

**FRONTLINE NURSING STAFF PROVISIONS FOR SELF-DETERMINATION
WITH NURSING HOME RESIDENTS WITH COGNITIVE IMPAIRMENTS: A
SCOPING REVIEW IN PARTNERSHIP WITH LOCH LOMOND VILLA**

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A Report Submitted in Partial Fulfillment
of the Requirements for the Degree of

Master of Nursing

in the Graduate Academic Unit of Nursing

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This report is accepted by the
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THE UNIVERSITY OF NEW BRUNSWICK

October, 2020

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ABSTRACT

Making decisions about daily activities is important for older adults' health and well-being. In nursing homes, frontline nursing staff are challenged with preserving residents' self-determination in the face of ritualistic care routines and time pressures. Staff may also experience tension when their professional responsibilities require them to protect residents against their own unwise decisions that pose a risk to their safety. This tension is amplified in the care of residents with cognitive impairments. This report represents the findings from a scoping review about nursing staffs' provisions for self-determination in nursing homes. It was conceived and prepared in collaboration with Loch Lomond Villa (LLV) as a community partner. This report maps the boundaries of nursing staffs' role in negotiating residents' self-determination. Nursing staffs' roles as investigators, advocates, protectors, and assessors emerged as critical roles to providing for self-determination. Based on these findings, recommendations are offered for practice at LLV.

DEDICATION

To the many residents who have shaped me by refusing my care, and to my mom and grandmother who role modeled nursing with care and compassion.

ACKNOWLEDGEMENTS

As with any project, this one exists only because I stand on the shoulders of giants. Dr. Rose McCloskey has been my never-ending champion and encourager. From the moment I first stepped into her office, I have been imbued with confidence that nurses can make a difference to practice through research. She is the best! Dr. Lisa Keeping-Burke has been a champion of scoping reviews and systematic reviews as research methodology, and her teaching has opened my eyes to what is possible in nursing research. Thank you to Cindy Donovan, who welcomed this project and recommendations for practice at Loch Lomond Villa with open arms. LLV is a special place, and I am honored to work with this organization as a community partner. Thank you to Dr. Sue O'Donnell, who has been with me every step of the way cheering me on. Thank you to Dr. Emily Read, whose comments on my initial proposal helped clarify ideas and brought balance to the project. Thank you to Dr. Donna Bulman, who opened my eyes to the joys of concept analysis and helped me publish a paper with gentle and seasoned direction. To my colleagues at Ridgewood Veterans' Wing—thank you for your excitement about this project and your desire to read everything I write. It's overwhelming and wonderful to know that I work with humans who are eager to learn and do better by residents! Thank you especially to Susan Luckie RN, who is revolutionary in her dedication to listening to residents with cognitive impairments when they say "NO!". Thank you to my colleagues in the MN program who have helped me think through some challenging topics and supported me as I completed a statistics class that claimed part of my soul as its own. Thank you, in particular, to Tanya MacFawn who has been 'my person' in this program. Thank you, as always, to my partner Carolyn

Martin and the number of cats who have been with me through this work—home is where my cup gets filled. This work was also graciously supported through the Alzheimer Society of NB/ Dr. Jed B. Sutherland Bursary and the Cutler Nursing Scholarship, for which I am extremely grateful.

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Introduction

In New Brunswick, nursing homes are residential facilities that are operated (whether for profit or not) for the purpose of providing custodial and nursing care to people who “by reason of age, infirmity or mental or physical disability are not fully able to care for themselves” (Government of New Brunswick, 2014, para. 1). When relocation to a nursing home is required, though, there is an expectation that care extends beyond the provision of these nursing and custodial services and incorporates individual values and preferences (Janes et al., 2008). The World Health Organization (WHO) recently identified autonomy (2015) and choice (2017) in older adulthood as priorities for public health initiatives worldwide. The WHO also encourages a global paradigm shift away from standardized care practices in nursing homes, toward person-centered care (PCC) practices (2015). Promoting self-determination is a priority action for nursing homes providing PCC. Self-determination includes opportunities for residents to communicate choices and preferences that are received and used to guide frontline nursing staffs’¹ actions. It is now widely accepted that the well-being of older adults living in nursing homes is enhanced when choice and self-determination are integrated into the daily

¹ I use the term ‘nursing staff’ throughout this report to describe all formal caregivers who provide or direct personal care for residents in nursing homes. While ‘nurse’ is a protected category reserved for Registered Nurses across Canada, this project follows the convention of the Canadian Nurses’ Association (CNA) in defining ‘nursing staff’ and ‘nursing care’ in long-term care facilities more broadly (2008). In LTC facilities, ‘nursing staff’ commonly includes all formal caregivers who provide or direct personal care, and ‘nursing care’ refers to all personal care provided by those staff members (CNA, 2012). For the purposes of this review, nursing staff included licensed nurses, registered nurses, practical nurses, nursing assistants, enrolled nurses, and advanced practice nurses. In the context of direct quotations, the original author’s language is maintained.

routines of the facility (Dewing, 2002), and yet it can be challenging to actualize this objective.

Promoting self-determination in nursing homes is not without its difficulties in practice. For example, a staff member's ability to honor resident preferences may be constrained by organizational and regulatory factors that promote clinical efficiency and standardized care practices (Bird et al., 2016). Empowering residents to make choices also looks quite different across cultural contexts, considering the unique and context-dependent definitions of autonomy and self-determination that are held around the world (Schopp et al., 2003). Nursing staffs' values and definitions of these concepts impact the care they provide (Bentwich et al., 2018). In virtually all countries, Registered Nurses are among the primary health care professionals (HCPs) responsible for ensuring residents understand the risks and benefits of treatments and behaviors (Nasrabadi & Shali, 2017; Schopp et al., 2003). Research reveals that even highly educated and reflexive Registered Nurses overestimate residents' levels of satisfaction with care and believe that they have fostered higher levels of self-determination than clients² actually experience (Schopp et al., 2003).

Fostering resident choice also means providing supportive environments for residents to make choices that HCPs might consider unwise. Unwise decisions are those that, from the perspective of HCPs, do not promote safety and dignity (Kalis et al., 2004;

² The term 'resident' is most commonly used to describe recipients of nursing home care (Bird et al., 2016). I prefer this language because it reflects the reality that nursing homes are both residence and care facility. When I speak to my own practice, the partner organization for this proposal, and nursing home-specific literature, I use the term 'resident'. I use the term 'client' throughout this proposal when referring to literature that is not exclusively about nursing homes. In the case of direct quotations, the language of the original author is maintained.

