that continuously offered caring advice and supportive guidance throughout my research training. Your positive encouragement and gentle guiding approach allowed me to grow and transform in this doctoral journey.

I would also like to acknowledge Mr. Jim Mann. Thank you for your help as a public advisor in this project. You taught me much about dementia and I wholeheartedly appreciate your expertise and generosity. Two family advisors, Ms. Gerlise Matz and Ms. Sheila Lamb gave me thoughtful suggestions, compassionate ideas, and timely feedback to enrich the project's success. I am also fortunate to have the tremendous support of two colleagues, Jenifer Tabamo and Doris Bohl. You two kept me grounded on the practicalities of the

Chapter 1: Introduction

> The applied research of the professional health disciplines is a foundationally and fundamentally practical enterprise. It exists because there is a pressing social need, and it seeks to find workable solutions on behalf of society. It has privilege within society commensurate with the importance of the expertise it represents. While theorizing may well have catalyzed our intellectual development beyond mechanistic means to study human phenomena in important new ways, it seems time to come out from under that particular shadow as a powerful force for making a difference in the health and health care of people.
>
> ~ Sally Thorne (2011)

This study is a response to an urgent call in my practice. I work as a clinical nurse specialist in a large urban Canadian hospital. Before this research, a needs assessment conducted in a medical unit of the hospital found that nurses reported that the most challenging aspect of their daily work was 'dealing with behavioral issues' in patients with dementia. Nurses were concerned that they were ill-equipped with caring for people with dementia and staff injuries related to behavioral events with patients with dementia. Many nursing staff said they had no training in dementia care even though they were caring for patients with dementia every day. The restrictive and unsupportive design of the physical environment was perceived as a contributing factor for the behavioral events among patients with dementia. Little activity space was available for meaningful stimulation or social interactions. In general, staff felt that while they were confident with the technical aspects of medical care, there was a need for improving quality and safety of dementia care. The desire to make change for increasing team capacity and for improving care experience of patients with dementia provided the impetus for this research.

My professional background was in gerontological nursing. I had worked in leading practice change projects in residential and acute care. My previous research experience has centred on investigating environmental impacts on people with dementia. In this doctoral project, I took an action research approach and worked with people with dementia, families, and a large team of staff and leaders to co-develop change. This approach was taken because of the urgent need for actions. The study began in January 2016 and progressed through a number of phases where I worked with the team together to co-inquire and co-design actions.

Structure of the Thesis

This thesis is divided into nine chapters. Chapter 1 provides an overview of the practical issues in hospital dementia care. I describe how the inadequacy of dementia care knowledge, a predominant culture of biomedical approaches, and environmental constraints contribute to the construction of complex problems in dementia care.

In Chapter 2, I take a critical review of the development of person-centred care for people with dementia in acute care. I also review selected literature on the physical and social environmental interventions. Chapter 2 situates the research focus within the extant literature and provides relevant content to inform specific actions in the research. I also argue for the vital importance to include people with dementia in research.

Chapter 3 outlines the philosophical underpinnings of action research, which builds on critical social theory and orients with social constructionism and an interpretive worldview. I also introduce appreciative inquiry, a specific form of action research that provided key concepts to guide and shape the study.

In Chapter 4, I describe the research design. This chapter clarifies the specific objectives of the study, the methods used and the participants who were involved, the data generation activities and the process of data analysis.

Chapter 5 through 7 comprises the findings of the research. First, I report research results that draw on data from the engagement of patients with dementia in go along interviews. Chapter 6 presents findings from the engagement of staff in video reflexive groups. Chapter 7, based on the synthesis of findings from the experiences of staff in research, I propose a new conceptual tool to support staff engagement in practice development.

Finally, in chapter 8 and 9, I discuss the overall research findings and present my final conclusions. Chapter 8 offers a critical reflection on the assumptions I held and the insights I gained in the conduct of the research. In chapter 9, I discuss what my research can offer people working in dementia and practice in dementia care. I review the key results in light of the literature and offer implications and recommendation for policy makers, educators, researchers, and practitioner.

1.1   Background

Older people with dementia are not only more likely to be admitted to hospitals, but they are also more likely to experience harms and adverse outcomes in hospitals. Staff members in acute hospitals face challenges in providing care for the growing numbers of people with dementia who have complex medical and mental health needs. Research has shown that behavioral and psychiatric symptoms (BPSD) are common in people with dementia in acute hospitals, affecting 75% of those with dementia at some point during their stay in acute care, which often leads to prescriptions for antipsychotic drugs (Sampson et al.,

2014). Given the growing number of older people with dementia in Canada and worldwide, improving dementia care in acute hospitals has become an urgent priority.

Hospitals are under tremendous strains from the rapidly growing demand associated with the aging population and chronic conditions, such as dementia. Older people with dementia, as with any other group of Canadians who become acutely ill, may require care in a hospital. Currently, older people with dementia are hospitalized at least three-times as often as age-matched older adults without the disease, and people with dementia tend to have longer lengths of stay, poorer health outcomes, and more hospitalization-associated disabilities (Covinsky, Pierluissi, & Johnston, 2011). The complexity of disease management in older adults with dementia is also reflected in more comorbid conditions and more drug use, compared to their counterparts without dementia (Bronskill, Corbett, Gruneir, & Stevenson, 2011).

Although unnecessary hospital admissions should be avoided, older people with dementia who have acute medical illnesses have the right to access care and deserve high-quality acute care services. The literature is increasingly reporting that unsupportive environmental features, such as the lack of familiar signage and orientation cues and insufficient knowledge about dementia in acute hospitals are contributing to poor outcomes in older patients (Clissett, Porock, Harwood, & Gladman, 2013; Dewing & Dijk, 2016; Gladman, Porock, Griffiths, Clissett, & Harwood, 2012). In a study by the Alzheimer's Society in England (2009), almost all (97%) of the nursing staff always or sometimes care for a person with dementia but only one in ten (12%) of the nursing staff felt that they had the training to support their work with patients with dementia. The same study also revealed a significantly higher use of antipsychotic medications and long lengths of stay in the group of

older people with dementia. Furthermore, families reported deterioration of dementia symptoms, poorer overall health, and loss of function of their loved ones following hospital admission.

The acute hospital setting is often a stressful environment for older people with dementia. While cognitive impairment makes adaptation more challenging, the restrictive clinical environment and unfamiliar routines can aggravate patients' vulnerability. Unmet needs and misunderstanding by staff can lead to frustration, angry outbursts, or responsive behaviors. Studies have shown that the behaviors of people with cognitive impairment are often attempts to communicate due to their unmet needs or attempts to exercise control to cope with disruptions to their personal routine (Dupuis, Wiersma, & Loiselle, 2012; Gladman et al., 2012). An unsupportive environment can trigger high anxiety, stress, and catastrophic behaviors, and the behavioral symptoms can also be indicators of medical problems such as infection or constipation. Older patients with cognitive impairment commonly suffer more unmanaged pain, anxiety, loss of control, sense of powerlessness, and disorientation (Moyle et al., 2011).

Dementia care experts underscore that the best way to address behavioral symptoms is not through the use of restraints, but by responding to the person's unmet physical or psychosocial needs (Algase et al., 1996; Cohen-Mansfield, Dakheel-Ali, Jensen, Marx, & Thein, 2012). Nevertheless, research that examines possible triggers and effects of proactive prevention on the development of behavioral and psychological symptoms of dementia is lacking (Kales, Gitlin, & Lyketsos, 2015). Moyle et al. (2011), who studied acute care management of older people with dementia, found that the risk management approach in hospitals often leads to the use of chemical and physical restraints. Focusing on limiting

behaviors, rather than addressing underlying unmet needs, can result in stigmatizing persons with dementia and unnecessary negative outcomes (Dupuis et al., 2012). Although best practice guidelines in person-centred care emphasize a holistic approach, recent evidence shows that chemical and physical restraints are often used as the first-line treatment in acute settings (Dewing & Dijk, 2016).

The public expects the healthcare organizations serve them with respect of human dignity. Rodney et al., (2013) point out that we have an absence of effective public policy (health as well as social and educational) to protect older people with dementia; change is needed to reduce ageism, and to ensure older adults are treated with dignity and respect.

1.2   Inadequate Dementia Care Knowledge

Nurses in acute care are often required to manage challenging behaviors of patients with dementia with only limited training that supports dementia education (Kynoch, Wu, & Chang, 2009). Gandesha et al. (2012) examined dementia care training among staff in 236 hospitals in the UK and found training deficiencies in many areas, including assessing cognitive ability, dementia awareness, recognition of pain in people with dementia, and use of restraints and associated risks. In a dissertation that investigated the factors that influence the use of restraints on elderly patients in acute care, the vast majority of nurses (94%) working in acute care hospitals believed that patients became more aggressive/agitated when restrained (Kynoch et al., 2009). De-escalation is a behavioral intervention commonly used by nurses in mental healthcare to respond to angry or aggressive behaviors, but the confidence, knowledge, skills, and techniques required to de-escalate a risky situation depend on training support and clinical experience (Kynoch et al., 2009). While little evidence supports the effectiveness of physical and chemical restraints to decrease BPSD, the use of

restraints raises many ethical and moral concerns for nurses. For example, nurses may intend to use restraints to keep a patient physically safe from falling, but emotional and psychological harm, and physical harm, can be done to the patient being restrained. Further, Health Canada and the U.S. Food and Drug Administration (FDA) have issued advisories and black box warnings stating that antipsychotic use in people with dementia may lead to mortality risk. In fact, a recent antipsychotic research study, involving a large sample of more than 33,000 older people with dementia, found that mortality was highest in those receiving haloperidol, followed by risperidone, and olanzapine (Kales et al., 2014).

Education that ignores local contextual relevance is unlikely to lead to effective practice change (Kitson, 2009). Nurses in a study by Chater and Hughes (2012) reported the importance of a team approach and having structured opportunities to reflect on practice together. Team reflection was also identified by Smythe et al. (2014) as an effective means to enhance practice. The study participants found that in-house education and learning from one another were helpful. In addition, Presho (2006) recognized that the intensity of the clinical environment poses a significant challenge for learning, which emphasizes the need to use flexible strategies that meet the needs of adult learners who may have a range of diverse learning styles. Nurses have identified time constraints as a key barrier to improving their knowledge, and therefore, a more practical approach is required to meet the needs of staff on the ward (Chater & Hughes, 2012). Other possible key barriers preventing practice development include lack of appreciation of team learning and lack of engagement of stakeholders (Kitson, 2009).

The context of the clinical environment has been acknowledged as a significant factor in spreading knowledge and practice capacity development (Kislov, Waterman, Harvey, &

Boaden, 2014). For example, contextual factors like leadership support, facilitation, and resources are believed to affect the extent of uptake of knowledge. Growing awareness and concerns that new knowledge is not adopted in clinical practice has pushed scholars and practitioners to find ways to speed up the knowledge translation. Alley, Jackson, and Shakya (2015) suggest integrating group reflexivity into the clinical environment to provide teams with the opportunity to question old practices and make ongoing developments. Currently, a dearth of research has been conducted in hospital settings with a focus on knowledge translation and the care of older adults (Boström, Slaughter, Chojecki, & Estabrooks, 2012). Research is needed to describe what makes the translation of knowledge in dementia care effective and sustainable.

1.3   The Predominance of Biomedical Approaches

In the biomedical model, dementia is defined as stages of decline, impairment, problems, and losses while the new culture of person-centred care underlines the salience of preserving personhood (Cowdell, 2010; McGreevy, 2015). The medical discourses construct dementia through the lens of disease, where dementia is the direct result of disease processes and pathological changes in the brain (Davis, 2004; Innes, 2009). Biomedical research related to dementia has investigated features of brain tissue and how the organic brain disorder might affect behavioral, mood, and cognitive problems. Scholars in dementia research are concerned that, in a culture where cognitive function is highly valued, care that supports personhood may be seen to be less important or it may be ignored in a "hypercognitive world" (Dewing, 2008; Katz, 2012; Post, 2000). A narrow approach that focuses on cognitive impairment and problematic behaviors not only affect the social expectation of how people

with dementia should be treated in acute care, but it also has serious implications for social exclusion.

Kitwood's (1997) work was fundamentally important in problematizing the biomedical approach, highlighting the significant impact of social environments on individuals with dementia. He explicated that the experience of people with dementia can be affected by 'malignant social psychology', negative interactions that cumulatively undermine the individual. Examples of malignant social psychology include ignoring, stigmatizing, and disempowering people with dementia. Sabat (2001) applied Kitwood's work and found that the malignant social psychology in the social environment could powerfully exacerbate dementia symptoms and the well-being of the person. Person-centred care involves acknowledging and honoring the personhood of the individual with a holistic approach (Kitwood, 1997). In person-centred care, addressing psychosocial needs is considered as important as accomplishing the medical tasks to optimize the patient's well-being. Importantly, person-centred care is not just another task to do, but rather, it is a theory to guide the approach to care (Kitwood, 1997). The delivery of person-centred care requires a shift in mindset and practice from the dominance of the biomedical approach to a new culture of care. Failing to support psychosocial needs and recognizing personhood can lead patients to feel devalued, and could trigger 'challenging behaviors' such as hitting out. A negative label could then be used to describe individuals with dementia as "violent," which could reinforce a stereotype and add a barrier to person-centred care.

Current research reveals a context where nurses in acute care are concerned about feasibility and operationalization of person-centred care (Dahlke, Phinney, Hall, Rodney, & Baumbusch, 2014). Some authors suggest that a lack of consistency and clarity in the

organizational philosophy that guides practice can create tension for nurses and other clinicians and contribute to the gap between rhetoric and reality in the application of person-centred care (Venturato, Moyle, & Steel, 2011). Therefore, more clarity is needed with relevance for specific acute contexts to enable the realization of person-centred care. Organizational support is also considered critical for making good dementia care possible. Kitwood (1997) wrote, "if an organization is genuinely committed to providing excellent care for its clients – if it is committed to their personhood – it must necessarily be committed to the personhood of all staff, and at all levels" (p. 104). More researchers are now suggesting that a relational approach is required to implement changes in dementia care for real-life clinical practice (Hung & Chaudhury, 2011; Lee, 2009; Lewis, 2009; Poole, 2009). In contrast to the traditional positivist approach, a relational approach seeks to understand and attend to people in context (e.g., social situations, environmental factors, and political climates) (Hartrick-Doane & Varcoe, 2015).

The traditional clinical processes in hospitals can lead to functional losses and other unintended harms during a patient's hospitalization. For example, meals served in bed can lead to social isolation, immobility, and poor nutritional intake and the lack of orientation cues can lead to disorientation and the use of restraints (Covinsky et al., 2011). New evidence shows that relational approaches (e.g., care planning in person-centred care) can yield a better understanding of behavioral expressions in the context of life history, social situations, and environmental factors, thus improving patient outcomes (i.e., reducing the incidence of functional decline at discharge, decreasing hospital length of stay, and increasing the likelihood of discharge to home) (Baztán, Suárez-García, López-Arrieta, Rodríguez-Mañas, & Rodríguez-Artalejo, 2009; Wong & Miller, 2008). Moving forward, research is needed to

create practical knowledge and strategies to better realize person-centred care in the acute setting for older patients with dementia.

1.4   Environmental Constraints

Environmental constraints can have a significant negative impact on persons with dementia and their care. The traditional design of medical units was intended for quick assessments and treatment of acute illnesses (Donnelly, McElhaney, & Carr, 2011). The fast-paced movements, the noise of call bells and alarms, and the puzzling layout and unfamiliar routines can trigger confusion and delirium in older people (Huang, Larente, & Morais, 2011). Other aspects, like disorienting signage, poor lighting, clutter, and the lack of space for safe walking have been found to cause confusion and affect the patients' functioning and sense of safety (Edvardsson, 2008; Gladman et al., 2012; Hung et al., 2014; Moyle et al., 2011).

As noted by Davis et al. (2009), little research has investigated the impact of the environment of care with regards to clinical outcomes for people with dementia, and most of the studies have been undertaken in nursing homes rather than hospitals. A significant knowledge gap still exists about the vital role played by the physical environment to improve the care of people with dementia in acute hospitals. To better meet their needs, greater insight is needed to understand how specific aspects of the physical environment might affect the feelings of safety and well-being of people with dementia. For example, people with dementia can have difficulties finding their way around and engaging with people in an unfamiliar environment. Increased stress and anxiety may reduce their ability to perform normal daily activities such as eating or taking a walk. Projects conducted in the UK have shown that relatively inexpensive interventions, such as changes to lighting and improved

wayfinding signage, can have a positive effect on reducing falls and responsive behaviors, reducing the use of antipsychotics, and improving staff recruitment and retention (Waller & Masterson, 2015). Dementia design expert June Andrews (2013) argues that good hospital design can be a great "therapeutic resource for the care of patients with dementia; therefore, staff in hospital teams should be trained with knowledge about dementia-friendly design and advocate for changes informed by research evidence."

Overall, growing evidence indicates that the quality and outcomes of care for people with dementia and staff morale can be improved by making physical modifications, including relatively inexpensive changes to the environment of care such as improving orientation cues and creating comfortable spaces for social engagement (Waller & Masterson, 2015). Due to rapidly growing societal demands, hospital services need to ensure that older patients, including those who are physically frail and have dementia symptoms, have access to safe and high-quality care in hospitals (Royal College of Nursing, 2015). As older people have become the largest group of users of hospital services, the hospital physical environment, care systems, and staff need to be responsive to the changing healthcare needs of the population (Canadian Institute for Health Information, 2011; Parke & Chappell, 2010; Royal College of Nursing, 2015).

1.5   Purpose

The primary purpose of this research is to produce new knowledge, based on the experiential knowledge of patients, families, and staff and leaders in multiple disciplines. I wanted to know what would be important in the physical and social environments for patients with dementia and what would improve their care experiences in the hospital setting. The issue of inadequate knowledge about dementia among staff in acute care settings and the

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need for physical environmental change provides the impetus for this inquiry. In this research, I worked with a group of participants to take actions in real-time situations for practice development and study the change processes as they occur. Practice development in this project means engaging the team (including patient participants and public advisors) to develop knowledge and make positive changes in the physical and social environments of the hospital. Staff engagement in practice development requires not only a committed workforce but also an organizational environment that would support democratic engagement. In a democratic engagement, participants should have opportunities to have their perspectives meaningfully engaged and different voices should be treated with respect.

In this study, patients with dementia who were admitted to the unit were asked to voice their opinions and give their perspectives on environmental issues and possible solutions. I included other key stakeholders, such as the staff and leaders, a public advisor, and two family advisors in co-visioning and co-designing change. Together, we asked critical questions about how hospital services are delivered to meet unnecessary routines, rather than aligning them with what patients actually need and want. We co-developed research products including a proposal for design solutions, a staff education toolkit package, a family communication tool, and a conceptual tool for staff engagement in practice development. As a goal, subsequent action activities that followed this project were expected to lead to ongoing improvements, enhanced safety and quality of care and continuous transformation of the culture to be more person-centred.

1.6   Significance of the Study

This study privileges the voices of patients with dementia and staff members working in a medical unit. This thesis presents their experiences, addresses a gap in the literature, and

offers contributions to dementia care in three important ways. The first contribution is linked to the creation of a heuristic tool to guide practice development. Based on the generated data from research, a useful conceptual tool (Team Engagement Action Making) was created. Actionable recommendations are offered to promote practice development by working in partnerships with all members of the team. The goal is to build a person-centred care culture to drive innovations and improvements in hospital dementia care. The results of this study lay the foundation for subsequent research to evaluate the impacts, further investigate the potential for applying appreciative inquiry theory in practice development, and refine the TEAM conceptual tool.

The second contribution is concerned with practice. This study generated practical knowledge and strategies to accelerate the translation of knowledge into action in the practice setting. I demonstrated how the patients' stories and reflexive groups inspire commitment and motivate individual and collective actions among hospital staff.

The third contribution is related to methods. This is the first study that invited older patients with dementia who are staying in the hospital ward to contribute their opinion and perspectives about knowledge creation, using videos and reflexive groups. The lessons learnt from this research offer guidance and strategies to enable the active participation of people with dementia in future research studies.

1.7   Summary

Two-thirds of hospital admissions are older people, and about half of them have cognitive impairments. As older people have become the major group of users of hospital services, hospitals need to ensure that their environment and workforces are responsive to the changing healthcare needs of the population. Physical and social environments that are not

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supportive for acute care settings can make hospital admissions physically and emotionally

difficult for older people with dementia, leading to detrimental and costly effects such as the

patients' functional decline and deterioration of well-being. Inadequate training support and

lack of practice development in dementia care have been identified as gaps limiting the

delivery of high-quality care for people with dementia. This research focuses on examining

the processes of engagement for change in a medical unit to develop person-centred care. The

study has two main goals: (a) to generate knowledge for supporting team engagement in

developing person-centred care, and (b) to "learn by doing," working with patients, families,

staff, and leaders to facilitate processes of change aimed at innovating and improving

dementia care.

Chapter 2: Literature Review

> We can choose to bemoan the increasing number of older people, or we can discover ways in which our aging demographic can enrich our world and provide us with a sense of hope…The first step in our journey toward reframing and reclaiming hope is to create an attitude of inclusion, rather than exclusion. Neither a homey physical environment nor a holistic mindset is sufficient unless we support them through our daily actions and interactions.
>
> ~ Allen Power (2014)

In this chapter, I address the state of scientific knowledge on environmental interventions and person-centred care. The intention of this chapter is to explore the relevant development and political debates about person-centred care, as well as to identify scientific evidence of environmental interventions that would inform specific actions in this project. The literature review serves three purposes. First, I review the development of person-centred care for people with dementia. The purpose is to provide a background and set the stage for the research. Second, to situate the research focus within the extant literature and provide justification for specific research actions, I provide a critical review of selected literature for both physical and social environmental interventions. The main themes arising from the literature demonstrate how this research builds on existing knowledge and addresses the gaps to generate new knowledge. Given the paucity of empirical research in environmental intervention for dementia design in acute hospital settings, evidence from quality improvement projects and research in residential care are also examined to explore the current state of practice development. Lastly, this chapter discusses the vital importance of including older people with dementia in research.

2.1   Person-Centred Care

Person-centred care has been used to describe good care in gerontological nursing (Kelly, Tolson, Schofield, & Booth, 2005; McCormack, 2004; McCormack et al., 2010). The concept of person-centeredness in gerontology originated from the definition of personhood by the social psychologist Kitwood (1997). Personhood was "a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust" (p. 8). This is to say that person-centred care supports personhood, with the focus on maintaining a sense of self and social identities that are beyond the diagnosis of dementia, and that is a critical aspect of dementia care. For Kitwood (1997), person-centred care is to draw attention to the subjective experience of the person and to shed light on how the social interactions around the person with dementia might affect their personhood and well-being. He strongly advocated for care that respected the personhood of the person with dementia.

Kitwood's work was influenced by the work of Buber (1984), who identified two different ways in which people relate to one another. This appears to be relevant to the maintenance of personhood in people with dementia. The two ways are described through the word pairs: "I-It" and "I-Thou." The I-It mode of relating occurs when a person relates to another in a distanced and non-involved way that fails to fully acknowledge the individuality of the other since the other is objectified. The I-Thou mode of relating, in contrast, involves meeting the other person as a genuine human being in a connected way.

Based on observations, Kitwood (1997) noted that the social environment in which the person with dementia lives could be supportive or damaging to their personhood, and to one's sense of self and well-being. He used the term "malignant social psychology" to

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describe aspects of care that can be devaluing, dehumanizing, and depersonalizing, and may reduce the person's sense of personhood. For example, "invalidation" was a concept that Kitwood used to depict failing to acknowledge the subjective reality of a person's experience and their emotional needs. On the other hand, "positive person work" is a term he used to conceptualize how one could uphold the personhood of an individual with dementia. The goal is to minimize negative interactions of "malignant social psychology," and replace them with "positive person-work". Examples of positive person-work include asking a patient about his or her preferences and working together to give the person opportunities to use his or her abilities. Such actions that respect and uphold personhood characterize person-centred care.

Kitwood (1997) provided a model of dementia that highlighted the interaction between neurological impairment, the psychology of the person with dementia, and the social environment. His enriched model acknowledges that one of the causes of problems for a person with dementia stems from the person's neurological impairment. It also argues that other factors play an important role in the experience of the person with dementia. These include health, biography, personality, and social psychology. His enriched model suggests that it is the complex interplay between these factors that determines the person's experience. Kitwood (1997) believed personhood is relational as it is influenced and maintained in a social environment. He explained that:

> the primary associations [of personhood] are with self-esteem and its basis; with the place of an individual in a social group; with the performance of given roles; and with the integrity, continuity, and stability of the sense of self (p. 8).

In a critique of Kitwood's work, Nolan et al. (2001) argued that Kitwood's theory is unidirectional in the sense that people with dementia are made dependent on others. Nolan et al. (2001) believed that 'relationship-centred care' is more appropriate because person-centeredness focuses on the primacy of the personhood of the person being cared for, at the expense of those doing the caring. The concept of personhood has also been challenged by some scholars as being non-political, and thus, limited in scope and impact (Bartlett & O'Connor, 2007). Scholars have also advocated for broadening the focus of person-centred care to consider structural and system factors as well as the socio-cultural context (Adams, 2010; Innes, 2009; O'Connor et al., 2007). Failing to attend to the impact of socio-cultural factors, such as social values, norms, beliefs, and assumptions, can lead to a narrow lens, rather than broader investigations of why persons with dementia are treated as they are within our society (Phinney, Purves, O'Connor, & Chaudhury, 2007).

Sabat (2001) argued that personhood is not necessarily lost as a result of the neuro-degeneration. Instead, it changes as a result of ways 'others' treat and view the individual with dementia. What is missing from Kitwood's (1997) model is the significant influence of the physical environment. The unsupportive features of the hospital environment may cause unnecessary challenges and risks for people with dementia. For example, lighting, signage, noise, and over- or under-stimulation may cause confusion and high stress for people living with dementia. Importantly, none of these factors are independent, but they interact intricately to affect the experience of persons with dementia (Hung & Chaudhury, 2011).

Kitwood (1997) maintained that a person-centred care organization would appreciate not only the patient but also the staff on the team. McCormack, Manley, and Titchen (2014) suggested that any organization committed to person-centred services must have ongoing

practice development, which is brought about by enabling teams to develop their knowledge and skills and by transforming the culture and context of care. A key challenge in building and sustaining person-centred care seems to be in helping staff develop the capacity to create conditions for learning. Further, a person-centred culture requires a greater focus on understanding the motivation behind practices and working with these motivations.

Despite the efforts to promote person-centred care, recent reports in the media and the literature repeatedly show evidence of poor care being provided to older people with dementia in acute hospitals. Critical debates and discussions are taking place regarding concerns about whether or not the staff in acute care have adequate knowledge and skills to provide person-centred care (e.g., Dewing & Dijk, 2016; Francis, 2013; Hemingway, 2013; Paley, 2014; Rolfe & Gardner, 2014). Edvardsson, Koch, and Nay (2010) developed instruments and indicators to measure how the person-centred care climate might be influenced by factors like organizational systems, environments, staff characteristics, and managerial styles. McCormack and McCance (2011) conducted a series of studies and identified important elements that influence person-centred practice, including the dynamics of power and control, the effect of institutional discourse, the care environment, appropriate skills mix, effective staff relationships, and shared values within the team. Ross, Tod, and Clarke (2015) investigated enabling factors in the work environment that facilitate person-centred care in nursing practice and found six Cs (Dewar & Nolan, 2013) that were important for high-quality person-centred care. The six Cs are care, compassion, competence, communication, courage, and commitment.

Research indicates that nurses in hospital settings do not always believe they have the time or resources to practice person-centred care that is being promoted at their workplaces

as they find themselves in work environments with serious structural constraints (Dahlke et al., 2014). Further, research related to acute hospitals has revealed that powerful socio-political forces that are at play in the hospital environment might shape the nurses' ability to do their work (Cheek, 2004; Liaschenko, Peden-McAlpine, & Parke, 2007; Rodney & Varcoe, 2012). Thus, while nurses have the agency to construct their practice, their choices are mediated or constrained by established patterns of understanding, local cultural values and beliefs, organizational structures, and material resources in their places of work. Furthermore, it has been increasingly acknowledged that the physical, social, organizational, and socio-political environments are deeply interwoven in the creation of the clinical reality (Wahl & Weisman, 2003).

In several reports, nurses expressed that inadequate staffing, high workloads, a lack of time, and inadequate system support were barriers to person-centred care (Byers & France, 2008; Gladman et al., 2012). Nevertheless, Edvardsson, Sandman, and Rasmussen (2011) argued that high staffing levels might not translate into better care when the staff is focused on tasks rather than meaningful interactions with people. Their grounded theory study revealed that the social environment significantly influenced people with dementia emotionally. A sense of 'homelessness,' was felt by patients when they seemed to be abandoned and lost, and when the staff was unable to provide meaningful engagement and help patients feel safe, connected, and welcome. Another common intervention used to keep people with dementia safe in the hospital is constant or close observation. A security guard or sitter could be placed on the medical unit to provide one-on-one observation for a patient. Recent systematic reviews found no evidence to support the clinical therapeutic value or

cost-effectiveness for using constant observation for older people with dementia (Canadian Agency for Drug and Technologies in Health, 2015; Dewing & Dijk, 2016).

Research has identified the need to create a positive therapeutic environment for people with dementia in acute care (Chater & Hughes, 2012; Cunningham & Archibald, 2006, Norman, 2006, Nolan, 2007). A dementia-friendly environment should consider both the experiences of a person with dementia in the environment and the environmental impact of these experiences (Fleming, Kelly, & Stillfried, 2015). In the following sections, I provide a critical review of the physical and social environmental interventions mentioned in the recent literature. Literature gaps and the current state of evidence will be identified to situate the research focus and provide justification for specific research actions.

2.1.1   Person-Centred Care and Patient-Centred Care

As the development of person-centred care for older adults becomes commonly accepted, governments and healthcare organizations around the world are becoming increasingly committed to ensuring that the care provided in healthcare services is person-centred. In the literature and practice, there is a tendency to assume the terms, "person-centred care" and "patient-centred care" mean the same and it is universally understood. Both "Person-centred care" and "patient-centred care" are frequently championed in healthcare improvement strategies. In the UK, the person-centred care approach is supported by national standards in the health service framework (UK Department of Health, 2015). In Australia and United States, patient-centred care has been recognized as a dimension of the broader concept of high-quality healthcare (Australian Charter of Healthcare, 2011; Berwick, 2004). In Canada, provincial health authorities are adopting person-centred care, (sometimes called

patient-centred care) as part of their mission to ensure quality and effectiveness of healthcare (e.g., Donnelly, McElhaney, & Carr, 2011).

There is an ambiguity in the literature and practice about the use of the terms 'person-centred care' and 'patient-centred care'. In this project I have explicitly chosen to use the term "patient" when referring to persons with dementia who are staying in the medical unit, while I use the term "person-centred care" to refer to the improvement strategies. I explain my reasoning for selecting this terminology in the paragraphs that follow.

Our place in a social role such as being a patient or a nurse prescribes normative expectations for behaviors and activities to be performed in the location. In a medical ward, nurses wear uniforms and patients wear hospital gowns. Nurses provide care and patients receive care. A patient is a person who is sick being treated in a hospital unit. A patient is a role that entails certain social meaning and common understanding. When a person with dementia is placed in the medical unit, how he or she is expected to be treated is socially constructed or culturally influenced. The social location, identity, and expected roles shape how a person thinks and acts in a place. I intentionally write the persons with dementia staying in the medical unit as 'patients' in this thesis because I want to stress the importance of social influence in patients' care experiences.

Do patient-centred care and person-centred care mean the same thing? Uncritical use of the two terms can lead to confusion as people may have different cultural assumptions, values, and emphasis for the term. Patient-centred care, according to the Australian Charter of Healthcare (2011), it is defined as:

> "Patient-centred care is health care that is respectful of, and responsive to, the
>
> preferences, needs, and values of patients and consumers. The widely accepted

dimensions of patient-centred care are respect, emotional support, physical comfort,

information and communication, continuity and transition, care coordination,

involvement of family and carers, and access to care. Surveys measuring patients'

experience of health care are typically based on these domains." (p.7)

McCormack and McCance (2017), writing from the UK, and from the perspective of nursing,

provide a definition:

Person-centredness is an approach to practice established through the formation and

fostering of healthful relationships between all care providers, service users and

others significant to them in their lives. It is underpinned by values of respect for

persons, individual right to self-determination, mutual respect and understanding. It is

enabled by cultures of empowerment that foster continuous approaches to practice

development. (p. 2509)

The above definitions show some commonalities and differences. Both definitions place a

strong emphasis on respecting the person or patients' rights in care and involvement of

patients or persons in care. An important difference is that person-centred care emphasizes

fostering a care culture in teams through empowering the work environment and continuous

practice development. Patient-centred care, by contrast, appears to adopt a more business

approach to organizational improvement, targeting performance measures and outcomes

(e.g., patient satisfaction survey, waiting time, length of stay, etc.). My main reason for

choosing person-centred care in this thesis is that the purpose of the project is to develop

practice with a team of people. Again, person-centred care is more team and relationship

oriented in order to change the culture in which people are providing and receiving care,

whereas patient-centred care is more corporate focused, meeting targets of organizational performance measures.

Patient-centred care tends to have an acute care narrow focus. An emphasis is on delivering the right diagnostic procedure and the right treatment. For example, a growing international campaign for patient–centred care is "choosing wisely", which suggests what medical interventions should be avoided – a patient-centred performance management system to reduce overtreatment (Kerr & Hayward, 2013). Dewing and McCormack (2017) raised a concern in a recent editorial:

> "the majority of definitions of person-centredness completely miss that person-centredness is about a specific type of culture, that incorporates but does not isolate care and one that needs to apply to everyone in an organization. It is not something that can be technically applied, and certainly, person-centredness cannot thrive or flourish in any type of workplace context and culture. (p. 2509)

Their comments highlight person-centred care is a continuous practice development that requires a culture shift in the whole organizations, rather than a quick-fix to reduce the length of stay or to maximize efficiency. There are growing studies that measure patient-centred care in terms of reduction in the number of diagnostic test orders and referrals, proxy's response on satisfaction, and the decrease in length of stay. Cost efficiency often is the key driver and strategy for promoting patient-centred care (Australian Charter of Healthcare, 2011). I agree with the importance of cost efficiency as one of the means to sustain healthcare operations. However, I view person-centred care as underpinned by core values in our humanity, which is the ultimate goal (end) of healthcare.

2.2   Physical Environmental Interventions

Going into hospital is a potentially frightening experience for older people with dementia. With unfamiliar surroundings and routines, older people who have aging eyes and hearing impairments can face great difficulties to adapt. A supportive environment has been depicted as a cohesive system of support that recognizes the experiences of persons with dementia, and contributes to their physical, emotional, and social well-being to remain engaged in everyday life in a meaningful way (Chaudhury, Cooke, & Cowie, 2017; Fleming, Goodenough, Low, Chenoweth, & Brodaty, 2015). This points to the importance of having a better understanding of the needs and experience of persons living with dementia. A growing recognition supports enabling environments that can minimize disability and provide opportunities to maximize abilities and functions, despite the losses and challenges associated with dementia (Chaudhury, Cooke, & Cowie, 2017; Davis, Byers & Koch, 2009).

People with dementia may have visual-spatial difficulties (Pollock & Fuggle, 2013). Dementia design experts document that people with dementia are more likely to resist walking on shiny floors, because they think they are wet, while dark shadows or spots on flooring may be misperceived as holes (Briller et al., 2001; James et al., 2017). Due to a higher sensitivity to environmental impact, sensory overstimulation, especially noise, often leads to frustration and confusion (Hung et al., 2014). While the changes that are experienced tend to be individualistic, people with dementia commonly find it more difficult to orient themselves to unfamiliar environments (Archibald, 2003). Although hearing acuity tends to deteriorate with age, older people's hearing can be particularly sensitive to some sounds and background noises from machines, equipment, telephones, trolleys, televisions, and other people's conversations. Exposed to long periods of continuous noise, people with dementia

can experience less efficient sleep, increased agitation, reduced tolerance for pain, and declines in cognitive functioning and memory (Dewing, 2009). As Briller et al. (2001) describe, memory problems and cognitive and functional impairment associated with dementia can make persons with dementia more vulnerable and sensitive to environmental effects.

Unfortunately, previous research in dementia-related design has focused on residential care facilities or nursing homes, and paid less attention to the specific challenges faced by people with dementia in the hospital environment. The changing demographics of hospital inpatients and recent reports of the poor quality of care in general hospitals have driven the need to investigate what can be done to improve the care of older patients with dementia.

My review of the literature on physical environmental interventions involved searching three commonly used databases (PubMed, CINAHL, and Google Scholar) for the years 2002-2016. The keyword search included 'dementia' and 'hospital environment' in each database. After removing articles that did not report physical environmental interventions, seven relevant articles on physical environmental intervention in hospitals were identified (Appendix H). Three studies used a pre-test and post-test design (Mazzei et al., 2013; MacDonald, 2011; Upton et al., 2012) and two studies were randomized controlled trials (Ancoli-Israel et al., 2003; Goldberg et al., 2013). Five studies were carried out in hospitals in the UK, one was conducted in Australia, and one was carried out in Canada. The rigor of the research was highly variable. Most of the studies did not describe details of the evaluation methods. Most studies in acute care were also published in last five years, indicating the emerging interest in physical environmental interventions for dementia care.

The key messages from the review of the literature in the physical environment for dementia care in acute hospitals can be summarized in three points. First, much of the literature on environmental dementia design is based on residential care, not acute settings. Although the need for more supportive designs for people with dementia in the hospital is becoming more widely recognized, few researchers have offered useful insights into what specific environmental strategies might work and why. The description of specific environmental modifications is also lacking. Second, no literature from a Canadian perspective is available for medical wards. The single Canadian study that was found from the searches was conducted in the mental health unit of a hospital (Mazzei, Gillan, & Cloutier, 2013). The small amount of literature that is related to dementia care environments in hospitals mostly comes from the UK (e.g., Waller & Masterson, 2015; Goldberg et al., 2013). While some of the findings may be transferable to the Canadian context, others are not due to the different healthcare systems. Third, direct perspectives of patients with dementia and their families are lacking to inform our understanding of their needs and experiences to find more responsive strategies to improve the quality of the care environment.

Although few studies have been conducted that specifically examine the environmental impact of inpatient medical units on patients with dementia, research conducted in related clinical areas supports the notion that the physical environment plays an important role in supporting the provision of good care. Some small studies and quality improvement projects, expert opinion articles, and anecdotal reports have confirmed the therapeutic potential of environmental interventions. On the whole, the literature upholds the claim that a supportive environment can promote functional ability and recovery, reduce stress and confusion, and enhance the safety of older adults (Andrews, 2013; Chaudhury,

Hung, & Badger, 2013; Cohen-Mansfield et al., 2012; Parke & Chappell, 2010). Researchers and practitioners consistently report that the conventional design of hospitals contributes to patient risk, while improved designs for the physical environment can compensate for sensory loss and cognitive impairment, and help support independence (Alzheimer's Society, 2009).

Recently, the Alzheimer's Society (2009) in England reported the detrimental effect of hospital stays on the independence of people with dementia. The Society reported that dementia was associated with increased lengths of stay and poorer outcomes. According to the report, over 25% of the people accessing general hospital services were estimated to likely have cognitive problems or dementia. Many older patients lose their independence and functional abilities in activities of daily living (ADL) while they are in hospital with the result that they are placed in nursing homes. Recent studies conducted with patients and families have identified that barriers in the physical environment do not support the well-being of people with dementia. In the study by Digby and Bloomer (2014), patients and families reported that they valued homeliness, a shared comfortable space for social conversations and family visits. For patients and families, "homeliness" meant "the place is fresh and light, not institutional, more homely …there was space and there were chairs" (p. 38). In another ethnographic study by Hung et al. (2014), patients and families described themes of four environmental attributes as being central to promote healing and coping: (a) therapeutic; (b) supporting functional independence; (c) facilitating social connections; and (d) providing a sense of safety and security. The families in this study highlighted that pods of homelike areas along ward corridors offered comforts and promoted socializations.

Environmental gerontologists suggest that a supportively designed environment can be an invaluable therapeutic resource to help people with dementia with way-finding, ADL function, and feeling more relaxed to engage in social interactions. In a recent nurse-led project by Waller and Masterson (2015), patients, families, and staff were involved in redesigning and modifying the physical environment of surgical units. The interventions included improving lighting, using accent colors and pictorial signage, and adding comfortable seating areas in the corridors. Nurses moved to a closer proximity to patients by working in decentralized stations in bed bays rather than from a central area. This made the staff more visible, with a consequent reduction in the use of call bells (Waller, Masterson, & Finn, 2013). The authors' evaluation found that relatively simple, cost-effective changes to the physical environment of care had positive effects on patients with dementia and those using and working in the services. The effects included a reduction in agitation and challenging behavior, a reduced need for antipsychotic medication, and a reduction in the number of falls. Their success led to a large-scale program, Enhancing the Healing Environment (EHE), which has supported over 250 multidisciplinary teams to make environmental improvements in hospitals and mental health settings (Waller & Masterson, 2015).