Rejnö et al., 2019). In spite of strong beliefs in the importance of self-determination, many nursing staff members describe their roles as protective in nature. They experience tension when resident choices stand in the way of their perceived duty to protect (Chiovitti, 2011). There is strong evidence that nursing staff members tend to enforce compliance with certain practices they deem necessary (e.g. bathing, toileting, medication administration), rather than facilitating resident choice.(Aveyard, 2004; Bird et al., 2016; Schopp et al., 2003) While this persuasion to comply is often done with benevolent intentions—termed ‘kind coercion’(Egede-Nissen et al., 2017, p. 759) in some of the literature—the repercussions for resident wellbeing can be significant. It can impact residents’ mental health, increase responsive behaviors of dementia, and decrease overall perceptions of quality of life (Papastavrou et al., 2016).

The struggle to provide protective care that continues to support self-determination is amplified in the formal care of people with cognitive impairments. People with cognitive impairments are increasingly speaking out against their loss of global decision-making power after diagnosis (Dewing, 2008; Fetherstonhaugh et al., 2013). It is now widely accepted that people with cognitive impairments are capable of making many care decisions for themselves in the early stages of impairment (Daly et al., 2018). This capacity becomes much less certain for people with advanced impairments. Practices continue in residential care for this population that have long been considered unethical for the rest of the population (e.g. covert medication administration) (Tweddle, 2009). The WHO (2015) notes that basic human rights (e.g. the right to refuse touch) are frequently denied to people with advanced cognitive impairments. Even in person-centered facilities, challenges persist in actualizing self-determination for residents with

cognitive impairment. These practices may persist because they are perceived as necessary to protect residents from making unwise decisions that their impairment is presumed to have facilitated. Research shows that nursing staff members often experience distress and uncertainty when they struggle to balance professional responsibilities with ethical obligations to the resident (Chiovitti, 2011). Particularly in instances where resident safety is at stake, self-determination can be difficult to negotiate (Egede-Nissen et al., 2017).

The existing literature on nursing staffs' provisions for self-determination is extremely heterogeneous, and it is challenging to derive recommendations for practice from such a disparate mass of literature. This challenge gave rise to the research project whose findings are described in this report. The project was a scoping review of the literature about frontline nursing staffs' provisions for self-determination with residents with cognitive impairments living in nursing homes. The goal of this project was to derive recommendations for practice for a community partner—Loch Lomond Villa (LLV). LLV is invested in improving long-term care experiences for people living with cognitive impairments. They are also invested in supporting staff, and the organization hopes to continue building nursing staff members' capacities to make ethical choices that are consistent with institutional values.

Existing systematic and scoping reviews concerned with self-determination fell into one of four categories: 1) reviews about substitute decision-makers' experiences of proxy decision-making for people with cognitive impairments (Cresp et al., 2018; Lord et al., 2015; Petriwskyj et al., 2014); 2) reviews about end of life care for people with cognitive impairment (Birchley et al., 2016; Brinkman-Stoppelemburg et al., 2014;

Connolly et al., 2012; Perrar et al., 2015; Sampson et al., 2005); 3) reviews about tensions raised by advanced care planning (Dixon et al., 2018; Exley et al., 2009; Houben et al., 2014; Martin et al., 2016; Robinson et al., 2012); and finally, 4) reviews about shared decision-making and older adults' experiences of making their own decisions about care (Daly et al., 2018; Sayers & Cotton, A, 2015; Truglio-Londrigan & Slyer, 2018) This scoping review maps the existing literature more broadly and focuses specifically on nursing provisions for self-determination with residents living in nursing homes. Nursing provisions are intentional reaction by nursing staff to choices expressed by residents. They include, but are not limited to, activities performed during direct or indirect care, request for permission to provide care or deliver a treatment, conscious efforts to dismiss expressed choices, or covert activities used to disguise a treatment or activity. The term 'provision' can be used to describe both the process of supplying something for use, as well as the amount of something that is supplied (Merriam Webster Dictionary, 2020). A provision is both process and phenomenon. I selected this term over more polarizing terms like 'support for' or 'denial of' self-determination, because it better reflects the relational back-and-forth process of self-determination and points to the degree to which it can be provided by nursing staff. It is also more value-neutral, recognizing that there are times when self-determination cannot be prioritized by nursing staff and times when it can only be facilitated to a degree due to competing safety concerns.

This scoping review is timely, considering the WHO's recent insistence on the importance of self-determination in nursing homes' practices worldwide (2015, 2017) and the orientation toward evidence-informed practice maintained at LLV. The findings

of this scoping review highlight the various roles nursing staff are called upon to assume as they negotiate self-determination alongside competing professional, institutional, and ethical demands. These roles form the basis of practice recommendations offered at the conclusion of this report.

Community Partner

The partner for this project is Loch Lomond Villa (LLV). This partnership was facilitated by an ongoing relationship between LLV and the University of New Brunswick, and by LLV's commitment to evidence-informed practice. LLV is an internationally recognized person-centered nursing home located in Saint John, New Brunswick. Its' campus consists of two large residential buildings (the Villa and the Village) and three independent living/assisted living apartment buildings. The first residential building, the Villa, is divided into three houses—Birch, Elm, and Evergreen—where residents receive personalized residential care. The Village is similarly divided into four residential care houses—Cedar, Dogwood, Maple, and Willow. Each building has many amenities such as glass-covered atriums, open air courtyards, cafes, libraries, movie theatres, and walking paths. Rather than striving for a 'home-like environment' as many nursing homes do, LLV strives to provide a true home and community for people who require extra support (Loch Lomond Villa, 2018). During a multi-phase expansion project that took place over the last twenty years, the buildings were remodeled and in some cases purpose-built for resident comfort (Herman Miller, n.d.). The layout and design of the buildings were developed in consultation with the residents, and each aspect of the houses was designed using person-centered design principles (see for example Brawley, 2005). Their vision is “that of an inclusive, resident-centered community that

encourages dreams, friendship and living with purpose” (Loch Lomond Villa, 2017, para. 2).

As much as dignity and respect were built into the design of the houses, they were also built into the culture of the organization. In 2010, LLV was recognized as a *Planetree Continuing Care Affiliate* (one of only two locations in Canada) for their excellence in providing PCC (Planetree, 2017). *Planetree* is an international organization that offers certification in PCC to organizations worldwide (Planetree, 2018a). According to *Planetree*:

Person-centered care is a systemized approach to delivering healthcare in a way that centers on the perspective of the whole patient and their loved ones, while promoting a healthy, encouraging environment for caregivers and addressing the health needs of the organization’s surrounding community. (2018, para. 3)

Their model (Figure 1) emphasizes that PCC is more than a best practice for improving health outcomes for residents. It also improves employee satisfaction and retention, organizational reputation, and communities more widely (Fazio et al., 2018). PCC organizations also focus on supporting staff, because staff provide better care when they feel respected and cared for themselves (Frampton et al., 2010, p. vii). This framework has been validated as one that improves client outcomes, job satisfaction, and organizational culture across the continuum of care (Cliff, 2012; Coulmont et al., 2013; Ellis L, 2008; Frampton et al., 2010; Gilpin, 2006; Gladstone et al., 2020; McNeal, 2019; Nolan, 1999; Stone, 2008)

While staff at LLV consistently provide PCC to their residents and have been recognized internationally for their commitment to honoring residents’ rights and self-

determination, challenges persist in providing this care in contexts where residents with cognitive impairments wish to make decisions that are perceived by staff as unwise.

Figure 1

Planetree Model of PCC



Figure 1. Reprinted from *Putting patients first field guide: Global lessons in designing and implementing patient-centered care* (p. 13) by Planetree Foundation, 2013, Wiley Press. Copyright (2013) Planetree Foundation.

Situating Myself in this Study

My own experiences as a Registered Nurse in nursing homes in New Brunswick have propelled me on this journey to understand the challenges of providing PCC in the context of cognitive impairments. I was originally drawn to this work because of the struggles I experienced providing person-centered dementia care that balanced protecting residents with respecting their individual desires. My colleagues and I engage with

remarkably complex ethical questions on a daily basis. We wonder about how we are to proceed when a resident clearly does not wish to receive a particular treatment, but their substitute decision-maker insists that their loved one would have wanted this if they could speak for themselves. Ought we listen to the person standing before us, or respect the decisions made by the person's chosen substitute decision-maker? Are advance directives (ADs) appropriate guides for end of life dementia care? How can we protect a resident from falls and other risks, while simultaneously promoting their independence and mobility? When does respect for a resident's right to choose shift toward caregiver neglect? Is hypodermoclysis a reasonable intervention for a resident who has stopped eating and drinking? These questions, among others, have ushered me into graduate studies. I began asking these questions early in my career, when I worked with a resident with whom I developed a very transformative relationship. They came to a head a little over a year ago when I worked with another resident who developed very aggressive tendencies.

The first resident was 98 years old and a veteran of World War II. He had moderately advanced Alzheimer's Disease at the time I knew him. He was even-tempered and funny, and he liked nothing better than lounging in his bed and occasionally dipping into his bedside table drawer for a nut cluster or chocolate covered goodie. Each morning I coaxed him out of bed to the bathroom to do his care, and he reluctantly followed my instructions all the while asking me if I would come back to bed with him. He wanted to marry me, he said, and he was disappointed each time that I pointed out that I am already married and also quite gay. In the first few months he expressed shock and some disgust about same sex marriage, asking questions about the

legalities of it all and less delicate questions about the logistics of loving a woman. Gradually, though, he began to adapt. Although he never remembered our earlier conversations, his responses started to change. Eventually, when I told him about my wife, he turned to me and said: “that’s why I fought in the war—so that people can live how they want” and he kissed me on the cheek. I was stunned by this exchange. In spite of his memory issues, this wonderful man had learned and grown. He never stopped asking indelicate questions and he never stopped asking me to marry him, but his transformation in attitude was remarkable. While many have dismissed this experience, saying that this resident must have supported gay rights all along, my gut tells me that there is more to this. What possibilities might open up in my practice, if I started to see people with dementia as humans who continue to learn, grow, and form deep relationships?

The second story is less pleasant, but no less instructive. I worked with a resident who had grown incredibly violent as his frontal lobe dementia progressed. He was constantly on high alert for intruders and people he perceived as threats. He was in his late 70s and had survived atrocities in the Korean War. By the time I came to know him, he had assaulted a number of other residents and staff. At times, he was funny and appreciative, and he enjoyed ice cream sundaes almost every day. I grew close to his wife, who struggled to understand this dramatic change in his personality. He was also in constant pain, making sitting and standing incredibly difficult. The care team was struggling to balance pain control with sedation, as we often do. In spite of his incredible pain, he persisted in his desire to use the toilet. One day as I was helping him to the toilet and I was bent over bringing his pants down, he punched me in the head. I now live with

a traumatic brain injury that affects most everything in my life. In reflecting on this event, I feel a great deal of empathy for the man who injured me. His pain was uncontrolled and his traumatic experiences in the war were never far from his mind. His behavior—however unfortunate for me—had meaning. What possibilities might open up in my practice, if I start to see aggressive and agitated behaviors as meaningful?

These experiences, among others, propelled me into graduate studies. They have offered me new ways of understanding cognitive impairments and challenging behaviors. This is not to say, of course, that I do not recognize the importance of prioritizing residents' and workers' safety over residents' rights to self-determination at times. HCPs are not free to let residents choose as they might like in all circumstances, given the realities of institutional standards, negligence and malpractice laws, and professional obligations to protect. These factors contribute to the challenges that frontline staff experience as they attempt to facilitate self-determination. Indeed, the challenge of negotiating self-determination alongside these real-world concerns sits at the heart of this inquiry. Following the recommendations of the WHO (2015) and the *United Nations Convention on the Rights of Persons with Disabilities* (Dickey, 2006), this project takes as foundational that self-determination is a basic human right that must be negotiated for all humans regardless of ability. The realities of negotiating this are, however, significantly more complicated and this challenge guides my partnership with LLV.

An analysis of the literature about self-determination in nursing homes has progressed quite organically out of my practice experiences. The findings from this project contribute to the ongoing conversation around improving nursing care for people living with dementia and other cognitive impairments.

Review questions

The overall aim of this scoping review was to map nursing provisions for self-determination while providing care to residents with cognitive impairment who are living in a nursing home. Specifically, the review sought to answer the following questions:

1. What role does self-determination play in the delivery of nursing care with residents with cognitive impairment living in nursing homes?
2. What are the documented strategies that nursing staff use to negotiate self-determination in residents with cognitive impairment?
3. Under what conditions do nursing staff perceive denial of self-determination in residents with cognitive impairment acceptable?
4. What language do nursing staff use to describe challenges negotiating self-determination in residents with cognitive impairment who are living in nursing homes?

The four questions that guided this review acted as a framework for organizing the literature and gave rise to important insights about nursing staff members' roles in negotiating self-determination. Nursing staffs' roles as investigators of residents' cues, advocates of residents' rights, protectors of residents' safety, and mediators of competing demand emerged through analysis of each of the review questions respectively.

Methods

This review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews (Peters et al., 2017) and according to an a priori

protocol (Morris et al., 2020). Scoping reviews are relatively new forms of research. The first framework for scoping reviews was published in 2005 (Arksey & O'Malley, 2005), and was expanded by Levac et al. (2010). The JBI methodology builds off of this expanded version, and includes nine distinct steps (outlined below). Scoping reviews are often confused with systematic reviews, which differ in a number of ways.