A supportive environment can aid in compensating for the loss of abilities and support functions. In a randomized control trial with 92 people with dementia, increasing light exposure throughout the day and evening was found more likely to have the most beneficial effect on sleep and circadian rhythms in patients with dementia (Ancoli-Israel et al., 2003). Misperceptions and difficulties in accurately interpreting the environment in people with dementia can be influenced by low lighting, shadows, and glare that may lead to

fear and responsive behaviors. In a literature review, Moyle et al. (2011) concluded that environments that meet the physical, emotional, and sensory needs of older people are keys for supporting older patients with dementia in acute hospitals.

Other studies show that specialized units for patients with dementia may be beneficial. In a large randomized controlled trial study involving 600 older patients admitted to an acute medical hospital, Goldberg et al. (2013) found that patients on the specialist unit spent significantly more time with positive mood or engagement (P=0.03) and experienced more staff interactions that met their emotional and psychological needs (P<0.001). More families were also satisfied with care (P=0.004). In an evaluation study of patients with dementia admitted to a specialist dementia acute medical ward, Upton et al. (2012) found improvements in the mobility status of patients, an increase in patients to be discharged back home, higher staff satisfaction, lower staff turnover, and fewer sick days, compared to patients admitted to non-specialist wards. In addition, a communal dining room and space for activities were reported to be associated with fewer behavioral events and a functional decline in the small specialized in-patient unit (Zieschang et al., 2010).

In the UK, the Royal College of Nursing (2015) recognized that the care of people with dementia is the core business of the general hospital, and that the physical environment plays a critical role in the provision of good care. More research needs to be conducted in partnership with nurses working at the point of care to address patient care issues affected by the environment. As Dewing (2009) asserted, when the environment supports person-centred care, patient well-being is enhanced and a more pleasant working situation is created for nurses.

As for the residential care sector, in a recent review of 94 empirical studies in long term care (residential care), substantial evidence was found on the influence of unit size, spatial layout, homelike character, sensory stimulation, and environmental characteristics of social spaces on residents' behaviors and well-being (Chaudhury, Cooke, Cowie, & Razaghi, 2017). The evidence supports that the size of the unit in residential care facilities seemed to have a significant impact on sensory stimulation of residents with dementia. More residents and staff in the unit, higher volume of traffic and louder noise can become distressing to residents with dementia. There is also evidence that demonstrated positive resident outcomes (e.g., reduced behavioral events, fewer distractions, and more social contact) when residents dined in the smaller dining rooms (Hung & Chaudhury, 2011). Research also found music was not only effective in improving the mood of residents but also seemed to affect the staff members caring for residents (Chaudhury et al., 2013). Long hallways in many nursing homes are problematic as they can decrease residents' spatial awareness, orientation, safety, and security (Chaudhury et al., 2017).

From the above, it can be seen that there is a growing amount of evidence in the literature on how physical environmental interventions may support care experiences of persons with dementia and the practice of person-centred care in care settings. In general, there is a growing body of empirical evidence and greater recognition for creating physical environments appropriate and responsive to meet the needs of persons with dementia in both residential care and hospital settings. However, the studies in physical environmental interventions tend to exclude only people with mild dementia. We do not know how people in different stages and with multiple types of dementia may respond to specific types of interventions. Few studies provide follow up and investigate sustained benefits. Research

with longitudinal study design is very scarce. Below, I point out issues in the literature of physical environmental interventions and outline key physical design features that support person-centred care.

Main Critiques of the Literature on Physical Environmental Intervention

- Many studies rely on measures from proxy (families and staff). There is a major overlook of the perspective of persons with dementia. Research of in-patients with dementia in the hospital setting is extremely rare. There is a need to innovate responsive methods to take into account the subjective perspectives of the persons with dementia.

- Many of the previous empirical studies focus on reducing behavioral problems, rather than examining quality of care experiences of people with dementia.

- Most research is cross-sectional. Longitudinal research is needed on the effect of environmental interventions over time on persons with dementia.

- Existing research in physical environmental interventions is mostly quantitative. The complexity of the interconnections of the organizational, social and physical environmental factors are poorly understood so qualitative research is necessary to explore this more deeply and gain a better understanding of how each aspect interacts with others in impacting the experiences of people with dementia.

- The population sample in current research remains relatively homogeneous. It would be important to include heterogeneous sample to reflect the population. For example, it would be important to include a more diverse group (e.g., those are non-Caucasians with different ethnic background, culturally diverse, and a range of different socio-economic status).

2.3   Social Environmental Interventions

The social environment encompasses a broad domain of human interactions, social relationships, care attitudes, and cultural milieus within a group of people in a given setting. For the purposes of this research, I focus on care approaches and interpersonal interactions in the social environment. Therefore, any training for dementia care or person-centred care is considered a social environmental intervention. Social environments are dynamic because they can be changed and influenced by new insights gained through inquiry and learning. Rasmussen and Edvardsson (2007) wrote: "nursing care and the physical environment of the ward are inseparable entities, interacting in such a way that it is the 'atmosphere' of a place" (p. 120).

The review of the literature on social environmental interventions involved searching three databases with keywords that included 'dementia' and 'training' and 'education'. Due to the paucity of dementia care training research conducted in hospitals, the search was expanded to include literature about dementia care training in residential care. The selected studies were sorted by author and country, intervention type, sample, implementation factors and outcomes, and type of evidence. After excluding duplicates and studies without evaluations of the training outcomes, 24 studies were identified (Appendix I).

My review found that the majority of studies were conducted in the UK, utilized a quantitative method. Seven studies took place in the UK (Scerri et al., 2016; Elvish et al., 2014; Fossey et al., 2006; Lyne et al., 2006; Surr et al., 2016; Robinson et al., 2015; Smythe et al., 2014). Three studies were in Canada (Gillies et al., 2015; Speziale et al., 2009; Landreville et al., 2005).

Six studies were conducted in hospitals (Elvish et al., 2014; Galvin et al., 2010; Gillies et al., 2015; McPhail et al., 2009; Smythe et al., 2014; Surr et al., 2016). There was a lack of research about dementia care education in hospitals in general but a few training programs began to emerge in hospitals in last few years. The training content varied greatly, ranging from focusing on medical diagnosis, cognitive assessment, medications (e.g., Galvin et al., 2010) to psychosocial care approaches (e.g., Gillies et al., 2015; Surr et al., 2016) and most of the training programs focused on reducing behavioral problems. Most of the studies did not examine facilitating staff engagement or the contextual factors in local settings. Two studies reported that low levels of management support led to poor attendance for education and poor uptake of new knowledge (Horner et al., 2013; Smythe et al., 2014). We know little about what might motivate and enable participants to develop and integrate newly learned knowledge and skills into practice and a significant knowledge gap exists in how staff engagement and the local environment might affect the introduction and use of new knowledge and skills.

The delivery of education varied from using traditional didactic learning and lectures, (e.g., Galvin et al., 2010) to using more group interactive learning based on experiential knowledge, combined with videos, role-play, and case study discussion (Speziale et al., 2009). Some of the education programs were taught by academic researchers while others were presented by local expert practitioners or trained champions. Elvish et al. (2014) argued that the professional background of the trainers would influence the effectiveness of the education, though no differences were found in their study that compared academics with clinical experts in the local setting.

Research designs included Clustered Randomized Control Trials (CRCT), Quasi-Experimental designs (QE) and QE with Quasi-Experimental Single group design (QES). Most studies used quantitative tools like questionnaires to measure staff self-reported efficacy, change in knowledge, and confidence after learning (e.g., Gillies et al., 2015; Finnema et al., 2005; Halek et al., 2013; Kuske et al., 2009; Speziale et al., 2009). Relying only on self-reported data would not necessarily capture how newly learned knowledge would be applied in practice. Change in practice would also need to be evaluated by observation and interview methods to capture the full complexity in real-world clinical practice. Although all of the reviewed studies were group interventions, most of the studies were targeted to nurses. Only a few studies (e.g., Gillies et al., 2015) included the whole team of interdisciplinary staff who would be interacting with patients with dementia on a regular basis. Qualitative inquiry that examined engagement in the change process and the experiences of staff was lacking. The local priorities and social processes may also have important implications for group learning and the mobilization of new knowledge to practice. What needs to be explored in individual and team learning is the process of staff engagement, negotiation, and collaboration in making knowledge practical and relevant to real life practice (Boström, Slaughter, Chojecki, & Estabrooks, 2012; Rodney et al., 2013).

In summary, this literature suggests some key recommendations for improving dementia education and training:

Key Features that supports Successful Dementia Education:

- Content needs to be relevant, practical and applicable to the role, experience, and practice of practitioners across disciplines. Use case studies based on real life clinical experiences to prompt reflective discussion.

- The teaching method should be interactive, involving active participation.

- The trainings provide experiential-based learning. Adequate time should be included for story sharing and group discussion.

- The education is delivered by an experienced facilitator who is able to adapt it to the needs of each group.

- The access to training must be flexible to accommodate operation needs, in house training, workplace learning and shorter adaptable sessions are more likely to attract higher attendance

- The design of the training program should include on-going facilitation in practice to support the application of training into practice. Continuous support (resource and leadership support) from within and outside hospital is needed for facilitator to make a lasting difference. Length of time needed for culture change to take place is longer than a study can provide.

- Practice tools, such as reminder cards, easy to read booklets are helpful to sustain learning and application of knowledge.

Of course these recommendations must be somewhat tentative given the limitations in this work. Some of the key limitations include:

- Governments, regulators and institutions do not have mandates or regulations to ensure practitioners who care for patients with dementia have dementia training. There are vast variations in provisions of dementia training programs between settings.

- A majority of dementia training research was conducted in the UK. There is a lack of Canadian perspective.

- The design of dementia education research was mostly quantitative, relying on self-report, based on immediate reactions (e.g., levels of satisfaction on the training, using questionnaires). Qualitative inquiry can help gain understanding of participants' experiences, what teaching technique or method works better and why.

- Learning general theory about dementia is not good enough. Participants reported that they value practicality and applicability of training content.

- Most of the trainings were targeted at nurses. There is a lack of interprofessional education to include other professions.

- More education programs took place over a short time period and then ended. There is a lack of follow-up or on-going facilitation to support knowledge application.

- Attendance to classroom training is challenging due to workload and staffing shortage. There is a lack of support from management to embed education into a part of clinical practice.

2.4   Including People with Dementia in Research

Those diagnosed with dementia who are not given an opportunity to speak their voice are most at risk of a denial of their citizenship because of the Pygmalion effect - "What one person expects of another can come to serve as a self-fulfilling prophecy." To ensure that people with dementia do not remain on the periphery of initiatives aimed at improving care interventions and service delivery, direct involvement is vital. Listen to the first-person voice.

~ Jim Mann, Advocate, living well with dementia

Swaffer (2014) questioned how researchers might have exacerbated stigma in their published writings, even though their intent was to promote positive change. To ensure that the voices of people with dementia are heard, people with dementia need to be involved in research activities (Dinand et al., 2015; Swaffer, 2014). Stigma and stereotyping of people

with dementia are commonly seen as their inability to communicate their experiences (Bartlett, 2012; Bartlett & O'Connor, 2007; Swaffer, 2014). Such stigma and stereotyping significantly hinders the inclusion of persons with dementia from contributing their perspectives of dementia care in acute hospitals. The first-person voice can provide compelling and useful insight that can drive dementia care practice development. Evidence continues to show that the perspectives of people with dementia often differ from those of their caregivers, in terms of their needs and their dementia experience (e.g., von Kutzleben et al., 2012).

In the last decade, a growing interest and increasing numbers of articles have been seen on the subjective experiences of people with dementia. People with dementia have been invited to share their perspectives in research through a collaborative, participative approach. Most of these studies, however, reside in the community and long-term care. For example, Dupuis and colleagues developed a research network called the Partnerships in Dementia Care Alliance (PiDC) and used appreciative inquiry and participatory action research to drive culture change in long-term care (Dupuis et al., 2014). Few studies in acute care have explored the perspectives of people with dementia, with the exception of Digby and Bloomer (2014), Hung et al. (2014), and Nowell, Thornton and Simpson (2011) that sought the views of patients and their families about the hospital environment. The narratives expressed by people with dementia in these studies highlight how individuals strive to preserve their sense of self and personhood in the acute hospital environment.

Because traditional interviewing in research relies on the memory and linguistic skills of the participants, which in the case of people with dementia, are well known to decline, a more person-centred approach is required to enable the active and meaningful engagement of

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people with dementia in research. Generating analyses that represent persons with dementia as active agents in their circumstances is necessary for developing new knowledge in dementia care. Evaluation research must endeavor to understand how interventions are experienced and evaluated by the service users (Nowell, Thornton, & Simpson, 2011). Recent evidence has demonstrated that some people with dementia are willing and able to express their views and experiences, contributing meaningful insight to dementia studies. In a recent paper, Swarbrick et al. (2016) proposed a model for involving people with dementia as co-researchers that would:

> centralize the vision and values of people living with dementia and their carers in research practice; embrace creativity, innovation and shared stories; and empower the experience of people living with dementia, their carers and neighborhood networks (p. 3).

Given the shift to recognizing people with dementia's expertise of their lived experience, dementia care research seems to need innovative approaches to ensure that the methods are sensitive and responsive to accommodate the needs of persons with dementia.

2.5   Summary

This chapter offers an overview of the development of person-centred care and the current debates in the larger socio-political context. The feasibility of realizing person-centred care has been questioned by the public due to numerous failures reported in the media and literature. Nevertheless, in the literature on physical environmental interventions, promising results have been increasingly shown to demonstrate that more supportive care environments can be created in hospital wards. Research has indicated the benefits from some of the environmental interventions, including reductions in falls and incidents of

challenging behavior; reductions in the use of antipsychotic medication; and improvements in staff recruitment and morale. The most important gaps in the literature on physical environment interventions include: (a) a lack of research in acute wards, (b) a lack of a Canadian perspective for dementia-friendly design in hospitals, and (c) the overlooking patient and family perspectives.

With regards to the social environment, the most important gaps in the dementia training literature include: (a) a lack of research to explore dementia education in the acute environment; (b) the need to go beyond focusing on reducing behavioral problems in patients with dementia and pay more attention to exploring what improves care experiences; (c) the need for qualitative inquiry to understand what leads to staff engagement and practice change.

Lastly, recent research has demonstrated evidence that people with dementia want and are able to contribute to research if the research strategies are responsive to their needs. Including patients with dementia in research would help to improve the quality and relevance of research outcomes.

Chapter 3: Philosophical Underpinning

The significance of the natural sciences in society was not derived from their claims to superiority in matters of truth, but in their contribution to the affairs of everyday life.

~ Kenneth Gergen (2014)

In Chapters 1 and 2, I presented an overview of the current range of complex issues in caring for older patients with dementia and the interventions for addressing the problems. Based on the gaps in the literature and practice, the primary purpose of this research is to develop knowledge that is actionable and theoretically generative using an action research approach. In this chapter, I first describe the philosophical underpinnings of action research, which build on critical social theory and orient with social constructionism and interpretivism. I then show the key concepts of appreciative inquiry, a form of action research that guide and shape the design of this research.

3.1   Action Research

Action research is an orientation to research, rather than a specific prescribed method for change (Bradbury, 2015). In the *Handbook of Qualitative Research*, Lincoln, Lynham, and Guba (2011) added the participatory paradigm, where experiential knowing and cooperative inquiry are the central tenets. Bradbury (2015) defined action research as "a democratic and participative orientation to knowledge creation. It brings together action and reflection, and theory and practice, in the pursuit of practical solutions to issues of pressing concern" (p. 1). This definition is especially useful for this project as it highlights the link between knowledge and action, as well as the collaborative process in engagement.

Action research builds capacity and empowers teams through their participation in a project because it emphasizes that research is conducted "with" rather than "on" people. Action research is about gaining a better understanding of practice issues in specific contexts, finding solutions for practice development, and improving the situation where the practice takes place. Action research assumes that groups share collective values that they wish to realize (McNiff & Whitehead, 2011). McNiff and Whitehead (2011) highlighted that action research emphasizes relational values, and its key ontological assumptions are value-laden and morally committed. Importantly, McNiff and Whitehead (2011) pointed out that participants in action research are not to be treated as objects or the means to an end; rather, they are to be treated as moral agents who can make a change for promoting social justice.

This research is informed by critical social theory (Habermas, 1984) and grounded in social constructionism (Berger & Luckmann, 1996; Gergen, 2009), an interpretive orientation (Heidegger, 1962; Gadamer, 2011). Berger and Luckmann (1996) describe the salience of social processes in the construction of knowledge by people together, through communication and social interactions. As Reed (2008) explains, in the worldview of social constructionism, "knowledge and social action go together points to the way in which developing an understanding of the world changes not only the way we think and feel but also the way we act and behave. Once we know the world in a certain way, we act accordingly in ways that reflect and fit in with this knowledge" (p. 56). Gergen (2009) is one of the most influential scholars who explore the potential of social constructionism for cultural change; Gergen (2009) asserts that there are no meaningful realities independent of social interactions. This is to say - meaningful social realities are actively and creatively produced by human beings through collaborative activities. One of the fundamental points

about social constructionism is that although constructions we make about the world are influenced by cultural and historical knowledge, this preconceived knowledge is not fixed. We have a choice to change and can shape the world through the way we talk and think about it. The ideas on the social process in the construction of reality and the possibilities for change provide important underpinnings for this action research in three ways. First, it encouraged me to ask questions that challenge the assumptions about the ways the dementia care practice is. Second, it alerted me to pay attention to the cultural context as any projects would always be shaped by the cultural context in which it is situated. Third, it pointed to the positive potential of action research as new conversations and social actions can lead to a new culture of care.

The key themes of social constructionism include:

- The social and cultural worlds are not given; meaning is created in and through social interaction,

- Knowledge is a social production, not a product of accurate representation of the world

- Knowledge and action are linked. Knowledge is constructed as we relate to others through processes of shared discourse and social negotiation.

- Knowledge from history, politics and culture influence how we think; and that how we use these depends on the situation and this can change

- A socially constructed reality is an ongoing, developmental, dynamic process that is reproduced by people acting on their interpretation

Through the lens of critical social theory, I see myself and the participants as change agents who can influence practice and our ways of being and becoming. At the same time, I

recognize that knowledge is socially constructed, contextual, and political, so that broader forces like history, culture, and politics can influence what is defined as knowledge. Rejecting the perspective of the positivist tradition that views an objective, dispassionate, impartial, and detached outsider as having a more accurate view and valid knowledge or truth, I believe that, as an insider and being part of the local context, I can act as an engaged interpreter. By working with others, I can help to create processes that allow people to recognize, unpack, and understand how realities are created and collectively discover new possibilities. Aligned with the interpretive tradition, I agree with Gadamer (2011) who said that knowledge is interpretation, and it is impossible to get outside of one's prejudice to understand or grasp the meaning of anything. For example, 'red' can mean 'love' on Valentine's Day, but it means 'stop' as a traffic light. The context always matters. Challenging the rationalist's notion of separation between mind and the world, Gadamer (2011) maintained that our access to reality is always mediated by preconception, because we live in a culturally embedded world. For Gadamer (2011), human existence is holistic – an ongoing interplay is always occurring between us and our world that constitutes human history and transforms the evolution of the world.

Epistemology is concerned with how we know what we know and how we come to claim that we know (Thorne, 2016). "Action research is not just a way of carrying out collaborative action, but it is a practice that makes claims about knowing" (Coleman, 2015, p. 392). One of the critical voices that questioned some of the limitations of positivism was Kuhn (1962), who argued that while a scientist would "try out and reject a number of alternative approaches, rejecting those that fail to yield the desired result, he is not testing the paradigm when he does so" (p. 144). Thus, traditional positivist science operates within a set

of accepted conventions about what counts as knowledge and how it can be demonstrated. Knowledge is never neutral but always partial, purposeful, and value-based.

Moving away from the positivist paradigm, critical social theorist, Paulo Freire (1970) argued that reality is not simply objective data, but is people's perception of it or a reflection upon the material reality. A fundamental underpinning of critical social theory is that social phenomena must be understood in terms of context. For Freire (1970), critical reflection is already action, and thus, action and reflection are linked. The goal of critical social theory is to transform conditions that lead to oppression. Like Freire (1970), Gergen (2014) views humans as transformers who can influence and shape the future, instead of being mere spectators. "We replace the captivating gaze on the world as it is with value-based explorations into what it could be" (Gergen, 2014, p. 287). Freire (1970) spoke of the pursuit of full humanity that cannot be carried out in isolation or individually, but only in fellowship and solidarity (p. 58). Thus, growth to become more fully human is a joint project, requiring educators and learners to engage in mutual dialogue.

Action researchers are committed to working collaboratively and have a deep respect for the right of people to be involved in making sense of their experiences. Therefore, action researchers ought to be open to multiple ways of knowing, and to partial and sometimes conflicting truths (Coleman, 2015). Collaboration is a key way to bring different perspectives together for developing a deeper and wider understanding of the issue. Reason and Canney (2015) emphasize that collaboration is also a political act as it affirms the right of people to contribute to the development of knowledge that will affect them.

Congruent with critical social theory and the interpretive approach is the idea of knowledge as created – a social achievement – rather than as an internal representation

(Gergen, 2014). For Gadamer (2011), understanding is like entering a dialogue with someone to find common ground. This is to say that knowledge is co-produced in engaged dialogue, which challenges the thinking of pursuing a universal truth in knowledge. Reason and Bradbury (2008) clarified that action research does not aim to produce knowledge that has a universal truth, but it is to pay attention to new action possibilities that can create new worlds of meaning. For Gergen (2014), the goal of research should be about making the future world better – "future forming". Through inquiry, we can change our cultural understandings to facilitate possible ways to think and act, which plays a role in creating a preferred future reality.

According to Gadamer (2011), meaning is not directly given but embedded in stories. My task as a researcher is to uncover and make meanings explicit. I am aware that I do not enter the research process with a blank slate. It is impossible for me to completely bracket my pre-understanding. Therefore, reflexivity and making my beliefs transparent is integral to the process and I also need to guard against imposing my viewpoint onto participants (Williamson, Bellman, & Webster, 2011).

As previously noted, critiques of the traditional social sciences have claimed that value-free knowledge production is untenable, and more politically informed and socially constructed types of knowledge need to be created. Action research has roots in critical perspectives that recognize the social process of knowledge construction. In critical social inquiry, the social conditions under which people make changes must also be understood (Reimer-Kirkham et al., 2009).

The key underlying assumptions of critical inquiry include:

- Knowledge is shaped by socially and historically-shaped power relations;

- Truth claims can never be separated from values;

- A critical lens helps to see through taken-for-granted situations to examine underlying structures and social relationships; and

- Critically oriented knowledge serves as a catalyst for action with a goal to transform the status quo, with enlightenment, empowerment, emancipation, and social change (Hartrick-Doane & Varcoe, 2015).

The critical lens in critical social theory is useful for guiding me to detect taken-for-granted situations, power relations, and dominant values that shape people's views and practices. As previously described, these features also are consistent with the worldview of social constructionism.

Habermas (1984), a founder of the Frankfurt School of critical theory, argued that truth becomes manifest only through exploring the validity of propositions in communicative action where participants aim at intersubjective agreement, mutual understanding, or consensus about what is right to do. In his discourse theory, the existence of various kinds of communicative spaces where people explore issues regarding public discussions is recognized as being aimed at a greater understanding of social life. Drawing on the insights of Habermas, Kemmis (2008) argued that action research must account for the collective perspectives of people involved, and include them in the research process. Here, it becomes clear that the multiple voices of people involved need to be respected and recognized to create relevant practice and responsive care. I am reminded "to hear the voices of all those affected by the situation at hand – not just the loudest voices or the voices representing official organizational roles" (Rodney et al., 2013, p. 270).

As Kemmis (2008) remarked, action researchers understand that practice is always influenced by the socio-cultural context. Kemmis (2008) argued that transformation requires not only changing the knowledge of practitioners but also changing the culture and shifting the power dynamics of the knowledge users and academics. Action research can be understood as a kind of process of communicative action undertaken in an intersubjective space. Through a process of open discussion and negotiation, participants are given a sense of power and legitimacy (Kemmis, 2008). In action research, a crucial value is to empower the participants, which requires a deep respect for the knowledge and experience that people bring to the research process, and a strong belief in the democratic process to achieve positive change.

3.2   Appreciative Inquiry

Appreciative inquiry is one of many types of action research (e.g., participatory action research, cooperative inquiry, first person action research, etc.). Cooperrider (1986) described appreciative inquiry as a form of action research that is appreciative, applicable, provocative, and collaborative. Ludema and Fry (2008) described appreciative inquiry as a process of collective learning, a strength-based approach, a powerful process of inquiry and anticipatory learning that enables participants in social systems to shape the world they most want by building new knowledge, creating positive energy, and enhancing cooperative capacity. Appreciative inquiry is appropriate for this study because it can facilitate change through a process of inquiry and it aligns with the strength or ability focus of a person-centred philosophy. For example, one of the important tasks in this research was to build team capacity to foster cultural change towards person-centred care by increasing dementia knowledge of all who work in the acute unit.

Appreciative inquiry has philosophical relevance to Heidegger's (1962) concept of 'care' that is the main character of beings. Heidegger (1962) posited that care has a threefold structure: past, present, and future. Beings are always situated in "being-in-the-world", and at the same time, they think ahead into future possibilities while engaging with the environment in the present moment. In appreciative inquiry, the focus is on the anticipatory mode of the future:

> Much like a movie projector on a screen, human systems are forever projecting ahead of themselves a horizon of expectation that brings the future powerfully into the present as a mobilizing agent. To inquire in ways that serves to refashion anticipatory reality—especially the artful creation of positive imagery on a collective basis may be the most prolific thing any inquiry can do (Cooperrider & Whitney, 2001, p. 21).

It is clear that Cooperrider and Whitney (2001) see the potential of appreciative inquiry lies in using the positive anticipatory image, that provides the "why" – a desirable motivation and opportunity to drive change. In appreciative inquiry, a core question to ask is – what do we most want to create?

The ultimate aim of this project was to innovate and improve practice. I took deliberate efforts to look for practical solutions to address pressing issues in clinical situations. I focused on change, and worked my best to generate commitment from the team to take action. For Reed (2008), appreciative inquiry is about using the inquiry (research) as a catalyst for actions and change. Strategically, I asked: What are our greatest opportunities in the current situation and how can we realize them? What are the small steps that would lead to the greatest impact? How do we move toward a future that we all desire? In the beginning, I also told stories of success and gave recent examples of hospital redesigns in the UK to help

the team envision what is possible. I kept moving to show progress in order to maintain the momentum and keep people engaged. Recognizing that moving toward person-centred care practice is a cultural change movement, this project is closely tied to the belief that staff, leaders, patients, and families can come together to imagine and build a better future of care services.

While there are many philosophical underpinnings in appreciative inquiry approach, I embraced three core concepts of the appreciative inquiry approach in this research. The rationale for adopting the approach appreciative inquiry was the good fit and usefulness of the core concepts for guiding my approach in this research. The core concepts are: positive engagement; collaboration; and critical and reflective practice. (See Table 1) These concepts were drawn from the current literature of appreciative inquiry (i.e., Bushe 2013, Cooperrider & Srivastva 1987; Ludema & Fry, 2008; Reed, 2008) and they align to the worldview of critical social theory (Habermas, 1984), where engagement, acting collaboratively, critical reflection and transformation are primary commitments. An important job for me in this research was to create a climate for collective learning, enlightenment and empowerment. It is important to note that, for the term empowerment, I do not mean seeing myself as an expert to empower others. Instead, I mean "*power with*", not power over. As a group (the researcher and participants), we gain power through learning together.

Table 1. Key concepts of appreciative inquiry that underpin this research

Positive engagement	- Explore what is possible in the future, and what can we do now - Avoid getting stuck with problems of the past - Appreciate people's talent and creativity, rather than fighting to fix people

Collaboration	• Support bringing people together to learn from each other
	• Respect each person, appreciate relationships
	• Work alongside people to learn with, to listen to and understand, rather than direct change
	• Ensure different perspectives can be voiced and heard
Critical and reflective practice	• Create time and space for self-reflection
	• Foster reflection in others, develop regular process to facilitate team reflection
	• Challenge prevailing assumptions, create positive disruption

Positive engagement

Practitioners, including myself, face clinical situations that are complex, sometimes conflict-filled and difficult to resolve in everyday practice. In some cases, misunderstanding, power relations, and politics further complicate things. Instead of getting stuck in problems, a positive approach opens up space for open dialogue. To make communication meaningful, an unconditional and non-judgmental approach appreciates the challenges people face and focuses on finding possible solutions (Bushe, 2011). Appreciative inquiry draws attention to team empowerment, which contributes to excellence and high performance (Ludema & Fry, 2008). It allows a way to explore and discover what is possible, transforming systems and teams in organizations toward a shared image of their positive potential (Cooperrider & Whitney, 2001). Although appreciative inquiry is strength-based, it goes beyond just looking at the positive. Central to appreciative inquiry is the concept of generative theory, which Gergen (1982) described as the:

…capacity to challenge the guiding assumptions of the culture, to raise fundamental

questions regarding contemporary social life, to foster reconsideration of that which is

'taken for granted' and thereby furnish new alternatives for social actions (p. 1346).

Bushe (2013) pointed out that appreciative inquiry can be generative in a number of ways: "It

is the quest for new ideas, images, theories, and models that liberate our collective aspirations

and alter the social construction of reality …[where] words create the world" (p. 7).

Collaboration

While the anticipatory future and positive imagery in appreciative inquiry are

believed to play a role in building rapport among people to support and sustain change

processes, Bushe (2011) asserts that the transformational potential of appreciative inquiry lies

in the attention paid to the relational realities:

Appreciative inquiry not only focuses on the best of what is, but it engages all

stakeholders in a process of re-imagining what could be and taking ownership for

what will be. This 'fusion of strengths' and 'activation of energy' is generally

considered essential to the generative momentum of the change process (p. 12).

Appreciative inquiry offers useful insights into the process of inquiry that enables staff

members in healthcare systems to shape the world they envision by building collective

knowledge, sparking innovation, creating energy to fix what is wrong or replace those

interventions that do not work, while continuously expanding team capacity (Bushe, 2011).

Critical and Reflexive Practice

Appreciative inquiry approach is a useful platform where people are brought together

to reflect. Critical reflection is a means of looking at practice to enable learning so practice

can be improved (Schön, 1991). Appreciative inquiry provided me with the theoretical

groundings to critically challenge old ways of practice, and question taken-for-granted assumptions through an open dialogue that breaks the 'same old' status quo and opens up new paths for possibilities. For example, framing questions in a way to ask about what helps to create high-quality care experiences for patients with dementia opens a curiosity window to energize people to think outside the box about their hopes and possibilities. The questions I ask can set the stage for a direction of dialogues and cultural movement. At the same time, I need to be mindful to ask: Is it possible that the questions I ask and the way I relate to people are felt to be coercive by some even though this is far from my intention?

In appreciative inquiry, care delivery and clinical practice are assumed to be socially constructed realities and the way in which people make meaning of their interactions is a key to clinical outcomes and human experience. Griten et al. (2017) further suggest, "we become what we inquire into" (p. 4). In other words, people tend to change their behaviors in the direction of the anticipatory image while they are being studied.

Critical Critiques of Appreciative Inquiry

Scholars and practitioners have pointed out the limitations of appreciative inquiry. Reason and Bradbury (2008) alluded to a common concern that a focus on positive stories and experiences will invalidate the negative experiences of participants and suppress potentially important and meaningful conversations that need to take place. van Kesteren, Beekhof, and Koster-Kooger (2017) argue that the polarization of either positive or negative experience ignores the fact that what is positive for some may be negative for others. Grieten et al. (2017) made a similar point that more appreciative inquiry scholars are transcending the positive/negative duality by studying the capacity of appreciative inquiry to enact generativity (e.g., opening the world to new possibilities).

Negative stories indeed can have a bigger emotional effect on people. People react more strongly to bad events. We have a tendency to be moved more by negative traumatic events. Sometimes, the negatives can be very effective in creating an urgency or a major threat to disrupt the "normal" or 'routine' practice. To reconcile the positive and negative paradox, I think it is necessary to appreciate that both the positive and the negative elements of life are important for positive change. I concur with Bushe (2011) that transformational change will not occur unless the change project addresses problems of real concern to participants. Positive emotion, constructive feedbacks, good learning, hope and optimism can be brought into negative events. Therefore, as a facilitator and a change agent, I have made every effort to create a safe and collaborative communicative space for participants to voice their opinion, and to create positive energy to move forward by working out practical solutions, rather than getting stuck in problems. For example, I tried my best in the inquiry process to offer positive guiding images of 'what could be in the future' and invite participants to co-construct visions of the future. I worked hard to create momentum fueled by hopes and positive energy, and considered a joint ownership of 'what will be'. As Grieten et al. (2017) wrote, "when people co-inquire into the life giving, the good, and the possible, they simultaneously change their system in that direction" (p. 4).

I have taken multiple roles as a researcher, an insider of the team and a facilitator for practice development. The following section gives an overview of my positioning in this research.

3.3   Positioning of the Researcher

The aim of the science of nursing is to contribute to better patient care. Moreover, the knowledge for nursing practice needs to be grounded in the concerns and problems that are

central to the practice of nursing and patient care. I believe that practicing nurses should also be involved in research as they are the actors carrying out the actions. I have a strong desire to integrate research and practice – bringing practitioners together to use research to develop practice and make positive changes. Practice development in the clinical field and knowledge development in the literature should be closely linked. I was inspired by the nurse, Marion Jones (1997) who argued that it is not useful to think of knowledge and action as being separated. Jones (1997) wrote, "theory is not an end in itself; the belief that it is perpetuates a gap and promotes the distinction between theory and practice" (p. 135). I agree with nursing scholars such as Manley et al. (2017) who suggest that we need more engaged scholars who push boundaries and work with people in clinical practice to drive bottom-up innovation and practice development.

As Bradbury (2015) argues, participation in action research recognizes meaning making in everyday practice as a political affair. I believe that a good way to help people solve problems is to work with them to come up with practical knowledge that is relevant to people. Meaningful engagement with practitioners in research enables practitioners to take ownership so that practitioners will take part in practice inquiry. Given the growing demand and increasing complexity in healthcare, practitioners need to be enabled to create and apply evidence to keep up with the rapid pace of changes in the field. More importantly, I believe that a democratic process, involving participation with stakeholders, is crucial to achieve sustainability. Below, I describe my multiple roles as a researcher-practitioner in this research project—as the researcher, an insider, and a facilitator.

3.3.1   My role as Researcher

What I bring to the research, with regards to roles, values, beliefs, and experiences will influence the research design and process. Essentially, my researcher reflexivity requires me to identify my beliefs and make them transparent. When I embarked on this study, I asked myself questions regarding my own capacity to influence and to be influenced by others, the right I have as the researcher to represent the views of participants, and my obligation to enable older people with dementia and bedside nurses to speak their voice. I believe the theoretical understanding of person-centred care has significant implications for the methodology of this research. For example, person-centred care is relationship-based, so it requires me to collaborate with and meet participants where they are, and work 'with' them, rather than work 'on' them, in co-producing accounts. I believe that when a theory is perceived to be relevant, appropriate, and realistic, and it is rooted in practice, some of the limitations and gaps between the theory and practice can be overcome. By working collaboratively with team members about the environment that matters to them, some of the challenges can be side-stepped and positive changes can be co-created. Through a critical lens, my role is to examine how structures and social relationships can shape the realization of person-centred care in acute care. For example, I gathered data as narrative accounts of what people say and do in the processes of creating change. My goal as the researcher is to inquire and document the processes of change in the context being studied. I examine what works and what does not work in relation to making change to increase our understanding of the complex change process in real life clinical practice.

Expecting the research process to involve many challenges, I used a reflexive research journal to chronicle my research decisions, choices, and rationales, and their

consequences. The reflexive journal not only helped me identify and understand how my assumptions and ideologies might affect the process, but it also served as a useful tool for self-analysis and for maintaining my socio-political awareness, which was crucial for working through the challenges (Alley, Jackson, & Shakya, 2015). My aim is to bring about practice development by critically analyzing issues of concern and working out practical solutions for change.

3.3.2   My role as Insider

As a practice leader in the setting, I played an active role as an insider to support the development of systems and practice (Coghlan & Brannick, 2014). I brought my personal knowledge and experience and my relationship to co-workers into the research. I gained an advantage in understanding the inner language, culture, and behaviors. At the same time, however, I had to pay attention to issues of power relations and how they might shape any interactions or exchanges. I recognized that the staff saw me as a clinical nurse specialist on the team (an insider); however, this also combined with my position as a researcher (an outsider). Some danger also existed in becoming lost in the roles and responsibilities. I needed to build on the closeness and familiarity I have with the setting, while creating some distance from it to see things critically and enable the change to happen. Coghlan and Shani (2008) called this 'first person skills' – focusing on holding and managing the tension between closeness and distance by developing the skills of critical inquiry in familiar situations where things are taken for granted.

My pre-understanding, clinical circumstance, and local politics are not static, but constantly changing. In the emerging nature of action research, how I hold my roles and thrive politically are challenges that need close attention. Not only must I manage these

challenges, but I also need to *inquire* into them and offer my learning to others who may wish to do similar projects in the future. Journaling and debriefing with my committee supervisors was an important mechanism for my practice of reflection and for gaining insight into pre-understanding, assumptions, and unquestioned thoughts. Action research allows me to take the critical stance to transform practice in a local situation (Coghlan & Brannick, 2014).

3.3.3 My role as Facilitator

As a facilitator, my role is to support the staff to gain more control of their practice and to encourage the voice of the silenced population – the patients with dementia. Greenhalgh (2017) emphasizes that effective facilitators take a democratic approach and motivate people to develop themselves. My goal is to work with staff, patients, and families to help them express their opinion and collectively advocate for change. To achieve such a goal requires me to politicize the action, participation, and knowledge generation (Bradbury, 2015). My facilitation is key to support the link between learning and action. Facilitation refers to helping people learn and mobilize the resources needed to achieve the collective goals (Berta et al., 2015). As a facilitator, I not only speak about action, but actually engage in action with the team. Through action in learning, the dominant status quo can be challenged, and new strategies that are informed by practical and theoretical knowledge can be sought to transform realities.

One important objective of this project was to open up opportunities for patients with dementia to speak for themselves, so they would be supported to exercise their agency and contribute to research that improves the care services in hospitals. Also, it was expected that the research process will enhance the professional development of nurses and other team

members by fostering their capability as knowledge makers, rather than merely as knowledge users. Working with the dominant discourse of the biomedical model and evidence-based practice, nurses and practitioners at the bedside need to feel in more control of their professional situation. The facilitator provides ongoing support tailored to local needs and circumstances, through activities that include introducing new ideas for change (Berta et al., 2015).

I develop and establish new work processes, clinical routines and social structures to sustain practice among staff in the studied unit. The extent of participation by the participants in action research is along a continuum from contributing as a consultant to working as a full co-researcher (Bradbury, 2015). As Reason and Bradbury (2008) wrote, "participation is political, asserting peoples' right and ability to have a say in decisions which affect them and claim to generate knowledge about them" (p. 9). In this research, the focus was on the engagement of staff so that people involved would feel empowered to construct knowledge from practice and apply knowledge in practice.

3.4   Summary

In this chapter, I described the philosophical background and underpinnings of action research and appreciative inquiry. Action research is a form of applied science having the dual purpose to generate knowledge and facilitate change. Action researchers take a critical stance to challenge positivist inquiries by drawing attention to local actors, and looking at contextualized meaning and the moral and political realities. Practitioners who participate in action research perceive themselves as agents who through cycles of action and reflection can transform practices by taking action. The underlying belief is that if participants are included in the co-creation of change, they are empowered to take collective action, which is more

likely to be sustaining. Appreciative inquiry is a form of action research that is value-based

and grounded in social constructionist, and that seeks to engage people in positive ways to

find new possibilities for innovation and improvement. Appreciative inquiry scholars work

on the understanding that the cultural context can shape people's action, and at the same

time, people can influence the culture by creating new conversations fostered by positive

energy. This research builds on the strengths of both aspects – not only using a positive,

strength-based approach but also relying on actions, team engagement, and empowerment.

Chapter 4: Research Design

> Action Research is an exploratory process, which is intended to be responsive
> to contexts, rather than prescriptive in its measures and processes…if nursing
> is to engage in action research, this must be done critically and reflectively.
> Careful attention must be paid to developing an inclusive and collaborative
> approach to knowledge and practice development.
>
> ~ Jan Reed (2005)

As described in Chapter 3, this action research was designed to develop knowledge and resources to meet real needs in the practice setting, and to contribute to building theory from and in practice. The qualitative methods allowed me to 'wonder' with others (Ellingson, 2009) and be flexible in exploring the options in the research process as new opportunities, insights, and relationships developed. Given the complexity of the context of inquiry, one must first understand the emerging forces that interacted and shaped how the research unfolded.

The original plan of the research was ambitious and included designing and completing physical and social environmental changes, as well as evaluating impacts. Although the research activities went well in the first six months, I subsequently encountered a few significant challenges. For example, the plan for physical renovation was delayed due to a change of project manager in July. In November, the key senior leadership (program director) left the organization, which caused further delays from physical renovations. More about this is described in Chapters 8 and 9. Due to the emergent nature of action research, the research questions and the planned research activities were adjusted to accommodate the events that happened in the field. With changing leadership, the completion of physical renovations was difficult to predict and the initial planning of my research question had to be

changed. After consultations with the committee supervisors, the research questions were reformulated as follows:

4.1 Research Questions

1. What did the engagement processes for change in the physical and social environments towards person-centred care look like in the medical unit?

2. Did the research project have any impact on supporting positive change?

Specific objectives

The purpose of the study was to improve dementia care in hospitals by creating knowledge and taking actions in the setting of a medical unit. To answer the two research questions, the study focused on four specific objectives:

1. Developing person-centred care and facilitating the processes of change;

2. Exploring ways to support the involvement of persons with dementia in research;

3. Examining the engagement process and enabling factors that can bring staff from multiple disciplines together to make change; and

4. Evaluating the impact of research in the change process.

4.2 Visual Methods

As identified in previous sections, social constructionism, interpretive approach, and social critical theory offer ways to examine the conditions, experiences, and phenomena of dementia care in the acute setting. In addition to these worldviews, and from the work in the emerging field of visual ethnography (e.g., Collier & Wyer, 2015; Iedema et al., 2015, Pink 2013), I used videos reflexive group sessions and observations to understand the cultural context in which actions took place and the way in which change happens. As Geertz (1973) maintains, 'culture' is not a system where the social events, behaviors, institutions, and

processes can be causally linked, but rather, it is a context where these processes can be intelligibly described (p. 14).

This study was designed to engage with the local complexity as it is naturally experienced. I immersed myself in the field to observe, participate, and work with patients, families, and staff to understand how patterns of actions were shaped by culture and how people can work together to influence culture. While visual ethnography may not have the exact same purpose to transform reality through social action, it does focus on the researcher's engagement to explore cultures, reveal assumptions, and construct meanings in everyday activities.

Visual ethnographic methods are useful for this study, because they focus on sense-making and the socially constructed nature of the context. The goal of this study is to support participants in making sense of practice. This included making sense of processes and making them more visible so that what was taken-for-granted could be brought to the surface for examination. To explore how practice could be improved in a given setting, the cultural context needed to be accounted for, with the characteristics of the team and how people in the social setting interacted with each other.

Research Cycles

Reason and Canney (2015) describe action research as typically working through a developmental process that involves cycles of action and reflection, while dealing with problems in complex systems. In relation to this research, an approach was needed that would permit action as a means of research, where changes can be developed for innovation and improvement while new knowledge about a situation is generated (Williamson, Bellman, & Webster, 2011). At its core, action research has two components: the actions and the

reflective understanding of the results of the actions. Koch and Kralik (2006) explain that action research is not rigid or prescriptive, rather it is flexible as it enables researchers and participants to focus on particular elements, going back and forth to reflect on, and make adjustments and modify plans and actions.

McNiff and Whitehead (2011) adapted Lewin's cyclical process of 'look, think and act' and developed cycles of "observe-reflect-act-evaluate-modify" by adding two components: evaluation and modification. The phases or steps are open to any direction of movement, not just linear and unidirectional. In a systematic review of action research, Waterman et al. (2000) remarked that it is difficult to make out the cycles in complex reality and to frame the steps of a cycle. In reality, all phases are interconnected and form part of a reflective, iterative process with a movement that is back and forth between the phases. Based on McNiff and Whitehead's (2011) model, I planned the research action cycles in three phases (summarized in Figure 1). Phase 1 (Engage and Look) examines the baseline and explores the physical and social environments before actions. Phase 2 (Think and Act) is action learning that takes place through changes in the environments. Phase 3 (Evaluate and Modify) involves evaluating what worked and what did not work, and developing suggestions and learning for future strategies. For example, evaluation and modification often occur simultaneously with re-thinking and acting in real-time. Again, the process in real-world situations is not rigid but fluid and requires constant iterative movements, improvisation, and adjustment.
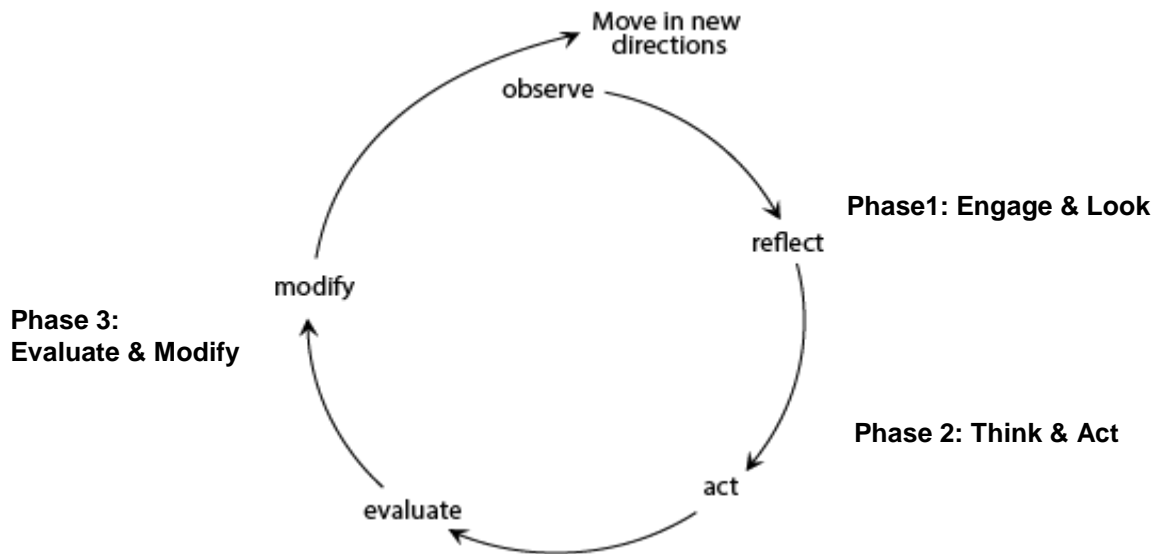
Figure 1: Phases of the Action Research Cycle

The insight gained from the research process is equally important as the product since it contributes to developing the capacities of the participants (Bradbury, 2015). The learning gained from the research process may also provide useful information for future actions toward continuous improvements in physical and social environments, which may be transferable to local or other similar settings. In keeping with the broad purpose of the project, the research activities were aimed to produce knowledge and action for improving dementia care in acute settings.

4.2.1   Setting

The study was carried out in a medical unit of an urban hospital in British Columbia, Canada (Figure 2). This location was chosen because I work at the medical unit. Practice development and care service improvement are part of my job roles in the setting. The unit has 31 beds and provides acute care to a general population of patients requiring complex

medical and nursing care. Typically, about a quarter of the patients have dementia; the common types of admitted diagnoses include stroke or cerebrovascular accident, sepsis, fall injuries, and dementia. Patients stay in the unit for a varied length of time, ranging from a few days to over a month.

Figure 2. Hallway in the medical unit

Care services are delivered by a multidisciplinary team, comprised of a hospitalist, geriatric psychiatrists, a patient care coordinator, a nurse educator, registered nurses, licensed practical nurses, personal care aides, occupational therapists, physiotherapists, social workers, a pharmacist, a dietician, and a unit clerk. I work in a part-time clinical nurse

specialist position and am responsible for providing clinical support in the unit and for older patients across the hospital. Another clinical nurse specialist works full-time and is responsible for providing clinical support for the general patient population across all medical units in the hospital. Most of the nurses are experienced and have worked with teams for many years. Generally, the nursing staff work 12-hour shifts in rotation of days and nights. Allied health staff work eight-hour shifts. A group of hospitalists rotates through the different units. The patient care coordinator is responsible for clinical issues, staffing, and the daily operation of the unit. The manager has multiple units and is responsible for budgets, labor issues, hiring staff, and risk management for problems or complaints.

The unit is laid-out with two, double-loaded corridors (rooms on both sides), and most of the rooms have three-beds. Six of the rooms are single-bed, and usually reserved for patients with infections, such as multi-resistant staphylococcus aureus (MRSA) that require careful isolation procedures. The nursing station is located at one end, which makes monitoring patients down the long corridor difficult. The unit has two entrance doors, one on each side of the nursing station. Patients often sit around the nursing station to watch the nurses work. The traffic through the two entrance doors often is a trigger for patients to leave the unit. Although the doors are locked, patients sometimes follow visitors and leave the unit, which is a significant problem in terms of patient safety.

One-on-one observation with security guards and untrained staff has been used on each shift to keep patients away from safety hazards, though it is costly and not without risk. A custodial approach to the observation process (i.e., watching or guarding the patient) for prolonged periods can lead to feelings of containment and an escalation of behaviors (Dewing & Dijk, 2016). In a recent environmental audit, the human factor specialist

indicated multiple environmental problems, including hallways that were unsafe for patients to wander or walk; handrails that were inaccessible due to linen carts and other equipment being left in the hallways, a lack of color contrast and adequate signage/cues to help patients way-find and orientate themselves. Using the action research approach, I attempted to address the issues in the physical environment and the need for dementia training for the staff in the medical unit.

4.2.2 Participants

I used convenience sampling to recruit leaders and staff participants (nursing and allied health practitioners) from the medical unit so that anyone working in the unit, including full-time or part-time staff, would have an opportunity to participate. Purposive sampling was used to select the patient participants. A small sample size of patient participants allowed me to spend more time with each to gain rapport and seek meaningful engagement in their participation. They were recruited to represent a range of various socio-cultural background characteristics and experiences.

Staff and leaders

A total of 50 staff members, including patient care coordinators, physicians, nursing staff, and allied health staff (e.g., occupational therapists and physiotherapists) participated in the study. Being inclusive was important and it ensured that no one felt pressured to participate. The desire of the staff to feel part of the change or to be uninvolved with the change was fully respected. Involving members across disciplines was important because the care of older patients with dementia requires a team approach. The staff sample included full-time, part-time, and casual staff who were present at the time of the study. Voluntary participation and withdrawal was emphasized during the initial recruitment and throughout

all stages of the research. To ensure a collaborative and democratic research process, I made my best effort to support the collective and individual needs of participants and to enable flexible levels of involvement throughout the process.

Morrison and Lilford (2001) advised that not all who are directly involved in the research will want to contribute at the same level, and thus, some participants may be content with a minimal involvement or consultation, while others may want to be more actively involved. Bradbury (2015) also explains that partnership in action research operates along a continuum from providing only inputs to being fully involved. Since the setting is a busy acute unit, any interference with operations or the clinical work of the participants had to be minimized. While flexibility is essential for staff engagement, I met with leaders and staff participants every second week between 2:30 pm and 3:30 pm. The manager gave permission for staff to attend the group sessions during the allotted time that was established for routine group meetings.

Patients

During the first few months, five patients with dementia, who were admitted to the unit during the time of the study, were recruited in consultation with the patient care coordinator and the nurses who knew the patients well. In the later stages of the research, two more patients were recruited to evaluate the impacts of the research. The sample of seven patient participants included individuals of both genders and different ethnicities, with different abilities and challenges (e.g., stage of dementia, physical functioning, personality traits, and openness for social interaction/engagement). Study information (Appendix C) was posted on the unit in public areas and handouts were made available to patients and families on a research board. Nurses asked potential patient participants if they wished to let the

researcher see them for questions and to explain the project. I did not approach patients directly for their recruitment.

Patients were not asked to participate in the study if they felt acutely sick, were bed-bound, or had any medical conditions that indicated they should not be moving in public space (e.g., infectious disease). Participants had to be able to communicate verbally. Participants were not included or excluded from the research on the basis of any scores on a formal measure, such as the Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975). Previous evidence has shown that MMSE scores do not necessarily correlate with an individual's level of insight or ability to communicate their views and such a relationship is probably not linear (Nowell et al., 2011). Furthermore, rather than focusing on exclusion criteria, experts in dementia research have suggested that individuals beyond mild cognitive impairment should be included to increase their opportunities to engage in research (Cowdell, 2010; Murphy et al., 2014; Dewing 2007).

Public involvement

Public and service user involvement in research is important because these individuals can provide a unique perspective based on their experiential knowledge that may not have been considered by practitioners and researchers. "Citizens can comment on the usefulness of proposed research, help to identify missing elements, inform research priorities, and apply research findings" (Canadian Institutes of Health Research, 2015). Two family advisors from the Community Engagement Advisory Network (CEAN) of the local health authority were also recruited. According to the CEAN's definition: 'family advisors' are family members of a patient who has experienced care at the local hospital. Families have unique expertise and knowledge and their participation offers invaluable perspectives on

improving care services. I met with the two family advisors in January 2016 to form an agreement about their role in the project. We decided to meet face-to-face and also use emails to communicate. The family advisors began by conducting an environmental assessment with me and provided ideas and feedback about the designs and suggestions for the physical environment interventions. The family advisors were also closely involved with developing staff education and approaches to improve the social environment.

Mr. Jim Mann, (real name, used with permission) a citizen who is living well with Alzheimer's disease, agreed to serve as a public advisor for this project. Jim Mann is an active advocate and has experience in an advisory position for organizational projects and academic research. On October 30, 2015, I met with him for an hour to discuss the research proposal. He provided insight into useful strategies for eliciting patient input. For example, he gave tips on ways of building rapport and offering reminders about the purpose of the research activities. We agreed to meet every 4-6 weeks throughout the research process. We mostly met at a coffee shop where we conversed about ideas and challenges related to the research. We also corresponded by email to work on project documents. Jim Mann provided an educational workshop to the staff at the beginning of the project, which was met with tremendous interest. At a later stage of the research, Jim Mann also came to speak at the hospital's 'All Staff Forum' to advocate for dementia care and our research product – *This is Me* (a communication tool). At a recent conference, Jim Mann co-presented a poster about meaningful involvement of people with dementia in research. Mr. Mann's involvement in this research has been important as he provided an invaluable perspective from having first-hand experience living with dementia. Jim Mann and the two family advisors read all papers in Chapters 5-7 and provided feedback on the findings of the research.

Nurses in a local chapter of the Gerontological Nurses Association of British Columbia (GNABC) also provided feedback on this research. On September 16, 2015, I met with nurses of the GNABC at their chapter meeting to discuss the research problems and strategies. They confirmed the significance of the research and expressed an interest in discussing implications of the findings when the research is completed. On February 25, 2017, I went back and reported preliminary research results and had a discussion with nurses in GNABC about practice implications. In sum, I believe that the meaningful involvement of patients and family advisors and public groups has helped to include their voices, enriched the study findings, and added credibility to the research.

4.3   Data Generation

In this section, I describe my approach to data generation and review the rationales for the chosen strategies. Multiple methods were used to generate data that made a rich and in-depth volume, and an ongoing interpretation/analysis was conducted to make sense of the data. My early reflections triggered more questions to investigate and enhance the integrity of the findings and the credibility of the conclusions. I collected data during a 12-month period in 2016, in a process that emphasized iteration between action and reflection, as recommended for action research. Qualitative data were collected from go-along interviews, participant observations, group discussions, field notes, memos, and journal writing. Table 2 provides an overview of the data generation methods in the various phases of the action research.

Table 2. Summary of research strategies and data generation methods

Phase	Research Strategies and Data Generation Methods
1. Engage & Look	- Environmental assessment with family advisors and staff - Go-along interviews with patients - Participant observations - Focus groups with staff in all disciplines to identify shared goals - Meetings with public advisors (a citizen living well with dementia and family advisors) to make agreements and plans
2. Think & Act	- Dementia education and action activities - Participant observations - Developing knowledge translation tools - Bi-weekly reflexive group sessions with staff - Ongoing data analysis and feedback sessions - Meetings with public advisors
3. Evaluate & Modify	- One to one exit interview with administration - Team reflection: what worked well and next steps - Evaluation of research impacts - Data analysis - Meetings with patients and family advisors to report preliminary results, research outcomes and inviting feedback - Refine knowledge translation tools based on learning from actions - Knowledge dissemination, going to other teams in other units and hospital to share research products - Conference presentations to share research findings and receiving feedback - Manuscript publications to contribute to literature

Environmental audits

An overall physical environment assessment was conducted using the guiding tool: Hospital Environment Assessment Protocol (HEAP) (Appendix A), which is adapted from the Therapeutic Environment Screening Survey (TESS) (Sloane et al., 2002) and current literature on dementia design. The researcher and each family advisor used the HEAP to conduct a systematic environmental evaluation of the physical environment in the studied unit. Staff and leader participants also conducted evaluations. The evaluation took approximate 30-60 minutes to complete (Appendix A). The HEAP measures four key therapeutic domains: (a) support functional ability, (b) safety and security, (c) familiarity and homelikeness, and (d) stimulation and social interaction. The purpose of the audit is to provide a comprehensive assessment and description of individual key elements of the physical environment, based on the literature as being important for providing good dementia care. Two nursing students who have had no training or background experience in dementia design tested the tool. It was found to be easy to use and free of jargon, and thus, was deemed to be suitable for family advisors and participants for assessing the hospital ward environment.

Go-along interviews

Go-along interviews (Carpiano, 2009) involve inviting participants to walk or move in a wheelchair with the researcher while being interviewed in a conversation. The interviews were video-taped using established ethnographic approaches (Collier, Phillips, & Iedema, 2015; Pink, 2008). I used a small, handheld recorder with a narrow-angle lens focused on the participant that also captured the background environment during our walk or movement. Patient interviews were pre-booked for times that would be most convenient to the individual

participants. Participants took part in two to four go-along interviews, each lasting 15-30 minutes. The first was focused on the hallway and activity space. More interviews were conducted based on the wishes of the participants and if more data were needed to clarify their responses to questions. No interviews were carried out in private areas such as bathrooms or shower rooms, to protect the participants' privacy.

The go-along interviews involved inviting participants to take an active role in commenting on whatever they wanted to tell the researcher about their experience in the environment as they walked with the researcher in the unit. This innovative approach enables people with cognitive or memory impairments to tell their views or opinions, and to explain the meaning of the environment as activities happen in real-time. The go-along interview can be a powerful strategy as it allows people with dementia to tell their story in their own way (Hung & Chaudhury, 2011). The participants can more easily express their opinions about any environmental aspect while they are in the environment where the materials provide useful prompts and support for their storytelling. More importantly, their embodied actions performed in the environment make implicit meanings visible, providing additional invaluable information. For example, the way in which a patient participant uses the handrail in the corridor quickly shows whether or not the handrail design is actually helpful.

I actively participated in co-creating the story by paying attention to the key themes that stood out as particularly relevant. I asked questions (e.g., tell me more about …) to prompt for more information. Other authors have described go-along interviews as an effective approach to empower the participants to co-construct their narratives, which encourages a more collaborative partnership for research (Pink, 2008). Knoblauck, Tuma and Schnettler (2015) describe the camera as the researcher's gaze: "the video camera contains,

so to speak, a built-in epistemology, as it records portions of what can be seen and heard" (p. 22).

For this study, the go-along interviews were modified with some flexibility to include patients with different levels of mobility capabilities. For patients who were unable to walk, I helped them to use their mobility device (i.e., wheelchair).

Patient participants could choose whether or not to have the interview video-recorded. Most of the time, patients allowed the recordings, though the camera was turned off on a few occasions during an interruption, during other social interactions, or during a care task. I provided opportunities for participants to review the videos before others saw them. They were also asked if they wanted to exclude any specific content from their videos. After viewing the videos, the participants were asked if they had any further comments about the materials.

To help older patients feel comfortable with the recording equipment, I always used a traditional flip-screen camera and let the patients handle the camera to get an idea of how it worked. None of the patient participants seemed to be nervous or uncomfortable during the video-recordings. The patient participants also found the interviews with the video-recorder to be enjoyable. One patient participant (Ann) said, "I enjoyed doing this [research]. You got me thinking about all kinds of things about this place [hospital]. The video stuff is fun."

Another participant (Rob) stated, "I am glad that you come to listen to what I said. You [the researcher], be sure to tell people that little things matter…." Rob's statement suggested that he appreciated this research that allowed him to tell about his experience and he expected the research would raise awareness and teach others through his stories for making changes.

All of the go-along interviews that were video-recorded were transcribed verbatim. I made field notes to record my immediate feelings, thoughts, and questions that may have needed further clarification in subsequent data collections. The amount of time spent on videos and the conversation topics was guided by the participants' preferences. Open-ended, prompting questions were used. For example, I asked, "Can you tell me a little bit about what it is like staying in the hospital here? What do you like and dislike about this environment? How do they make you feel?" (see Appendix B for the go-along interview conversation guide).

Participant observations

Participant observations allowed me to get closer to the experiences of the participants, develop relationships to the people in the field, and observe what was going on (Emerson, Fretz, & Shaw, 2011). By being in physical and social proximity to the participants' activities in the acute unit, I could be deeply immersed in their worlds to understand what the patients and staff were experiencing in their interactions with their environment. As a participant observer, I engaged patients, families, and staff in informal exchanges. During the participant observations, I explored how patients with dementia interacted with their physical and social environments through a lens of person-centered care. I paid attention to key aspects of person-centred care theory, as described by Kitwood (1997), and the design principles for dementia care that have been identified in the literature.

I conducted 20 hours of observations on weekdays and weekends. I made field notes of my observations, using a small notebook so that the "jottings translate to-be-remembered observations into writing" (Emerson, Fretz, & Shaw, 2011, p. 29). The jottings were expanded into full accounts of expressions, actions, verbal and non-verbal activities, and

events. The observational data were taken to the focus group sessions for group reflection and analysis. I regularly made journal entries to keep track of my ideas about my observation and conversations in the group sessions. Maintaining an ongoing reflexive analysis of my thoughts throughout the research process helped me to see how I arrived at my interpretations and findings.

Focus groups

Focus groups are defined as a "carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment" (Krueger, 1994). In healthcare research, focus groups are effective for getting interactive opinions and can be used for program development or to evaluate an existing program or intervention. The objectives of the focus groups were to engage participants in the change process and gather their perceptions and experience-based assessments of the effects of environment on their practices and patient experiences. The participants in the focus group sessions also critically analyzed pertinent issues and possible solutions while engaging in team reflection about the gathered data.

The focus groups with leaders and staff members working on the unit during the first phase helped to capture the different perspectives and views about the supportive and unsupportive aspects of the physical environment and practice challenges, which allowed me to 'tease out previously taken for granted assumptions' (Bloor, Frankland, Thomas, & Robson, 2001, p. 6). A series of 31 focus groups were conducted with staff members and leaders on the team (e.g., care coordinators, nurses, care assistants, occupational therapists, physiotherapists, and physicians). Nine of the focus group sessions involved viewing videos of patient stories and following up with team discussions – in Chapter 6, they are called video

reflexive groups. Most of the sessions lasted 30-60 minutes and were arranged to occur at 2:30-3:30 pm, every other Wednesday, in a conference room at the unit. At each session, 6-12 staff attended. It was not always the same people who attended the focus group each time, depending on who was working that day and who wanted to or was able to attend. Samples of the focus group questions are listed in Appendix D. Due to the emerging nature of the study, many of the group questions and discussion topics were triggered by the participants, which is in-line with the participatory paradigm. In action research, the emphasis is on the philosophy of doing research 'with' as opposed to doing research 'on' participants. In a video-reflexive study of the dying experience of patients, Collier et al. (2015) found their patient participants had expert knowledge of their illness experience and care issues, and their video footage provided a medium for the voices of patient participants to be heard, opening up the discussion among care providers about patients dying in hospitals.

Phases of the Research

Following the tradition of action research and appreciative inquiry, the researcher gathered the participants to co-inquire about their condition and then work together to find possible ways to innovate and make improvements. To explain the research processes, I describe the journey in three phases, even though, in reality, overlapping and iterative movements occurred back and forth between the phases. Knowledge translation activities (e.g., conference presentations to present research data and early findings) were integrated into all three phases. Table 2 shows a summary of the research strategies and data generation methods used in the three phases of the research. In phase 1, environmental audits, go-along interviews with patients, observations, and focus groups with staff and leaders were undertaken. In phase 2, a range of person-centred care education and action activities were

carried out. Focus groups with staff and leaders were held with continuous reflection and ongoing data analysis. In phase 3, I focused on evaluating the impact of the research, based on staff experiences and group sessions to reflect together. One hospital administrator was interviewed. The participants were encouraged to tell stories of their experiences in the research and practice, and talk about their hopes and dreams. For example, I asked them: Tell me what is exciting about this dementia research and what contributed to the success? What could we do more of? I began knowledge dissemination as soon as I had developed research products (e.g., education package). Data generation, analysis, and knowledge dissemination were carried out simultaneously in phase 3. I went to other teams in other units of the hospital and other nearby hospitals to share research products. I also presented my early research results at conferences to share the research findings and seek feedback from a wide-ranging audience (patients, families, researchers, practitioners, and the public). Manuscripts were prepared for publications to contribute to the body of knowledge in the literature.

4.4   Data Analysis

Reason and Bradbury (2008) described action research as "an evolving process of coming to know, rooted in everyday experience" (p. 5). For action researchers, the process of inquiry is as important as the outcome, since people in the research setting can develop skills of inquiry and can learn over time. Thus, I considered the analysis to be an opportunity to learn together and lead the growth in research and co-inquiry. I used a fluid and intuitive qualitative approach, as described by Ellingson (2009), to allow more opportunities for naturally occurring data to emerge from multiple sources during the research process. To ensure scientific rigor, I used an iterative process for analyzing and comparing the data across theories, literature, and the gathered data to provide a deep, complex, and thorough

understanding of the studied phenomenon from multiple angles. Richardson (2000) used the term 'crystallization' to describe this qualitative data analysis method, which embraces multiple possible interpretations of reality:

> Crystallization provides us with a deepened, complex, thoroughly partial understanding of the topic. Paradoxically, we know more and doubt what we know. Ingeniously, we know there is always more to know (Richardson, 2000, p. 934).

Crystallization fits well within social constructionist and critical paradigms because it recognizes that the analysis should consider and include multiple perspectives (Ellingson, 2009).

Drawing on the interpretive approach based on Gadamerian hermeneutics, I focused on understanding people in context. I strived to understand what and how specific environmental attributes affected the care experiences of patient participants. I focused on the meaning of staff experiences. As Gubrium and Holstein (2008) indicate, "the goal is to capture – through multifocal analysis – the contextual influences and dynamics that shape narrative" (p. 262). As Ellingson (2009) explained,

> this effort requires commitment to analytic thinking, conscious reflection, and strategic choices concerning which details to include, what the artistic account's purpose and audience are, and what moral or lesson it portrays (p. 60).

More details of the data analysis are shown in the three papers (Chapters 5-7). In the initial phase, I began watching all unedited visual data and reading the transcripts and field notes several times to gain a sense of the whole of what had been said. I edited each video and divided the clips into themes using Final Cut Pro version 10.3.2 software (Apple Inc.,

2016). The visual data, transcripts, and field notes were pooled and coded in NVivo11 software (QSR International) to facilitate the analysis.

I held biweekly data analysis meetings on Fridays during the lunch hour with a clinical nurse specialist (Jenifer Tabamo) and a nurse educator (Doris Bohl) to review the key points in the videos and transcripts, and compared and discussed our individual interpretations and tentative analyses to develop a clear focus for further development.

Through an iterative process of discussions within and between staff groups, themes were developed, modified, and refined. The analytic approach was a social process that took multiple cycles and involved different people to view the data multiple times in different ways. While I was responsible for initiating the analysis, the process was supported by continuous discussions with unit leaders and supervisors of the research committee through regular research meetings. To promote co-inquiry and co-learning, I invited participants to participate in the data analysis by providing feedback and contributing input to develop the themes. Leaders and staff participants were involved in discussing the early findings from the data that moved the project forward. Public advisors, Jim Mann and two family advisors, Gerlise Matz and Sheila Lamb also gave feedback and input.

Facilitating collaborative dialogue and sharing of our ideas during the project was integral to the change process and the research outcomes. In the end, leaders and staff participants also helped to create tools for disseminating the findings. For example, the educator was involved in creating two posters and co-presenting our results at two conferences. To "involve and improve" were important objectives of the study and consistent with action research philosophy. The participants determined their degree of involvement in the data analysis, depending on their availability and workload, and depending on the clinical

priorities and unit operations. In 2016, the hospital went through an accreditation and I had to cancel a couple of focus groups since the preparation for accreditation was a high priority for the clinical leaders and staff.

Due to the busy clinical realities and limited time, I avoided presenting exhaustive data and the text-heavy details that make meaningful stakeholder participation difficult. On the other hand, I did not want to analyze the data in a hurried or superficial manner, without considering the details and nuances that would give meaning to the inquiry. Therefore, I brought only relevant details for meaningful engagement. The analysis was supported by visual images and tables of selected excerpts to help organize the information and findings for a clear and logical presentation. Through repeated reviewing, checking, and comparing of coded data to confirm they fit the themes across the dataset, and while working with staff participants, I refined the themes to ensure they provided answers to the research questions and clearly represented the participants' stories.

4.5   Ensuring Research Quality

In conventional research, recommendations are made for action after the research is finished. For action research, in contrast, the action is an integral part of the research process. At the heart of action research is the production of actionable knowledge, learning in action, and moving the current condition toward the desired changes. Bradbury (2015) proposed seven core elements for assessing the quality of action research, as discussed in the following subsections.

Clear articulation of the objectives

Action research is primarily concerned with practical value, which involves considering the process of how to make change and the effect of change. For this project, the

two main goals were to examine: (a) how a team of staff were engaged to make change in the physical and social environments, and (b) the research impacts in supporting positive change in the unit. The specific objectives were to:

1. develop person-centred care;

2. explore ways to support involvement of patients with dementia in research;

3. examine the processes of staff engagement, bringing staff in different disciplines together to make change; and

4. evaluate the impact of research in the process of change, identifying lessons learned to inform practice, education, policy, and research.

Enacting participative values

One of the goals of action research is to promote ownership of practice change, resulting in greater sustainability (Lazes, 2007). This kind of research is appealing for nurses and other practitioners on the team because it addresses real needs in everyday practice, build on positive strengths and motivations, and give staff support and resources to contribute in the change process. Participation began with an open invitation to everyone on the team (full-time, part-time, or casual staff in all disciplines) and continued with mobilizing participants who could best help with changes. For some, best help would mean recognizing to be a part of the change; for others, it meant offering ideas or more active participation in planning, action, evaluation, and dissemination.

Contribution to practical knowledge and theory

Action research is grounded in practice, and thus it challenges expert knowledge, which speaks about action without actually engaging in action. The relationship between theory and practice is of prime importance to action researchers. For this project, much of my

work involved bringing attention to person-centred care, addressing the gap in aspects of the physical environment, and working with patients, family advisors, and staff to co-produce actionable knowledge. The aim of the research was not to produce universally generalizable answers. Because developing person-centred care in hospitals is complex, understanding how knowledge can be produced and implemented in a particular context is useful for clinicians, educators and policy makers. While the generated knowledge primarily reflects the views of participants in a medical unit, I provide a rich description of context and research processes to enable readers to judge what might fit in other contexts, to enable transferability.

Illustrating the process and outcomes

Selecting appropriate methods to answer the research questions is important for bringing rich contextual information to assist transferability. In action research, the inquiry itself is a form of action. For this project, the questions I asked in the focus groups became vehicles for engagement. Data analysis and the evaluation meetings became a crucial component of developing skills and capacity in the team. Another important strength offered by action research is the useful insight about the change processes. Even when outcomes turn out to be unfavorable, action research can still lead to an in-depth understanding of issues by providing a map of the processes of change so that "more sophisticated questions [can be] posed" (Herr & Anderson, 2005, p. 86). In this case, when things did not go according to plan, the challenges that showed up in the research process provided invaluable lessons, as discussed in Chapters 8 and 9.

Producing ideas that guide action in response to need

Heron (1996) claimed that "all forms of knowing are for action." He further asserted the distinction between knowing that and knowing how. His point suggests that practical

knowing is developed through action. In this study, I focused on collective learning by using appreciative inquiry principles to explore how members of the team might articulate their shared knowing and develop joint action. The intentions include empowerment, collaboration through participation, acquisition of knowledge, and social change (Glasson et al., 2008).

Demonstrating reflexivity

Action researchers are required to have the commitment to develop self-awareness and reflexivity. Through rigorous processes and thoughtful iterative analyses, and ongoing critical questioning, I aimed to work with the complexities to develop "the most intricate and conceptually linked interpretations possible" (Thorne, 2016, p. 194). Being a researcher and a practitioner working in the organization can be a disadvantage as I can get so close to people and organizational life that it could hinder my ability to step back to do effective data analysis. Therefore, regular journaling, debriefing with peers (another doctoral student and two co-investigators), and monthly meetings with my supervisor were key resources for me to be effective in the data analysis. In particular, using my journals to identify my assumptions, record project events, and critically reflect was crucial in guiding the development of my thinking and subsequent approaches for the research. A critical reflective article in Chapter 8 and much of the content in Chapter 9 were written based on my journal.

Contributing to a larger community beyond the immediate context

Although action research focuses on local inquiry, it can have broad implications to a wider knowledge base. Reason and Bradbury (2008) drew attention to the need to ensure issues raised by action research are addressed at both micro and macro levels, suggesting that researchers need to pay attention to the implications of their findings within the wider context. In Chapter 2, I made associations between the literature and my inquiry to show how

they connect across a wider knowledge base. In the findings, I link the results to a wider knowledge base to identify the implications. The insight gained can deepen the collective understanding of important issues in the care of older people with dementia within the acute care context and provide strategies for others to draw on when addressing similar concerns. The research work that was conducted with leaders, staff, and patients provided empirical evidence to inform policy and system change.

4.6   Ethical Considerations

"The underlying value of research ethics is respect for human dignity" (UBC Office of Research Ethics, 2015). Research ethics guidelines ensure that "research involving humans is sensitive to the inherent worth of all human beings and the respect and consideration they are due" (UBC Office of Research Ethics, 2015). This research involves people with dementia. Having dementia does not mean that a person automatically lacks the capacity to give consent. People with dementia have the right and should be supported to take part in research if they wish to participate. Researchers have the obligation to help people with dementia understand studies in which they are involved (Dewing, 2007). To address the challenge of obtaining informed consent with a population of people with dementia, I followed current consensus guidelines, treating consent as an ongoing process, seeking assent, and respecting the dissent of potential participants who lack the consent capacity for research (Black, Rabins, Sugarman, & Karlawish, 2010; Dewing, 2007). For example, assent was sought before each observation session to remind the participants with dementia about the purpose of the research and their right to withdraw at any time. If a participant indicated verbally (e.g., saying 'no') or non-verbally (e.g., wanting to leave), their dissent and

withdrawal were respected. I carefully monitored verbal and non-verbal cues about the acceptability of the research activities.

Patient participants were given a choice about using or not using videotaping in the interviews. Because the go-along interviews were conducted in the public spaces of the unit (e.g., corridors), the identity of the study participants were likely known to others. This risk was explained to the participants in the consent form, and they were told of our plans to protect this information (Appendix E). Participants were also given an option - if they agreed to the videotaping, but did not want the video data to be presented, the data would be transcribed in a narrative form with the removal of any identifying information. If a participant agreed to the release of the video data, he or she was given an opportunity to review the footage beforehand. The intention to use data including video footage for academic and education purposes was made clear in the consent and data release form and explained to participants. Participants were also informed about the risk that a viewer could recognize the body or voice of a participant in a video.

Similar to the study of patient safety and dying experiences (Collier et al., 2015), all patient participants indicated that they expected their videos to be used in conference presentations or for staff education, and they felt that the videos would teach the staff and others about their experiences. Respecting the dignity of the participants, following professional ethics and good judgment, and using common sense were important strategies to safeguard the rights of participants (Williamson et al., 2011). Using clear communications and working collaboratively with all participants (patients, families, leaders, and staff) ensured that they would benefit and be empowered by the research, and not devalued or harmed. All participants had an option to waive confidentiality in the consent form, when

asked if they would consent to be identified by real name in the study results. For action research, Herr and Anderson (2005) explain that participants may want to forego anonymity, and be acknowledged for their contribution to enhancing the quality of patient care. In this study, most staff participants (including leaders) and one patient participant signed the waiver form. For the participants who signed the waiver form, real names were used to acknowledge their contributions. Pseudonyms were used for other participants as per their wish to remain anonymous. Indeed, in their decision-making, the participants appreciated the opportunity to assess their own vulnerability and to state how they wanted to be credited as a co-creator of the research findings. As I prepared the research manuscripts, some staff members asked me when they could expect to see the publications. I informed them about the process and, in turn, they motivated me to write.

Unless the participants waived their right to confidentiality, the data related to participants were made anonymous and pseudonyms were used. I treated consent as an ongoing process and fully respected and made every effort to accommodate their choice, even if they changed their mind.

Ethics approval for the study was obtained from the Research Ethics Board of the University of British Columbia and from the local health authority. My work position as a clinical nurse specialist means that I do not provide direct supervision of staff nor do I provide regular direct care to patients. After a patient gave permission as a participant, I would visit them and provide more information, answer questions, and explain the consent process. Participants were assured that if they declined to take part in the study or withdrew at any time; it would not jeopardize the care they received in the unit at the hospital.

Because of my position as a clinical nurse specialist in the unit, the participants could perceive my power, which could undermine the democratic process for participation. To ensure that the nurses did not feel pressured or coerced to participate in the study, I made every effort to be as collegial and transparent as possible. The study information sheet was carefully written with explanations that the project was a joint effort of collaboration and exploration. Whenever possible, I provided updates about the progress of the research. I listened to concerns of staff and encouraged a feeling of teamwork in the action research study.

Finally, researchers have ethical obligations to translate knowledge, which is not simply a transfer of information. It requires multifaceted interactions between those who create knowledge and those who may use knowledge for its possible implementation into practice (CIHR, 2015). In this project, the knowledge users, including patients, families, and staff members were invited to contribute their expertise in their own way. The collaborative work was integrated into the processes of knowledge synthesis and dissemination.

In the next three chapters, I present the findings. The particular focus of this research is to explore how people are engaged in the change processes towards developing person-centred care in the medical unit, and to evaluate the impact of the research on change. In Paper A (Chapter 5), I address the involvement of patients with dementia by describing the stories of hospital experiences told by the patients themselves. In Paper B (Chapter 6), I address the experiences of staff engagement in video reflexive groups as told by staff members in all disciplines. Paper C (Chapter 7) discusses research impact - how research drawing from appreciative inquiry facilitated commitment and actions to influence change in

the medical unit. A conceptual heuristic tool - Team Engagement Action Making (TEAM) is

proposed based on data generated in this study.

Chapter 5: "Little Things Matter!" Exploring the Perspectives of Patients with Dementia about the Hospital Environment

This is the first finding chapter, published in International Journal of Older People Nursing. Research results reported in chapters 5-6 set out the answers to the two research questions. In this chapter, I address the involvement of patients with dementia by describing the stories of hospital experiences told by the patients themselves – part of the answer to the first research question: What did the engagement processes for change in the physical and social environments towards person-centred care look like in the medical unit?

Figure 3. Four of the early patient participants

5.1   Background

Population aging is expected to lead to more people living with dementia in Canada and around the world. By 2030, more than 75 million people are expected to be living with dementia worldwide (WHO, 2012). A recent UK study found about half of the older patients (over 70 years of age) admitted to hospital had cognitive impairment (Goldberg et al., 2012). In Canada, older people represent near half (45%) of emergency hospital visits, and many of them admitted for assessment and treatment have dementia (Canadian Institute for Health Information, 2016). Studies have repeatedly reported that older patients with cognitive impairment have worse outcomes compared to those without impairment --including longer lengths of stay, decline in function, and higher mortality rates, while hospital environments have been criticized for being inadequate and insensitive to the needs of older adults with dementia (Clissett, Porock, Harwood, & Gladman, 2013; Dewing & Dijk, 2016; Goldberg & Harwood, 2013). Given the demographic shift in patient population, the workforce and the physical environment of hospitals need to adapt and become more responsive to the changing healthcare needs of the population (Canadian Institute for Health Information, 2016; Parke & Chappell, 2010).