Systematic Reviews versus Scoping Reviews

Both scoping and systematic reviews are considered secondary research studies. They seek to answer a question (or series of questions) based on research already undertaken (Ortega & Barker, 2019). Systematic reviews tend to be carried out with the purpose of evaluating the effectiveness of specific healthcare interventions, or with the purpose of proposing recommendations for practice based on the best available evidence (Cochrane, 2020). In a world of quickly accumulating health research, systematic reviews enable HCPs to “assimilate large amounts of information quickly, which speeds up the decision-making process” (Ortega & Barker, 2019, p. 141). Systematic reviews of randomized control trials are often called the “gold standard” of research because they help researchers identify, collate, and synthesize the best available evidence about a topic in order to make practice recommendations (Ham-Baloyi & Jordan, 2016; Teing, 2007). Systematic reviews also sit at the center of evidence-based practice (Joanna Briggs Institute, 2020).

Scoping reviews follow a similar procedure and are similarly rigorous explorations of the literature. Colquhoun et al. (2014) offer the following definition of scoping reviews:

A scoping review or scoping study is a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge (p. 1294).

Scoping reviews address exploratory questions, with the objective of mapping conceptual boundaries of a given topic. While similar in their adherence to an a priori protocol and strict inclusion and exclusion criteria, scoping reviews differ from systematic reviews in two key ways: 1) its goals are not necessarily to address a single practice question but rather to map the conceptual boundaries of a particular topic (Grant et al., 2017; Peters et al., 2017); 2) the process does not include critical appraisal of the quality of included articles. A scoping review identifies, collates and synthesizes heterogeneous literature in order to identify research gaps and make recommendations for future research.

Considering the breadth of the literature about self-determination, I opted for a scoping review over a systematic review for this study. While systematic reviews more commonly serve as the basis for practice recommendations, in this case I selected a scoping review because the topic of self-determination is exceptionally broad and has yet to be mapped in the literature around dementia and residential aged care. A number of concept analysis have been done on self-determination and older adulthood (Bakitas, 2005; Ekelund et al., 2014), but have tended to neglect those with cognitive impairments living in aged care. Self-determination is a foundational concept in the human rights and nursing literature, but there is little consensus on which topics fall under its' umbrella when cognitive impairment is considered. By mapping the literature and nurses' roles in

relation to self-determination, I have been able to identify the topics that fall under the umbrella of facilitating and restricting self-determination in this context. The recommendations that follow from this mapping are provisional, but they I hope they provide a useful starting point for future point-of-care research and more refined systematic reviews.

Procedures

There is little consensus about the proper procedures for conducting a scoping review (Tricco et al., 2016). This project will follow the procedures outlined by JBI (Peters et al., 2017). The JBI framework for scoping reviews builds on Arksey and O'Malley's (2005) framework, as well as the enhancements to their framework proposed by Levac et al. (Levac et al., 2010). The nine steps of scoping reviews, as outlined by Peters et al. (2020), are:

1. Define and align objectives and review questions
2. Develop and align inclusion criteria with objective and review questions
3. Describe the planned approach to evidence search, selection, data extraction, and presentation of the evidence
4. Search for the evidence using a reproducible search strategy
5. Select the evidence
6. Extract the evidence
7. Analyze the evidence
8. Present the results
9. Summarize the evidence in relation to the purpose of the review and review objectives, and make conclusions about the implication of the findings

Considering the heterogenous fields of self-determination, cognitive impairment, and PCC in nursing homes, a scoping review according to this trusted procedure was considered an appropriate approach for this project. It should be noted, here, that systematic and scoping reviews have been critiqued for their emphasis on aggregation and systematization, which can foreclose opportunities to describe tensions and important differences in a field. Unless completed using a carefully planned and rigorous protocol, scoping and systematic reviews have the potential to eclipse important differences (Chambers et al., 2018). The sections below outline the specifics of the protocol that guided this review.

Inclusion criteria

Types of participants

This review considered research and narrative reports on nursing provisions for self-determination in residents with cognitive impairments who are living in a nursing home. Nursing staff included licensed nurses, registered nurses, practical nurses, nursing assistants, enrolled nurses, and advanced practice nurses. Residents with cognitive impairments included residents of a nursing home identified as lacking cognitive capacity to make informed decisions by medical, legal, or nursing professionals. It was not necessary that residents' cognitive impairment was the result of Alzheimer's disease or a related dementia. There were no limitations on age, gender, race, or ethnicity of nursing staff or residents.

Concepts

The concepts examined in this review were self-determination and nursing provisions. As noted above, self-determination included opportunities for residents to communicate choices that were received and used to guide nursing staffs' actions. Nursing provisions were any intentional reaction by nursing staff to choices expressed by residents.

Context

The scoping review considered research reports and narrative articles that reported on nursing provisions for considering and responding to self-determination in residents with cognitive impairments who are living in a nursing home. Nursing homes included any setting identified as a nursing home, including residential care facilities, aged care facilities, hostels for the aged, and long-term care facilities. Only nursing provisions that took place in these settings were included.

Types of Sources

This scoping review considered both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies were considered for inclusion. This review also considered descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion.

Qualitative studies were considered that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative descriptive, action research, and feminist research. Likewise, systematic reviews and text and opinion papers that met the inclusion criteria were considered for inclusion.

Search strategy

The search strategy for this report was developed in consultation with a librarian at Horizon Health Network. The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. I undertook an initial limited search of CINAHL, PubMed and ProQuest Nursing and Allied Health, and then I analyzed the index terms and the keywords contained in relevant titles and abstracts. Keywords included in the preliminary search were: self-determination, autonomy, safety, dementia(s), Alzheimer's Disease, memory loss, cognitive impairment, cognitive dysfunction, home for the aged, long-term care, nursing home(s), residential care, and residential aged care facility. I then undertook a second search using identified keywords and index terms across the following databases: CINAHL (EBSCO), Medline (Ovid), Embase (Elsevier) and ERIC (EBSCO). The full search strategy for all included databases is included as Appendix I. The search for unpublished articles included ProQuest Nursing and Allied Health Database, ProQuest Dissertations and Theses, and Google Scholar. Lastly, I searched the reference list of all identified reports and articles for additional studies not captured by the search strategy.

Only articles published in English were included. As well, only articles published within the last 25 years (1995 onwards) were included, as this time period was considered

most relevant to the realities of modern gerontological nursing practice and the emphasis on self-determination in person-centered care (Daly et al., 2018). This time limit also reflects modern perspectives on including individuals living with dementia in their own care (Dewing, 2002).

Study selection

Following the search, all identified records were collated and uploaded into EndNote V8 (Clarivate Analytics, PA, USA) and duplicates were removed. The remaining citations were imported into Covidence (Veritas Health Innovation, Melbourne, Australia), where I screened titles and abstracts of all citations for congruence with the inclusion criteria. A member of my supervisory committee served as the second reviewer (R.M.), and all disagreements were resolved through conversation with another member of my supervisory committee (L.K.-B.). I retrieved studies that met the inclusion criteria in full and imported their details into the JBI's System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia). I screened all full-text articles, along with my second reviewer (R.M.), and all full text articles that did not meet the inclusion criteria were excluded. Reasons for exclusion are outlined in Appendix II. Any disagreements that arose around an article's inclusion were resolved through discussion with a second member of my supervisory committee (L.K.-B.).