Recent review studies have revealed that there is limited research into the patient outcomes of hospital design, and most of the existing environmental intervention research regarding dementia care has been conducted in residential care settings (Chaudhury, Hung, & Badger, 2013; Fleming, Goodenough, Chenoweth, & Brodaty, 2015). Another significant problem is the lack of knowledge about the first-person perspective from patients with dementia. There is misconception and stereotype that people with dementia cannot communicate their views (Cowdell, 2010), despite an increasing body of research illustrating

that people with dementia have important insights to offer and can contribute to knowledge production in meaningful ways (Phinney, Chaudhury, & O'Connor, 2007; Phinney, Dahlke, & Purves, 2013; Sabat, 2002). Swaffer (2014) rightly argued that doing research about dementia without involving people with dementia cannot provide a true portrayal of salient issues for this group and ignoring the experiential knowledge of people with dementia hinders the validity of research evidence. Research evidence has shown that there is incongruence with what care providers report and what is observed about the experience of people with dementia (Innes, Kelly, Scerri, & Abela, 2016). Swaffer (2014) argued the literature has been giving wrong descriptions of people with dementia and has created misconceptions. She explained:

> Much of the published research is biased through the use of family carers as the main cohort group, or having them in attendance when people with dementia are interviewed, and so the carer voice remains the same voice in the dementia literature (p. 710).

In addition, the white paper by the Dementia Action Alliance (2016) located in the United States pointed out that professionals might have a limited perspective about the lived experience of people with dementia. Care providers in acute care settings tend to have priorities in medical procedures, infection control, risk management, and length of stay. Patients may have different values and other priorities. Research that provides understanding of patients' needs and experiences from the perspectives of patients with dementia is needed to inform meaningful changes in hospital environments. The issues that patients with dementia consider as priorities ought to have practical implications for effective allocation of resources, thus making relevant and responsive changes. Given that patient stories can be

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pivotal drivers for changes in the broader healthcare context (Bate & Robert, 2007), patients

with dementia should be supported to give their voice in research and be included in

conversations about the hospital environments and services that affect their care and

experiences.

Overall, in the literature, there is a growing recognition of the need for more inclusive

designs for people with dementia and a better dementia-trained workforce to ensure hospital

stays do not add disabilities and compromise well-being (Francis, 2013; Innes, Kelly, Scerri

& Abela, 2016). Researchers and practitioners have reported that the traditional designs of

acute hospitals are not responsive to the specific needs of people with dementia. Studies

reported that unclear signage, poor lighting, clutter, and a lack of space for family visits, and

opportunities to engage in meaningful activities are common problems in hospital design

(Digby & Bloomer, 2014; Hung et al., 2014). Concerns have been voiced related to the

experience of people with dementia in hospitalization who are experiencing high distress; at

the same time, nurses are constrained in attending to that distress by structural environmental

factors as well as a lack of the staffing support required to provide person-centred care

(Cowdell, 2010). Moyle, Borbasi, Wallis, Olorenshaw and Gracia (2011) found that the acute

care environment influenced staff attitudes with regards to the care of people with dementia,

leading to excessive monitoring of patients and less emphasis on meaningful interactions

between staff and patients.

The challenges of dementia care in acute hospitals are complex; therefore, it is

necessary to examine the processes through which the care experience of patients with

dementia may be impacted by both the physical and social environments in dynamic

interaction. For the purpose of this study, physical environment refers to the built features in

the environment, such as wall color and lighting; social environment involves human factors, which include care practices in a relational context.

5.2　The Person-Centred Care in Acute Care Study

This paper is part of the *Person-Centred Care in Acute Care Study*, which is an action research inspired by a quality improvement project by Waller, Masterson and Finn (2013). Waller and Masterson (2015) reported positive effects on patients with dementia (e.g., reductions in falls and the use of antipsychotics), by making simple environmental changes in a surgical unit (e.g., enhancing colors and adding comfortable seating areas for social interactions). Although this quality improvement project offered good support for environmental strategies, it did not report details of the methodology and the processes of stakeholders' involvement. It is unclear whether patients with dementia were involved, and if so, what they contributed and how the inquiry took place.

Given the identified gaps in the field of dementia research in acute care, this research began with exploring the experiences of patients with dementia – their firsthand perspectives of the hospital environment. In particular, I used go-along interviews to engage patients with dementia to identify: what and how specific environmental attributes impacted their care experiences and what they wished to see as improvements to the issues they identified. This paper reports data related to the first phase of the larger research project that aimed to make physical and social environmental changes for improving the care experiences of patients with dementia in a medical unit of a large urban hospital. The research was designed so that insights provided by patient participants in phase one would inform actions for developing physical environmental changes and staff education in phase two, and serve as a part of the

base for assessing impacts made by the changes in phase three. The processes and findings for phases two and three will be reported in future papers.

5.3   Design and Methods

5.3.1   Theoretical grounding

The study was part of an action research study underpinned by critical social theory (Habermas, 1984) and interpretive approach (Gadamer, 2011). The interpretive approach was helpful in making sense of patients' narratives to convey understanding. The participatory perspective of action research emphasized the value of researching 'with' rather than 'on' people (Bradbury, 2015) - a particularly salient approach for people (such as patients with dementia) who are among the most marginalized in our society. In the study, patients with dementia were not treated as passive subjects to be studied, but as active agents who had important contributions to make. This approach embraces Habermas's theory of communicative action (1984), which suggested the conditions necessary for egalitarian communication include freedom from manipulation and domination of power. In action research, there is a deep respect for the rights of people to have their say in how knowledge is generated about them. As Kemmis argued (2008), the inquiry itself in action research is a form of political action. In this study, patients with dementia in the medical unit were invited to tell their stories, experiences, and suggestions for making improvements in the hospital environment. Through the processes of elicitation and recognition, patient participants were given a sense of power and legitimacy of their knowledge about the environment and expertise of their lived experiences.

5.3.2 Setting

The study took place in a 31-bed medical unit of a large urban hospital in Canada. The unit provides assessments and treatments to a general population of patients requiring medical and nursing care. Typically, about a quarter of the patients have dementia and the common types of diagnoses include cerebrovascular accident, heart or lung diseases, sepsis, fall injuries, and confusion. Patients stay in the unit for a varied length of time, ranging from a few days to several months.

The unit has a layout with two, long double-loaded corridors (each corridor has patient rooms on both sides). The nursing station is located where the two corridors meet, and is situated between two locked entrance doors. Many patients like to sit around the nursing station to watch nurses doing their work. The traffic through the two entrance doors often triggers conflicts with patients trying to go off the unit and staff members are under constant stress trying to monitor and control the exit. Walls are painted a pale neutral color and handrails are in light-brown, which is similar to the wall color. Linen carts, beds, wheelchairs, and other equipment line the corridors, which at times limits access to handrails. Various paintings are hung on the walls, but they tend to be obscured from vision by the tall linen carts and staff signs (e.g., infection control, violence alerts). A television for patient use is placed at the entrance to a corridor that is close to the nursing station. Meals are brought to the unit in trays and patients eat in bed. Most of the rooms have three beds, although a few are single-bed rooms that are usually reserved for patients with infections that require careful isolation procedures.

5.3.3   Participants

Purposeful sampling (Patton, 2015) was used to identify patient participants to gather in-depth and meaningful insights. Nurses who knew the patients on the unit provided assistance in recruiting the patient participants with diverse characteristics to maximize variation. Among the five participants, three were men and two were women, with an age-range of 65 to 84. All participants had a diagnosis of dementia, including Alzheimer's disease, vascular dementia, or an unspecified subtype of dementia. They had a wide range of functional abilities and difficulties. Some were independent and steady in walking; others were wheelchair or walker users. We included patients who were identified as having behavioral and psychological symptoms of dementia, including agitation and aggression. Some were unsteady in walking and had struggles with wayfinding. Some had more difficulties in word finding; others were skilful in articulation. Their ethnic backgrounds were also diverse, including descendants and immigrants of European, American and Asian origins. Participants had varied education levels and occupational backgrounds, including an artist, a photographer, a fashion buyer, an odd job worker and a business owner. The decision of selection was based on the logic of seeking information-rich cases (Patton, 2015). The small sample allowed us to yield not only a deeper understanding of patients' experiences but also commitment and actions of staff to make change.

5.3.4   Ethical considerations

Ethics approval was granted from both the University Research Ethics Board and the local health authority. The research followed current consensus guidelines, treating consent as an ongoing process, seeking assent and respecting any dissent of the participants (Black, Rabins, Sugarman, & Karlawish, 2010; Dewing, 2007). Written consent was initially

obtained and verbal assent was sought before and during each interview session to remind participants about the purpose of the research and their right to withdraw at any time. A family member signed the participant information and consent form in cases where the participant was unable to do so. In the consent form, participants were given options to allow the researcher to use video or not at each interview. Note taking and audio recording were offered as alternative options. I booked appointments with each participant to do the interviews so they have time to consider the options. In the study, no patient participants declined videoing. During each interview, I checked and rechecked participant's verbal and nonverbal response in changing situations. For example, one day, a participant told me a story with videoing. A few minutes later, she decided that she wanted that story to be deleted. I respected her wish and deleted the story in front of her.

5.3.5   Data generation

Ethnographic methods, including go-along interviews technique and videoing (Iedema, Long, Forsyth, & Lee, 2006) were used to support patients with dementia to voice their views and experiences about the hospital environment. During each conversational interview, patient participants were asked to take the lead in topics that they considered as important and wanted to discuss while taking for a walk together in the corridors of the medical unit. Following the participant, I used a small, hand-held camcorder with a narrow-angle lens focused on the participant or on particular features of the environment. Instead of relying on memory recall, participants were invited to talk about what they saw, heard and sensed in the immediate environment while moving through the unit. When objects or artifacts were visually accessible and events were taking place in the environment, participants with dementia were better supported to tell stories about experiences and express

their views, an approach that has been used in previous studies (Hubbard, Downs, & Tester, 2003; Hung, 2015). At the same time, experiencing the environment with the participant together made it easier for the researcher to understand and make sense of meanings that the participant was trying to convey. In order to bring focus to the research topic, occasionally, the researcher asked what the participant liked or did not like about a specific feature of the environment and the associated reason. What could be changed to make the environment better was also inquired. Each patient participant was interviewed two to four times, with each session lasting around 30 minutes. A few interviews involved a one-on-one walk, while others involved two participants at the same time, based upon the request of the participants. All narratives in the videos were transcribed verbatim, while the visual recordings helped to capture both verbal and nonverbal expressions, as well as materials in the environmental context. Field notes were taken to record immediate feelings, thoughts, and questions that could require further clarification in the data collection.

To gain a background understanding of the everyday activities in the studied environment, participant observations were conducted in the corridors of the unit. A total of 20 hours of observation was conducted during weekdays and weekends over a three-month period (January – March, 2016). Participant observations allowed the researcher to get close to the experiences of the participants, and develop a connection with the patients in the field while observing the general activities (Emerson, Fretz, & Shaw, 2011). During the observations, the researcher either sat in a chair or stood in a corridor, sometimes conversing with the staff, patients, and families. Field notes were written in a notebook to record details of how the patients were interacting with other people and the physical environment.

Exquisite attention was paid to small mundane activities and striking events (Katz & Alegria, 2009), as well as reactions of patients and staff as they unfolded in situated moments.

5.3.6   Data analysis

Drawing on the interpretive approach based on Gadamerian hermeneutics (Fleming, Gaidys & Robb, 2003), the data analysis focused on understanding people in context, which means interpreting what and how specific environmental attributes affected the care experiences of patient participants. Data analysis was iterative and conducted with data collection. Three broad analytical phases were involved and these phases were carried out in a cyclic mode throughout the analysis process, requiring repeatedly return to data and the coding to refine the theme development. For a preliminary analysis in the initial phase, I began with watching all visual data and reading of the transcripts and field notes several times to gain a sense of the whole. The visual data, transcripts, and field note were pooled and coded in NVivo 11 to facilitate analysis. Both inductive and deductive approaches were used. While the data set were primarily coded inductively, concepts based on the literature in environmental design for dementia care were also used for deductive coding. For example, 'nothing to do' was an inductive code used to capture segments of narratives. 'Color contrast' was a sensitized concept, a deductive code, informed by the literature. The process involved going back and forth between the data and the literature.

Understanding people in context also means coming to a social agreement through dialogue (Gadamer, 2011). Therefore, the second phase involved two co-investigators and (Jenifer & Doris) and I reviewed the key points in the videos and transcripts together in biweekly research meetings where individual interpretations and tentative analyses were

compared, challenged, and discussed to bring a clear focus to be further developed. Collectively, particular video clips were selected to illustrate key themes.

Patients were provided opportunities to view their own video-recordings. Three of them viewed their video-recordings; the other two chose not to view. When videos were played back to patient participants, they tended to make more comments on their appearance in the video, rather than the content of the data. With permissions given by patient participants, video clips and extracts of transcripts were reviewed with frontline staff and leaders in focus groups/ reflexive sessions.

The third phase of analysis in nine video reflexive sessions provided opportunities for the team to discuss the issues patients encountered and possibilities for future actions. The discussion focused on what could be learned from the patients' stories shown in the videos. A total of 50 staff in the team attended the groups, including nursing staff (30), physicians (15), and allied health, including staff in physiotherapy and occupational therapy (5). The overall analysis process involved moving from considering the parts (what patients said) to the whole (what happened in the background and context) and back to the parts. With the expanded understanding of the whole, meaning of the parts can be widened (Fleming, Gaidys, & Robb, 2003). For example, discussion with staff revealed how stereotypes of dementia and physical appearance had caused misunderstanding of what a tall patient participant meant in his language and behaviors. Details of life history and stories of care interactions provided a broader lens to understand his narratives.

Through an iterative process of discussions within and between staff groups, themes were developed and modified and refined based on agreements. The analytic approach was a social process, which took multiple cycles and involved different people to view the data

multiple times in different ways. The two co-investigators (Jenifer Tabamo and Doris Bohl)

participated in the video reflexive sessions with the staff. Although I initiated the analysis,

the process was supported by continuous discussions with co-investigators and supervisors of

the research committee through regular research meetings. Thus, the final themes developed

were a shared interpretation of the researchers and participants involved.

5.3.7   Ensuring credibility and quality

The quality of action research hinges on the participatory processes and the

production of actionable knowledge to move toward making improvement of human

experiences (Bradbury, 2015). In this study, participative values were enacted through

collaborative working with patients with dementia, a seldom-heard group (Swaffer, 2014).

Multiple groups of stakeholders were involved in multiple steps of data analysis to ensure

that the themes were the best possible representations of the data. Direct quotes from the

narratives were used to help readers make judgments of the fit of representations. As

Gadamer (2011) has explained, there is no single interpretation that is universally true, and

understanding can only be achieved by consensus through dialogue (between people or

between reader and text). To ensure the scientific rigor of the study, we performed an

iterative hermeneutic process systematically, using gathered data, emerged interpretations

and available literature to make a coherent set of themes.

5.4   Findings

Data analysis yielded insights about the key aspects of the hospital environment's

impact on the care experiences of patients with dementia, and what patients with dementia

wished to see as improvements related to the issues they identified. The characteristics of the

physical and social environments were described to impact positive and negative care

experiences of people with dementia. Here, we present the findings as four inter-linked

themes. First, *a place of enabling independence* points to the importance of positive

engagement of the brain and body. Second, *a place of safety* means not only being physically

safe, but also feeling emotionally and psychologically safe. Third, *a place of supporting

social interactions* speaks to the essential need to have opportunities for human connections.

Fourth, *a place of respect* describes the central concern that patients with dementia need to

feel socially included and have their rights respected in the hospital.

Figure 4. Key aspects of a supportive hospital environment

5.4.1   A place of enabling independence.

For the participants in this study, being a patient in hospital meant a loss of

independence. The reduced opportunities to perform everyday activities affected their sense

of autonomy. They wanted the hospital to be a place of enabling independence rather than

disempowerment.

Participants described that the hospital should afford patients opportunities to do familiar things that they always enjoy and consider as purposeful. The meaningful activities serve a vital function to keep the brain and body active, which contributes to health, healing, and well-being. For the participants, simple day-to-day activities such as going for walks or meeting someone for conversation were essential in promoting a feeling of independence. One participant said, "I can't sit and do nothing at all. Every day, I make my bed. I always come out to find someone to talk to. It's nice that if you are capable of doing things. It's just the way I am. I'm very independent. I do everything. It's very, very important".

One barrier that stopped some patients to come out to the corridors to walk was the clutter of linen carts, medical equipment, hallways beds, etc. The combination of simultaneous loud sounds from other patients, the staff, and alarms ringing made the environment confusing and distracting. Busy and crowded signage on the walls concerning infection practice and other reminders/notices made the place even more over-stimulating. One participant referred to the clutter thus: "Chaotic clutter makes the brain feel getting overloaded by too many stimuli, overly charged with electricity if you know what I mean."

One patient suggested small practical changes could make a difference, "The corridor could look very inviting if it's done properly with shelving and if it's up nicely". She went on to offer ideas of how to organize shelving in aesthetically pleasing styles suggesting that the corridor would look much calmer and be twice as wide if the clutter was put away in storage and if the confusing signage was replaced by beautiful artwork.

An environment that is difficult to navigate and comprehend can have a negative impact on independent functions. According to the participants, wayfinding was a common concern, which made independent navigation challenging if not impossible. Two patients

commented that the identical room doors and non-distinguishable hallways made finding their room difficult. One of them said, "Especially when I am tired, room numbers on the wall was not always helpful. I don't really see them and I don't find number meaningful for me" Another patient echoed, "Personally, at times I get a little stuck with the number too, remembering the numbers". One patient mentioned that different colors should be used in each wall so it would help patients to know they were in right corridor for their room. She recommended: "The color can be a contrast; it can be the same but then a deeper tone".

Another patient suggested that bright colors should be used to encourage people to get out of the bed and come out to walk. She explained,

> In a hospital, you wouldn't feel quite so much in it if you had some color around. People staying in bed all day could get stuck in thinking about their situations and become very worried and depressed. The use of color can help uplift a patient's mood and emotions. Thoughtful variations of color and art painted on the wall could make the place look more homey. I think that half the walls could be one color and half another color…color would make the hospital feel more comfortable. I think it could be fun colors, all different colors. People feel they are at home a little bit, not so much stuck, dying or whatever. It would give them a nicer feeling about where they are.

For this patient, color can be powerful in terms of stimulating senses, shaping the ambience of the place, reducing anxiety and worries, encouraging mobility as well as improving mood.

The lighting in the corridors was identified as a significant contributor to the use of space and patient mobility, especially for those who had eye conditions or were visually impaired. One participant who had a common age-related eye disease refused to go into dark

areas in the hallways. He also seemed to have difficulties with glare on the floor. In the

interviews, he tended to walk around the glare spots on the floor, which could increase the

risk of falling. Interestingly, observations showed that many patients did not use the handrails

on the walls, and this could be for two possible reasons: the clutter of clinical equipment and

hallway beds often blocked access to the handrail, and the color of the handrails did not

contrast with the background (both were in neutral color). To encourage independent walking

and mobilization, a participant suggested the need to have seating areas in the corridors.

"Because people get tired when they walk down the hallway, just putting a simple piece of

furniture at various places could help people rest and feel safe to walk."

5.4.2   A place of Safety

Many participants spoke of the need to be in a place of safety as a priority, with this often

described as a psychological need to feel safe emotionally, not just physically. Psychological

safety is associated with the physical features and relational aspects of the hospital milieu.

Feeling emotionally unsafe with other patients seems to impact psychological safety, which

has implications for increasing anxiety and reducing abilities to cope with perceived threats.

When asked what would help them to feel safe in this environment, patients mentioned how

some aspects of the aesthetics and practicality of the environment were significant to their

feelings of safety. For example, a patient, Terry[1] who had difficulties in visual-spatial

[1] Terry is a pseudonym. Terry and his family gave permission for this video to be used for academic and education purpose. See details of the consent process in section 4.6 of Chapter 4 and consent form in Appendix D. Consents were obtained from participants for videos to be shown in this dissertation. This chapter has been published without videos. Hung, L., Phinney, A., Rodney, P., Chaudhury, H., Tabamo, J., & Bohl, D. (2017). Little things matter. Exploring the perspective of patients with dementia about the hospital environment. International Journal of Older People Nursing, published online in open access: http://onlinelibrary.wiley.com/doi/10.1111/opn.12153/full

Video 1: Terry

perception, told the researcher that he felt threatened when people moved too quickly or were too close to him. "I don't feel right with those people coming by. Boom! Like this, all the time." (see Video 1 about Terry).

Terry also felt unsafe to go to some areas in the corridors that were cluttered with equipment. The noise of patients calling out or crying also frustrated him. "See how they cry? It's common. I'd rather stay away from them because I'd probably smash their head." It was evident that the environmental features can have significant impacts on the feeling of safety emotionally and psychologically. Also, feeling safe can be just important as being physically safe for patients with dementia. During the interview with the same patient on one occasion, I noted that he became unbalance as he flinched and pulled himself away from a patient who got close to him. He was very sensitive to any movement in space and felt he constantly needed to protect his personal space. Similar scenarios of people encountered in busy and

crowded traffic often were triggers of conflicts in the corridors. A participant described how overcrowding with equipment in the corridors could evoke feelings of danger and actual risk:

The brain needs to relax to function. Feeling stressed definitely does not help. Well, here's one example right by us. This is for blood pressure. It's a danger to people who are not as conscious up there [pointing to the brain]. I mean that's very unwise to have it where it is. You can't rely on somebody walking and necessarily stopping if their minds are somewhere else or got caught up with too many things; then they're not focused on their walking space.

The same patient further explained that the abilities of people with dementia might be reduced by changes in their attention and concentration. "I find it very hard for me to concentrate on anything when too many things were coming to my brain at the same time, which makes me feel exhausted." Another patient commented that a tidy and organized place would show respect for patient safety. In the video review sessions, staff in the team collectively commented that more attention should be paid to consider the needs of patients who are older, frail, and have cognitive or other functional difficulties, instead of organizing the supplies and equipment only for staff's convenience.

A variety of views were expressed on what contributed to feeling safe or unsafe and how best to enhance a sense of safety in the ward. One patient said, "We have a person who keeps going up too close and is always moving so fast in the hallways…she could easily push you over." Another patient added, "There is a very confused guy who goes into other people's bed at night. It is vitally important to have enough nurses around… The nurses here are quick to act to keep everyone safe." Another patient nodded her head and agreed with the statement that having nurses available and nearby would help her feel safe. Also, one patient

commented about the need to have places to get away from the stress of noise. "It would be nice if there is a place that I can sit quietly with a cup of tea".

5.4.3   A place of supporting social interactions

In the observations, a sharp contrast was seen between the experiences of the patients and those of the staff. The traffic in the corridors was heavy and fast paced, and the general ambience of the unit was dominated by clinical activities. The housekeeping staff worked non-stop, sweeping and cleaning. Some of the nurses did not always walk, but hopped and ran, and the lab technicians were frequently pushing the diagnostic equipment through. The patients, however, sat for hours and had nothing to do. The participants expressed their feelings of boredom while the staff was under time pressure to get their tasks done. One staff worker said, "For us, we're like running around, busy. For them, it's like, what are we doing? There's nothing to do." Another staff added, "We should have room for activities, a little area for coffee or tea. The patients feel so bored here." The issue of profound boredom was a consistent theme expressed by all participants. One patient explained having nothing to do could become a stressor affecting health:

> I guess one of the stressors involved with being in the hospital is you don't have too much to do. The hospital is a very boring place to be because nobody does anything – zero. There's nothing for anybody to do. They just sit around and hope for the best. People need positive distractions to allow them to redirect their thoughts to good memories about themselves or good things about life.

The patients reported that activities are important for health and well-being as they can support the feeling of social connection, purpose and a sense of belonging in the world.

Positive conversations are needed in social spaces to spark positive convivial emotions for the patients.

One patient shared his experience of being ignored, which was perceived as demeaning and offensive. When he was asked about how he found the hospital place where he was staying. He responded: "Too many people here, they don't look either, one way or the other. And I don't like it." For him, not being acknowledged and not included in a conversation meant people didn't care or value him for being there. Social interactions are considered important because they not only provide social and cognitive stimulation to help maintain function, but conversation affords opportunities for expressions of personal identity and a sense of being accepted as a member of a group (Ryan, Bannister, & Anas, 2009). For the participants interviewed, it was evident that what was really important in their care experiences was to be treated as someone who mattered. Participants spoke of the importance of being accepted as a valued person in the world. One patient shared her thought in this way:

> An adjustment to being in the hospital is, you know, has an effect on the patient. It's very hard for me, not just physically but also emotionally. It takes time to adjust. Hopefully, I make a few friends through the process, so I don't feel so alone.

She went on to suggest a possible solution:

> I think the hospital should have volunteers to come in to do things with patients. Have a room where people can do what they're good at; paint or they like to do macramé. I don't like sitting in my room all the time, so often I'm out here looking for someone to talk to. I'm a friend of [a patient's name], yeah. I like her. We talk, we can relate to things that happen in the city. It's interesting to hear her point of view.

The importance of maintaining a sense of normalcy and continuity was evident in the narratives of the participants. Participants also insisted that patients need to have opportunities to engage in familiar activities, things that they always enjoy and like to do to maintain a sense of identity, express who they are and increase self-esteem.

Another patient suggested having a space to do programs of activities would be helpful because involvement in activities offered patients a way to express their emotional and psychological needs, which was not always straightforward for some patients:

Activities offer a way to express oneself. You might find out that some patients suppress their problems because they don't talk about it or not able to say it out. Rather than hold in some areas of difficulties that relate to their psychological problems and frustrations, through art or music, people would have a venue to express what they're feeling, what they would like to say.

Another patient added, "Yep, activities would help nurses to know what's more important to a person and why." This is a very insightful comment. More knowledge of a person's life permits the nurse to incorporating patient's value and belief into the planning and delivery of care.

5.4.4 A place of respecting patients' rights

A common theme voiced by the participants was the concern of social exclusion, and that patients should have their rights respected in the hospital. Participants spoke of how their rights to autonomy and control deserved respect. Having their viewpoints disregarded has led them to feel devalued and disrespected. In one case, a patient shared his experience of being restrained and how it made him feel sad and powerless.

I spend my day being tied up in this chair most of the time. They worry about I fall.

The first time I fell because I was not used to the kind of floor here in the hospital.

The second time my head was a little dizzy. After that, they tied me up. I am one guy

who can do nothing. (see below, Video 2: Tan)

Video 2: Tan

Feeling disempowered, this patient went on to explain that there was no hope for his

future. "The future is not for me, no one can help me", he remarked. In despair, he felt there

was nothing he could do as his perspective and wishes were overridden.

The hospital has least restraint policy, "Restraint may be initiated only when the

patient's behavior or actions could result in harm to self or others, and interventions that

maximize freedom have been attempted, and deemed unsuccessful. Whenever possible, the

patient and/or substitute decision maker must be involved in the decision-making process."

However, patients with dementia are often assumed as incapable of making care decisions so hospital staff would go to the family to seek opinion. Sometimes, family's perspective may not necessarily be the same as the patient's. In this case, the son did not want his father to take risk of falls and insisted on restraint use. The patient however had good insights into the risks of being restraint and would rather have the freedom to walk. He explained, "My body and legs are getting weaker because I could not exercise when I am being tied up".

Another patient expressed deep resentment about being denied of a pair of scissors. He felt strongly that his rights were being violated. He felt his voice was not heard or respected. Being a patient with a diagnosis of dementia constrained his ability to exercise citizenship rights. Patients were not allowed to have any scissors in the ward because staff believed it was too risky and patients might hurt themselves. In protest, "Tell the people who run the show that little things matter. It would be nice to be able to do things like having a small pair of scissors to cut things." This patient told the researcher that he likes cutting interesting newspaper clippings, which was something he had always enjoyed to do all his life.

Other issues related to respecting rights that were raised by patients included their experiences of social exclusion and discrimination on the unit. One patient Rob felt that due to changes in his cognitive function and the label of dementia, he was viewed and treated as a sub-class on the ward. He said, "I want to be one of you guys... I don't have the freedom. And I swear it's not right. I just can't fathom the system. They have the rights over me." He explained further: "Patients, who are not with it, just don't have the freedom. If you're not with the freedom, then we might as well be dead." In this case, the patient felt that a loss in

freedom means losing humanity. It was evident that how others treated him impacted how he

viewed himself. He called himself a loser:

> I feel like being a loser! Yeah. It's a shame, you know, you guys have your freedom,
>
> and you know what, I have none. My door isn't locked. But your doors are locked.
>
> You can go out to eat. The only thing I get is from the buggy (kitchen cart). The
>
> freedom that I get is a piece of shit. Yeah, it shouldn't be like that, you know. I have
>
> no right. I can't even go out there and buy anything, like the small things, like going
>
> to a coffee shop. It's terrible to live one-sided.

This patient gave a strong expression of his feeling of injustice and inequalities of power.

(see Video 3, Rob)

Video 3: Rob

Social inclusion was also pertinent to the participants. Being recognized as a full citizen meant not only having rights for themselves but also involved having responsibilities and opportunities to help others. One patient suggested,

> In the hospital, we are just a number, which does not mean much. Maybe it (working in the project) just makes you feel that you're contributing to people beside yourself. I think that we all have something in our mind that we should be able to say because we're not just only ourselves.

All participants expressed that they appreciated being asked about their experience and views of the hospital environment. They felt that contributing their opinions and suggestions to improve the environment meant they were being respected, and their views mattered. They were excited about the interviews, video making and spoke highly about the experience. A patient described making video stories of her experience as being fun and its process offered a positive distraction, which helped her to adjust to being in the hospital. Another patient said participated in the research work made her feel a useful member of the community and that she had done a good deed. At the same time, the participants clearly expressed that they expected that the new knowledge would become part of education and would inform actions in making improvements.

5.5   Discussion

The current study explored what and how specific environmental attributes might impact the care experiences of patients with dementia and what suggestions patients with dementia wished to see as improvements to the issues they identified. The analysis has shown that the relationships between environmental attributes and care experiences of patients with dementia are complex, with both the physical and social environment having significant

impacts on the care experience of the participants. Participants told insightful stories about their experiences and persuasively described what mattered to them in the care environment of the hospital.

A place of enabling independence was a theme that showed up early and consistently across data in interviews and observations. Congruent with the literature, qualities of lighting, color, and objects were identified by the participants as pertinent factors in the physical environment supporting and hindering their feeling of independence. The data have shown that some participants faced difficulties with sensory overstimulation. Also, visual impairment could significantly decrease the stress thresholds. For improvement, participants suggested using shelving and storage to reduce clutter. They also indicated that color might be used to reduce the risk of getting lost and make wayfinding easier. Fun and bright colors were preferred. Other studies have made similar recommendations (Chaudhury & Cooke, 2014; Karlin & Zeiss, 2006)

Sensory deprivation and boredom were also a common and paramount issue. Participants explained that a place that supports social interactions is essential for their well-being. This is similar to another study in an acute psychiatric unit that found older patients with dementia perceived social connection through having things to do with others was essential to maintain self-esteem and well-being (Hung et al., 2014). The participants in this study suggested helpful strategies included creating activity space and comfortable areas for conversations. These strategies are in line with the recommendations written by scholars in dementia design (Andrews, 2013; Calkins, 2013).

Because dementia can affect a person's memory and communication skills, which can lead to feelings of insecurity, it becomes more important for them to be in places that feel

emotionally safe. Participants explicated that a place of safety should afford opportunities to do familiar everyday activities such as going for walks. Overcrowded hallways and fast paced traffic led to apprehension, anxiety and psychological distress. This is similar to the findings of Edvardsson, Winblad, and Sandman (2008), who described feeling safe and cared for as central for older people in the hospital. They defined the therapeutic environment as constituted by the physical environment, the staff in the environment, as well as the general climate of care. Participants in this study mentioned that having nurses close by helped them feel safe. Other studies had reported similar results, that when nurses were right there, fear was decreased (Hung et al., 2014; Shattell, Hogan, & Thomas, 2005).

One of the important points that was clearly voiced by the patients in this study, though scarcely mentioned in the hospital environment literature, was the notion of respect for citizenship rights. The patient said that the restrictive environment not only meant a loss of freedom, but also a loss of their rights. Scholars in nursing and humanistic geography have written about the power of place in determining how a person may be with others (Casey, 2009; Liaschenko, Peden-McAlpine, & Andrews, 2011). Casey (2009) argued that a place has the power "to direct and stabilize us, to memorialize and identify us, to tell us who and what we are in terms of where we are" (p. xv). Patients in this study strongly voiced how they were affected by environmental constraints and structures imposed by the hospital place. Their capacity to perform in the hospital environment was influenced by how they were accommodated by the physical environment, clinical structures, and the social climate. This study offers preliminary first-person insight of these issues; future research should further investigate the potential for supporting patient involvement in environment design and

service development by using a rights-based approach (Kelly & Innes, 2013) and a participatory approach.

Interestingly, some of our results differ from those of Digby and Bloomer (2014), where the patients said the physical environment did not matter as long as the care was good, the noise was accepted as being normal, and the colors were not identified as being important. As a possible explanation, the setting they investigated was a new, modern, and purpose-built facility. In contrast, the setting of our study was of a traditional design having many challenging physical environmental features. In our study, the patients referred to the importance of colors, the clutter, and the need for comfortable seating places. Our findings, which referenced the importance of colors, clutter, and the need for comfortable seating places, are congruent with Bromley's (2012) suggestion that the aesthetics of the hospital environment are relevant to person-centered care since the design decisions "send substantive messages about hospital priorities, power relations and moral values" (p. 1065).

As a final point of discussion, as we have noted above, action researchers emphasize the agenda of emancipatory politics, which requires careful connections between the methodology and the concerns of the population (Bradbury, 2015). Patients are experts of the illness and care experience. To gain real learning for responsive change, researchers and leaders need to be committed to 'working with' patients in service evaluation and development. Our findings demonstrate that older patients with dementia have useful knowledge for contributing to service development. Instead of emphasizing problems, their narratives have provided practical solutions for improving the hospital services. Our data also illustrated that some of the concepts brought up as highly valued by people with dementia

were in clear conflict with what was considered as priorities by staff in the unit. What safety means to staff often trumps the perspective of patients.

5.6   Limitations

A limitation of this study is that patients who did not speak English were excluded. Another limitation is the fact that the investigation focused on public areas in the corridors. Future studies should include the bedroom and bathroom areas, which likely present other challenges. The views reported here were from the perspectives of patient participants. The views of frontline staff, physicians, and the organizational leaders will be reported in another paper. For a redesign of healthcare settings, main challenges for research are not only about identifying the needs of the patient group or the team of staff, but also negotiating an integration of all these needs into the already existed built environment. It requires a collaborative approach that involves all stakeholders and methodology that helps to address the different environmental domains and perspectives in a holistic way (Iedema et al., 2015).

5.7   Implications and Conclusions

This research provides empirical support to the importance of creating positive, supportive environments in hospitals by paying attention to the physical environment and social processes in the place. There are key implications for nursing practice, service development and future research. First, nurses working in acute care are well positioned to take an active and leading role in bringing patients' voices forward in everyday practice. Identifying the specific needs those patients with dementia experience in the hospital environment could inform practical strategies to provide more responsive care. Our results indicate that patient stories captured in videos permitted a rich and more nuanced description of patients' experiences than what is possible with quantitative measures. Thus, recording

video clips and viewing them in staff reflexive sessions has great potential to offer easily accessible advantages that are valuable for team learning in the local context. Future research should examine the challenges, risks and benefits of using videos for practice development.

Second, leaders who are responsible for service development and hospital design or redesign need to recognize the problems voiced by patients about the hospital environment. Participants in this study explained how environmental features restricted patients' agency to maintain health and well-being and they offered simple, practical and inexpensive solutions to improve the existing environment. Also, the physical features were only a part of the hospital environment which is a complex combination of multi-components, including nurses' availability, dementia knowledge, and care practice. Therefore, a multipronged approach is required to create an optimized care environment in acute care settings.

Third, future research is needed to better understand how to best support involvement of patients with dementia in making service improvement and respecting their rights in making healthcare decisions. While the findings of the small sample cannot be generalized, we can learn a great deal from their direct perspective and their involvement in the research. In this study, the technique of go-along interviews was used. I found the combined conversational interview with the use of environmental cues in the immediate context was effective in supporting patients with dementia to express their views. More research is needed to further investigate how go-along interviews may serve as a useful tool in dementia research in terms of meeting the need to examine how physical and social dimensions of the environment might interact and influence the person in organic ways.

To conclude, this study reveals how the hospital unit is a complex system with environmental components that interact to influence the experiences of patients with

dementia. For the patients with dementia who participated in this study, a good hospital environment needs to be a place enabling independence, a place of safety, a place that supports social interactions and a place of respect. The participants highlighted in particular the challenges they faced in disempowerment and a loss of citizenship rights. I call for political efforts in research and practice to seek a shift away of seeing patients with dementia as passive to more active citizens, who have rights to participate in research and projects aiming to re-design healthcare services that directly affect them.

Chapter 6: Using Video Reflexive Groups to develop Practice in a Hospital

In Chapter 5, I discuss patient engagement by describing the go-along interview results, which address the first part of the first research question on the engagement process. This provides the second part of the answer to the first research question. I report the staff experiences of participation in video reflexive groups.

6.1 Background

Person-centred care has been widely recognized as best practice in healthcare. Nevertheless, current research reveals a context where nurses in acute care are concerned about the feasibility and operationalization of person-centred care (Dahlke, Phinney, Hall, Rodney, & Baumbusch, 2014). Despite years of promoting person-centred care, recent reports in the media and literature repeatedly show evidence of poor care being provided to older people with dementia in acute hospitals (e.g., Dewing & Dijk, 2016; Francis, 2013). Critical debates and discussions have been held about whether or not the staff and clinicians in hospitals have adequate knowledge and skills to provide person-centred care for patients with dementia. Person-centred care involves acknowledging and honoring personhood of individuals using a holistic approach (Kitwood, 1993). Research indicates that the dominance of the biomedical culture, a lack of clarity about the meaning of person-centred care theory, time constraints, and inadequate resources are the main barriers to implementing person-centred care in acute hospitals (Venturato, Moyle, & Steel, 2011).

Because the clinical care for patients in acute hospitals involves complex processes and is highly contextual, the application of the person-centred care theory would require local adaptation and negotiation for the competing priorities. To make general principles

applicable and relevant, the workforce must find achievable ways to make change and improvements (Iedema et al., 2015). More attention should be paid to understanding how practitioners apply practical knowing to achieve person-centred care in particular complex and uncertain practice situations. Exploring how beliefs and practices of individuals and disciplinary groups can shape practice and influence patients' experiences requires a systemic perspective of the current state, and the possibilities and requirements for supporting the team in moving toward the future state. Open dialogue between team members can help develop a shared intelligence, with a shared ability to question the status quo, and a shared accountability for solving problems together. Research is needed to find useful ways to generate robust contextual knowledge that tells how practitioners may apply good practice principles and resources in particular situations replete with uncertainty and complexity. Senge (2013), a scholar in organizational development, argues that the hospitals that will be effective in the future will be those that discover how to tap into people's commitment and continuously build capacity to learn at all levels.

The engagement of patients is also important because their experiences and perspectives can help to ensure that research is relevant to their concerns and priorities. Although more attention is being paid to investigate the impacts of dementia on people affected by the disease, patients with dementia in hospitals have rarely been invited to participate in research or in the development of health services. Research has demonstrated that when people with dementia are involved in meaningful ways, they have important stories to tell about how dementia affects them and what could be done with care services and the environment to meet their needs (Dupuis et al., 2012; Phinney, Dahlke, & Purves, 2013). The purpose of this paper is to critically examine the perspectives of staff on how the use of

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videos of patient stories and reflexive groups can contribute to the development of person-centred care in a medical unit. This work was performed to address an action research question – What does the engagement process look like in the development of person-centred care?

6.2   Video Reflexive Groups

Using video reflexive groups in the acute setting is an innovative and evolving approach to engage frontline hospital staff in practice development. Iedema et al. (2015) describe video reflexive ethnography as a methodology that is informed by theory that people learn and change and are enabled to question and disrupt their habituated ways of being and acting. Video allows the researcher to capture the situated nature of human experience and actions in dynamic ways (Knoblauch, Tuma & Schnettler, 2011). Unlike photography, video enables recording and revealing processes that take place in time sequence, thus opening an opportunity to view the dynamic interactions between individuals and their environment. As Pink (2013) points out, as video allows visual and audio recordings of subtle and simultaneously complex proceedings in time and space, video ethnography is increasingly used in projects to empower people to make change.

Rather than being top-down, video reflexive groups focus on the insight and experiential knowledge of frontline staff and patients from the bottom up (Wyer et al., 2015). Lee (2009) used group reflection in an action research study to evaluate a nurse-led unit in a hospital. She found that group reflection was valuable for enabling the participation in the research process and practice development. In another study, Chater and Hughes (2012) highlighted that structured didactic training was insufficient for preparing hospital staff for dementia care; regular huddles in the unit were more accessible for the staff to learn together

and from each other. Huddles are short gatherings to enable team members to stay connected, review work, and make action plans.

Carroll, Iedema, and Kerridge (2008) used videos to study clinical communication among intensive care unit (ICU) clinicians and nurse managers in Australia. Using a hand-held digital camera, the researchers recorded eight, one-hour communication periods on four units. The researchers showed the video clips and facilitated "reflexive sessions". The video reflexive sessions involved showing clips of recorded video to a small group of clinicians with team reflection on the content of the video clips. Following the video playback and reflective process, professional communication and patient safety issues were identified and the participants implemented strategies to improve the communication and other processes. The participants emphasized the positive impact of reflecting on the video recordings. One participant commented, "I learned something and it only took 15 seconds!" As a result of the video feedback, the staff implemented changes in the patient "handoff," to improve communication and patient safety in transition.

More recently, Collier and Wyer (2015) used videos to involve patients in their patient safety research. Collier was concerned with end-of-life care while Wyer was focused on infection control. In both of their studies, patients could identify safety risks that the clinicians were unaware of, and shared strategies that contributed to the safety of their care. Although the use of videos in health research is not new, the involvement of patients with dementia staying in hospitals to make videos for staff learning is new.

6.3   Purpose

Given the lack of research involving patients with dementia and staff using video reflexive groups to make practice improvements in acute hospitals, the purpose of this study

is to examine how video and reflexive groups may serve as enablers to mobilize change and improve the care experience of patients with dementia in a medical unit. The specific goal is to answer two questions: Can bringing team members together to participate in videos reflexive groups contribute towards a collective commitment and team engagement for developing a culture of person-centred care? If so, how does it work?

6.4   Design

This study was part of a larger action research inquiry into the processes of change in physical and social environments in terms of person-centred care in a medical unit. Drawing on the orientations of action research (Bradbury, 2015) and appreciative inquiry (Bushe, 2011), the study focused on finding possible solutions and using the abilities and strengths of those involved. Visual techniques included making videos with patients with dementia and engaging the staff in video reflexive groups.

By taking actions to make environmental change in real-time, the aim of the research was not only to build theoretical knowledge but to also generate practical knowledge for practitioners to improve dementia care in the acute care setting. Moving away from the positivist paradigm that sees truth as discovered on the basis of value-neutral evidence, action researchers are committed to collaboratively working and engaging people to make sense of their experiences (Bradbury, 2015). Because human experiences and meanings are socially constructed, the open dialogue and sense-making in groups can be seen as a form of social and political action, influencing the future reality (Gergen & Gergen, 2012).

The traditional approach to problem-solving is focused on what is wrong, which can be energy-draining and overwhelming. A blaming approach can have a corrosive effect on relationships that otherwise would drive change (Grieten et al., 2017). Instead, I used the

appreciative inquiry approach, focusing on strengths and possibilities, and relying on relationships and communication to build a commitment for change. Bushe (2011) described appreciative inquiry as a way of thinking and doing that moves away from a hierarchical, expert-based, diagnostic model toward a more participatory and collaborative approach.

Reflexivity is a key component to enhance the quality and credibility of the research. Scholars using visual methods have emphasized the centrality of practicing reflexivity, which goes beyond describing the motives and experiences of the researchers. As Pink (2013) expounded, reflexivity does not simply explain the researcher's approach, but it reveals the processes by which the positioning of researcher and participants are constituted and through which knowledge is produced. For this study, the researchers have a shared commitment to respect the voice of patients and frontline practitioners in the setting. I believe that a rich practical knowledge and wisdom can be gained if staff participants and I pay careful attention to listening to what people say. One of the strongest emotional comments I heard was the disempowerment that patients with dementia experienced in the care setting. Through the video-recording process and the reflexive groups, a desire and vision was repeatedly expressed to create a socially inclusive and responsive care environment. I sought to understand not only the experiences the people described, but also how meanings might be made and re-made in the process. Recognizing that power differentials and relationships can have significant impacts on the participants, I took time to build rapport, invest energy, and use flexibility to accommodate and engage patients and staff/practitioners.

6.4.1   Data generation

I am clinical nurse specialist, and service improvement is part of my job role in the setting. Co-authors, Jenifer Tabamo and Doris Bohl are clinical nurse specialists and nurse

educators who work in the same hospital. The unit provides assessment and treatment to a general population of patients requiring medical and nursing care. Patients, in general, are admitted for symptoms of medical and/or mental illnesses such as fractures, pneumonia, heart and lung diseases, dementia, delirium, and depression. I conducted interviews and made videos with seven patients with different types of dementia while they were staying in the units. Three of the patients were men and the other four were women. Nurses who knew the patients well assisted the researchers with purposive patient recruitment. Patient participants were chosen to include different subtypes and stages of dementia, various physical functional abilities, and different types of social backgrounds.

The video-recording took place in public spaces such as corridors or in the conference room for the 31-bed medical ward. Each patient was interviewed with video-recording two or three times, generating a total of 210 minutes of video-recording. I used a handheld camera to video-record the environment following the patient participant's lead. The researcher asked the patient to show what they liked and disliked about the hospital environment. The production of go-along videos (Carpiano, 2009) offered a participant-driven, multi-sensory, and co-created approach to capture the complexities of the patients' experiences, while they were interacting with people and the hospital physical environment. The materials in the environment provided prompts and made storytelling easier for the patients with dementia. Occasionally, the researcher would ask prompting questions to allow embodied actions to be clarified or understood. The moving together took the interview content to concrete, practical, and experiential aspects. The video data showed the patients' bodily performance and verbal stories about how they navigated, experienced, and interacted with the social and physical environments in the medical unit.

Convenience sampling was used to invite staff participation to the reflexive focus groups. Participants were free to join one or more groups. A total of 50 staff, including nursing staff (30), physicians (15), and allied health workers (5) attended the groups. Physicians attended a separate group in one session because it was convenient and part of an established routine (monthly "lunch and learn"). Other participants attended groups that were held Wednesday afternoons on the unit. I held a total of nine reflexive groups that played patient videos. To ensure safe operations on the unit, staff members took turns participating in one of the two groups that were scheduled back to back. While some of the staff members attended the group, other team members on the unit could attend to the patients' needs.

Video reflexive sessions and focus groups took place in the conference rooms of the hospital. The video clips of five to ten minutes were projected onto a screen on the wall to allow the group to watch it together. After viewing the video clips, I facilitated a discussion, using open-ended questions and prompts. The group discussions were audio-recorded and transcribed verbatim. The purpose of the video reflexive groups was to provide staff participants with an opportunity to discuss and reflect on what could be learned from the patients' stories shown in the videos. Appreciative inquiry questions were used to facilitate the discussion, such as: What are your thoughts after hearing what this patient said about the care environment? What are your feelings and emotions? What could we learn from this? From your perspective, what should be done to make an improvement?

6.4.2 Analysis

The data analysis was guided by previous video-reflexive ethnographic research (Collier & Wyer, 2015). It involved multiple cycles and different groups of staff to view and review the issues multiple times in different ways. First, I video-recorded each patient and

offered the clips for patients to review. Three patient participants and one family member watched their videos but the other participants did not wish to review the videos. The acquired videos of the patients' stories were then processed, edited into clips, labeled, and transcribed in NVivo 11 software (QSR International). Subsequently, the videos and transcripts were brought to bi-weekly research meetings to be reviewed with other co-investigators on the research team. After a group discussion, a key video clip and a section of transcripts were selected to be presented to the staff in the reflexive groups. In the reflexive groups, staff participants watched the video clip together and I facilitated a discussion about the video content. The discussion was audio-recorded and transcribed verbatim. Based on the transcripts and the video data, I conducted coding, using both deductive and inductive methods. For the deductive coding, sensitizing concepts identified in the literature were used to identify patterns. At the same time, new codes were added inductively to signify specific narrative content. The analysis process involved an ongoing movement iteratively and systematically from parts to the whole, and from the whole to parts, to check for disparities and common patterns. Exemplars were then chosen to represent substantial themes. The analysis process was supported by continuous discussions with co-investigators and supervisors of the research committee through regular research meetings. Individual and group reflection took place at various times. Memos were written to record the reflections and ideas for possible subsequent steps, and the rationale for the decision-making. This process prompted the decision to add a focus group with physicians (who were unable to attend the groups in the afternoons) and recruiting patients who participated in the art workshops (to learn about changes in the patients' experiences).

6.4.3   Ethical considerations

This study received approval from the research ethics committees of the university and the local health authority. I followed ethics guidelines from the literature on dementia care (Dewing, 2007) and visual ethics (Puurveen, Cox, & Phinney, 2015). The process of obtaining consent was an ongoing process that included the initial written consent and ongoing verbal assent processes prior to and during the video-recording. The patient participants and their families also signed a separate data release form to give permission to use the video-recordings for purposes of education, reflexive group sessions, and practice development. Patient participants were given opportunities to review the video clips. Staff members who attended the reflexive groups signed written consent forms. The intention for using videos for academic and staff education purposes was explained in the consent process. All participants were given an option to waive their confidentiality and to be identified to acknowledge their contribution. For those who signed the waiver, their real names are used. For those who chose to remain anonymous, pseudonyms are used.

6.5   Results

The aim of this study was to examine the roles of the video reflexive groups in creating commitment and actions to develop person-centred care in the medical unit. Our analysis indicated that five inter-related themes were important for team engagement in the development of person-centred care; namely: (a) seeing through patients' eyes; (b) seeing normal strange and surprised; (c) seeing inside and between; (d) seeing with others inspires actions; and (e) seeing team support builds a safe culture for learning.
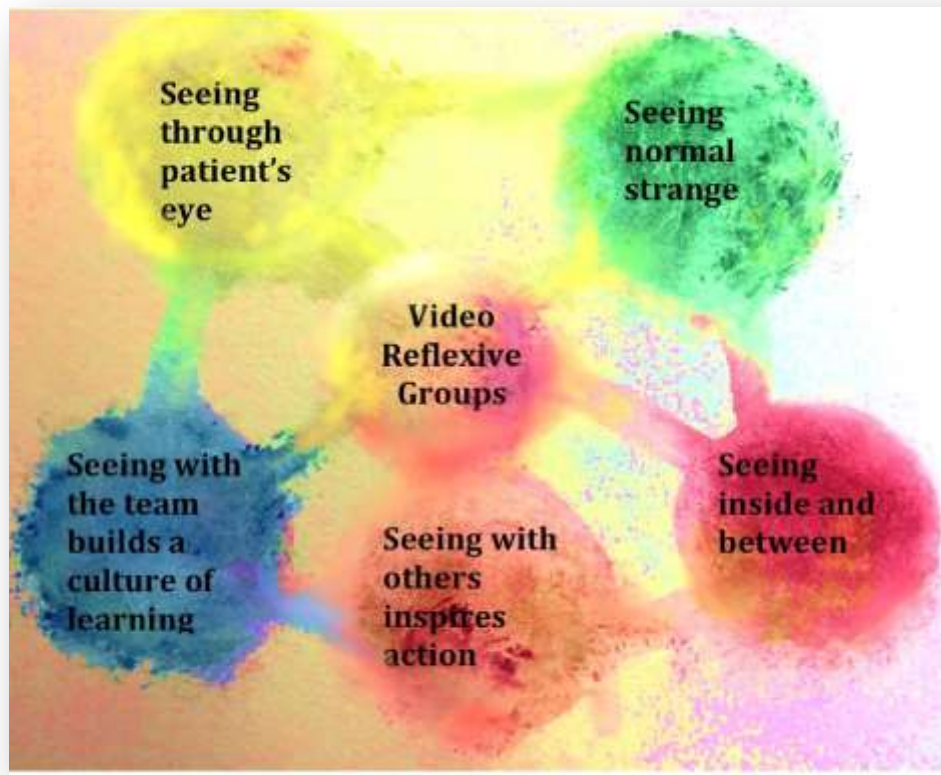
Figure 5. Seeing in five ways

6.5.1   Seeing through patients' eyes

Seeing through patients' eyes refers to the empathetic meanings that emerged in the context of new, emotionally shared, and embodied experiences. In the video viewing sessions, team members attended to how feelings were expressed by the many voices of the body. Attention was drawn to changes in the eye, constriction in the throat, sadness in the chest, and emotion in facial expression. The multiple voices of the body shown in videos enabled patients to tell their stories in a visceral way. Videos not only showed the patients' lived experiences in linguistic narratives but also by embodied expressions, and strong emotional feelings. One nurse, Sharnjit commented:

From the screen, wow, it feels like we're looking at the environment from the

patient's eyes, looking at the environment and walking in that video. It seems like

he's scared to go to the other end of the hallway because it's dark. I think I see the

problems, people rushing by, the noises, sounds of people screaming or crying and

the physical-ness of it. I had no idea that the hallways are too stimulating. Yeah, it is

too much.

The staff recognized that their professional perspective could be very different from

that of the patients. Another staff member, June also commented about the video showing the

perspective from the patient's side:

And really, when you see it in the video you realize, wow, when we come to work,

we see everything as useful tools for ourselves, and then when I see it from his eyes,

it is not for him this place. Yeah, the stuff is confusing and disabling. The hallways

are so crowded, it's really sterile and, you know, just kind of oppressive. The place is

more tailored to us, not the patients. Either for convenience or, you know, like

accessibility.

The video-recordings enabled the staff to appreciate the difficulties that patients with

dementia encountered. Examples of stigma, stereotyping, and misunderstanding were

brought up for discussion.

I felt like he was misunderstood so, I feel really bad for him. I mean, it's his feelings

so I don't really know, but I felt like he wanted just to talk and not be judged. He

looked intimidating and people misunderstood the appearance or, you know, there's a

stigma attached to his appearance (Mary, nurse).

A unit clerk, Georgia, who worked in a flow position shared her experience with this particular patient:

Because I'm not a regular on this floor so when I do come on, I listened to the report. I heard he's aggressive and he's rude, but then as soon as I go, I feel like nine out of ten times when they're supposed to be verbally aggressive or agitated, it's usually they're misunderstood. I think he just wanted to have somebody to talk with, had some fun. Not just focus on the task but see him as a person If somebody was coming at me and not explaining what they're doing and they're not even listening to what I'm saying or taking it wrong then, you know, I might get upset about it too.

In the reflexive sessions, staff in different disciplines shared what they learned from hearing the narratives and viewing the movements of the scene as it unfolded moment to moment. Their comments triggered deep empathetic reflections in the group. An occupational therapist, Carola said:

What I noticed in the video is there was nowhere for him to go. Everything is not for him. The bed in the hallway wasn't for him; the equipment's not there for him. It's like, I'm stuck here in this hallway on the thin line. Nothing, there is no place to sit and relax. Now I understand where the aggression comes from, you know? I would get angry if I was tied down or I wasn't allowed to do other things that other people can do. I can see he's frustrated, it makes me feel sad for him.

Other staff spontaneously echoed the impact of the video. After a few minutes of watching the clips, they realized that, "We can learn a lot actually from the patients themselves." Another nurse Bernard added, "It made us realize how messy our unit is, and the environment can be very distracting to our patients."

6.5.2   Seeing normal strange and surprised

After viewing the moving images on the screen, the staff who were participating in the video reflexive group remarked that they found new interpretations for the phenomenon that was taken-for-granted. The group sessions provided space and time to allow participants to generate new insights and give meaning to what otherwise might have gone unnoticed. Participants reported that the video-recordings threw an unexpected, surprised light on things. Many of the staff said they had not seen the significance of the issues being faced by the patients until they saw the video clips in the group. The videos gave them a view of the current state, and how patients were experiencing the care environment in situ. A nurse Maria explained it in this way:

> Looking at that video, I'm like, I can hear everything right now. Just watching it from here, feels like my body was there. But when I'm actually in the hallways, I don't seem to be bothered. Walking in the hallway, it feels normal to us. But, when we watch this video, I can see, oh my goodness, Oh my gosh, there's so many things, If I was him; I don't know what to think…This opens my eyes. It's good to reflect. We need to reflect more…

Another staff Ashley said:

> I had no idea of what it was like for him. There is nowhere to, he didn't say escape, but, to me, I would want to escape. Seeing those same floors and same walls and nowhere to go, wow! So, I am surprised with that kind of feeling.

By watching and discussing the patients' stories, and gaining a heightened sense of their experiential perspective, the videos drew attention to areas of habitual practice that had become taken-for-granted and unchallenged. A nurse, Glenda illustrated it by saying:

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Well, when I work I don't really realize that's how it feels. Even when people scream, we're like, oh that's just who they are. We got used to it and became too tolerant. It felt like normal.

A nursing aide, Nancy added:

I didn't realize the patients were lined up seating in front of the nursing station. It's so hard to converse sideways, so uncomfortable; some can't even turn their head. You're going to have neck ache talking like that.

For me what stood out is how we are caught up in the day-to-day task, like, how we do the hand over or in our report, calling someone as aggressive. She is hitting and kicking again. Now through our discussions, we are more aware of the bigger picture and we know more about the person. When we are working with a person, there's probably something that we can negotiate in here (Bernard, nurse).

One of the staff said, "I am so surprised to see the other side of Helen." Many staff in the group reacted in the same way. They were surprised to see Helen was calm and happy in the art workshop. Helen was labeled as 'elopement risk and physical aggressive'. Helen told a volunteer that she wanted to go home. She did not understand why people held her down and gave her injection. In her care plan, she was to be given injection when she approached the door. In the video, Helen was pleasant and social in the art workshop. She worked with a volunteer and co-created a painting of a bird. A staff commented, "Wow, she is kind of actually teaching, contributing and making the painting with the young volunteer together. This is amazing!" The video and reflexive group changed how the team saw Helen. After that, Helen's care plan was changed and she received no more injections for approaching the door.

6.5.3 Seeing inside and between

The reflexive groups served in a dialogic process that allowed for open exchanges of viewpoints and personal experiences. Through the participants' story-telling of their own experiences, hidden assumptions could surface for the group discussion. The participants said that they liked the reflexive sessions because they could hear everyone's different opinions. Nurses stated that the discussions allowed them to think about and compare their care approaches to some of the problems. Also, viewing the videos brought the staff to more affective dimensions of learning. A nurse Gracita stated:

> It's a bit emotional when you're talking about these things. It's quite private in some ways, your thoughts about these kinds of things, so when you can look into the thought process between for people you work with, I think you feel more connected and I think.

By comparing the exchanges of experience and stories, the team learned much more about patients as persons. A few nurses spoke about how easy it is to let assumptions and misconceptions affect how individuals might be perceived and approached. One of the very experienced nurses Sharanjit said,

> Dealing with patients with behaviors is challenging. There's no question about it. On the chart, you read the patient is aggressive plus plus last night but every day is a new learning experience, and we take, like, one thing at a time.

Everybody had different ideas and interpretations, and used different approaches. The operationalization of person-centred care requires a form of skilled sense-making to understand the meaning behind behavioral symptoms. In the groups, the staff from different disciplines continuously tried to combine what they knew as existing knowledge with new

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ideas. A nurse Shirley stated:

> When I was helping Terry, I was really scared. But, what I didn't realize was that he was scared as well. He is a big man and tall. Hearing from you guys, I see how you used humor to work with him.

By watching the videos and discussing the patients' stories, the participants gained a heightened sense of having things in common. Most of the staff expressed their group's shared feeling of team commitment. The video aroused a shared awareness of the complexity of clinical situations in which they were all involved. As the video somehow reframed and configured the background, staff members could see what was happening in new ways. They learned to appreciate the complexity of the clinical environment and the patients' experiences.

> When you know that we're all working to a similar goal, you feel more comfortable also talking to people. If you feel like you know them a little bit better, it's easier to ask them questions. You don't feel kind of intimidated to ask anything. Then it's better for everybody. Working as a team. I think it makes a huge difference. It's like a marriage. Or like a family. We are like brothers and sisters. We fight and we argue. Then we go and have fun together. When it comes down to it, we know we're there for each other (Isaac, nurse).

6.5.4   Seeing with others inspires actions

The video reflexive groups motivated affective learning and inspired actions, in three ways. First, the groups allowed the participants to think, see, and feel together as a group. Second, affective learning was important to cause changes in the ways of being. Participants

used emotive words like feeling sad for the patient, feeling annoyed, and feeling frustrated. Third, the new perspective created by shared interpretations changed the ways of thinking and being. Team members reported that the dialogue in the reflexive group made them observe themselves differently and they become more interested in the patients. One nurse coordinator Roselin remarked that the conversations made them:

> See the people, not as a dementia person, but the person as a whole. And the part about the stigma and how we think and talk about people, we really have to be sensitive to that.

The staff reflected that specific aspects of the environment mattered. A nursing aide Prem commented:

> We can't just ignore it. It has meanings for them. Now I feel I am more aware of the environmental factors. I am enlightened.

Physicians spoke about what they heard and viewed in the videos that resonated with the everyday narratives of their patients. One physician Maria commented:

> Every day one of my patients will say that they haven't slept all night because of the noise and screaming or calling out. I think that people were coming in, we set them up for failure in that environment.

Another physician Peter added:

> Walking down those halls, it's like walking down through the janitorial storage room. It's like things are falling on top of you, there're boxes falling over…

It was evident that the intense emotions generated energy for everyone to make changes. During the discussions, many offered possible solutions. A nursing aide spoke

about another hospital that organized their linens with shelves. Many spoke about the need for facilities and space for meaningful activities. Most agreed with the idea to expand volunteer services and provide dementia training for volunteers. A physician Michael suggested putting signage on the floor because,

> for a lot of older patients who are kyphotic and they're looking at the ground, it's hard for them to see the number of the room that they're at.

Although the video showed one patient's story at a time, the discussion often linked to individuals and the local unit, and to the larger patient group in the hospital. A physician John mentioned his concern about the unintended consequences of pooling resources to make improvements in one unit: "You've got to think about hundred patients or more that we have to serve a very similar need." This concern illuminates the inherent tension in the complex hospital system as creating positive change in one part may lead to negative impacts in another.

In some areas, the videos made issues visible and tangible. The video data enabled clinicians to appreciate and recognize the impact of some of their habitual behaviors. The following statement by a nurse Jane illustrates how the subtle interplay between a patient's movements and the environment could give the staff a new perspective about spatial perceptions:

> I see he flinched when someone all of the sudden shows up right at his face. That teaches me to slow down, not come up on somebody all of sudden or don't pass by them too fast.

Another staff Shalini followed the point:

> It was interesting to see how much you missed, like you are so busy doing work out there and you see a video like that and you're like, wow, what happened, what was that? Like, I didn't even notice, he was flinching when people were going right by him, you know? Or seeing why he did that and seeing that it was like, okay, that makes sense. I didn't see that when I was working but it's so obvious in the video.

Seeing often meant more than just looking. The group mentioned seeing to understand the phenomenon and the particular experience of the patient. Affective learning was not merely effective at inspiring commitment to action, but it acted as a springboard for furthering learning and problem solving. A nurse Cecilia commented:

> Now I learned that the environment, like the noise and everything is very important, how they make patients feel, affect their ability to think as well. It makes me pause to think again what cause my patient's behaviors. If you don't know what was happening to him, it's like wow, we have heard much negative stuff from rounds and reports. Blaming and labeling, "He's aggressive."

In response to that comment, another nurse Roselin said:

> I wish we could do more for not just the medical side of why people are here, but also for their other needs, their emotional needs. Maybe we should start thinking of if we could have little nooks that are more like you would have in your home with, you know, like a plant or a cozy seat, or something to read, or something to do rather than stare at the hospital stuff, just the equipment we need.

Another nurse Brenda said:

> Patients with dementia need a more homey kind of environment. Paintings and color
> would bring out the feelings of a more humanized place. A family portrait can help
> them feel at home as well. Well, I think it helps us too because if we know who the
> family is, through those pictures, it helps and us to connect with the patient and that
> helps the patient feel safe.

6.5.5   Seeing with team support builds a safe culture for learning

One important aspect of a safe culture for learning is trust. The group reflection gave
the staff an opportunity to discuss success and failures. The trust that was built among the
team members, where individuals knew they were not alone and they had others on the team
to support them, helped to build the culture of safe learning. None of the new knowledge
would likely take root unless the culture and priorities of the hospital system were aligned.
Inescapably, the adoption of new ways of working relies on a safe culture of learning. A few
participants reported that they felt safe and more confident to question some aspects of the
current state with their colleagues. Others said that the reflexive groups helped them build a
collective mindfulness for future practice. Georgia commented:

> We know that we have support and that the co-workers will help us out if something
> happens. So, we don't put anyone at risk or get hurt. We just share our ideas, like,
> okay, what should we do in similar situations, we can give suggestions for possible
> solutions or try different approaches. We just help each other to keep everyone safe. I
> think that you can care for patients better when you feel connected to the people
> you're working with.

The staff clearly explained that the reflexive groups gave the team an opportunity to build trust, which is essential for creating a climate of safety and openness. A nurse Bernard added:

> It's teamwork. With a team, you can kind of say, yeah we're on the same page and we all work together and for the same goals. It's kind of nice to see the problems in here as a team, work out solutions together. So we feel connected. It's like you know that when you do something new and creative, someone is there to support you. I think the positives come from everybody, and managerial that when we have the same attitude, we know we're supported.

The affective component of the "teamness" made it easier for team members to ask questions and share their knowledge. Thus, this kind of untapped team intelligence can become unlocked. The collective creativity could also be learned, practiced, developed, and cultivated in regular group reflections. If done well, a cultivated environment of safe learning can continuously grow and enlarge the capacity of team members and their sense of efficacy in dealing with unpredictable changes. When the team feels confident with experimenting with actions together, it becomes more resilient, effective, and productive.

6.6   Discussion

In this chapter, I discussed how video reflexive groups are effective as a new platform to engage the staff in making collective commitments for developing person-centred care. Through five ways of seeing, the team members were engaged in developing person-centred care by emotional motivations. The main role of the researchers in this project was not to teach participants how to improve their practice, but to help them see themselves and identify solutions that will work for them (Bradbury, 2015). Viewing the videos of patients' stories

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opened a space and encouraged the participants to talk about their practice and the actions of others. Learning was apparent in the reflexive groups as the participants learned to appreciate and consider the perspectives of patients, heightening their empathy and desire for actions to care for patients. In a recent study by Scerri, Innes, and Scerri (2016), the authors used appreciative inquiry workshops to implement person-centred care in two hospital wards. Nevertheless, instead of using patient stories told by patients firsthand, they asked the staff and families to narrate about the care being provided to persons with dementia in the hospital. Although I agree with the findings of Scerri et al. (2016) that learning from people's experiences can be a catalyst for innovation and development, I believe that learning from the patient's experience as told directly by the patient is even more powerful. This study has a unique contribution to the knowledge base by using the first-person voice of patients with dementia in video reflexive groups for learning and service development. Similar to the suggestion of Wyer et al. (2017), by presenting video clips of compelling patient stories, the team can be enabled to consider how they might tackle complex situations in new ways.

Domecq et al. (2014), in a systematic analysis, found patient engagement not only improves the research enrolment but also helps knowledge translation in the synthesis and mobilization of knowledge. In this study, despite diverse opinions among staff participants, they were deeply motivated to learn from the patient stories. The literature warns that engagement can become tokenistic if participants do not find that the engagement offers a meaningful benefit (Domecq et al., 2014). The staff in our groups reported that their participation in the reflexive groups enabled them to feel valued and heard. The discussions about psychologically safe environments covered issues that mattered to the patients. Similarly, Gordon, Ree, Ker and Cleland (2016) found that video reflexive groups in their

leadership study allowed clinicians to visualize practice in the moment and view the complexities from new angles.

The reflexive sessions offered a medium to solve problems that clinicians had been trying to solve on their own. For many team members, articulating a private experience was critical for making sense of what has been happening and what might be possible in the future. This finding was similar to those of Collier, Sorensen, and Iedema (2015) with regards to video feedback and patient safety. These authors called their video feedback sessions "reflexive groups" and they saw how the clinicians who viewed the videos on site, while the event was taking place, were central in producing new ways of understanding and enacting changes in practice. In the study, the clinicians remarked about their increased understanding of their patients' background, the clinical situation, and the relevant social context that could offer insight into creative solutions. Team reflection and sense-making with colleagues was helpful to the team, because the exercise of co-interpretation moved implicit knowledge to explicit knowledge or from the unintelligible to the intelligible. Individual and private ideas could be moved out of hiding and into the open, explicitly shared space in co-creating practical and sharable knowledge.

Traditional hospital systems can keep people in a perpetual and reactive mode of firefighting. Often, practitioners are busy dealing with crises every day, which undermines their time and energy to build a proactive culture of learning. Taking the time to reflect enables people to identify the opportunities for change that are aligned with what they do. By highlighting common goals and practical possibilities that emerge from existing local environments, the reflexive group gave participants more confidence to recognize and mobilize their own change potential. Because people understand the need to underpin

changes and because they are part of the shared voice, they can more quickly implement change into practice. In this study, I presented an innovative approach using videos of patient stories and staff reflexive groups to enable a novel kind of sense making. The results suggest that the videos produce team reflexivity, and new insights and a collective commitment to operationalize person-centred care. The staff mentioned that social bonding, relationships, team dialogues, regular reflections on practice, and shared visions are important for developing a person-centred care culture.

Open dialogue is required to balance the rights and needs of patients with dementia to deal with difficult challenges such as those in clinical situations. Learning from the experiences of patients can help clinicians see their practice in a new light and challenge the deep-seated assumptions that may not be obvious. The hidden social stigma of dementia and cultural ideology needs to be brought to the surface for reflection.

Like Cook's (2003) research, the videos in this study were useful for involving people with dementia in the research. The participants indicated the benefits, including their positive feelings in contributing to research and service development. Luttrell (2010) pointed out: "The use of videos allows those who might otherwise go unnoticed to be recognized and afforded voice in the body politic" (p. 233). In our study, the videos and reflexive groups had practical implications for sensitizing practice, challenging practice, and inspiring actions to change practice. The screening of the video stories told by patients encouraged the participants' critical reflection and allowed the participants to reflect on their experiences in ways that are not possible with traditional didactic education. By drawing attention to the patients' stories, this research helps to shift the attitude and conversations away from the dominant discourse that portrays patients with dementia as being problems. Instead, the

patients with dementia were viewed and treated as valuable resources of practical knowledge within the local context. In real-life practical reality, relying only on decontextualized evidence and best practice guidelines is often insufficient. Person-centred care theory does not provide a recipe for solving the "how to" in a given situation. Instead of expecting linear causes and effects, good dementia care requires full attention to the whole person, with regards to the biological, psychological, and social domains. Involving the staff at the point of care to tap into the broader collective creativity and intelligence is vital for linking knowledge to practice.

Finally, we know that the common barriers in participatory research are the time constraints and lack of trust. As Covey (2006) said, changes happen at the speed of trust. In our experience, spending a small amount of time and energy to build team capacity and trust can have lasting benefits in a culture of safe learning. As demonstrated by van Bogaret et al. (2017), interdisciplinary collaboration and communications are key predictors of burnout and work engagement; I argue for using a video reflexive group to improve the effectiveness of the teamwork.

The study has two limitations. First, I included participants who were frontline staff and physicians, but did not include top organizational leaders. The attitudes of the top organizational leaders can significantly influence the practice and culture of the whole organization. Whether or not the top leaders consider patients with cognitive impairment as experts, able to contribute to the knowledge for service development, would shape the social discourse and local cultural practice. Sponsorship and attention from the highest level of the organization could be the key to encouraging and sustaining new practice. Visionary leaders should enable teams to reach their full potential and should invest resources to support

regular reflexive groups with videos of patient stories (Shanafelt & Noseworthy, 2017). In a recent study of developing dementia champion community practice, researchers found that formal organizational endorsement and recognition are needed to achieve larger and lasting impacts (Mayrhofer, Goodman, & Smeeton, 2016). Hospitals need to be able to identify ways to engage and equip the workforce with the capacity to innovate. The second limitation of this study is that I did not video-record any of the care interactions in the medical unit. Future research is needed to explore the benefits and challenges of video-recording care interactions involving patients with dementia in hospital and using the videos for learning and practice development.

6.7   Summary

This chapter presented staff views about using visual methods for team engagement that were derived from an action research study to co-develop person-centred care in a medical unit. I found that videos and reflexive groups are powerful means for the staff to recognize the need to develop person-centred care. Positive energy to drive change was generated in open dialogues following the review of videos. I also described the benefits and barriers to using the patients' stories, and practical reasons for paying attention to the marginalized, seldom-heard group that can offer solutions to problems. Our analysis indicated five, inter-related themes ("seeing in five ways") that were important for team engagement in developing person-centred care: (1) seeing through patients' eyes; (2) seeing normal strange and surprised; (3) seeing inside and between; (4) seeing with others inspires actions; and (5) seeing with the team builds a culture of safe learning.

The insights and experience of the staff and physicians can shed light on how best to engage interdisciplinary teams in hospitals to make practice change and service

improvements. Our study suggests that regular team reflection and building a culture of open

dialogue and team learning are pivotal in the process. Videos and reflexive groups have a

great potential for supporting staff engagement in co-developing person-centred care in the

acute setting.

Chapter 7: Bridging Research and Practice: Building the TEAM

This chapter discusses research impact. It provides the answer to the second research question: Did the research project have any impact on supporting positive change in the medical unit? The discussion focuses on the research experiences of staff, their accounts on how the research influenced their practice development in the unit. Also, based on the dataset, I propose a conceptual tool, Team Engagement Action Making (TEAM), as a heuristic guide, to support others to do similar work in practice development. I hope this tool will stimulate interest and invite conversations in doing research in practice to advance knowledge and practice development. This tool is a not fixed but evolving heuristic. Further development and refinement will improve it's utility.

7.1   Introduction

Nurses and other staff working in hospitals are facing numerous challenges and opportunities, because of the growing demand for acute care for people with dementia. The development of knowledge and skills is urgently needed to improve hospital dementia care. Involving clinicians to develop knowledge in practice may serve as a useful strategy for producing and using knowledge, and developing dementia care practice. In literature on dementia care, the gap between the rhetoric on person-centred care and the practice realities is apparent. In recent years, most of the research has described dementia care in hospitals as task-focused, with "little to celebrate about" (Dewing & Dijk, 2016). Academic researchers and practitioners in clinical settings are challenged to find feasible ways to operationalize person-centred care to bridge this gap. Despite the concerns of the supporting staff to build capacity, few studies have looked in detail at the role of research in practice development.

Little evidence is available on how to best engage staff to inquire practice and at the same time motivate them to make positive change.

Research knowledge is often not translated into practice. One factor that contributes to the gap can be: practitioners are not involved to influence knowledge production. Researchers in applied fields like nursing are interested in understanding the processes that enable the adoption of research findings and the sustained use of knowledge for practice development. A lack of success has occurred in making changes in practice by adopting research knowledge on the care of older adults (Draper, Low, Withall, Vickland, & Ward, 2009). New methods are needed to mobilize change. Traditional efforts that were focused on problems led to discouragement and blaming, which often took away the energy for change (Cooperrider, 1986). More attention must be paid to the social process of meaning-making and human interactions (Bushe, 2011). The need exists to move away from the deficit thinking approach to an approach of appreciation and openness to possibilities (Reed, 2008). Some authors have reported that nurses feel burnt out, and they have highlighted that job satisfaction is strongly correlated with collaboration with members of a multi-disciplinary team, having autonomy and a sense of purpose (van Bogaert et al., 2017; Zangaro & Soeken, 2007). Bringing people together to co-inquire and reflect on what is, and what could be, with regards to workplace issues is often neglected due to the pressures of day-to-day work. Those who work at the point-of-care should be empowered and given opportunities to contribute to solutions for their practice.

7.2 Appreciative Inquiry

Appreciative inquiry is a relatively new and innovative approach in research and practice development for dementia care, being more widely known as a method in

organizational development in the business world (Bushe, 2011). Adopting a social

constructionist view, and based on the principles of mutual respect and positive dialogue,

appreciative inquiry has been reported to be useful in supporting change in nursing practice

(Reed, 2008; Scerri, Innes, & Scerri, 2016). Cooperrider (1986) developed appreciative

inquiry as a research method in his doctoral studies at Case Western Reserve University,

while investigating successes in the Cleveland Clinic. Appreciative inquiry is a way to

explore, discover possibilities, and transform systems and teams in the organization toward a

shared image of their positive potential (Cooperrider & Whitney, 2001). Appreciative inquiry

shifts the focus from problems to possibilities, while using the strengths of the team as

leverage to make change. Tapping into the core motivations for change by using a positive

inquiry approach can unlock the collective intelligence and build team creativity (Hung et al.,

2016). Adopting a collaborative approach, appreciative inquiry works from the grass roots

up. The positive mindset helps to build collaboration to support the co-creation of future

practice.

Aligned with critical social theory, appreciative inquiry supports an egalitarian form

of open dialogue. Challenging the dominant hierarchical power relation, appreciative inquiry

empowers practitioners to become change agents and create positive disruption to innovate

practice. People at the point of care are encouraged to engage in project collaboratively to

improve the work situation and move toward shared visions for a better future (Trajkovski et

al., 2015). Instead of implementing prescribed interventions, appreciative inquiry works by

engaging staff in conversations and building new shared narratives, resulting in contextual

changes to the power dynamics (Bushe, 2011). By bringing staff together to co-create

change, it not only creates channels for socially reinforcing change, but it also increases the

potential for a larger impact at scale (Willis et al., 2016). Unlike the punitive style of performance management, appreciative inquiry supports learning and reflection in a positive and collaborative climate (Curtis et al., 2017; Dewar & Nolan, 2013).

Appreciative inquiry has been criticized for focusing on the positive experiences but failing to address the negative problems (Reason & Bradbury, 2008). It is important to point out that using a 'positive approach' does not mean ignoring problems (Bushe, 2011). A positive approach appreciates the negative experience and reframes it constructively into an opportunity to make improvement. Instead of remaining stuck in a dual between positive and negative, Bushe (2012) argued that the power of appreciative inquiry as a change method depends on "allowing for ongoing generative conversation between practitioners and researchers" (p. 17). For Bushe (2013), asking generative questions is crucial to transformation. Generative questions refer to the inquiry that challenges the status quo, so that new ideas and thinking "become compelling images... generat[ing] change because people like the new options in front of them and want to use them" (p. 12). Ludemea and Fry (2008) describe appreciative inquiry as:

> … much more than just a wish to be positive. It is a robust process of inquiry and anticipatory learning that enables participants in social systems to shape the world they most want by building new knowledge, spurring inventiveness, creating energy, and enhancing cooperative capacity (p. 280).

7.3   Bridging Research and Practice

Appreciative inquiry blends research and practice as it fosters the interdependent relationship between reflection and action (Reed, 2008). Appreciative inquiry has been successfully used as a research methodology to facilitate practice change in a number of

studies. For example, Dewar and Nolan (2013) used appreciative inquiry to develop the 7Cs of caring conversations to support integrating relationship-centred care in practice. Kavanagh et al. (2010) also used appreciative inquiry in their research about pain management. Appreciative inquiry has been reported as a catalyst for practice change, emphasizing collaboration in research and practice development (Watkins, Dewar, & Kennedy, 2016).

Despite the evidence showing promise for using appreciative inquiry to bridge research and practice, researchers have not systematically analyzed how appreciative inquiry might play out as a strategy for mobilizing change in practice in the acute hospital setting (Watkins et al., 2016). As Greenhalgh (2017) emphasizes, one crucial aspect of knowledge translation is the extent to which staff in the organization are supported to come together to hear about new ideas, discuss their interpretations (what does this mean for me?) and reframe the mental models of what is possible. Similar to the work of Dewar and Nolan (2013), this study combined appreciative inquiry with action research to focus on developing practice change while generating data for theory building. The three core appreciative inquiry principles guided the research process were: positive and collaboration approach and critical reflective practice (Cooperrider & Whitney, 2001). The specific purpose of this paper is to discuss and theorize how research may help to engage staff in practice development. The specific research question I asked: Did the research project have any impact on supporting positive change in the medical unit?

7.4   Setting and Participants

One 31-bed medical unit in a large urban hospital was purposively selected for the study. Before the project, patients with dementia, families, and staff in all disciplines voiced their concerns and needs for improvement in the local physical environment and for staff

knowledge in dementia care. To create a more appropriate hospital environment for patients with dementia, I worked with a team of interdisciplinary staff to plan and make changes in the physical and social environments. I used convenience sampling in this study to recruit leaders and staff participants (nursing and allied health practitioners) from the medical unit so that anyone working in the unit, including full-time or part-time staff, would have an opportunity to participate. The staff attended one or more focus groups during protected work time at 2:30-3:30 pm in a conference room at the unit. Participants included a total of 50 staff members (nursing staff, allied health practitioners, unit leaders, and physicians) and 1 senior administrator in hospital management.

7.5   Methods

7.5.1   Data Generation

Qualitative methods, including focus groups (n=31), interviews (n=1), and observations (20 hours) were used to generate data for the research. I facilitated focus group sessions every second Wednesday afternoon during 2016. All conversations in the focus groups were audio-recorded and transcribed verbatim. I also conducted 20 hours of observations on weekdays and weekends and made ethnographic field notes of my observations, using a small notebook (Emerson, Fretz, & Shaw, 2011). One 30-minute exit interview was conducted with a senior hospital administrator at the administration office in November 2016 before she left the hospital and the project.