Data extraction

I extracted data from the included articles using an extraction tool I developed for this review (see Appendix III for final version of tool). The extracted data included

specific details about the participants, definitions of self-determination, specific contexts under which self-determination was considered (e.g. restraints), study methods and outcomes of significance to the four review questions. I presented and discussed each element of the extracted data with my supervisory committee to ensure consistency and fidelity to the original works.

Study inclusion

A comprehensive database search of the literature yielded 3784 potential titles, and 21 records were identified from additional sources. Of these titles, it was determined that 1933 were irrelevant to the review questions and were hence removed. A full-text screening of the 155 remaining articles was conducted and through this process 98 additional articles were removed. The reasons for the exclusion of the full text articles that did not meet the inclusion criteria are provided in Appendix III. The search yielded a total of 17 articles for inclusion in this review.

Results

Characteristics of included studies

Study designs

A description of all articles is included in Appendix IV. As per Table 1, six (35%) of the articles were research studies. Of these, two were grounded theory (33.3%)(Janes et al., 2008; Tarzia et al., 2015) and one each of phenomenology (16.7%) (Johansson et al., 2009), qualitative descriptive (16.7%) (Clarke & Davey, 2004), ethnography (16.7%) (Hertogh et al., 2004), and mixed methods (16.7%) (Di Napoli et al., 2013). Five articles

Figure 2

PRISMA Flow Diagram

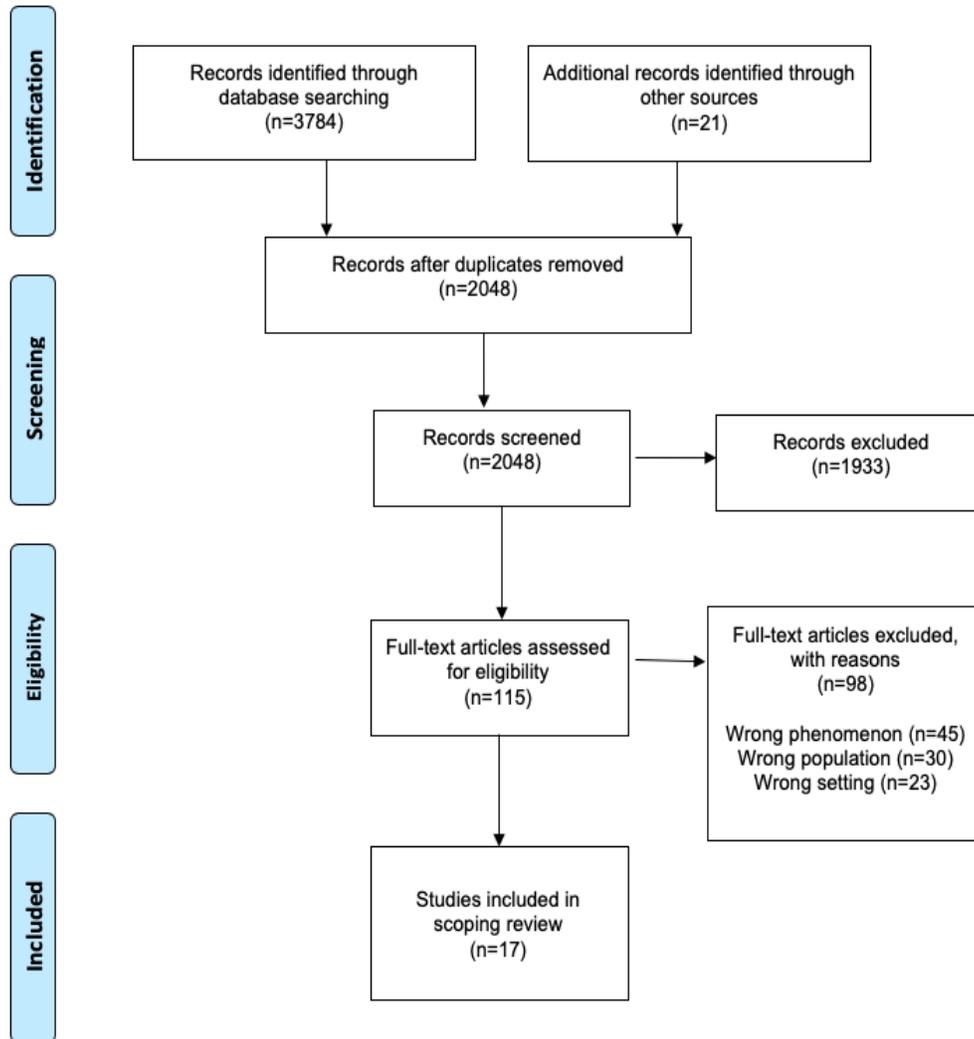


Figure 2. PRISMA flow diagram. Adapted from “Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement” by D. Moher, A. Liberati, J. Tetzlaff, & D. Altman, 2009, *Annals of Internal Medicine*, 15(4), p. 264-269. Copyright (2009) Moher et al.

were case study reports (29%) (Behrens et al., 2018; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Karlsson et al., 2000; Spielman, 1997), five were narrative reports (29%) (Beck

& Vogelpohl, 1995; Dewing, 1999; Greenwood, 2007; Woodrow, 1996; Young & Unger, 2016), and one was a theoretical discussion (16.7%)(Bolmsjö et al., 2006).

Table 1

Description of articles (N=17)

Type of paper	
<i>Research</i>	6 (35.3%)
Grounded Theory	2 (33.3%)
Phenomenology	1 (16.7%)
Qualitative Descriptive	1 (16.7%)
Ethnography	1 (16.7%)
Mixed Methods	1 (16.7%)
<i>Case Study Reports</i>	5 (29.4%)
<i>Narrative Reports</i>	5 (29.4%)
<i>Theoretical Discussions</i>	1 (5.9%)
Year of publication	
Prior to 2000	5 (29.4%)
2000-2015	9 (52.9%)
2015-2018	3 (17.6%)
Country of origin	
United States	4 (23.5%)
United Kingdom	3 (17.6%)
Sweden	3 (17.6%)
Canada	2 (11.7%)
Australia	2 (11.7%)
Germany	1 (5.9%)
Israel	1 (5.9%)

Netherlands	1 (5.9%)
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Publication dates

Just over half of the articles were published between 2000 and 2015 (n=9; 52.9%), (Bolmsjö et al., 2006; Clarke & Davey, 2004; Di Napoli et al., 2013; Greenwood, 2007; Hertogh et al., 2004; Janes et al., 2008; Johansson et al., 2009; Karlsson et al., 2000; Tarzia et al., 2015) with the remaining published either prior to 2000 (n=5; 29.4%)(Beck & Vogelpohl, 1995; Dewing, 1999; Ehrenfeld et al., 1997; Spielman, 1997; Woodrow, 1996) or after 2015 (n= 3; 17.6%)(Behrens et al., 2018; Eisenmann et al., 2016; Young & Unger, 2016).

Country of origin

The articles included in this review originated from several different countries, including the United States (n=4; 23.5%)(Beck & Vogelpohl, 1995; Behrens et al., 2018; Di Napoli et al., 2013; Spielman, 1997), United Kingdom (n=3; 17.6%)(Dewing, 1999; Greenwood, 2007; Woodrow, 1996), Sweden (n=3; 17.6%)(Bolmsjö et al., 2006; Johansson et al., 2009; Karlsson et al., 2000), Canada (n=2; 11.7%) (Johansson et al., 2009; Young & Unger, 2016), Australia (n=2; 11.7%)(Clarke & Davey, 2004; Tarzia et al., 2015), Germany (n=1; 5.9%) (Eisenmann et al., 2016), Israel (n=1; 5.9%) (Ehrenfeld et al., 1997), and the Netherlands (n=1; 5.9%) (Hertogh et al., 2004).

Review findings

The literature about nursing staffs' provisions for self-determination is extremely heterogeneous. This heterogeneity presents a unique opportunity to explore the breadth and scope of the literature on this topic. The four questions that guided this review acted as a framework for organizing the literature and gave rise to important insights about the nursing role in negotiating self-determination. Nursing staffs' roles as investigators of residents' cues, advocates of residents' rights, protectors of residents' safety, and mediators of competing demand emerged through analysis of each of the review questions respectively.

Review question one

What role does self-determination play in the delivery of nursing care with residents with cognitive impairment living in nursing homes?

The role of self-determination was described as mandated, implausible, in the articles included in this review. Self-determination was described as mandated in eight articles (47.1%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Hertogh et al., 2004; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996). As reflected in Table 2, self-determination played a role in care because it was mandated by: 1) government policies (n=6; 75.0%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Hertogh et al., 2004; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015), 2) professional standards (n=3; 37.5%) (Hertogh et al., 2004; Spielman, 1997; Woodrow, 1996), 3) advance care plans (n=2; 25.0%) (Beck & Vogelpohl, 1995; Bolmsjö et al., 2006), 4) family wishes (n=2; 25.0%) (Beck &

Vogelpohl, 1995; Tarzia et al., 2015), and 5) organizational policy (n=1; 12.5%) (Tarzia et al., 2015). In spite of this mandate, all 17 articles pointed to issues that interfere with these mandates and complicate the role of self-determination in the care of residents with cognitive impairments.

Table 2

Factors that Mandate a Role for Self-determination in Practice (n=8)

	Government policies	Professional standards	Advance care plans	Family wishes	Organizational policy
Beck & Vogelpohl, 1995	X		X	X	
Behrens et al. 2018	X				
Bolmsjö et al. 2006			X		
Hertogh et al. 2004	X	X			
Karlsson et al. 2000	X				
Spielman 1997	X	X			
Tarzia et al. 2015	X			X	X
Woodrow 1996		X			
TOTAL n (%)	n=6 (75.0%)	n=3 (37.5%)	n=2 (25.0%)	n=2 (25.0%)	n=1 (12.5%)

Self-determination was also considered impractical or implausible mostly because of process issues that arise during the provision of direct care that impact nursing staffs' interactions with residents (e.g. team dynamics, professional responsibilities, family wishes) (n=14; 82.4%). Another common finding was that self-determination was implausible because of residents' characteristics or limitations (n=9; 52.9%)(Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Eisenmann et al., 2016; Janes et al., 2008; Johansson et al., 2009; Woodrow, 1996; Young & Unger, 2016). Residents with cognitive impairments are often depicted as

limited in their ability to express themselves and to be understood, resulting in few opportunities to discern their wishes. Staff attitudes and beliefs often foreclosed opportunities for self-determination to play a role in care (n=6; 35.3%) (Beck & Vogelpohl, 1995; Dewing, 1999; Greenwood, 2007; Janes et al., 2008; Spielman, 1997; Woodrow, 1996). In particular, staff members' limited ability to see "beyond the label" (Dewing, 1999, p. 588) of dementia hindered their capacity to discern self-determination (Beck & Vogelpohl, 1995; Dewing, 1999; Greenwood, 2007; Spielman, 1997).

The limited skill set of hands-on care providers was also identified as an impediment to self-determination in six articles (n=6; 35.3%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Clarke & Davey, 2004; Ehrenfeld et al., 1997; Janes et al., 2008; Tarzia et al., 2015). Specifically, unregulated care workers such as nursing assistants, resident attendants, and personal support workers were described as lacking the communication skills (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Ehrenfeld et al., 1997), education and knowledge about dementia (Janes et al., 2008; Tarzia et al., 2015), and critical thinking skills (Behrens et al., 2018; Ehrenfeld et al., 1997) needed to support self-determination. Three articles highlighted *all* nursing staffs' tendencies to misinterpret passive acceptance of treatment as meaningful engagement, rendering self-determination implausible even in cases where residents seem agreeable to care (n=3; 17.6%) (Beck & Vogelpohl, 1995; Hertogh et al., 2004; Young & Unger, 2016). Similarly, routinized care was noted to leave no room for self-determination in three articles (17.6%)(Clarke & Davey, 2004; Dewing, 1999; Tarzia et al., 2015). Other common reasons cited for making nursing provisions for self-determination implausible included things such as legal requirements that limit nursing staffs' actions (Spielman, 1997), restrictive

institutional policies (Behrens et al., 2018), economic constraints (Janes et al., 2008), architecture (Woodrow, 1996), and an organizational culture of dependence (Beck & Vogelpohl, 1995) were also noted to make nursing homes difficult places to support self-determination.