Action research involves three phases: phase 1 (Engage and Look) to examine the baseline and explore the physical and social environments before actions; phase 2 (Think and Act) as action learning that took place through changes in the environments; and phase 3 (Evaluate and Modify) to evaluate what worked and what did not work. Table 3

shows examples of the questions asked in the three phases of the action research cycles. Although the cycles seem linear, they often went back and forth and overlapped in some cases. In the first month of the focus groups, I asked: what possibilities do you see? The intention was to engage staff to share their imaginations and visions. More energy and effort was invested in action and reflection after the initial period. For example, a series of peer teaching videos were recorded to allow for creative and dynamic engagement, and to enrich the fun and team memories of the experiences.

Table 3. Inquiry questions

Research Phases	Goals	Question Examples
Phase 1 (Engage and Look)	Vision, goals and team agreement, current state, and priority needs	What possibilities do you see for this research? What are we doing well and what are the opportunities? What might our future look like?
Phase 2 (Think and Act)	Video reflexive group; co-design of actions, reflections and evaluation of actions taken	What do you like to have in the staff education? What can we do better to generate more excitement for shared learning?
Phase 3 (Evaluate and Modify)	Reflection on experiences of participation in research and practice development, changes; identify lessons learned and future plan	What is your experience in participating in the research? What do you need to sustain the development?

In the videos, the staff articulated their interpretations, meanings, and experiences of person-centred care. In the summer, I also wanted to reinvigorate the participants and keep them interested in contributing to the project. I held an educational fun fair to bring a large number of staff together to celebrate learning. More than 50 staff (some of them were from other units) attended the fun fair. A few focus groups were also conducted to revisit the question of what people wanted to become and their vision of dementia care. In phase 3, the

focus group questions asked about staff experiences in the research and practice development.

7.5.2 Data Analysis

The data analysis involved a participative approach based on appreciative inquiry strategies (Reed, 2008). The appreciative inquiry literature provided sensitizing concepts (e.g., co-inquiry and build capacity) for deductive coding, while an inductive approach was also used to allow concepts to emerge from the data (e.g., make it easy and fun). I held bi-weekly data analysis meetings with two practitioners (Jenifier Tabamo and Doris Bohl) to go through data, make sense of possible meanings, and identify the key themes. Highlights and summaries were brought back to the team members of the studied unit for group discussion. In the group discussion, I facilitated conversations to decide whether or not individual team members had other interpretations or new key points. From the results of the analysis, we then went on to develop action activities. For example, our group analysis revealed that not knowing the patient's biography and individual routine was a significant gap in practice. I suggested to use a tool, *This is Me* from the Alzheimer Society. We discussed the need to simplify the tool and make it fit the format of the existing care plan. Then we worked together to customize the document (see Figure 9).

Following each action activity, we gathered as a group to analyze the method and effects. Regular meetings were held with three academic supervisors to discuss data generation and the analysis. We worked diligently to ensure that the analysis was systematic. Rigorous thinking was embedded in a full range of activities, including seeking and validating information with participants, checking parts and the whole dataset in the analysis, and working together with various groups for interpretation/meaning-making of the findings.

I kept a research journal to record personal reflections, and bi-weekly research meetings with co-investigators were held to keep up-to-date with the data analysis and to challenge individual assumptions.

7.5.3 Ethical Considerations

The university ethics board and the hospital approved the research. The inclusive approach in action research can raise questions about ownership and responsibility for the research (Reed, 2008). In this study, co-ownership of the project was encouraged with practitioners being involved to drive sustaining efforts for actions in practice development. I assumed full responsibility for the entire research project. The level of involvement for each researcher was kept flexible. For instance, Jenifer Tabamo took notes at each focus group while Doris Bohl helped to bring staff into the focus groups. Jenifer Tabamo and Doris Bohl also co-authored this paper and have co-presented the project at conferences for knowledge dissemination. Other participants led action activities such as peer teaching and video production. Careful attention was paid to ensure that ethical principles of mutual respect and fairness were applied. All participants signed written informed consent forms. All participants were also given an option to waive their confidentiality and be identified to acknowledge their contribution. For those who signed the waiver, their real names are used. For those who chose to remain anonymous, pseudonyms are used.

7.6 Findings

I identified three key interactive themes that captured the dynamics of the engagement process for change and the experience of staff in research for practice development. The themes were: Appreciating the power of co-inquiry; Building team capacity; and Continuous development. Embedded in the three interactive steps, there are ten

enablers as key components of the processes: 1) insist on inclusion; 2) focus on what works; 3) embrace complexity; 4) connect the heart; 5) connect the head; 6) adapt to needs; 7) build a big tent; 8) make it easy; 9) real-time testing; and 10) keep pace. Figure 6 shows the framework, the three interactive steps and ten enablers. These components are interlinked, reinforcing each other to enable change in practice development.
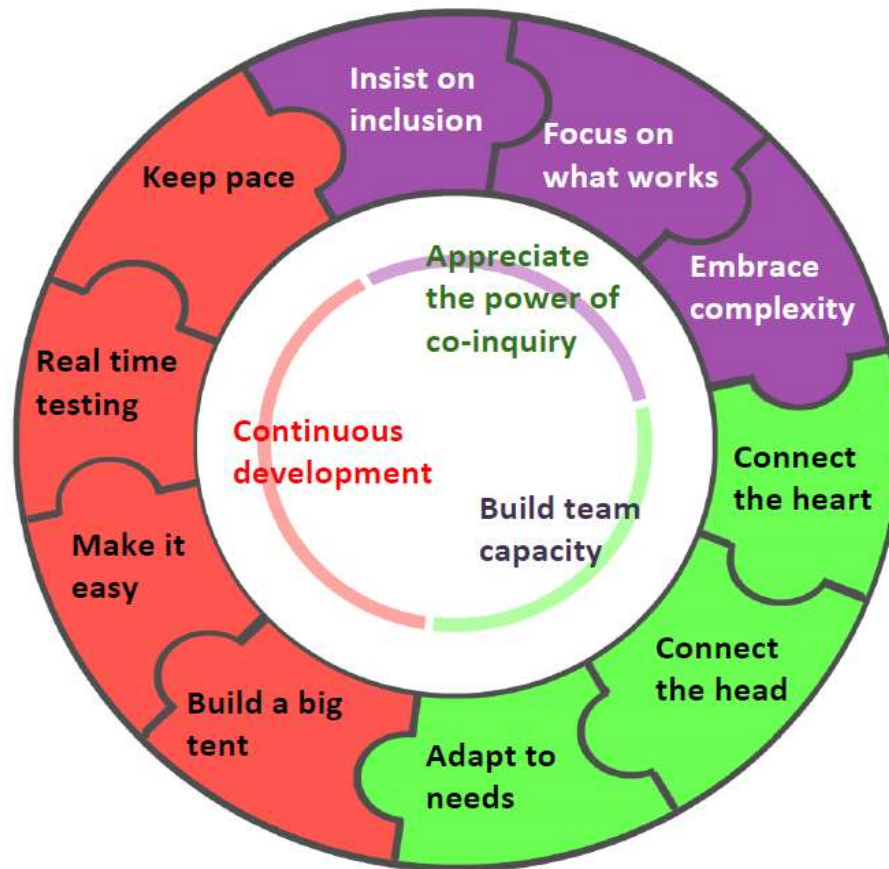
Figure 6. Team Engagement Action Making (TEAM)

7.6.1 Appreciating the Power of Co-Inquiry

The power of appreciative inquiry demands a shift in mindset from fixing people to appreciating the team as social capital with immense capabilities to evolve. The positive co-inquiry is not only a process to find shared solutions but it is also a way to deepen shared

understanding and clarify collective visions. In this research, the team developed a habit of holding biweekly meetings for exploring their ways of thinking and for interpreting the meaning of particular issues or events. Through the shared process of reflection, the practitioners' personal, professional, and cultural beliefs were open to review. The participants' curiosity about this novel approach of co-inquiring in research and their recognition of the need to co-create good practices for staff and patients motivated their participation in the research. Three components were embedded in this first theme: 1) insist on inclusion, 2) focus on what works, and 3) embrace complexity.

7.6.1.1 Insist on inclusion

Inclusion was highly valued throughout the project. Staff members in all disciplines were invited to be part of the change in design and process of inquiry. The level of involvement was flexible, ranging from being informed to being a co-researcher. To enact the participatory approach, a strong emphasis was on involving staff in all disciplines to co-develop educational activities to enhance learning in the unit. During the first few months, I taught a dementia care training program, Gentle Persuasive Approaches (GPA) to stimulate a passion for developing person-centred care (Speziale, Black, Coatsworth-Puspoky, Ross, & O'Regan, 2009). The GPA was a one-day workshop that had been successfully adopted in the older adult mental health program in the hospital. Staff members heard about the GPA program from colleagues and requested the educational program. After six months, most of the staff in the medicine unit (nursing and staff members in other disciplines) had attended training. The GPA program generated a tremendous amount of positive energy. A staff member reflected on why GPA was successful in this unit:

Inclusion. It engaged everyone. You know I have worked in the environment that you process certain knowledge, but others do not know about it. Even if it is called the best practice, it won't be adopted. The fact that this project has involved all the staff so people feel that they have ownership. They are contributing at every step in the way; people feel involved and heard - I think a sense of ownership is the key (Darryl, physiotherapist).

This comment illustrates that an engaged team is more set up for practice change because of the sense of ownership about their practice. The term ownership can be interpreted as an individual feeling of being part of the research, with an opportunity to shape change through expressing their opinions and priorities. Ownership can also imply a joint accountability, which is closely linked to sustainability. As Reed (2005) suggested, doing research in practice may make knowledge development a part of practice, where knowledge may continuously develop through experiential learning. Learning about available research evidence and practice tools also provides a new perspective for thinking about and approaching challenges. It was like adding a new tool to the toolbox:

Coming to the research group, the staff gets updated easily. Some of the research knowledge we heard is conducted outside in other countries and it is current. If you've been working for quite some time in the same location, like here, it's really refreshing to see oh, there is a new way to do this, there a new way to do that. It helps me to think, oh, Let me try the new trick next time to see it helps (Isaac, nurse).

Other team members explained how inquiring together and hearing stories of others can inspire commitment and evoke team emotion, which then becomes a source of commitment. The team leaders were impressed by how keen the participants were:

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It's not a struggle to get people to come. People want to come. I see people are
committed when they come to the meeting. Everyone speaks and contributes (Brenda,
patient care coordinator).

Another care staff (Nancy) echoed, "We are not shy anymore." The staff members
appreciated the social process, and were confident and enthusiastic about exchanging the
know-how among themselves in the group sessions:

I knew I always love coming to these meetings. I appreciate it because it makes me
better for our unit. You get to learn new things from each other.

Working closely with sponsors and well-connected local leaders was also
instrumental for the success of the project. Two co-investigators, Jenifer Tabamo and Doris
Bohl are well-established experts: they seem to know everyone and they are well respected.
Jenifer Tabamo played a key role in promoting the research work to a larger community as
she works closely with physicians, leaders, and practitioners in the hospital. Doris Bohl was
helpful in getting local staff involved, as she was able to co-ordinate people and clinical
routines to enable action activities to take place.

7.6.1.2 Focus on what works

Inquiring about what is useful and effective in solving real practice issues and what
people highly value can lead to new transformative results. Transformation requires shifting
to a new norm, where people adopt new ways of thinking and new identities (Willis et al.,
2016). Staff members considered the research to be contextually relevant and effective
because it provided them with practical and applicable knowledge. What were considered to
be useful knowledge within the team in the medical unit were interventions that were

perceived to be feasible, achievable, and acceptable in the clinical field. It was often referred

to as a new way of thinking and working:

> When we encounter a difficult situation, someone would say, have you tried the GPA
>
> (Gentle Persuasive Approaches)? For example, when a patient is upset, if you leave
>
> him alone, try to go back later. Then it is okay. It's called - Stop and Go. I think we
>
> have the GPA into people's mind now. The GPA is bubbling. It feels good that our
>
> staff can use the new knowledge. It is excellent (Nancy, care worker).

In this account, we can see how new storylines were created as people found positive

experiences and talked about them. The storylines made up a new narrative through telling

and re-telling, which allowed building a new prevailing culture to replace the old. Stories can

invoke inspiration and motivation. The stories people told to each other every day create a

new social reality so what people choose to say can have an influence on the outcomes

(Frank, 2010).

The participants also clarified that what works is not necessarily a fixed recipe.

Practical knowing requires creating a situated ability to apply knowledge in the moment. This

underscores the contextual aspects of the 'what' and 'how' in a particular clinical situation. A

nurse explained it well:

> The new technique does not always work because each patient is different and each
>
> situation is different. Sometimes, you got to improvise a bit. The idea is good and
>
> useful, but sometimes you got to tweak it. Like, the validation technique helps you
>
> think about what the person may need emotionally. But what I'd say to the patient to
>
> validate emotion may be different depending on the situation (Sharanjit, nurse).

Wanting to contribute to improve patient care was a reason for people to participate in the inquiry. Telling successful stories in focus group sessions made team members feel proud about themselves, which fostered a team spirit.

Playing with possibilities, the team found new effective ways to transform their work. For example, in the Comfort Mitts project, nurses and other staff knitted brightly colored mitts for patients with dementia, which reduced the use of restraints (Figures 7 and 8). Several staff who were involved in the project were invited to speak about the project at different venues (e.g., at a regional conference held by the Patient Safety and Quality Council). The Comfort Mitt project created a "buzz" with more people talking about it and more related actions. The buzz (a kind of open and self-organizing promotion caused by excitement in the social group) quickly fostered a sense of legitimacy. For example, when nurses were challenged by the infection control, they stood up and argued for the benefits of comfort mitts. They discussed about what needed to be taken into account in terms of ensuring safety (e.g., single patient use, washing, what kind of yarn should be used or not used). Patients said they liked the bright colors and the creativity shown in the mitts.

Figure 7. Comfort mitt made by Lillian

Figure 8. Comfort mitt made by a volunteer

7.6.1.3 Embrace complexity

Having staff participants ensured that the research would be focused on real concerns and clinical situations so that new knowledge generated would meet local acceptance and utility. The participants were asked what it felt like to be involved in the research project, to support improvements in the care of patients with dementia. Staff members responded that they appreciated embracing the people's complex experiences in the inquiry. One nurse elaborated:

> This project concentrated on people. The nurses are the ones that see the people. They're the ones who are going to tell you how people are acting. It's not so categorized. Like, I am in a research program. I get a survey every three months, and it's all the same questions. "How do you feel? Satisfied? Very satisfied?" It doesn't capture much about my experience. People aren't just numbers. People experiences are much more complex (John, nurse).

In the focus group, the staff spoke at length about how each situation was unique and complex. The learning by doing was a constantly adjusting process in the application of knowledge. Storytelling was a good way to give a more realistic view of how the contextual factors influence a given situation. By combining the stories from the team members, a deeper level of understanding could be reached. For example, the staff spoke about working with patients with dementia as it tends to require a deliberate effort to slow down, pause, and reflect, and a willingness to look beneath the surface to explore one's own assumptions and the assumptions of others. A nurse explained:

> If you don't try to look behind the behavior and try to explore what might be going on with the patient, you can easily fall into the quick solution, he is agitated, and he needs a PRN or restraint. Also what works for one patient may not work for the other, so it can be tricky for new staff who are not used to this population. I heard my friends in other units saying they feel scared to work with people with dementia. You got to know remembering the techniques are not good enough; knowing how to use them appropriately in different situations to produce the effect is the key (Sheila, nurse).

Developing practical knowledge requires a high level of artistry. The staff appreciated the power of co-inquiry and learning different perspectives from each other. A nurse leader said, "Before [the research] we didn't know what to do, everybody was just kind of floundering." The learning together helped staff gained practical knowledge and confidence. Often, it was the personal stories of what happened to a nurse or what a physiotherapist heard from the patient that broadened the picture of clinical problems.

Patients came in with crisis-like situations and acute medical needs. Nurses have to figure out a way to get the medical procedures done because the patient can be very sick. The patient may be in sepsis and blood must be drawn. They kept trying and knew what works. Such knowledge in a particular clinical situation is useful and should be shared (Toni, Physiotherapist).

Team learning in the focus groups often led to a change in attitude, and challenges to the assumptions of what might be possible. Based on resources from the Alzheimer Society, the team implemented projects such as 'This is Me' and 'My Daily Care Needs'. 'This is Me' (Figure 9) is a communication tool that enables families and patients to tell the clinical team important details about their care. Small details, like "what might upset me" and "what comforts me," provide invaluable knowledge to promote safety and quality of care. The one-page format for 'This is Me' was developed to match the individualized care plan, called 'My Daily Care Needs'.

This is

Me

Family,
Please use this leaflet to help us
get to know your loved one

Vancouver
Coastal**Health**

This is **Me**

My name is: _____

I prefer to be called: _____

Vancouver
Coastal**Health**

I would like you know the following information about me:

How I like you to communicate with me	My Preferences on Eating and Drinking, Medication
Things that may upset me	What makes me feel better
My Rest and Sleep	My Mobility
My Hygiene Needs (e.g., bathing & toileting routines, what helps)	How I like to spend my time, People & Things important in my life

Staying in the hospital can be difficult. This form provides an opportunity for the staff to see your loved one as a unique person who is part of a larger network of relationships. This is not a medical document and should be completed by individuals who know the person well. Date: _____ Completed by: _____ Relationship: _____

Figure 9. This is Me

7.6.2   Building Team Capacity

Team capacity building is a collective social process of developing skills in the affective and cognitive domains. This is not about just providing education to the staff. It requires connecting the heart and the head of people in the team to learn together and to turn knowledge into collective action. Environmental and cultural factors influence how well the team can adapt, learn, problem-solve, and take up innovations. Relationship building in a well-connected and supported climate is a key to building team capacity.

7.6.2.1 Connect the heart

The participants needed to feel connected emotionally and they wanted to contribute to having an excellent team. Instead of being passive recipients of change, the staff wanted feel themselves as active contributors:

> When you get into this kind of discussion, and then you know that it will be implemented, you would want to join in. We are doing this because we want to be able to create a better environment and give better care for the patients. It's like a game changer when people see that there's something happ*ening from this* (Isaac, nurse).

Adopting an appreciative orientation was vital for connecting the hearts of people. Story-sharing was a preferred and effective way to engage the staff emotionally and the narratives that were produced in the group sessions and action projects (e.g., peer-teaching videos and the fun fair) allowed people to feel that they belonged and were helping to foster a team spirit. The following comment illustrates the complexity of dementia care, which needs support, safety, candor, connection, and trust:

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We each have a different view about something, when a person has an issue, is not sure what to do, or not comfortable with something, I think it's helpful that we come together and talk about it. I think this is very "teamness". These meetings drive a lot of team spirit, most of all, of course it is the contribution part, and we are all in this together. When I look at our unit isn't for everyone. Not everyone wants and can work here, right? For those of us here, we have a sense of unity. I sense that. Coming to these meetings, we can share our opinions. Sheila may have her opinion, I may have mine, hearing each other's, we can come together (Georgina, unit clerk).

Tapping into the core motivation of the staff members who wanted to contribute to the team, seemed to provide an impetus for change. The participatory approach helped the team connect their hearts through building trust, dialoguing, and teamwork. The group also used their previous experiences for reflection. Their comments brought home the point that practice development projects require meaningful engagement. When asked to comment on their experience, a common response was:

We feel that we're being valued and heard. I appreciated the fact that we asked for education in the beginning and we got it. Compared to other projects, sometimes you don't feel like you're being heard. They'd come, the projects have already been finished, then they present to you and say, this is what you're going to do, let *us know if you have any feedback* (Cathy, Occupational Therapist).

7.6.2.2 Connect the head

The goal of connecting the head was to grow the collective intelligence by learning together. It requires team members to listen to each other, instead of talking at each other. It also requires the team to let go of the comfort and power associated with "knowing." The

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openness helped to create an environment that allowed critical thinking and growth in team capacity.

> I think there is the risk that people could make judgments about each other based on what they say. But I think in our group, we are comfortable with each other, and we know why we are doing this. It is all about for the patients. That's what *we are here for* (Georgia, unit clerk).

Because the point-of-care practitioners adopt new knowledge, it makes sense to engage them in finding solutions. People tend to support what they help to create.

> Any paradigm shift involves you actively using your brain. When you are asked to problem solve and contribute, you are taking a risk. You don't know how others may react to your idea. But when you actually took the risk in providing opinion, the project takes roots better with people being together. As each is contributing a part to the whole, the whole team adopts the project, carrying out the new behaviors (Darryl, physiotherapist).

Working together on the team challenges each member on their guiding assumptions that they may have formed for their current perspective or way of thinking. In team dialogue, an opening can be created with new ideas and interpretations. For example, a staff member Sharnjit spoke about how she discovered a lot about a patient who seemed to be intimidating and physically aggressive.

> When I was helping this patient, I was really scared. Because he is tall, and he's got some built up, right. He said he knows Kung Fu, and I think someone said he is a black belt in martial arts. Once he said to me, that's bullshit, I am going to hit you. I

felt he is just an aggressive man. Now hearing from you guys, I come to understand that he is scared, too. It seems like he is just human, who sometimes need to laugh a bit.

The staff spoke about the work they do as requiring constant learning and support from each other. "Every day is a learning experience; you got to listen to those who say no, why this is not going to work, ask them what will make it work." The staff maintained that their work must tap into the accumulated wisdom of the whole team.

7.6.2.3 Adapt to local needs

Responding to the needs voiced by practitioners was important. The staff said that their most pressing concern was safety. In the beginning, many staff members reported feeling scared and under-equipped in terms of their knowledge and skills in dementia care. They had a strong desire to find practical tools that would support safe care. Through a series of dementia education activities, the staff increasingly became aware of many effective ways for interacting with patients with dementia. A range of tools was developed to make the application of research easy. These included short videos, pocket cards, a brochure, and a game (see Appendix F and G for the description of the tools).

The videos magnified the energy available for change work. In the videos, the staff spoke about what person-centred care meant for them. They also spoke about how some of the practical tools can be used to support their work.

It is very refreshing to see the videos. I am very impressed. I haven't seen anything like this before. It is so exciting to see the people in the video, who are actually the staff on the unit, and it was filmed right on the unit, our own place. I have watched them so many times, again and again (Bernard, nurse).

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Many benefits were found from customizing education to meet the needs of the local context. Involving members of the team to do peer teaching was motivating and fun for the team. One nurse, John said, "watching the videos are so much more fun than reading a paper." Another staff appreciated that the videos gave short and relevant messages, which made them more effective for learning. "It was kind of a really bite-size thing – right to the point. Here you go, one message at a time, pretty cool." The staff pointed out that any tool that was made in the unit felt like it was "'home built'. Like it gives you a feeling of, it's ours. If it's done in other places, there is a hesitant in between, I don't know. When it is made in our unit, by our team, our colleagues, we can trust it." The customization not only provided more relevant information and credibility, but it gave a sense of status, agency, and identity. Although staff reported earlier that learning new knowledge from outside is important, they clearly indicated that tailoring knowledge to make it fit to use in their particular context is imperative.

Another important point that was brought up by the educator was the specific need in the acute context:

> I think that dementia care in an acute care setting is unique. We need to treat the patients with acute medical needs and to address the dementia needs that might impact the hospitalization and patient outcomes. We get a lot of information with acute care issues. But, sometimes the dementia piece is not in the forefront. I think this research project is helping us to realize the person behind the acute medical issues, right? I think the research is beneficial because we face different challenges in the hospital, compared to those in residential care. It is important to attend to their

urgent medical needs, and at the same time be creative in meeting the emotional and psychological needs of dementia (Doris, educator).

7.6.3   Continuous Development

Practice development is a continuous process of improvement towards a culture of person-centred care. The goal of the project was to help the team develop knowledge and skills so the team would be engaged and empowered to come up with innovative ideas for change. In considering the continuous nature of development, four factors emerged as being substantial for enabling the process of becoming. The four key factors are: 1) building a big tent; 2) making it easy and fun; 3) real-time testing; and 4) keep pace.

7.6.3.1 Building a big tent

Looking back, we were able to bring staff together into ongoing interactions and foster a space for learning conversations to take place at the micro-level of a unit. Our shared goals to improve dementia care aligned with the vision of the staff and leaders at multiple levels. To achieve ongoing development and sustainability, participants emphasized the connection between the unit and the larger context outside the unit – building a bigger tent. Building a big tent is about collaborating with other units and communities, and combining strengths for making larger and long-lasting impacts. To do this, we need to zoom out and look at the big picture, and align the project with other initiatives and wider responsibilities of the organization. We worked with staff and leaders of other teams in some of the actions (e.g., inviting them into the education, and sharing the tools we developed) to create more opportunities for extending the significance and achieving a larger impact. The program director Leighanne said:

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We need to know what seems to be working and then how can we mimic that in other areas. I honestly believe that patients with dementia are living in our surgical units because they also need surgeries. So, I am interested in how we take the learning from this work and put them into practice widely. How do we do that across the board?

As previously mentioned, changing practice is a social process, and shared ownership is needed to support mutuality and to drive the actions. In the project, people used terms like: our unit, our patients, our future, etc. In addition, many staff members spoke about wanting to use their learning to help others beyond the unit. The physicians, in particular, emphasized that many patients with dementia were on other units and they expected this project to spread the practice development to other units across the system:

> Instead of investing all resources into one child, what are you doing with the rest of the family? We have to think about keeping our eyes on the prize of the success, and you need to think about 100 patients or more, that we have to serve a *very similar need in other units* (John, physician).

7.6.3.2 Making it easy and fun

Focus group sessions were booked every second Wednesday afternoon, and the meetings were integrated into existing routines to build a regular process. We learned that the biweekly meetings made the project easier to manage since short frequent meetings provided opportunities for the team to contribute ideas on what otherwise might be forgotten or simply in need of some adjustment. Meeting at the same place at the same time was effective for building a habit. We also kept the action activities at a small scale, so they would be easy to execute. The benefit of seeing the success in early phases helped to build high motivation and collective commitment. For example, we used gamification (Hanus & Fox, 2015) in one of

the learning events. We turned the rehabilitation gym on the unit into a vibrant environment for learning about dementia through games. The event was a big success, because it was fun, challenging, and competitive. Over 50 staff members attended the event. In the fun fair event, the room was filled with laughter, excitement, and mutual learning (Figures 10 and 11). Fun was a significant driving force behind the educational activities, which was important to the group from the very beginning. A nurse commented about the fun fair:

> I like this because it challenges me. I learn something new each time when I can't answer a question. It's so nice to see everyone is having so much fun. We should *have more of this kind of event* (Bernard, nurse).

Figure 10. Staff Virna got the answer in the Double F dementia education

Figure 11. Angie gained points in the Double F dementia education

7.6.3.3 Real-time testing

An important lesson from the project was to build in time to share stories about how

the work was actually having an impact on the lives of patients and staff. After hearing

compelling stories about how something had worked, the staff applied their knowledge to

quickly test it, which accelerated the learning. For example, an occupational therapist, Carola

was excited to share her successful experience of using a hand grab release technique that she

learned in GPA. Positive stories like Carola's helped to engage other team members to use or

to test out the new knowledge. For clinicians in the applied world, the usefulness of some

new knowledge can be validated in action. Knowledge is not something to be separated from

practice. One nurse commented that "this project is beneficial because it can take effect right

away." Another staff member echoed the idea and was surprised that simple activities like painting classes could have significant impact on some patients:

> Yeah, like it surprises us too. I know some of the patients really look forward to it and are excited to do it. They look forward to it because it feels good to paint with a group, the social atmosphere; they get to do something they really enjoyed.

The staff spoke about the need for learned knowledge to be applied to see how it works, and under which conditions it could work better. A lot of experimentation with the specifics had to take place right away in real-time and quick corrections or adjustments were occasionally needed to make new knowledge work. For example, we tried painting at the bedside at first but quickly learned that the patients actually wanted the social processes – painting and chatting in a group. In our study, we noticed that new knowledge gained significance through its utility, and whether or not people found it useful in routine practice. Because the inquiry and actions were joined in the project, the uptake of knowledge was quick. Adaptations and modifications could also happen at the same time, which made practice changes efficient and effective.

7.6.3.4 Keep pace

Although the one-year project demonstrated positive changes in the social environment, we have not achieved outcomes in physical environment changes. When the program director left her position, we were less certain that the promises would materialize. The delay in the physical renovations also caused some doubts among the staff. At the end of the study, the participants wanted to have a longer study for more evaluations of the outcome and sustainability. A strong desire was expressed to keep pace with the momentum of action activities and evaluate long-term impacts. Some individuals asked if we would continue the

research. Others asked for ongoing facilitation and support. One staff member commented about his concerns for the physical renovations:

> There are a lot of dreams that we put on the paper. Pardon me for being a cynic. But I have worked in the system for 25 years. Until you see the dream realized in concrete form, having that space to work in, and work with that space for a while, then you potentially see ways to make that space more malleable and changing it. So having a three to five year follow-up of a project that I think it involves with tweaking things that we consider as good and making them better (Darryl, Physiotherapist).

Despite the participants facing frustrations and uncertainties about the delay of physical renovation, we took time to celebrate successes to keep up the positive appreciative spirit and continued moving forward. A summary report for the action activities was created in a sketch (Figure 12), which showed our accomplishments. Social connection, a shared positive memory, and collective joy helped to fuel our desire for continuous development. In terms of resources for future research, what the staff wanted the most was to have protected time to work on the change project.

Figure 12. Summary of research activities

7.7   Discussion and Implications

The purpose of the study is to discuss and theorize how researchers may engage practitioners to co-develop knowledge and practice. Appreciative inquiry principles were used to assist the development of the conceptual tool Team Engagement Action Making (TEAM). The tool is grounded in the empirical evidence of participants' experiences and it offers a useful heuristic means for detailing the dynamic relationships of how complex factors interplay in a practice context. A very practical use of the tool is for stakeholders' discussion – as talking points to stimulate more reflection on what needs to be considered to facilitate change in practice. More research is needed to explore the heuristic value and users' experiences with this proposed tool. Further investigation is required to evaluate and refine the tool in order to gain a fuller understanding of how the steps and enablers interact in change processes. Also, academic researchers and practitioners can use this common tool to work together in order to advance knowledge production and practice development.

The conceptual tool is intended to be used flexibly and creatively, rather than as a rigid set of steps. Person-centred care is not just a matter of following prescribed procedural steps but complex practices that require collective learning, teamwork, and continuous development. It is important to point out that the ten enablers in the TEAM are not intended to be a checklist for tick off without understanding the theoretical basis of why that particular factor is key to the engagement process and how each fit with all the other factors. Also, the steps are not linear and rigid. Substantial interactions and overlapping can occur between the steps and the enabling factors. While they tend to reinforce each other, each piece plays a distinct role in the development of person-centred care. The TEAM is a tool to prompt and guide thinking and discussion. The use of the guide requires a systematic and rigorous

approach to practice development, supported and valued by people at all levels in the hospital. Top leaders must see engaging staff in knowledge production and application as one of their strategic priorities. As the program director Leighanne said at the beginning of the project, "people who know the problems are the staff themselves so they give me the good ideas to solve problems, and my job is to support them to operationalize it."

The results of this study lend support to the research by West, Lyubovnikova, Eckert and Denis (2014) that leadership is vitally important in nurturing and sustaining a culture of high-quality care. Similarly, Ham (2014) argued that regulatory rules and top-down targets are inadequate levers for bringing about responsive changes to meet complex challenges in the current environment of healthcare. In a recent dissertation, Mitchell (2014) describes a problem-focused culture can lead to less accountability and more blame, whereas a positive solution–focused culture elicits accountability. People avoid responsibility when they are afraid to be blamed for a problem.

A collaborative and positive inquiry approach

This study affirms that appreciative inquiry was useful because it allowed for a study and practice changes to happen in real-time (concurrently). The small-scale testing and trials allowed for rapid responses for validation and adjustment. Instead of using coercion, people were willing to come forward to co-design action and co-create better practice (Curtis et al., 2017). In this research, staff members provided input and decided among themselves about what their dementia education should look like. They had a lot to say about their practice and what they wanted to change. Their involvement gave a sense of liberation and empowerment, which led them to have an increased awareness about possible alternatives and a range of

action learning. Instead of feeling being judged for wrong-doing, the staff members developed a safe space for themselves to critically reflect and make change in their practice.

As Bushe (2013) states, "momentum and sustainable change require positive affect and social bonding" (p. 2). Our results suggest that asking positive questions, such as 'what would you like to see more of?' or 'what is possible?' engages people more effectively. People wanted something new and something positive. The inquiry touched people's hearts. Talking about and listening to the stories connected people and built team relationships. Building trust and collaborative relationship helped to lessen the impact of potential problems of power dynamics in the organizational hierarchy. As mentioned previously, generative questions are necessary to make transformative change, and generative questions engage people to imagine new images and ideas, to challenge what is. Evidence in the literature noted that disengaged staff who often viewed change as yet another program to be tolerated until superseded (Willis, 2016).

Research for practice

Greenhalgh (2017) points out that there is a substantial mismatch between what researchers produce and what clinicians want and need in practice. Ioannidis (2016) asked - why most clinical research is not useful and found clinical research does not always address real practice problem and rarely reflect patient priorities. Similarly, participants in this research clearly emphasized that knowledge they value is something that helps them solve real problems (clinical utility) and improve patient care (patient benefit). Bradbury (2015) explicates that the way research translates into practice is by actionable knowledge where the inquiry is connected to the needs of those involved. Seeking knowledge is part and parcel of everyday practice in nursing and other disciplines of healthcare. I argue knowledge

production should be more integrated in clinical practice. Knowledge is linked with action. This research contributes to the field of practice development in dementia care by problematizing the notion of knowledge as a separate thing from practice in the field, generated by researchers and used by practitioners.

In the study, the staff spoke about wanting to contribute, and their hopes and wishes to do good for the patients. The common meanings, shared purpose, and collective direction opened a new path for continuous development. As Gergen (2014) indicated, research should be linked to create what is to become, a future-making performance. Facilitating frontline engagement is integral to practice development, but it is far from being easy to achieve. The process entails constantly attuning to what is happening in the context, with listening, adjusting, and responding to local needs. We propose that the dynamic, three-step framework presented in this paper could support researchers in working alongside practitioners in the development of practice. This research applying appreciative inquiry core values, collaboration and positive inquiry helped staff feel valued and empowered. Future research should further explore the usefulness of the framework for engagement in similar care contexts.

Our findings are congruent with a study conducted by McCance et al. (2013) with ten nursing teams in a large UK organization. They found the staff engagement in their program was characterized by positive ways of working, building relationships and maintaining momentum. They were also challenged by conflicting priorities, limited staffing and resources and organizational restructuring in acute care. As McCormack et al. (2015) wrote, "Establishing a person-centred culture requires a sustained commitment to practice developments, service improvements, and ways of working that embrace continuous

feedback, reflection, and engagement methods that enable all voices to be heard" (p. 3).

Barriers and challenges to engage staff in practice development

Three main barriers and challenges to practice development in this study were the heavy workload, change in leadership and competing priorities. Our results suggest that the necessary conditions for staff engagement in practice development are giving staff protected time, resources and autonomy to innovate, take risk, and apply new and improved ways of delivering care. Having a stable and supportive leadership is more important than ever before as the current climate of healthcare is constantly changing and having a focus on budget and cost efficiency. Change is difficult to sustain if leaders do not stay long enough in position to provide ongoing support. As Holmes et al. (2016) noted, changes in leadership can be extremely disruptive and can take years to adjust to. The resource constraints and high leadership turnover that hospitals face represent a significant risk to sustain organizational support for continuous development (Rodney et al., 2013). Top leaders and managers must value the development of workforce and focus on the quality of care despite the financial challenges. Constantly asking staff to do more with less to meet budget targets can demotivate staff and lead to disengagement and burnout. Without careful consideration of the contextual factors, it is easy to jump on the accusatory bandwagon and blame staff for the deficiency of dementia care in hospitals. As Rodney (2011) wrote, "we need to know more about how to make progress towards better ethical practice and policy, and political in the sense that we need to know more about how to foster stronger democratic dialogue within care-delivery and policy structure" (p.9). The acknowledgment of competing (often conflicting) priorities in organizational context highlights the pressing need to develop practice using collaborative and positive approaches to achieve a better end - quality of care.

Much more future research needs to be done to learn how to work with conflicting priorities in the constantly changing healthcare context.

The TEAM guide has relevance to sustaining change in an organization. Sustainability – achieving the ability to keep a continuous engagement in practice development is not an easy task. Sustainability is considered as when new ways of working and improved outcomes become the habit and norm; not only has the practice changed, but the thinking and working behind are fundamentally shifted, and the processes in systems are transformed as well (Bushe, 2011). Data in the UK has shown that higher scores in staff engagement are associated with the better rating of patient experience, and lower mortality rates (Greenhalgh, 2017). Central to sustainability are aligning project goals with organizational vision, investing resources for staff to have ongoing team reflection and shared learning. Future research should further explore how continuous engagement may contribute to the development of a person-centred culture that embraces team growth and resilience. There is also a need to identify ways to not only engage staff but also leaders as full sponsors. The findings of this study help to focus attention on how people in a team of a medical unit were brought together to make practice development. What remains to be explored is - how organizations can scale up significant and systems-wide change.

7.8   Summary

In this paper, we discussed how a research informed by appreciative inquiry can help to engage practitioners to generate knowledge from practice to improve practice. Practice development is a continuous process for transforming individuals and the team. Without the engagement of the practitioners (knowledge users), the intention of research and relevance of research outcomes could easily become misaligned. To bridge the gap between research and

practice, strategic support must be provided to create an environment to engage practitioners in knowledge production. The TEAM guide was built based on the analysis of the research in a medical unit, informed by appreciative inquiry. We hope that the TEAM guide will stimulate interest and help promote practitioner engagement for taking action and changing the culture in the acute setting with regards to person-centred care. Further testing of the guide through empirical research is necessary to establish its utility in research and practice.

Chapter 8: Critical Reflection

> Human beings love change… People don't resist change. They resist being changed – always have and always will – until when? It's that special moment where being changed is transformed into being charged, being commissioned, being called authentically into co-creation.

> ~ David Cooperrider (1986)

Figure 13. Lillian and a patient participant in a go-along interview

In this chapter, I present a critical reflection article, published in International Practice Development Journal. This article is a critical reflection on my doctoral research. Two key critical reflective questions I asked myself: "What assumptions did I hold about practice development?" And "Why is involving practitioners to co-create change important?"

In a recent hospital conference, a senior leader suggested that simply by working more and harder, we might not able to keep up with growing demands and rapid changes in healthcare systems. She invited the staff members in the audience to help find innovative solutions to new models of care. The senior leader believed that there is a web of strengths, potential, and talents in the organization. I felt her faith and trust in the staff of the organization was encouraging. In the same conference, I led a workshop, called "Embracing Change." In that workshop, I used examples in my doctoral research, which involved a team of staff in the hospital to take actions to innovate and improve dementia care. While the goal of the workshop was to inspire the audience making practice changes, I found myself deeply inspired by the comments from the audience. One person said, "I think there are lots of great opportunities to make a difference in patients' care if we are willing to find creative ways to do things differently." The comments largely emphasized the great potential of paying attention to the human side of our work, engaging others to make change together for compassionate care – the 'how'. The audiences' comments included: (a) "small actions can make a big difference in patients' experiences"; (b) "change can start with anyone of us in the hospital"; (c) "there is no need to wait for large-scale structural change".

This article is a critical reflection on my doctoral research, inspired by the comments from the conference audience. Two key critical reflective questions I asked myself: "What assumptions did I hold about practice development?" And "Why is involving practitioners to co-create change important?" Based on my reflection on the above two questions, I describe the value of using Appreciative Inquiry to research practice development in this paper. The insights and lessons learned from involving a team of practitioners in research are discussed.

8.1   What Assumptions did I hold about Practice Development?

My biggest assumption about practice development was investigating practice problems might affect morale and generate resistance to change. From my clinical experience, people often feel they are being judged and blamed for practice problems, so they resist change. However, I was surprised and impressed by the positive response to change in the large conference audience. The optimism generated by the first few comments uplifted the positive energy in the room. It began with a comment by a nurse – "I think there are lots of great opportunities to make a difference in patients' care if we are willing to find creative ways to do things differently." Then, another nurse said, "small actions can make a big difference in patients' experiences." After that, there were discussions about hope and desires, which ignited more positive emotions about making change together. The compelling images of what people wanted more of in their practices were highly motivating. The openness in the air of the conference room bolstered a sense of commitment and social cohesion. I was convinced that people do not resist change if they invested themselves into the co-creation of change. The audience comments led me to reflect further on how the core principles of Appreciative Inquiry may offer useful support for people to make change.

Scholars (e.g., Grieten et al., 2017) have described that Appreciative Inquiry as a strength-based change holds potential to offer positive effects to practice development. Philosophically, drawing from social constructionism, Appreciative Inquiry proposes that organizations are meaning-making systems, in which social reality is continuously created and re-created through social interaction (Gergen, 2014). As a researcher, I have choices to make about what I ask, and how I ask the question. If I ask what works, I can get people to participate in the construction of a reality of potential. Indeed, the inquiry process can be

considered as a form of action, a way of engaging with others in creating practice development (Reed, 2008). Appreciative Inquiry views practitioners as active agents who can influence their future reality through the way they talk and think about it (Bushe, 2011). As Reed (2010) described, the core principles of Appreciative Inquiry include positive engagement, collaboration and critical reflective practice. In the following, I illustrate how positive engagement, collaboration and critical reflective practice provided useful guidance for my research.