Table 3

Self-determination as Implausible (N=17)

	Process issues	Resident characteristics	Staff attitudes/ inability to see beyond label	Lack of skill	Misinterpret passive acceptance	Routinized care	Legal requirements	Restrictive policies	Economic constraints	Architecture	Organizational culture
Beck & Vogelpohl 1995	X	X	X	X	X						X
Behrens et al., 2018	X	X		X				X			
Bolmsjö et al., 2006	X	X									
Clarke & Davey 2004		X		X							
Di Napoli et al. 2013	X										
Dewing 1999			X			X					
Ehrenfeld et al. 1999	X			X							
Eisenmann et al. 2016		X									
Greenwood 2007	X		X								
Hertogh et al. 2004	X				X						
Janes et al. 2008	X	X	X	X					X		
Johansson et al. 2009	X	X									
Karlsson et al. 2000	X										
Spielman 1997	X		X				X				
Tarzia et al. 2015	X			X		X					
Woodrow 1996	X	X	X							X	
Young & Unger 2016	X	X			X						
TOTAL n (%)	n=14 (82.4%)	n=9 (52.9%)	n=6 (35.3%)	n=6 (35.3%)	n=3 (17.6%)	n=3 (17.6%)	n=1 (5.9%)	n=1 (5.9%)	n=1 (5.9%)	n=1 (5.9%)	n=1 (5.9%)

As depicted in Table 4, nursing staffs' role in supporting self-determination is described in conflicting ways including implausible, ideal, mandated and as a skilled

response to residents' desires. Authors noted that although supporting self-determination was ideal (n=17) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Greenwood, 2007; Hertogh et al., 2004; Janes et al., 2008; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996; Young & Unger, 2016) and mandated (n=8),(Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Hertogh et al., 2004; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996), it was also a challenge in practice and often verged on impossible (n=17) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Greenwood, 2007; Hertogh et al., 2004; Janes et al., 2008; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996; Young & Unger, 2016). In order to bridge the gap between expectation and reality, nursing staff were described in most articles as requiring unique skills in balancing competing expectations and decoding resident behavior in order to promote self-determination. In order to satisfy requirements and ideals for self-determination, nursing staff were positioned as needing to be highly skilled investigators who decode residents' intentions from vague signs and expressions. Nursing staffs' role as investigator was described as an important bridge between the reality of care and the ideal of care. This skill was described in 9 articles (52.9%)(Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Greenwood, 2007; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996). Nursing staff were described as interpreting vague institutional policy and continuing to look for

clues about residents’ wishes in their life stories (Dewing, 1999; Hertogh et al., 2004; Karlsson et al., 2000), facial cues(Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Dewing, 1999; Woodrow, 1996), and family requests (Beck & Vogelpohl, 1995; Behrens et al., 2018; Clarke & Davey, 2004; Hertogh et al., 2004; Spielman, 1997; Tarzia et al., 2015). Nursing staff were described as relying on “intuition and personal perceptions”(Beck & Vogelpohl, 1995, p. 144) to accomplish the goal of discerning resident wishes, and using residents’ remaining communication abilities “such as facial expression and mood” to indicate choice (Woodrow, 1996, p. 502).

Table 4

Self-determination as Implausible, Ideal, Mandated and Skilled Investigator (N=17)

	Implausible	Ideal	Mandated	Skill
Beck & Vogelpohl 1995	X	X	X	X
Behrens et al. 2018	X	X	X	
Bolmsjö et al. 2006	X	X	X	
Clarke & Davey 2004	X	X		X
Di Napoli et al. 2013	X	X		
Dewing 1999	X	X		
Ehrenfeld et al. 1999	X	X		X
Eisenmann et al. 2016	X	X		X
Greenwood 2007	X	X		
Hertogh et al. 2004	X	X	X	X
Janes et al. 2008	X	X		
Johansson et al. 2009	X	X		X
Karlsson et al. 2000	X	X	X	
Spielman 1997	X	X	X	X
Tarzia et al. 2015	X	X	X	X
Woodrow 1996	X	X	X	X
Young & Unger 2016	X	X		
Total n (%)	n=17 (100%)	n=17 (100%)	n=8 (47.1%)	n=9 (52.9%)

Review Question Two

What are the documented strategies that nursing staff use to negotiate self-determination in residents with cognitive impairment?

The review identified 17 different strategies used by nursing staff to support self-determination in residents with cognitive impairments. The number of strategies in each article ranged from one to eight (Table 5). These strategies were grouped together based on similarity to form three categories, including resident preferences, teamwork and interdisciplinary support, and organizational support.

As noted in Table 5 fourteen articles (82.4%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Dewing, 1999; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Hertogh et al., 2004; Janes et al., 2008; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996; Young & Unger, 2016) identified resident preferences as a strategy to support self-determination. In employing this strategy, knowing residents' past or present preferences was integral for nursing staff to uphold self-determination in the care of residents with cognitive impairments.

The most common strategy in supporting residents' current wishes was a person-centered care approach, including positive communication between nursing staff and residents (n=11; 78.6%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Clarke & Davey, 2004; Dewing, 1999; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Janes et al., 2008; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996). "Positive communication" strategies (Clarke & Davey, 2004, p. 20) included presenting information at a speed that residents could understand (Dewing, 1999), acknowledging residents' subjective realities (Woodrow, 1996), validating their emotions (Beck & Vogelpohl, 1995), and treating residents as adults worthy of attention and respect (Dewing, 1999; Spielman, 1997). An advance care plan was identified in four articles(28.6%)(Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Eisenmann et al., 2016;

Young & Unger, 2016) as an ideal way for residents to share their wishes with health care providers, because they are put in place before the resident loses their ability to make rational decisions. Three articles (21.4%) (Beck & Vogelpohl, 1995; Woodrow, 1996; Young & Unger, 2016) identified relying on a substitute decision maker (SDM) to learn about residents' past preferences. Three articles (21.4%) described nursing staffs' pathways to supporting self-determination through learning about previous habits, decision-making patterns, and preferences before impairment but were vague in their descriptions of how nursing staff might go about doing this (Beck & Vogelpohl, 1995; Hertogh et al., 2004; Woodrow, 1996). Preventative actions to mitigate risks of current preferences (Johansson et al., 2009) and an openness to residents' unexpected actions (Greenwood, 2007) were each identified as integral to supporting self-determination in one paper (n=1; 7.1%). Johansson et al. (2009) identified preventative actions like installing ribbing on bathroom floors and removing obstacles from hallways as strategies that could help an unsteady resident walk independently while mitigating the risk for fall. Greenwood (2007) described the importance of openness to the unexpected, by which he meant remaining open to the possibility that residents might surprise caregivers with their level of comprehension of their surroundings.