My doctoral research was an action research in dementia care, aimed to find practical solutions to innovate and improve the physical and social environments in a medical unit. Practice development was an important goal of the study. As noted by Dewing, McCormack, and Titchen (2014), practice development involves "the engagement brought about by teams developing their knowledge and skills and changing the culture and organization of care'. (p. 9). As Appreciative Inquiry stresses on bringing people together to innovate, improve and develop practice through shared learning in the practice setting, I invited a team of inter-disciplinary practitioners to attend biweekly group sessions to reflect on practices and co-develop changes towards person-centred care. As Schön (1987) noted, much of the meanings are hidden in practitioners' everyday experience. Reflecting back, it was the regular team reflection in those group sessions that inspired interest (or 'willingness' as mentioned by the conference audience) and opened up opportunities for new ways of practice. As McCormack (2010) points out, practice development is an 'engaged scholarship' involving collaboration between the researcher and practitioners to co-develop ideas and put them into actions together.

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8.2   The Importance of Involving Practitioners to Co-Create Change

An important value for me is authenticity, meaning my espoused values (my being) and my ways of working with others (my acting) in research must be congruent. Through practicing reflection, I constantly reminded and challenged myself in taking reflexive actions in my interaction with participants involved in the project. For example, in the beginning, I worried that people might come into a group session and turn it into a complaint session. Appreciative Inquiry provided useful guidance and helped me to shift my negative mindset to appreciate the positive potential of the group. I reframed my thinking and carefully asked questions in a positive fashion. For example, instead of getting stuck with problems, I asked what we could do to create positive change. We sat in the groups together to imagine possibilities for future realities. The team reflection in group sessions offered opportunities for individuals to share stories of what they would like to see more of, what worked and why.

The team was always excited to hear small actions undertaken by their colleagues, such as how it made a difference by taking a minute to acknowledge emotion or using a Google image (e.g., a kitty) in the phone to connect with a patient. The good stories made the team feel good and quickly accelerated more energy and power in creating transformation. For example, one patient used a chair to block her room door at night. In a huddle, a nurse leader questioned whether or not they should let her have that chair in the room. Trying to take the chair away from her had caused anger and catastrophic behaviors. Other nurses explained that this patient liked to sleep with no clothes on – it was her routine! Breaking the rules and allowing her to have the chair at the door helped the patient to feel safe. That conversation clarified the shared value of helping patients feel safe is a priority. After that,

they had no more behavioral events due to the chair blocking the door. It was understood that the patient was trying to protect her privacy.

Staff commented that the new ways of practice had meaningful impact because the ideas came from a team of practitioners who knew what would be feasible and applicable to practice. People were excited to support what they helped to create. The grassroots approach attracted the talents of a great number of practitioners. For example, a few staff in different disciplines (including nursing staff, pharmacist, occupational therapist, physiotherapist, etc.) co-produced a list of peer-teaching videos, which generated a lot of buzz about dementia and person-centred care. Good storylines quickly spread out to other units of the hospital. The enthusiastic responses from the participants not only developed rapport leading to shared positive team memories, but also increased my confidence to move forward in the research. As a group, we developed a habit and a disciplined way of thinking positively, which supported the growth of the group and the researcher. The team insisted to make the work fun. In the summer, we organized a Fun Fair, used concepts of gamification to engage staff in fun learning. Even though the team had a code blue (a patient had a cardiac arrest) an hour before the event, team members were able to shake off the stress and came to the fair.

In the research, there were ups and downs like a roller coaster ride. Together, we experienced a transformation towards taking an appreciative approach in working with a range of challenges along the research journey. There was uncertainty about funding for carrying out proposed physical renovations. After we had funding approved, a principal sponsor in senior leadership left the organization. To keep up and re-energize our positive spirit, we learned to embody a positive stance and interact in an appreciative way. For examples, we would spend time in each workshop to celebrate small successes and share

positive stories with the group, which gave us energy and power to continue with the work and experiment creative ways to develop person-centred care in the hospital unit. The project taught me that it is necessary to have faith, confidence, and trust in attempt to develop collaborative work. In the absence of faith, it would have been impossible for me to see the courage, skills, and growth among the people in the project. A key strength of Appreciative Inquiry is that it helps to surface the deeply desired values of the group and enables transformational change and growth. As Bushe and Marshak (2015) emphasize, transformational change requires new ideas, new conversations and new ways of looking at things. They further stress that transformation shifts not only what people do but also how people think and define who they are in organizations. In other words, transformational change emerges when there is a shift in the collective thinking and acting of the group.

8.3   Insights Gained

I gained useful insights and learned important lessons through using Appreciative Inquiry to research practice development. The experience has transformed my thinking and acting in practice development in two important ways: from individual competence to collective intelligence, and from fixing the problem to unlocking the talents and potentials.

8.3.1   From Individual Competence to Collective Intelligence

In my twenty years of experience in healthcare, I had been socialized in the environment of focusing on competency in individual staff. An important overlooked aspect was the value of building collective intelligence in the team. Through a year of teamwork in biweekly group sessions, I learned that the social and emotional bonds could have an impact on supporting team resilience and building a safe learning environment. It was the trust and social connectedness and inquiring together that grew collective intelligence. Collaborative

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and positive experience in research gave us a sense of team cohesion and made us feel "together we can make a difference!", just like what the conference audience said, that "there is no need to wait for large-scale structural change" to start to take actions. I have also learned that meaningful change started with co-visioning what people want for their future. It was evident that staff in all disciplines including physicians wanted to be part of the conversations that were taking place in practice development. People needed to feel they share each other's aspiration and concerns. Fortunately, our leaders in the organization acknowledge that change does not need to be rolled out from the top. With good support, the practitioners can initiate change themselves. I agree with the comment made by the conference audience, "change can start with anyone of us in the hospital". The group in the research actively acted for themselves, rather than passively waited to be done for. For example, we asked ourselves what can be done to better support patient with dementia pulling intravenous lines. Nurses gathered themselves and used social media to recruit volunteers to make comfort mitts to cover the intravenous lines for patients with dementia. Staff turned the conference room in the unit to a social place for art-making. In the art-making process, most patients demonstrated calmness, relaxation, sustained attention, pleasure, and self-esteem. One patient said that, "this room feels so different, it's not about being told to take medication and stuff like that, it feels normal here, it's fun and you talk to someone and have a good time." Through the research, I come to realize that at the heart of the Appreciative Inquiry is a call for engaging the collective intelligence.

8.3.2   From Fixing the Problem to Unlocking the Talents and Potentials

The traditional approach to a problem focuses on a diagnostic approach that begins by asking what is wrong? (Bushe & Marshak, 2015) Reducing the problems of a team or

organization to a simple reality of people as parts that need to be fixed can be disheartening and energy draining. In the research, physicians and staff stressed that people matter. As Bushe (2011) describes, organizations are webs of human relationships, conversations, and interaction. Imagine working with a team that consisted of people that know themselves well and are empowered to bring their strengths and talents, full potentials and authentic self to work. Through the research, I learned to move from "let me tell you how to fix this", a monological position, to "let us explore", a dialogical position (Bakhtin, 1981). The success of change does not simply depend on the researcher's expert knowledge, but on the degree to which the participants can better understanding their practice and take actions together for transformation. Through critical reflection in open dialogue, the team was enabled to discover alternative possibilities, and take reflexive actions. Reflexivity entails the ability of team members to acknowledge and take account of the many ways they themselves can influence practice (Lee, 2009). By having faith and supporting practitioners to take actions, people can gain confidence and begin to realize that they have the potential and capacity to have an impact in their practice. As the audience in the workshop highlighted, every member in the team can be a change agent and can make a difference. A small action can make a big difference in patient care. For example, I used patient stories to inspire the team to think about what could be done differently. When a compelling patient story was told, such as a patient's perspective of being restrained, many staff came up with small actions that they could do to improve patient care. After a staff took the restraint off and walked the patient, the story was spread and others followed. Another example, a patient wanted to leave the unit. One staff got punched in an attempt to stop the patient leaving. After that, security guards were called each time the patient approached the door. In the group session, a staff

said: "why don't we just gently follow her out to another unit and walk her back." It worked. The story was shared and the rest of the team adopted the approach.

8.4   Summary

This article describes my experience of using Appreciative Inquiry to co-create changes with practitioners for practice development. I found the core principles of Appreciative Inquiry - positive inquiry and a collaborative approach - provided useful guidance in engaging practitioners to participate in research and practice development. For practice implications, inter-disciplinary practitioners in acute hospitals need to make space for regular team reflection to enable reflexive practice. To confront stretching demands and complex challenges in current healthcare climate, leaders need to tap into the power of collective intelligence in teams to make innovative and sustainable changes. A sense of being able to influence or make a difference motivates the practitioners to contribute and take actions. Hospital managers and leaders should provide resources and remove barriers to empower the practitioners to address issues that matter and have direct impacts on patient care.

Chapter 9: Implications and Conclusion

> We have an enormous reservoir of collaborative potentials awaiting congenial
> circumstances of expression. The challenge is to discover and develop means
> for unleashing the flow.
>
> ~ Kenneth Gergen (2009)

In this final chapter of the thesis, I point out what my research can offer for people working in research and practice in dementia care. I connect the research questions with the literature and philosophical principles, and discuss lessons learned and implications. The chapter is divided into three parts: The first provides a summary of findings to address the research questions. I will review the key results in light of the literature to provide an understanding of their relevance and transferability. The second part suggests implications for policy makers, educators, researchers, and practitioners. The third part examines the study's limitations and challenges, and provides the final conclusion.

Figure 14. A bird travels back to home – co-created by a patient and a volunteer

9.1   Summary of Findings

My study aimed at developing person-centred care in the hospital setting by involving patients and a team of staff in the medical unit to come up with practical strategies. The stories told by staff from multiple disciplines gave concrete examples of what motivated their commitment and engagement in making changes to improve care and practice. The stories told by patients with dementia pointed out what mattered most to them, what would help, and why. The outcomes of this research contribute in three ways:

1. They have led to the development of a conceptual tool – Team Engagement Action Making (TEAM) that provides useful support for staff engagement in practice development and speeds up the spread of knowledge in practice.

2. They provided evidence for the effectiveness of practical strategies that can be used to accelerate the translation of knowledge into practice in the investigated site.

3. They demonstrated the positive and powerful impacts of using patient stories to inspire staff commitment and motivate change in acute care.

This research asked two questions. In the following sections, I summarize how my findings address these questions, and in particular, I highlight how the study results support, challenge, and add to existing knowledge in the development of person-centred care within acute care through engagement with patients and a team of staff across disciplines.

9.1.1   Research Question 1.

What did the engagement processes for change in the physical and social environments to person-centred care look like?

The literature that was discussed in Chapter 2 indicates that we have scant knowledge about strategies that help engage people to develop person-centred care in the hospital setting. Most of the research has been conducted in nursing homes. Evidence about what contributes to building and sustaining team commitment for making practice change is lacking. In particular, no direct perspectives of patients with dementia have been examined. This study addresses the gap by using the perspectives of patients with dementia, who persuasively argued that little things in the physical and social environments matter. Involving patients with dementia helps to ensure that the study is focused on the priorities of patients and that it will produce relevant and meaningful results.

This research challenges the dominant discourse that focuses on problems associated with dementia. The findings indicate that a strength-based positive approach and seeing person-centred care as a way of being and doing that respects patients as partners in planning and developing care can ensure that services are delivered to meet the needs of patients.

Video 4: The ART & SCIENCE of Person-Centred Care

The video 4, 'The ART and SCIENCE of Person-Centred Care' is one of the research products based on the research data. Pocket cards and educational brochures were developed with the participants and research advisors to promote awareness and motivate change in attitude and behaviors. The findings in this research indicate that working together to co-create innovative solutions offers hope and a positive venue to make a meaningful difference. The authentic shared aspirations foster social bonds and identity among the team members. See Appendix F and G for the key action items in this research and images of the education toolkits. Video 5 was developed by a team of interdisciplinary staff to share the perception of what person-centred care means. Many staff in the same unit and other units reported that they used peer knowledge developed in this video as part of everyday practice. A few educators from various settings (e.g., surgical wards, rehabilitation units, and community care) said they used the information in this video to influence practice.

Video 5: What Person-Centred Care Means to Me

As described in Chapters 6 and 7, the processes of engagement for change in the physical and social environments to person-centred care drew on core concepts of appreciative inquiry (e.g., collaboration, positive approach, and focus on action). The evidence described in Chapters 5-7 confirms that developing and testing knowledge in and from everyday experience in the field can accelerate knowledge translation. This finding is consistent with nursing literature that discusses engaged scholarship: integrating research and practice development would benefit applied science in healthcare by making collaborative research and innovative learning (Lavery, 2016; Manley et al., 2017; McCormack, 2011). Manley et al. (2017) described this as a new way of moving towards working in a 'joined-up' way.

This research is timely since it addresses the pressing need for knowledge and processes that enable people in acute institutions to innovate and improve dementia care. The new conceptual tool, 'TEAM' builds on the underpinnings of social critical theory and action research, emphasizing the vital processes of co-visioning, co-inquiry, and co-creation. As Storch (2015) suggests, successful and sustainable change comes from engaging with people in responsive conversations, offering new possibilities, and allowing people to respond to the social reality that emerges from conversing with participants who have diverse ideas and points of view. Thus, bringing a diversity of voices from patients and staff across disciplines into the development of change is pivotal. This supports recent literature in healthcare that finds staff who are more engaged to be more likely to deliver high-quality care (Bakker, 2011; West et al., 2014).

This research argues for the value of staff engagement for the team in developing positive energy to generate innovative ideas for change. In particular, the data showed that

team reflective learning sessions (Figure 15) provided staff members with regular opportunities to gain insight about their daily work. This is congruent with the definition of engagement proposed by Dewing and McCormack (2015):

> Engagement is characterized by the presence of vigor, dedication and absorption. Where persons experience enhanced engagement, they will have resilience, a willingness to invest effort in self, in others and an activity or purpose, along with the ability not to be easily fatigued. Engagement is manifest in three modes: intrapersonal, interpersonal and in groups or communities. (p. 6)

Before the research, the staff reported feeling unable to respond to the needs of patients with dementia due to environmental and structural constraints that generated a sense of powerlessness. In the research, using a joint process of sense-making to co-create meaning, staff had more energy to cope with difficult clinical situations. Strong evidence is presented in this study that regular group meetings helped the staff gain collective intelligence, emotional, psychological and social connectedness that enabled team learning and better ways of relating to patients. The narratives by the co-workers gave them practical wisdom, which resonates with the findings of Dewar and Nolan (2013) that much of the knowledge among nurses was generated through everyday practice with patients and other team members.

In this study, the evidence shows the heightened awareness of the patients' perspectives and the experience of co-workers, which allowed staff to relate to one another in more engaged ways, with higher energy and vitality (Dewing & McCormack (2015). For example, as previously mentioned in chapter 7, a staff member said, "*I knew I always love*

coming to these meetings. I appreciate it because it makes me better for our unit. You get to

learn new things from each other".

Figure 15. A video reflexive group session in the conference room

9.1.2   Research Question 2

Did the research project have any impact on supporting positive change in the

medical unit?

Chandler (2013) identified the impact of research: "as the influence, effect,

demonstrable contribution, change or benefits that result from the research" (p. 3).

Greenhalgh et al. (2016) also argued that the impact of research goes beyond academic

publications and citations, advocating that the impact of research happens when a

contribution actually reaches people and gives benefits in the real world. This research adds to the literature by showing evidence of change in practice in real-time. The evidence presented in Chapters 6, 7, and 8 demonstrated change in attitude, knowledge and behaviors among staff in everyday practice. The study results support the notion that testing small change that is quick and nimble in the micro process increases team capacity to make sense of complex clinical situation and act effectively. This is consistent with what Kislov, Waterman, Harvey and Boaden (2014) wrote in their recent knowledge translation paper on healthcare organization that emphasizes the need for "creating opportunities for healthcare staff to improvise, experiment and learn from mistakes whilst engaging in the practice of knowledge mobilization" (p. 7).

Strong evidence demonstrated that the research supported processes of making positive changes in the medical unit and beyond. Throughout the course of this project, the scope of the research grew exponentially. We provided dementia care education for all staff in the medical unit and many staff in other hospital units, and I also received requests from practitioners from other hospitals to share the research outcomes. Thus, the project had more reach and a larger external impact. To gauge the internal impact, I asked the staff participants – Did the research make any difference to their practice? What did they appreciate the most about the research work? What were the lessons learned? What would they like to see in the next step?

To judge the impact of research, Egan and Lancaster (2005) suggested that researchers should move beyond a set of concrete activities or action plans to a more open process where the focus is on empowering and improving the conditions for continuous change. The regular group discussions and analyses were important and effective in building

emotional connections in the team and to motivate people to keep going forward. The research approach enabled team members to learn together in novel ways.

Being real, positive, and flexible was the key. We recognized that as situations changed, some opportunities for pursuing certain goals might fall apart while others could arise up. Some ideas became impossible, while others that were previously impossible became viable. For example, the funding for the art workshop stopped after the program director left. The comfort mitts project was unimagined before, but quickly gained momentum and support. Staff in the hospital and citizens in different communities began joining in to make comfort mitts and created a larger impact. In addition, many staff members (nursing and non-nursing) joined the weekly study group sessions for three months (June-August) to learn about new knowledge in gerontology (Figure 16).

The evidence shows that the research generated a great deal of new interest in dementia care and contributed to the evidence-based practice movement in cultivating a person-centred care in hospital care. Working with a team of staff, the study developed local knowledge that had useful meaning and was applicable to practice. Appendix J provides a visual timeline of the research activities in a period of 12-months. The study made an important contribution not only by applying new knowledge to practice, but also by connecting the hearts and heads of individuals to transform their thinking into new and collective ways.
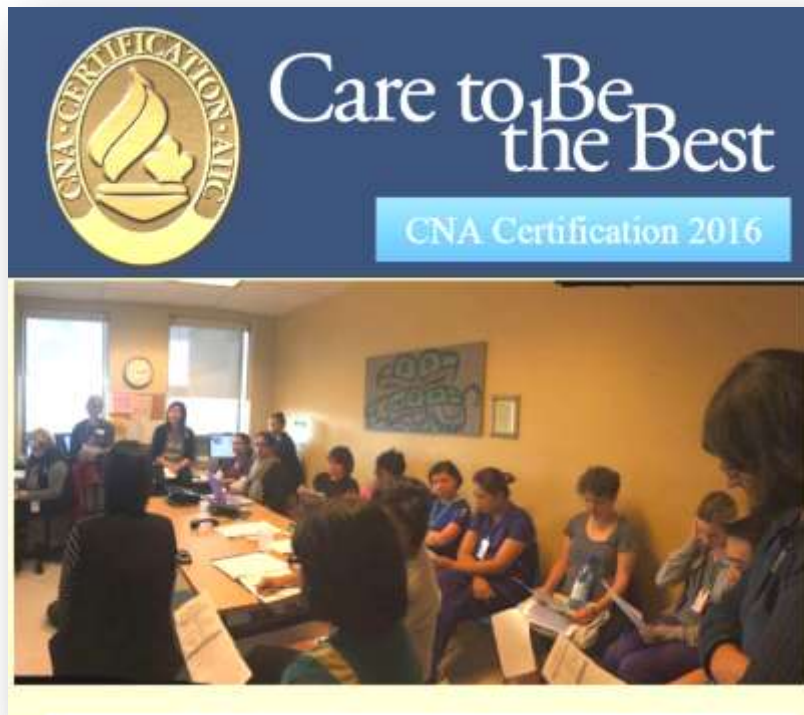
Figure 16. Study group for Gerontology Specialty Certification

As mentioned in Chapter 7, the staff commented about the value of dementia education and increased knowledge in dementia care and person-centred care. In the Gentle Persuasive Approach training, staff reported that the new knowledge was practical and useful and that they could apply the new knowledge in their practice.

The sharing of stories in the dementia education opened doors for the staff to become more compassionate and seek opportunities for meeting patients as persons. A renewed understanding and passion about person-centred care was evident in the team as more and more staff members received dementia training. Frank (2010) suggests that stories can animate, entertain, enlighten, and connect people; and stories can make a particular perspective plausible and compelling.

The staff not only learned knowledge about dementia care, but also demonstrated a change in attitude. A notable shift occurred from a medical, task-focused perspective to a more person-centred cultural view. As mentioned in Chapter 6, the value of watching video clips of patients' stories in the reflexive groups was in their initiation of new conversations about the patients' perception of their hospital experience. The stories that were told directly by patients often challenged the staff members' assumptions, such as the sensory experience in the corridors. As indicated in Chapter 6, a patient expressed how frightening it was when he was outpaced and ignored. The staff reported being surprised by the impact and became more sensitive to the needs of patients.

As described in Chapter 7, the staff reported that the research project was empowering. Before the research, in a needs assessment mentioned in Chapter 1, many staff members said that they felt scared and challenged when caring for patients with dementia. Similar to reports in the literature, most staff members in acute settings have little or no training in the care of older people with cognitive impairments and dementia (Clissett et al., 2013; Moonga & Likupe, 2016). As reported in Chapter 7, according to a nursing leader: "Before [the research] we didn't know what to do, everybody was just kind of floundering." As the research progressed, I observed many staff use more positive approaches that enhanced the well-being of patients. For example, more social conversations could be heard about the lives of patients after 'This is Me' and 'My Daily Care Needs' were implemented as strength-based communication and care planning tools. More attention was paid to the person as a whole, rather than to a particular task. For example, as written in Chapter 8, one patient used a chair to block her room door at night. In a huddle, a nurse leader questioned whether or not they should let her have the chair in the room. Other nurses explained that this

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patient liked to sleep with no clothes on – it was her routine! Breaking the rules and allowing her to have the chair at the door helped the patient to feel safe. More examples of behavioral changes among the staff were described in Chapters 6, 7 and 8.

As Kitwood (1997) asserted, the social environment around persons with dementia can have a significant impact on their experiences. In this project, the staff learned of the importance of seeing who the patient is, what is important to the person, and how things affect the person as a whole. Since no manual is available for every particular complex situation, the staff learned to come up with innovative ways to improvise and meet the needs of their patients.

In Chapter 6, the patients' perceptions indicated that boredom and having nothing to do negatively affected their health and well-being. The biggest direct impact of positive change on patients' experiences was improvement in social engagement. As described previously, the staff reported that patients looked forward to the art workshop and patients reported how they enjoyed the social atmosphere of the art workshops. The comfort mitts project involved creativity and social and embodied sensory experiences (Figures 7 and 8, in Chapter 7). As written in Chapter 7, staff who were involved in the comfort mitts project were invited to present the project at a regional conference held by the Patient Safety and Quality Council. The Comfort Mitt project created a "buzz" with more people talking about it and more related actions. Patients responded positively with the mitts. Many said they liked the bright colors and the creativity shown in the mitts, and they enjoyed having social conversations with people about the mitts.

As mentioned in Chapter 8, whenever Helen was stopped from leaving the unit at the exit door, she reacted with strong emotions. She punched a few of the staff and caused some

injuries. Helen was invited to attend the art workshop, where the encounters with art not only

created opportunities for storytelling, but they were the means by which people could share

their life inspirations. The art elicited stories of the past, connected patients in shared

experiences, and allowed positive relationships to form. Helen was viewed as being

'aggressive and difficult to handle' before the team got to know her in the art workshop. The

staff and physicians were surprised by the impact the art workshop had on Helen (see a rose

painted by Helen in Figure 17). After she began attending the workshop, Helen was no longer

'an aggressive and difficult patient', but was seen to be intelligent, talented, and sociable.

The art workshop afforded opportunities for people to show their social skills, humor,

strengths, and beauty (see a creative art made in the art workshop in Figure 18).

Figure 17. A rose painted by Helen

Figure 18. Creative art made in the art workshop

As previously reported in chapter 8, in the art-making process, most patients demonstrated calmness, relaxation, sustained attention, pleasure, and self-esteem. One patient said that, "this room feels so different, it's not about being told to take medication and stuff like that, it feels normal here, it's fun and you talk to someone and have a good time." Findings of this research add to the evidence from other research (Phinney, Moody, & Small, 2014; Sauer et al., 2014) where art activities can lead to benefits at mental, social, and emotional levels. An important lesson learned here is that the way we provide acute care for patients with dementia is not fixed. There are alternative possible ways to create a healing environment that are more supportive and responsive to the needs of patients with dementia. To change the current culture of acute care requires us to imagine what a hospital environment for patients with dementia can be. Figure 19 showed a patient used watercolor and pen ink to create his portrait. In the following section, I will describe the next step following the project – the future possibilities.

Figure 19. A patient used watercolor and pen ink to create his portrait

9.1.2.3 The Next Step

The conclusion of this project does not necessarily mean the end of the work. The ongoing utility and effectiveness of the developed tools have not been evaluated or tested for their sustainability. The impacts of the proposed changes in the physical design have also not yet been evaluated. The planning for subsequent research projects has begun with two main goals. First, I intend to refine and test the emerging conceptual tool (TEAM) to theorize further about the engagement process of change, and link the research for change in the practice setting with practitioners. This guide is a new approach to change in care settings, and could ignite innovations and improvements in dementia care in hospitals.

In this thesis, I provided examples of developing and testing some of the new tools, such as the ART and SCIENCE of Person-Centered Care, comfort mitts, and video reflexive groups. The successful stories offered hope and illuminated a new direction for the grassroots involvement in developing a culture of innovation. In the next 5-10 years, I plan to continue to work with patients and practitioners to stimulate further change. I plan to investigate the sustained impacts of the actions taken in the physical and social environments. Moreover, the tools that worked well need to be up-scaled to spread their utility and the knowledge internally within the hospital and externally. Given the challenges that nurses and staff face in delivering high-quality person-centred care, ways for unleashing, enabling, and nurturing the collective talent and team capacity for innovation need to be identified. I wish to understand how shared solution finding, and effective teamwork can increase safety and quality of care within the context of hospital dementia care. I also want to know how a grassroots movement could drive the culture change over time and what enables such a social movement, requiring a radical shift of power.

In addition, I intend to extend some aspects of the research related to environmental design and care strategies. I will be working with the developers of dementia education, Gentle Persuasive Approaches (GPA) to redesign the upcoming new edition. GPA is the most used dementia care training curriculum in Canadian settings, (universities, hospitals, and community care). I am also working with the British Columbia Patient Safety and Quality Council and Learning Technologies in Vancouver Coastal Health to develop dementia education to ensure practitioners in the province receive fundamental dementia training.

9.2 Study Implications

In this thesis, I have used the action research approach to develop knowledge that is actionable and theoretically generative. This study contributed to the understanding of how appreciate inquiry can effectively uplift the team spirit and bring people together to co-develop knowledge in the context of a hospital setting. The voices of a diverse group of participants provided useful insights into their participation with the complex process of change. The following sections summarize four key implications of the findings. The issues that are raised are of direct relevance to practitioners, clinical leaders, educators, policy decision-makers, and researchers in the field of dementia care in hospital settings.

9.2.1 Change is changing

The work being carried out in today's hospital environments is more complex than before, which makes the building of relationships and teamwork even more necessary to accomplish change and make practice applicable and sustainable. Despite the efforts that are beginning to emerge in quality improvement initiatives such as 'Releasing Time to Care" based on *lean* principles (Smith & Rudd, 2010), very few change projects actually successfully change practice and improve patient care. Often, a pre-determined solution identified by the top to drive efficiency can lead to a lack of shared purpose and resistance to change in teams (McCormack & McCance, 2017). Managers, decision makers, and policy developers need to recognize and value staff engagement in the processes of practice change. The change model is changing, and research shows that the traditional top-down approach has limited success in responding to the challenges in the current healthcare system (Ham, 2014, West et al., 2014).

The old model of change has been taking too long and using too many resources in the planning. In following the old, dominant model of change, healthcare organizations are investing energy to make detailed plans, getting buy-in, and coming up with strategies to overcome resistance. The rigid top-down plans that demand compliance are causing resistance. Instead, the new model of co-creation can work positively for all to produce a sustainable, endorsed, and appreciated approach to change. Co-creation brings in those who are affected by change from the start, allowing them to bring their strengths and expertise at an early stage.

The new change model values social power, a collective way of working, rather than domination by leadership. In the new change model, teams in hospitals are viewed as meaning-making systems where practice realities are co-constructed, maintained, and changed through social processes and various factors such as cultural and political interactions. For scholars in organizational development (Bushe, 2011; Gergen, 2014; Storch, 2015), everyone on the team plays a role in creating and changing a culture through the stories they tell about their experiences and through their ideas they develop as a road to action.

This thesis has shown that patients with dementia can contribute significantly to hospital service development. Balik et al. (2011) regards organizations as moving through a continuum of "doing to" and "doing for," with the goal of "doing with" as the true partnership in care and in the design of systems of care. The patients' stories in this research were emotionally engaging, intellectually generative, and action provoking. As pointed out by Dewar and Nolan (2013), the most important contributions to quality of care may not be measurable. Policy makers need to have a more eclectic view about what matters most and

what counts as evidence (not just what is measurable). To-date, hospitals are actively seeking

ways to not only better understand patients' experiences, but also to involve them in

meaningful ways to innovate and improve practice, systems, and the environment (Balik et

al., 2011). Policy makers and hospital leaders need to make commitment to support

developing processes for collaboration and co-creation with patients and families. Examples

can include providing learning programs for patient and family engagement and partnerships

with community networks to build capacity for collaboration. National and provincial

research funding agency should acknowledge the value of person-centred healthcare

research, broadening the scope of patient-oriented research.

Figure 20. A patient painted this landscape while telling stories

Figure 21. Sarah pushes her art cart to work with patients at the bedside

9.2.2 Talk is action

Talk is action! Bringing people to learn together has been advocated by nursing

scholars (e.g., McCormack, Dewing, & Titchen, 2013) as an important way to engage and

develop practice. Processes of inquiry that are flexible and inclusive, and that edify

relationships can reveal a variety of perspectives without privileging any of them. This

allows greater coherence and responsive change to emerge in a productive way. In this

project, I did not stand outside of the construction of reality, acting as an objective observer

in the group interactions. My presence was part of the 'discursive narrative' (Bushe

&Marshak, 2015) that influenced the meaning-making that took place in social construction.

As Reed (2008) explicated, the talk and co-inquiry in appreciative inquiry is intervention. The way I asked a question could influence the effects of the research. As Southern (2015) suggests, constructing powerful questions to engage people in ways that support learning and facilitate change is an art. Berger (2014) suggests that a beautiful question can serve as a catalyst for action and change. Therefore, educators and practice leaders should pay more attention to the language used in the talk. Effective talk builds team relationships and promotes trust, which cultivates the psychological safety to allow people to ask questions about the gap between knowledge and action (Greenhalgh, 2017).

As Lewis (2016) argues, the change process should be more 'heterarchial' rather than hierarchical. Indeed, when the change ideas come from talents and strengths of a large group, they are much more innovative and applicable. Researchers, policy makers, educators and practice leaders need to value diversity to ensure that different voices are heard. More resources and research funding should be invested to support practice development that brings researchers and practitioners together. To accelerate the uptake of new knowledge in practice development, meaningful engagement is important. People will support what they help to create.

Gergen (2014) emphasized that research can be seen as 'creative construction,' 'future forming,' or 'world-making'. He argued that the aim of research is not just to illuminate existing problems (mirroring what is), but to devise practice that can achieve better outcomes. He defined good science as being judged by its generative capacity that is: "The capacity to challenge the guiding assumptions of the culture, to raise fundamental questions regarding contemporary social life, to foster reconsideration of that which is taken for granted and thereby furnish new alternatives for social actions" (Gergen, 1978, p. 1346).

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Figure 22. A painting made on a windy day that had filled the city with maple leaves

In the literature, the growing evidence demonstrates that practice development requires a supportive environment for team learning and mutual support (Dewar & Nolan, 2013; West & Markiewicz, 2016). Nevertheless, little evidence is available to show how such environments can be created by leaders and change agents to enable staff at all levels to contribute, innovate, and find solutions for problems they face everyday. While the TEAM guide offers educators and leaders a useful heuristic tool for staff engagement in practice change, the guide needs further development and testing to articulate a more complete understanding for supporting change that would bring transformative results. As mentioned previously, Bushe (2011) argued that transformation requires new ideas, new conversations, and new ways of looking at things. Transformation means not only new practice, but

enlarging the capabilities and generating processes to imagine and engage in 'world-making' (Gergen, 2014).

Figure 23. Transformation; a patient showed excitement when he saw the color emerge

9.2.3   Connect the brilliance

As Gergen (2009) pointed out, knowledge is an activity (action) rather than an internal representation. Knowledge is actively constructed as we relate to others through processes of social negotiation, shared discourse, and the creation of social structures. If we see knowledge as a 'communal production' (Barrett, 2015), we can appreciate that we are always moving towards cultural understandings that offer new opportunities for us to act.

Bradbury (2015) maintains that all knowledge is political. Certain kinds of knowledge would be considered legitimate and hold more power over others. Just like any large organization, the hospital environment is vastly hierarchical. In this research, many of the

practitioners who work in different disciplines did not feel that they had the power to change the prevailing cultural ways of doing things. For example, the management typically makes decisions about priorities and what can be changed. Hospitals and healthcare systems need to recognize the untapped potential for learning and co-creating, and for making the most from meaningful partnership opportunities.

A growing awareness indicates that patients and families can have an important role in improving the quality and safety of healthcare. The Canadian Institute of Health Research (CIHR) identified patient engagement in healthcare research to make investments in research more accountable, as it provides new insights that can lead to innovative discoveries and ensure that research is relevant to patients' concerns. In the strategy for Patient-Oriented Research (SPOR) of the CIHR, the goal is for patients and families, professionals, practitioners, and policy makers to collaborate together in creating and sustaining the momentum for change (CIHR, 2017). Internationally, the Institute of Patient- and Family-Centred Care (IPFCC) leads a movement of culture change to promote partnerships among healthcare providers, patients, and families. Educators, practitioners, and policy makers need to tap into the power of the collective creativity, and find innovative ways of working to respond to the complex challenges. In doing so, space is needed for regular team reflection and to enable critical reflexive practice.

Similarly, Manley, Sanders, Cardiff and Webster (2011) argued for the need to pay more attention to target practice development at the micro-systems level (at the local setting where patients, families, and staff interact). Nurses know their job better than anyone else so nurses are well placed to see possibilities to make change. Practitioners working at the bedside are the active actors who can take responsibility in leading and influencing change in

practice. Gallagher, Curtis, Dunn, and Baillie (2016) also used the action research approach to empower nurses to lead care improvements. They found that, as change was seen as a collaborative venture with the alignment of needs, they were able to generate active engagement and a high level of enthusiasm. In their project, nurses reported feeling empowered and that their voices were heard and valued.

9.2.4 Put people first

Conventional research still follows the old, dominant way of thinking, viewing organizations as machines from an engineering perspective in terms of productivity, efficiency, and fixing the broken parts of the machine (Bradbury, 2015). New models for change are needed to keep pace with the changing world. Person-centred care culture is not a static place but an emerging process, with continuous change being part of the process of becoming. Lewin's (1948) classic model of change – unfreeze, change, and refreeze – remains influential but it is no longer helpful for understanding the emergent and interactive nature of today's world. Instead of conceiving hospital environments as industrial machines that need fixing and would return to a fixed (refreeze) stage, we need to shift our thinking to understand that people working in hospitals are not machines. Hospital leaders and change agents need to put people first. People are beings in flux, and always undergoing change. A growth mindset and continuous development would be more helpful. According to Barrett (2015), organizations are in perpetual motion, continually in the process of becoming. New thinking on becoming, the continuous flow and flux, offers new opportunities for researchers to unpack these concepts and reveal the complexities of engagement and change. The innovation and improvement work is in continuous development; we do not unfreeze and refreeze it.

Putting people first is inclusive leadership. More focus should be centred on connecting people with a shared vision, with priorities given to the deeper purpose – patient care. Being able to influence or make a difference can be deeply motivating to practitioners, who are working closely with patients at the point of care. As Dewing and Dijk (2016) suggest, more empirical studies that analyze what works well should be encouraged, as they can be powerful levers for validating existing practices, and for developing important local-based theory and change. Researchers should explore the value and benefits of conducting research in partnership with people in the clinical settings. Further work is needed to examine how appreciative inquiry can be used effectively to integrate research and practice development. As Gergen (2014) asserts, the ultimate aim of research is to make the world better, and to contribute to human life. The need also exists to engage citizens, patients, and families in research, giving community members a greater say in the future direction of research.

9.3 Implications for Policy and Broader Issues of Justice

In this section, I discuss implications for policy and broader issues of justice. It is important to recognize the interdependent relationships between the local (micro) and the broader system (macro) levels. To elaborate, how national and provincial systems set up their mandates and policies influence how local organizations structure care delivery and arrange their strategic priorities. The organization strategic priorities can have important effects on how individual teams and practitioners tailor the care they provide to patients in the hospital units. All levels interact with and are influenced by the other. Similarly, staff members at the unit level have agency to influence the practice culture, which is mediated by

the organizational context and by the way in which services more generally are structured according to priorities of government and systems.

At the national level, on June 22, 2017, Canada became the 30th country to launch a national dementia strategy. The passing of Bill C-233 shows the commitment of the Government of Canada to see an integrated national plan for dementia care as a priority. The strategy will develop specific national objectives; encourage greater investment in research; coordinate activities with international organizations; and help provinces develop clinical guidelines for treatment and best practices in dementia care that can be shared across the country. A responsive national strategy would require meaningful collaboration with stakeholders, including people with dementia and care providers working in care settings, as well as managers, senior leaders, executives and politicians.

An inclusive society should support people with disabilities to be politically involved to create changes or influence the service development that is relevant to them. As I am writing this, thirty-nine people with dementia are attending the Alzheimer Europe Conference in Berlin to speak about their voices in dementia research. It is evident that, in some countries, the movement of activism has begun among people living with dementia who are forming working groups to voice their desire to shape the services that affect them. My research has shown how in Canada, much more attention should be paid to the value of patient engagement in policy imperatives. Funding and resources should be provided to empower individual citizen and groups to be involved in making recommendations to local services and wider system approach. There is a need for a shift to recognize the rights and agency of people living with the disease. The findings of this study show the kinds of

supports that could be provided for people with dementia to play a bigger part in healthcare culture change, shifting to a more engaged model, working in partnership.

In this project, at the organizational level, although many of the practice development activities raised awareness, created positive energy and concrete actions for developing person-centred care in the hospital, some of the action plans did not receive adequate organizational support and structural resources to realize their full potential. The project shows the strengths and possibilities as well as the difficulties of applying a grassroots participatory approach in research and practice development. If person-centred care is to be realized and sustained, it needs to be made explicit and visible within daily accountability practices. Hospital policy should ensure the rights of people with dementia are always maintained regardless of old age and disability. Evidence of respecting patients' rights, seeing people as active social agents, and meaningful involvement in care through collaborative decision-making all need to be made part of the everyday practices of all staff in the team. Organizational processes are required to ensure all admissions include gathering vital information about the person (i.e., *'This is Me'*), along with disease symptoms and medication history. As previously described, '*This is Me'* is a one-page communication tool to be completed by the patient and family. Such a tool can serve as a starting point in support of family partnership in care planning.

Managers and leaders need to consider their responsibilities and accountabilities in care delivery and support for practice development. Although meeting measures of performance including financial targets and length of stay is important, more attention should be paid on the roles they can play to support the team to provide good care. Also, leaders need support to develop their skills to support others. Leadership development training such

as appreciative inquiry should be provided to support managers and leaders at all levels.

Based on the lessons learned in the project, I made recommendations for practice, education, policy and research (Table 4) and sent the same to participants and leaders of the hospital.

Table 4. Recommendations for practice, policy, education and research

Recommendations for Practice, Policy, Education & Research

Unlock the potentials. Involve not only staff, but also patients and families to co-create meaningful results

Make space for team reflection to enable critical reflexive practice. Person-centred care requires deliberate efforts, routines and processes to continuously build a safe culture for learning

Keep the deeper purpose at the center of policy and practice development to motivate engagement. Don't forget about why

Take a positive and collaborative approach to generate energy to make change; use of appreciative inquiry to challenge status quo and find new possibilities in practice development and staff education

More work is needed to understand the effects of physical environmental interventions and how a specific aspect may interact with other factors in enabling person-centred care

Stop doing what is not working, tap into the power of collective creativity to innovate new ways to respond to stretching and complex challenges

Make big impact by first taking small and nimble actions that will have direct effect on patient care and add joy in work

Togetherness and relationship build stronger capacity and resilience. Future research should further investigate what nurtures and sustains staff engagement. How team resilience might be maintained in turbulent times?

A sense of being able to influence or make a difference motivates practitioners to contribute and take actions. Provide resources and remove barriers to support people at the point of care to lead change

More interdisciplinary research. Provide funding and support to enable researchers and practitioners to conduct research together in and for practice

9.4   Limitations and Challenges

This study took place in one hospital setting so it is important to acknowledge the limitation of its scope for transferability. The setting in which I conducted this research is a particular 'organizational context' where the team has their own history, attitude, relationships and ways to relate with each other, as well as with the organizational environment. The social and physical environments of the medical unit offer a range of supports and constraints to staff's practice and patients' experiences. Readers need to consider how the knowledge generated in this study may be applicable to their own settings and decide how they may adapt and adopt the knowledge.

Conducting action research in acute care is challenging because it demands a democratic and participatory process and the environment is complex in terms of the power inequities. Academic background, education levels, professional status, and language can create power inequalities among people in hospitals. Action researchers (e.g., Williamson, Bellman, & Webster, 2011) have reported that a patient's short-term stay, staff movements between units, shift work, heavy workloads, and the fast-paced nature of acute care present significant challenges to research.

9.4.1   The dark side of representing a partial view

It is impossible to bring to the table all those who want to be included or might be involved in the change process. In this study, many staff expressed their desire to be more involved in the research if not for being constrained by their workload and time. Reason and Bradbury (2008) described participation as both epistemological and political. They explained that the hospital environment can be understood as a sea of voices that are multi-layered in reflecting the competing and hierarchical discourses. Thus, engagement is a

complex process that invites continual questioning about how we come to know what we know in the inquiry process. Meaningful engagement needs to acknowledge interactions as imbued with a shifting and dynamic emphasis with different weights given to different worldviews (Hynes et al., 2012). Meaningful engagement goes well beyond focusing on who sits around the table. An additional focus must cover how we hear, engage with, and represent others. Due to the multiple voices coming from different worldviews, collaboration means more than simply reaching a consensus or choosing a particular representation. For example, some of the participants believe that a story of local nurses' experiences is important knowledge, while others believe that quantitative measurements of a large dataset is more valid knowledge.

Curtis et al. (2017) remind me that the researcher needs to adopt an open attitude, be present in the moment, and ask questions about the assumptions and sense-making. I did my best to be open to contradictions, while listening and recognizing different voices or worldviews in the inquiry, and I tried to understand how they interact with each other. I realized that neither the legitimacy of quantitative measurements nor people's experiences should be ignored. The task of creating a safe space where people with diverse ways of seeing, knowing, and theorizing can engage with practitioners is challenging but necessary for appreciating the democratic principle of action research, allowing all to be heard. Again, this research was limited to the voices of those who were able to participate. Staff members in disciplines like housekeeping, while invited to participate, did not attend any focus groups.

9.4.2   What are the negatives about being positive?

Innovations are needed in hospital dementia care as decades of earlier problem-focused approaches have failed to yield the desired outcomes. Although the positive

approach in appreciative inquiry offers a way to reframe how people are engaged in the process of sharing knowledge, critics such as Barge and Oliver (2003) and Bushe (2011) have pointed to the challenge of using too narrow an interpretation of appreciation. 'Being positive' may be positive for someone, but negative for another. As mentioned in Chapter 7, scholars like Grieten et al. (2017) indicate the shift from using simplistic dichotomies (positive versus negative, and strength versus deficits) to using the generative capacity of appreciative inquiry. Bushe (2015) warned that a 'can do' frame of mind can produce an unhappy place when people are unable to express what they feel or experience. Koster-Kooger (2016) further argues that positivity can cast a shadow that treats resistance as a problem.

Fitzgerald et al. (2010) point out the tendency in the appreciative inquiry approach to ignore problems. From my observations, I did not hear of any participants in the study complain of issues of self-censorship (i.e., silencing issues and problems) that could restrain their creativity or generativity. The institutional hierarchy and differential access to group sessions constrained some people from participating in the dialogue. The housekeeping staff, for example, simply did not have a chance to join in. Some of the nursing staff from other medical units managed to attend the dementia education but some were not approved by their managers to attend. Some signed into the educational workshop but were called back to work due to a staff shortage. Physicians in the focus groups expressed their concern about focusing the research on only one unit. Some felt that the given unit was privileged over other units where support is also needed to the same extent.

9.4.3   Keeping the ball rolling

Maintaining the momentum of the project and keeping internal and external parties of the hospital informed and involved was a challenging task. From the start to the end, I communicated by email, by phone, and in person with participants, co-investigators, public advisors, and university committee supervisors. I met with staff bi-weekly in group sessions and had research meetings with co-investigators biweekly. I sought advice and informed each advisor about the progress of the research in the one-to-one meetings. In between, I processed and organized a large volume of data in the form of visual, audio, and text. I met with my supervisors monthly to discuss data and findings. The process required immense efforts to juggle details and communicate effectively with all parties.

A bigger challenge was to spend time to nurture and maintain relationships to ensure meaningful engagement. At times, it was difficult to keep up with the politics occurring in the hospital. I was limited by the amount of energy and time I had to spend. For example, I struggled to connect with the project manager to keep track of the progress of physical renovation. I provided my research results and advocated the use of evidence to assist the renovation planning. As I was not able to attend every meeting, I lost track of how the decisions were made by leaders and the progress of the renovation planning. The manager was extremely busy, and I did my best to assist her whenever she asked for my help. For example, I helped to find box frames and ordered safety glass to make the low-cost memory boxes. While the project committee decided that a standard procedure was required to install the memory box, no-one decided who should take ownership to put in and replace the materials in the boxes. Consequently, the idea of the memory boxes was put on hold. I did not push the idea as I realized that it was not a good time to challenge the committee. I admit

that it was not easy to rock the boat to drive change and at the same time manage to stay in the boat. In this case, I used the Gentle Persuasive Approach, "stop and go' to keep the ball rolling. As Coghlan and Casey (2001) suggest, nurse action researchers face the challenge of having to "maintain their credibility as effective drivers of change and as astute political players. The key to success lies in assessing the power and interests of relevant stakeholders in relation to aspects of the project" (p. 677).

9.5   Conclusion

This thesis applied appreciative inquiry as an action research approach to critically examine the engagement process of change towards person-centred care in a medical unit. The lenses of social constructionism, interpretive approach, and critical social theory enabled me to engage in co-inquiry with patients, families, and a team of practitioners for change. In this thesis, I described in detail about how a positive and collaborative approach, underlined by appreciative inquiry led to positive changes in attitude, knowledge and behaviors in practice within the medical unit. The data generated from focus groups and observations demonstrate that the research provided useful support to motivate commitment and actions among participants in the team. This thesis offered important lessons learnt about engagement in this practice development work. I have three main conclusions from the research:

First, I argue for a new positive and collaborative approach to engage people from all disciplines in the team to work together in practice development. Rather than a quick fix solution to a problem, practice development is a continuous process to team empowerment and building a culture of person-centred care. The problem-focused approach has been limiting in generating energy and collective creativity to innovate and improve dementia care

in the past. This research has demonstrated that appreciative inquiry can offer uplifting energy and connect collective intelligence to make change possible. Person-centred care is an ongoing journey. Shifting the thinking to continuous development requires change agents to be flexible and pay close attention to the processes, where continuous adaptation and improvisation are often required. The evidence in this research demonstrates that changing a culture of practice to be person-centred requires commitment and actions at all levels. Without leadership support, it is difficult to sustain any change. From hindsight, I have learnt that both an engaged workforce and a supportive leadership are needed to enable and sustain effective change. A supportive leadership is a culture that values staff engagement and is committed to the development of the workforce.

Second, emerging from this research is a conceptual tool - Team Engagement Action Making (TEAM) that can serve as a heuristic guide, to support staff engagement in practice development. This is a useful tool that offers flexible guidance for researchers and practitioners to use. I plan to do more work to continue to develop and refine this tool in my future research. Additionally, the outcomes from this project show that research in the workplace can contribute to knowledge and practice development. I worked with a large team of practitioners together to co-produce knowledge. Through active facilitation and systematic inquiry, research in practice in collaborative ways can support integration of knowledge production and practice development. Future research should pay more attention to the dynamic inter-connection of research and practice, and to knowledge and action. What is also needed to further explore is the generative potential of action research, especially with appreciative inquiry in creating opportunities to maximize the collective talents of patients, families, and practitioners in all disciplines.

Third, the study demonstrates that there are patients with dementia who are able and want to contribute to research to improve healthcare services if appropriate methods are used to support active and meaningful participation. This is the first study where patients with dementia were provided opportunities to comment on the hospital environment in video-recorded interviews, and the team who cared for the patients were invited to reflect on the insights patients provided. This study offers a unique contribution to the knowledge base in the field of hospital dementia care by beginning to use first person voices of patients with dementia in video reflexive groups for learning and practice development.

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Appendix A: The Hospital Environment Audit Tool (HEAP)

Unit: _____ Date: _____ Time: ___:___

TYPE OF UNIT

CORRIDOR SPACE

A-1. SUPPORT FUNCTIONAL ABILITY

1. Rate the "lighting intensity" in the corridor:

Plenty (adequate natural lighting complemented with artificial lighting)………...…..2

Reasonable (heavy reliance on artificial lighting; inadequate in some areas)…….....1

Poor (mostly inadequate lighting)…………………….…….……………….....0

2. To what extent "glare" is present in the corridor:

Minimum glare, lighting is fairly even………………………………...………….2

Some glare in certain areas (e.g., floor, windows, tables)…………………..……1

Strong glare from multiple sources (e.g., floor, tables, windows)………......……0

3. To what extent handrails present in the corridor are visible and easy to use:

Strong color contrast with the wall and easy to grasp …………………………....2

Mod color difference and ease to grasp glare …………………….....................…1

Weak or no color contrast and difficult to grasp……………………….......……0

A-2. PROMOTE MOBILITY

4. To what extent does the unit facilitate walking/ wandering/ mobilization?

     a. Dead Ends:

          Path with no dead ends.. 1

          Path that leads to dead ends or alarmed/secured doors....................0

     b. Places to Sit:

          Path with places to sit..1

          (along or adjacent to corridor including alcoves)

          Path with no places to sit...0

B. SAFETY AND SECURITY

4. Is there adequate space and absence of obstacle/clutter that allow ease of movement in the corridors? (Circle one category in each row; add to get score)

Short corridors (3)	Moderately long (2)	Long Corridors (1)
Formal decentralized nursing station (3)	Informal space for chart & meds (2)	No space for nurses to work (1)
No clutter/obstacles (3)	Some obstacles (2)	Several obstacles and clutter (1)

     Total Score

5. Which of the following describes the physical environment's support in staff supervision?

Staff can view all patients and get to individual patients easily and quickly...............2

Staff can view and/or easily access most of the patients except for a few..................1

Long corridors and/or awkward layout hinders staff supervision.............................. 0

6. Are restraints used to keep patient in chairs?   Yes …(1)   No.....(0)

C. FAMILIARITY AND ORIENTATION

7. To what extent does the corridor contain way-finding signs, decorations and other features that give a more familiar and comfortable atmosphere?

Very familiar and comfortable:

(Clear signage and landmark objects to help way-finding, culturally
relevant artifacts, warm, ambiance)……………..…..3

Moderately familiar and comfortable:

(Adequate signage but lacks strong color contrast, there are some domestic
decoration)......................…………… ………………………………………………2

Somewhat familiar and comfortable:

(Signage exists but lacks color contrast, unclear graphics/ text, there
are some decoration but somewhat poor quality).....…………………………….........1

Not familiar and comfortable:

(Poor signage with no color contrast, unclear graphics/ text, merely
institutional feel, no familiar decoration).....……..…………….........………...…….......0

D. SOCIAL INTERACTION

8. Are there comfortable seating areas to promote meaning interaction?

Multiple options of seating areas and they are relaxing and comfortable…............2

There are limited seating areas available and somewhat comfortable …..…………1

No seating areas.. 0

9. Overall, does the entrance and corridors look welcoming and functional to promoting SOCIAL INTERACTIONS?

	Very Low				Very High
Attractive/ inviting	**0**	**1**	**2**	**3**	**4**
Functional for social interactions	**0**	**1**	**2**	**3**	**4**

E. OVERALL PHYSICAL ENVIRONMENT OF THE CORRIDORS

10. On a scale of 1 to 10, provide your global assessment of the corridors as it appeared during your observation.

Mode   ]

Highly   Very
confusing   comfortable
and non-   and highly
functional   functional

Appendix B: Go-Along Interview Conversation Guide

1. How do you find your way here?

2. Can you tell me a little bit about what it is like staying in the hospital here?

3. What do you like and/or dislike about this environment? How do they make you feel?

4. What are the key things in this environment that help you feel more comfortable?

5. What might help you feel safe?

6. What changes would you like to see in the hospital environment that would make you feel more comfortable? Tell me more about: why they would make you feel better

Appendix C: Study Information Poster

Person-Centred Care in Acute Care

What is the purpose of the research?

The purpose of this research is to examine the processes and impacts of changes in the physical and social environments of an acute unit through implementing person-centred care.

Who is conducting the research?

Principal Investigator: Dr. Alison Phinney, Associate Professor, UBC, Nursing

Co-Investigators: Lillian Hung, PhD Candidate, UBC, Nursing
                           Dr. Paddy Rodney, Associate Professor, UBC, Nursing
                           Dr. Habib Chaudhury, Professor, SFU, Gerontology
                           Jenifer Tabamo, Clinical Nurse Specialist, VCH
                           Doris Bohl, Clinical Nurse Educator, VCH
                           This study is part of Lillian Hung's doctoral thesis.

What are the procedures?

Focus groups: Staff members and leaders of the unit are invited to attend focus group sessions. The focus group sessions will take place in the conference room on the unit for 30-60 minutes. You will be asked to share your thoughts and experiences of making changes in the physical environment and care approaches (social environment).

Observations: Observations will be conducted in public areas (e.g., corridors). The researcher will observe how participants interact with the environment.

Interviews: Patients are invited to take the researcher for a tour of the unit, e.g., Go for a walk together in public areas such as the corridors and have a conversation about the environment, (patients in wheelchairs may be assisted by the researcher). At each interview, the patient participant will be given a choice to use videotaping or not.

Environment Assessment: Family advisors of the hospital or families of patients are invited to conduct an environmental assessment with the researcher (it may take 30-60 minutes)

Please contact the researchers if you want to know more information about this research.

Appendix D: Informed Consent Form for Patients and Families

Participant Information & Consent Form for Patients & Families Person-Centred Care in Acute Care

Principal Investigator: Dr. Alison Phinney, Associate Professor, UBC, Nursing

Co-Investigators: Lillian Hung, PhD Candidate, UBC, Nursing
Dr. Paddy Rodney, Associate Professor, UBC, Nursing
Dr. Habib Chaudhury, Professor, SFU, Gerontology
Jenifer Tabamo, Clinical Nurse Specialist, VCH
Doris Bohl, Clinical Nurse Educator, VCH

This study is part of Lillian Hung's doctoral thesis.

1. Invitation

We are inviting patients and families on CP7CD unit to share with us their experiences and opinions about the implementation of the person-centred care, involving physical environmental changes and staff education.

2. Who is funding the research?

The funding for the study comes from Canadian Institute of Health Research (CIHR) and VCH Robert H. Ho Scholarship.

3. What is the purpose of this research?

Working with leaders, staff, patients and families, we would like to create, deliver, and evaluate changes made in the physical and social environment of an acute unit. What we learn from this study will help to inform the development a good practice guideline and staff education to implement person-centred care in other acute settings.

4. How is the research done?

Researchers are conducting focus groups with staff and leaders, interviews with patients and families. Observations will be conducted in public space e.g., corridors or other social places to learn how patients may feel about the environment.

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If you are a patient and would like to take part in this study, you will be invited to do two to four go-along interviews. A walk-along interview is a conversation that takes place while you are going for a walk with the researcher. The interviews will take place in public spaces only, such as the corridors and social activity space. The researcher may ask you about what you like and dislike about things (e.g., color of the wall) in the environment, how do they make you feel. The interview is semi-structured, meaning you can decide the focus of the conversation on any aspect of the environment that matters to you most. Each interview will last about 15-30 minutes. The researcher may assist patients in wheelchairs to move along the environment. At each interview, patient participant will be given a choice to decide to use videotaping or not. Only with your permission, video- taping will be used. The researcher will try her best not to record those not participating. During the study, the recording will be kept in Lillian's password protected computer and only Lillian and Dr. Phinney will have access to them.

If you are a family member of a patient staying on the unit and would like to take part in this study, you will be invited to do one or two environmental assessment with the researcher, using a standardized audit tool. This will involve walking through the environment and rating specific features of the environment. For example, you will be asked: Do you think the handrails in the corridors are visible and easy to use?

5. Results of the research

The results of this research will be shared with other healthcare professionals, researchers and members of the general public. We plan to publish the results in academic journals and present the results at professional conferences for researchers and healthcare practitioners.

6. What are the potential risks of taking part in this research?

Taking part in an interview may result in a loss of privacy. However, you can decide how much you are willing to share your experiences. You do not have to answer any question if you do not want to. You may also get tired during the interview. If so, you can take a rest, or continue the interview on a different day.

7. What are the potential benefits of taking part in this research?

There may not be any direct benefit to you to take part in this research, although you may find it satisfying to share your experiences as a way to contribute to new knowledge about how to improve the environment in an acute care setting. You may also find the walk-along interviews enjoyable.

8. Confidentiality

Your interview will be transcribed into written form and only members of the research team will see this transcript. The transcript will be anonymous. This means that all identifying information will have been removed or changed and you will not be identified by name in any reports or presentations of the completed study. Pseudonyms will be used on all research related documents. Information that discloses your identity will not be released without your consent unless required by law. However, because the interviews take place in public space, others may be aware that you are a participant in this research and may have opportunity to overhear what you are saying during the interview.

Your consent to take part in this study is accompanied by a separate consent for the researcher team to use video/ text data for team reflection in staff group sessions and other education purposes such as student training and conference presentation. In such instances, the confidentiality of the data will be strictly maintained. Participants' names will not be revealed. However, it is possible that a viewer may recognize face or voice in recording. If you agree to the additional use of the data for the educational purpose, please sign the attached data release form and indicate your specific preference.

During the study, the recording will be kept in Lillian's password protected computer. All study files will be saved on a password protected hard drive and stored in a locked filing cabinet in Dr. Phinney's research office for at least a five-year period. After that time they may be deleted from the hard drive. All recording and computer devices will be encrypted.

9. Who can you contact if you have questions about this research?

If you have any questions about this research, please contact the principal investigator or one of the co-investigators. The names and telephone numbers are listed on the first page of this form.

10. Who can you contact if you have complaints or concerns about this research?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

11. Participant consent and signature

Taking part in this study is voluntary. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on care services you receive at the hospital. Thank you for taking the time to consider providing consent to take part in this study.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.

_____

Participant Signature   Date

(or Substitute Decision Maker signature)

_____

Printed Name of the Participant (or Substitute Decision Maker) signing above

_____

Mailing Address (optional for study report)

DATA RELEASE FORM
Person-Centred Care in Acute Care

In this form, we are seeking your consent to allow us to use your data for educational purposes such as staff education, team reflection, students training, and conference presentations for researchers, scientists and practitioners. In all such instances, your identity will not be revealed. However, it is possible that a viewer may recognize face or voice.

_____

Participant Signature   Date

_____

Printed Name of the Participant signing above

OR

_____

Substitute Decision Maker signature   Date

_____

Printed Name of Substitute Decision Maker signing above

Check off all that apply:

(1) I agree for video clips to be used for education and conference presentation. ☐

(2) I agree that anonymized notes taken of what I say to be used for education and conference presentation. ☐

Appendix E: Informed Consent Form for Staff & Leaders

Participant Information & Consent Form For Staff & Leaders
Person-Centred Care in Acute Care

Principal Investigator: Dr. Alison Phinney, Associate Professor, UBC, Nursing

Co-Investigators: Lillian Hung, PhD Candidate, UBC, Nursing
Dr. Paddy Rodney, Associate Professor, UBC, Nursing
Dr. Habib Chaudhury, Professor, SFU, Gerontology
Jenifer Tabamo, Clinical Nurse Specialist, VCH
Doris Bohl, Clinical Nurse Educator, VCH

This study is part of Lillian Hung's doctoral thesis.

1. Invitation

We are inviting staff members and leaders who are working on the unit to share with us their experiences and opinions about the implementation of the person-centred care, involving physical environmental changes and staff education.

2. Who is funding the research?

The funding for the study comes from Canadian Institute of Health Research (CIHR) and VCH Robert H Ho Scholarship.

3. What is the purpose of this research?

Working with leaders, staff, patients and families, we would like to create, deliver, and evaluate changes made in the physical and social environment of an acute unit. What we learn from this study will help to inform the development a good practice guideline to implement person-centred care in other acute care settings.

4. How is the research being done?

Researchers are conducting focus groups with staff and leaders, interviews with patients, and standardized environmental assessment with families. Also, observations will be conducted in public areas (e.g., corridors) to learn how patients may experience the care environment.

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If you take part in this study, you will be invited to attend focus group sessions. The focus group sessions will take place in a conference room on the unit for 30-60 minutes. You will be asked to share your thoughts and experiences of making changes in the physical environment and care approaches (social environment).

The focus group discussions will be audio-recorded and transcribed for accuracy. The recordings will be stored on a password protected hard drive in Dr. Phinney's research office. The recordings will be stored for at least a five-year period. After that time they may be deleted.

5. Results of the research

The results of this study will be reported in a graduate thesis and may also be published in journal articles and books. We plan to present the results at professional conference for researchers and healthcare practitioners. We will send you a report on the findings if you provide a mailing address below your signature (Optional).

6. What are the potential risks of taking part in this research?

Taking part in focus group sessions may result in a low risk of discomfort in sharing personal opinion. However, you can decide how much you are willing to share your observations and thoughts.

7. What are the potential benefits of taking part in this research?

There are potential benefits of improving the environment of the unit where you work. We also hope that the information learned from this study can be used to benefit teams in other acute care settings to improve the quality of care of patients with dementia.

8. Confidentiality

We encourage participants not to discuss the content of the focus group to people outside the group; however, we can't control what participants do with the information discussed.

The focus group discussion will be transcribed into written form and only members of the research team may see this transcript. All identifying information will have been removed or changed and you will not be identified by name in any reports or presentations of the completed study.

All study files will be saved on a password protected hard drive and stored in a locked filing cabinet in Dr. Phinney's research office. All recording and computer devices will be encrypted.

9. Who can you contact if you have questions about this research?

If you have any questions about this research, please contact the principal investigator or one of the co-investigators. The names and telephone numbers are listed on the first page of this form.

10. Who can you contact if you have complaints or concerns about this research?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

11. Participant consent and signature

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.

_____

Participant Signature   Date

_____

Printed Name of the Participant signing above

Appendix F: Key Action Items in Research

Action Item	Description
Dementia workshop with Jim Mann	Jim is an advisor, and a person living well with dementia. In this one-hour workshop at the hospital, he taught about key aspects in physical and social environments that can have a significant impact on people with dementia.
10 Design Solutions	This document is of proposed design solutions for improving the physical environment of the unit. Key items include: adding small seating areas, using warm colors for walls, making social space for meaningful activities, creating small nursing stations in the hallways.
Gentle Persuasive Approach Education	A full-day education workshop, with 4 modules, including person-centred care, changes in the brain, communication techniques, and protective strategies to use in risky situations.
Double F - Fun Fair Dementia education	Using gamification to reinforce dementia education. In the gym, this one-hour fun fair was packed with games such as jeopardy, snakes and ladders, photo booth, prizes, food and laughs.
Art workshops	Every Tuesday, an artist, Sarah invited patients to join her to co-create art in the conference room of the unit. Sarah also pushed her art cart to the bedside to work with individual patients.
Gerontology Specialty Nursing Certification	Nurses on the unit attended weekly study groups to learn/ review 12 topics in gerontological nursing and they wrote the exam for specialty certification. Topics included: pain management, delirium, etc.
Peer Teaching Videos	The staff co-produced short educational videos on topics such as delirium, types of dementia, etc.
Comfort Mitts	This project involved the staff in the hospital and volunteers in the communities to help make comfort mitts. The comfort mitts covered IV lines, replaced restraints, engaged social exchanges, and reduced anxiety.
Video Reflexive Groups	After watching short videos of the patients' stories, a team of staff collectively reflected and discussed what could be done to improve patient care and experiences.

Action Item	Description
This is Me & My Daily Care Needs	'This is me' and 'My Daily Care Needs' are strength/ ability-based tools to help the staff get to know the patients' likes and abilities. This is me is one page and to be filled out by family members with the patient. It shares the same format as 'My Daily Care Needs,' which is an interdisciplinary care plan.
The ART & SCIENCE of Person-Centred Care Toolkit	This toolkit includes pocket cards, videos, photos, and graphics. The 'ART & SCIENCE' presents good practice principles based on data gathered from patients, families, and staff involved in the project. The toolkit also has links for ordering 'This is me' and 'My Daily Care Needs, and instructions for making comfort mitts, etc.

Appendix G: Education Toolkit (brochure, pocket cards, and pen)

The Art & Science of Person-centred care

A	Acknowledge emotion
R	Relax the pace, slow it down
T	Take note of key life history and habits

Vancouver CoastalHealth

Lillian Hung Clinical Nurse Specialist

S	Stop and Try again
C	Calming down
I	Inquire meanings behind the behaviors
E	Easy prompts
N	Non-verbal, bodily expression
C	Collaborate, work "with"
E	Embrace the moment, make the interaction fun

Good Hospital Care

Person-Centered Care for Patients with Dementia

" The brain needs to relax to function. Patients need a calm environment to do their best " (Susan, Patient)

Vancouver CoastalHealth

ART & SCIENCE of person-centred care

Appendix H: Selected Literature on Physical Environmental Intervention

Study	Methodology	Sample	Interventions	Outcomes
Chaudhury et al. (2017) Canada	Literature review on the impact of physical environment on residents with dementia in long term care	103 papers (94 empirical studies and 9 reviews)	Physical environmental interventions in residential care (LTC)	There is substantial evidence on the influence of unit size, spatial layout, homelike character, sensory stimulation, and environmental characteristics of social spaces on residents' behaviors and well-being in care facilities. However, research in this area is primarily cross-sectional and based on relatively small and homogenous samples.
Chaudhury, Hung & Badger (2013) Canada	Literature review on physical environmental interventions supporting dining experience in long term care	22 papers	Physical environmental interventions supporting dining experience in long term care (e.g., lighting, unit size, furniture, etc)	Overall, the evidence confirms that appropriately designed physical settings play an important role in creating a person-centred dining environment to support best possible mealtime experience for the residents and person-centred care practice.
Waller & Masterson (2015) UK	Quality improvement projects, each project was led by a clinical team	26 NHS trusts projects in acute and community hospitals	Projects awarded to improve ward environments and social spaces, e., improve lighting, using accent color, pictorial signage, comfortable seating areas	The evaluation found that relatively simple, cost-effective changes to the physical environment of care have positive effects on people with dementia and those using and working in the services. These include reducing agitation and challenging behavior, reduced need for anti-psychotic medication, and a reduction in the number of falls
Digby & Bloomer (2014) Australia	Qualitative study, semi-structured interviews from current inpatients with dementia and their family carers.	7 patients with dementia & 4 families	Purpose-built rehab facility	Participants valued homeliness, privacy for the patient and for conversations, a shared space without a television and a connection to the outside; accommodating families, providing quiet spaces and

Study	Methodology	Sample	Interventions	Outcomes
				appropriate amenities were also important
Mazzei et al (2013) Canada	Observational case study, pre and post intervention	6 older people with dementia and responsive behaviors, ages 59-79	Purpose-built acute care unit to meet the needs of older people with dementia, e.g., use color to assist way finding	In pre-intervention, patients liked to congregate around the nursing station. In post-intervention, patients spent 24% less time in the nursing station area and more time in the dining room. This suggests that the spatial behaviors of patients were influenced in different ways by the physical design (PRE and POST) of the acute care space.
Goldberg et al (2013) UK	RCT	600 older patients admitted for acute medical hospital and, identified as "confused" on admission.	Joint staffing by medical and mental health staff, enhanced staff training in person centred dementia care; provision of purposeful activity; and environmental modification	Patients on the specialist unit spent significantly more time with positive mood or engagement (P=0.03) and experienced more staff interactions that met emotional and psychological needs (P<0.001). More families were satisfied with care (P=0.004). No stat. significant differences between the two groups in length of hospital stay, mortality
Upton et al (2012) UK	Data obtained during the evaluation period (Dec 2010 - Dec 2011) was compared to patient activity data from May 2010 – Nov 2010.	Patients with dementia admitted to new Cross Hospital between Dec 2010 - Dec 2011	A specialist dementia acute medical ward, dementia-friendly physical environment	Cases of hospital acquired pneumonia decreased, mobility of patients has improved, a trend for more patients to be discharged back home, Staff satisfaction has improved, low staff turn-over and fewer sick days, but length of stay did not reduce as expected

Study	Methodology	Sample	Interventions	Outcomes
MacDonald, (2011) UK	A quality improvement project, data collected from the November 2010 audit (following the intervention) were compared with baseline data from Nov 2009.	Six wards with the highest % of dementia patients	Environmental modifications (details not given) and dementia education for staff	A trend towards reduced number of bed moves and length of stay, a trend towards a reduction in discharges to long term care, a decrease in the use of antipsychotic medications in hospital
Ancoli-Israel et al (2003) UK	Randomized control trial with 3 treatment groups	92 people with dementia	Morning bright light, evening bright light or morning dim red light.	Increasing light exposure throughout the day and evening increase the likelihood of having better sleep at night

Appendix I: Selected Literature on Dementia Care Education

| Study and Country | Intervention Name | Sample | Implementation Factors | | | Outcomes and Impact | | | Follow up | Research Designs |
			Dissemination	Organization Context	Facilitation & Staff Engagement	Patient/Resident	Staff competency	Staff and Team Experience		
Scerri et al. (2017) UK	Literature review	14 papers of dementia training programmes in hospitals								
Surr & Gates (2017) UK	Literature review	20 papers of dementia training programmes in hospitals								
Scerri et al (2016) UK	Person-Centred Care	2 hospital wards	24 workshops	-	Using appreciative inquiry to facilitate reflecting learning	DCM, improvement in comfort, no improvement in occupation, inclusion	Improved attitude according to (self-developed survey)	-	4 months	QES
Elvish et al (2014) UK	'Getting to know me', 6 hours program	607 staff in 3 NHS Trusts North West England	7.5-hour training workshop	-	-	-	Increase in staff confidence, and knowledge in dementia and changes in beliefs	-	-	QES
Surr et al (2016) UK	Person-Centred Training for Acute Care Care	41 staff (32 of them are nurses) in one NHS acute hospital	A half day foundational training and higher level of adding 3 days in-depth knowledge training,	-	-	-	Improved in staff satisfaction, ADQ (personhood) , but not in self-efficacy SEWDR and ability to develop caring relationship CES	-	4-6 weeks 3-4 months	QES

Study and Country	Intervention Name	Sample	Implementation Factors			Outcomes and Impact			Follow up	Research Designs
			Dissemination	Organization Context	Facilitation & Staff Engagement	Patient/Resident	Staff competency	Staff and Team Experience		
Gillies et al (2015) Canada	GPA Gentle Persuasive Approaches	600 staff in a general hospital	7.5 hour workshop to train the whole interdisciplinary team	-	-	Reduction in restraint use	Improved in efficacy in applying GPA in practice	Reduction of sick time and time loss due to injury	-	CRCT
Robinson et al (2015) UK	General dementia care training	44 staff, nurses and allied health, housekeeping staff on 2 wards, ortho and trauma	2-day education, care bundles for the environment, nutrition and communication	-	-	-	increased knowledge, confidence of dementia care	-	-	QES
Smythe et al (2014) UK	Brief Psychosocial Training Intervention BPTI	81 staff of 3 wards completed survey 15 staff interviewed	6-week classroom-based program, Poor attendance	-	-	-	ADQ ADKS,	MBI	-	QES
Halek et al (2013) Germany	Dementia care mapping	9 NH, 3 nursing units Intervention group, 2x3 units in comparison groups	2 members of each nursing home received DCM training 4-day course	DMA	Feedback to staff & action-planning cycles	NPI FAST QOL-AD QUALID	ADQ	COSOQ CBI	3 years	QE
Horner et al (2013) Australia	Medical care for patients with Cognitive impairment	Nursing staff in 2 Geriatric medicine wards	Online module, with support by a resource officer.	-	-	-	Poor uptake, 26 nursing staff agreed to undertake the education, 6 completed	-	-	QES

Study and Country	Intervention Name	Sample	Implementation Factors			Outcomes and Impact			Follow up	Research Designs
			Dissemination	Organization Context	Facilitation & Staff Engagement	Patient/Resident	Staff competency	Staff and Team Experience		
Galvin et al (2010) US	Dementia-friendly hospitals: Care not crisis	540 staff 4 Hospitals	7-hour workshop, including 5 modules, screening, assessment, communication	-	-	-	Improve staff confidence, and knowledge in dementia and attitude	-	3 months	QES
Speziale et al., (2009) Canada	Gentle Persuasive Approaches	99 staff in Tertiary mental health	7.5-hour workshop to train the whole interdisciplinary team	-	-	Reduced 50% of incidents of physical aggression	Improved in efficacy in applying GPA in practice	-	3 months	QES
Chenoweth et al., (2009) Australia	Person-Centred Care	289 NH residents 30 staff	2-day person-centred care training sessions for 2 care staff 2-day Dementia Care Mapping training sessions for 2 care staff	TESS-NH	Site visit & regular phone contact	Improved CMAI with sustained effect No change in NPI No change in QUALID	-	-	4 and 8 months	CRCT
Kuske et al., (2009) Germany	Dementia care education	10 NH, 20 wards, 210 residents 96 staff	3-month dementia care training, twice a week, 13 one-hour sessions to train the whole team	-	-	Reduced physical restraints use No improvement anti-psychotics use	Improved competence	No change in burnout and health complaints	6 months	CRCT
McPhail et al., 2009 Australia	What is dementia and disease management	28 staff in a hospital ward	10 sessions of didactic lectures, including diagnosis, pain assessment and medications, etc	-	-	Reduction o in aggressive behaviors 4 months post training	Staff reported improved in knowledge and skills	-	4 months	QES

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Study and Country	Intervention Name	Sample	Implementation Factors			Outcomes and Impact			Follow up	Research Designs
			Dissemination	Organization Context	Facilitation & Staff Engagement	Patient/Resident	Staff competency	Staff and Team Experience		
Davison et al., (2007) Australia	Peer support in Dementia care education	113 NH Residents 90 staff	8 session so dementia care training	-	5 peer support sessions facilitated by research team	No reduction in CMAI, with a + trend -	Improved attitudes, knowledge and skills in managing behaviors	No change in burnout	6 months	CRCT
Fossey et al., (2006) UK	Person-Centred Care	12 NH, 306 residents staff not stated	10 months didactic training	-	Skill modeling and supervision by research team over the study period	No reduction in CMAI Reduction in antipsychotic use No change in well being in DCM	-	-	12 months	CRCT
Lyne et al., (2006) UK	Care plan training	14 NH 256 residents 166 staff	Four 3-hour weekly sessions	-	Weekly 1:1 mentorship	Improved depressed symptoms GMS -	-	-	33 weeks	QE
Landreville et al., (2005) Canada	Training for managing agitation	21 NH residents 26 staff in a single NH	Five sessions of 90-minute class training on prevention and management of agitation	-	8-hour weekly meeting to provide feedback and support supervision	Improved CMAI -	Improved self efficacy, increased use of learned techniques	-	2 months	QES
Finnema et al., (2005) Netherlands	Emotion-Oriented Care	14 NH 146 residents 99 staff	Two half-day training on care planning, one staff on the unit to be advisor, advanced course 7-days	-	3 network meeting for advisors; monthly visit by consultant	Improved emotional adaptation for residents with mild – moderate dementia -	Increased knowledge and skills in emotion-oriented care	Improved stress symptoms (GHQ)	7 months	CRCT
Teri et al. (2005) US	Dementia training based on	31 NH residents 25 staff in 4	Two half-day with 4 sessions		-	Reduction in agitation, depression and anxiety NPI, RMBPC, ABID,	No improvement in competency; Staff reaction to		-	CRCT

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Study and Country	Intervention Name	Sample	Implementation Factors			Outcomes and Impact			Follow up	Research Designs
			Dissemination	Organization Context	Facilitation & Staff Engagement	Patient/Resident	Staff competency	Staff and Team Experience		
	person-environment fit theory and social learning theory	Assisted Living facilities				GDS, CAS	behavior improved			
Magai et al., (2002) US	Non-verbal sensitivity	3 NH 91 residents 20 staff	Ten one-hour sessions over 2 weeks on emotional expression and validation skills	-	On-site consultations 3 leadership sessions	No reduction in CMAI and BEHAVE-AD, Cornell; increased positive affect	-	Improved staff affect BSI (depression, anxiety, somatic)	-	CRCT
Burgio et al., (2002) US	Behavior management skills	2 NH 88 residents 106 staff	4 weeks behavior management training (5-hour in-service over 3 days)	-	Hands on training on the unit, one care interaction a day for 2 weeks; verbal and written performance feedback	Improved in CMAI at 4 week and sustained at 3 and 6 month f/u	Decrease ineffective communication strategies	-	3 and 6 months	QE
DeYoung, et al., (2002) US	BMP Behavior management program	32 NH residents	28 hours in house program 1 hour orientation to NHBPS	-	-	Slight reduction in total # and frequency of behaviors by 3 months with significant reduction by 6 months NHBPS	-	-	2 weeks, 3 month, 6 months	QES

Comments: The implementation factors (i.e., evidence, context and facilitation) are categorized based upon the PARiHS model developed by Kitson et al (2008). The quality of the published evidence was categorized as evidence generated from clustered randomized control trials (CRCT), quasi-experimental designs (QE) and QE with single group design (QES).

Instruments: ABID, Agitated Behaviors in Dementia; ADQ, Attitudes to Dementia Questionnaire; ADKS, Alzheimer's Disease Knowledge Scale; BEHAVE-AD, Behavioral Pathology in Alzheimer's Disease Rating Scale; BSI, Brief Symptom Inventory; CAS, Clinical Anxiety Scale; CBI, Copenhagen Burnout Inventory; CES, Caring Efficacy Scale; CMAI, Cohen Mansfield Agitation Inventory; Cornell, Cornell Scale for Depression in Dementia; COSOQ, Copenhagen Psychosocial Questionnaire; DCM, Dementia Care Mapping; DMA, Dementia Milieu Assessment; Geriatric Depression Scale; FAST, Functional Assessment Staging; GHQ, General Health Questionnaire; IBM, Interactional Behavior Measure; LPRS, London Psychogeriatric Rating Scale; MBI, Maslach Burnout Inventory; MIBM, Modified Interaction Behavior Measure; NHBPS, Nursing Home Behavior Problem Scale; NPI, Neuropsychiatric Inventory; PERSON-CENTRED CARE, PAS, Pittsburgh Agitation Scale; Person-centred care; QUALID, Quality of Life in Late Stage Dementia; QUIS, Quality Interactions Schedule; RMBPC, Revised Memory and Behavior Problem Checklist; TESS-NH, Therapeutic Environment Screening Survey for Nursing Homes; NHBPS; Nursing home behavior problem scale, NHBPS; RAS, Ryden Aggression Scale; ABMS, Aggressive Behavior Management Scale; PBI, Problem Based Index, SEWDR, Staff Experiences of Working with Demented Residents questionnaire

Appendix J: Timeline of the Research Actions

1 (Jan)
Information session,
Environmental audits,
Focus groups,
Patient go along interviews

2 (Feb)
Workshop presented by Jim Mann
Focus groups,
Patient go along interviews,
GPA workshops

3 (Mar)
Daily safety huddle began,
Weekly care plan meeting began,
Video reflexive groups
Ten design solutions proposal
Patient go along interviews,
Focus groups

4 (Apr)
Video reflexive groups,
Making person-centred care video,
Geriatric conference to present early
findings

5 (May)
Focus group
ART & SCIENCE person-
centred care video

6 (Jun)
Focus groups
Gerontology study groups
Making what is dementia video
Making pocket cards
Art workshops began
Double F fun fair learning event

7 (Jul)
Tiles making with staff and families
Physician focus group
Comfort mitts project began
Focus groups

8 (Aug)
Focus groups

9 (Sept)
Online module,
Infection control comfort mitts
Focus group

10 (Oct)
'This is me' project
'Good hospital care' education toolkit
Comfort mitts community exhibition
Share findings in Dementia conference in
Sweden & Qualitative Health Research
conference in Kelowna

11 (Nov)
Leadership sponsor left
Exit interview
Focus groups
Embracing change workshop

12 (Dec)
All Staff Forum
Focus group
Present research findings
in the IHI conference in
Florida, US