A total of nine articles (52.9%) noted teamwork and interdisciplinary support as a strategy for self-determination. The use of structured approaches to ethical decision-making models that relied on teamwork was described in five articles (55.6%) (Bolmsjö et al., 2006; Greenwood, 2007; Hertogh et al., 2004; Spielman, 1997; Young & Unger, 2016), and an interdisciplinary team approach to decision-making was discussed in four

Table 5

Strategies to support self-determination (n=17)

	RESIDENT PREFERENCES (n=14)						TEAMWORK & INTERDISCIPLINARY SUPPORT (n=9)					ORGANIZATIONAL SUPPORT (n=13)						
	Communication & person-centered care	Advanced Care Planning	Substitute Decision Maker	Previous habits	Preventative actions	Openness to residents' unexpected actions	Ethical models	Interdisciplinary team	Prioritizing residents' needs	Standardized care plans	Openness to unexpected	Education	Consistent staffing patterns	Supportive organizations & colleague recognition	Purpose-built environments	Open communication about institutional policy	Staff support	Staffs willingness to take risks
Beck & Vogelpohl 1995	X	X	X	X								X	X		X		X	
Behrens et al., 2018	X								X									
Bolmsjö et al., 2006		X					X							X				
Clarke & Davey 2004	X											X						
Di Napoli et al. 2013												X						
Dewing 1999	X																	
Ehrenfeld et al. 1999	X							X				X						
Eisenmann et al. 2016	X	X										X	X					
Greenwood 2007						X				X								
Hertogh et al. 2004				X			X					X						
Janes et al. 2008	X							X						X				
Johansson et al. 2009	X				X							X						
Karlsson et al. 2000																		X
Spielman 1997	X						X	X										
Tarzia et al. 2015	X											X						
Woodrow 1996	X		X	X			X		X					X				
Young & Unger 2016		X	X				X	X							X			
TOTAL n (%)	n=11 (78.6%)	28.6% (n=4)	21.4 (n=3)	21.4% (n=3)	7.1% (n=1)	7.1% (n=1)	55.6% (n=5)	44.4% (n=4)	11.1% (n=1)	11.1% (n=1)	11.1% (n=1)	53.4%	23.1% (n=3)	15.4% (n=2)	15.4% (n=2)	7.7% (n=1)	7.7% (n=1)	7.7% (n=1)

articles (44.4%) (Ehrenfeld et al., 1997; Janes et al., 2008; Spielman, 1997; Young & Unger, 2016). One article emphasized the need to prioritize a resident's needs over the needs of the institution (11.1%) (Woodrow, 1996), while another emphasized the importance of standardized care plans that are subject to regular team review (11.1%) (Behrens et al., 2018). One article (11.1%) (Beck & Vogelpohl, 1995) noted that staff need to support one another and encourage breaks when frustrations run high, as they often do when residents' choices conflict with nursing staffs' preferences around the provision of care.

Thirteen articles (76.5%) identified strategies that involved organizational support for staff in their efforts to uphold residents' self-determination. Staff education around dementia, person-centered care, and residents' rights was described as helpful in seven articles (53.4%) (Beck & Vogelpohl, 1995; Di Napoli et al., 2013; M. Ehrenfeld et al., 1997; Eisenmann et al., 2016; Hertogh et al., 2004; Johansson et al., 2009; Tarzia et al., 2015). Staffing patterns that maintained consistency for residents was identified in three articles (23.1%) (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Spielman, 1997), and two articles (15.4%) (Bolmsjö et al., 2006; Janes et al., 2008) noted supportive organizations that praise and recognize staff accomplishments as facilitating residents' self-determination. Two articles (15.4%) (Beck & Vogelpohl, 1995; Woodrow, 1996) identified purpose-built environments as a strategy to ensure residents' freedom of movement which supported nursing staff in their efforts to allow residents to self-determine. One article (7.7%) (Young & Unger, 2016) identified open communication between the organization and the resident/their family about policies around refusal of care and covert administration of treatment. Staffs' comfort in talking risks to support

residents was also found to contribute to residents' self-determination in this context in one article (7.7%) (Karlsson et al., 2000).

Review Question Three

Under what conditions do nursing staff perceive denial of self-determination in residents with cognitive impairment acceptable?

All but two articles (Dewing, 1999; Eisenmann et al., 2016) included in this review identified at least one condition that nursing staff felt would make it acceptable to deny a resident's self-determination. A total of 24 conditions were identified where nursing staff perceived it was acceptable to deny the self-determination of residents with cognitive impairments. The number of conditions identified in each article range from two to 17 (see Table 6). These conditions include structural and procedural conditions.

Structural conditions involve organizational, professional or legal resources that affect the conditions of work (Kilpatrick et al., 2016). These include barriers such as policies and practices of the institution, knowledge and training deficits, organizational culture, economic constraints, legal regulations, availability/continuity of staff, economic resources, legal requirements, and availability of staff, and organizational leadership. Eight articles noted structural issues.

The most common structural issue cited was institutional policies and procedures (n=5; 62.5%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Hertogh et al., 2004; Tarzia et al., 2015), followed by lack of education and training (n=4;

Table 6

Barriers Nurses Identified to Supporting Self-Determination

	STRUCTURAL (n=8)								PROCESS (n=15)															
	Policies & Practices	Knowledge /training deficit	Org Culture	Economic constraints	Legal Regulations	Staff continuity	lack of resources	Org Leadership	Protection	Respecting Family	Protection of other residents	Adherence with routines	Unfamiliarity with residents	Workload	Professional responsibilities	Ineffective communication	Assume resident incapable	Resident compliance	Following others	Depersonalized care	Competing needs	Advanced Directives	Individual values	Lack authority
Beck & Vogelpohl 1995	X	X	X	X		X	X		X	X	X	X	X			X	X	X		X	X	X		
Behrens et al. 2018	X	X		X	X				X		X	X	X	X										
Bolmsjö et al. 2006	X		X	X	X			X			X	X	X		X	X							X	
Clarke & Davey 2004		X									X					X	X	X						
Di Napoli et al. 2013									X	X														
Ehrenfeld et al. 1999			X								X													
Greenwood 2007									X								X							
Hertogh et al. 2004	X								X															
Janes et al. 2008							X					X		X										
Johansson et al. 2009									X															
Karlsson et al. 2000									X	X				X	X					X				
Spielman 1997									X	X					X	X								
Tarzia et al. 2015	X	X				X				X	X			X										X
Woodrow 1996													X		X									
Young & Unger 2016										X								X	X					

TOTAL n (%) of papers that identified each condition	n=5 (62.5%)	n=4 (50.0%)	n=3 (37.5%)	n=3 (37.5%)	n=2 (25.0%)	n=2 (25.0%)	n=2 (25.0%)	n=1 (12.5%)	n=8 (50.0%)	n=6 (40.0%)	n=5 (35.7%)	n=5 (33.3%)	n=4 (26.7%)	n=4 (26.7%)	n=4 (26.7%)	n=4 (26.7%)	n=3 (20.0%)	n=3 (20.0%)	n=2 (13.3%)	n=1 (6.7%)				
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Table 6

Conditions Nursing Staff Perceive Make Denial of Self-Determination Acceptable

50.0%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Clarke & Davey, 2004; Tarzia et al., 2015), economic constraints (n=3; 37.5%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006), organizational culture and emphasis on dependencies (n=3; 37.5%) (Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Ehrenfeld et al., 1997), legal regulations (n=2; 25.0%) (Behrens et al., 2018; Bolmsjö et al., 2006), lack of continuity amongst staff (n=2; 25.0%) (Beck & Vogelpohl, 1995; Tarzia et al., 2015), lack of resources generally (n=2; 25.0%) (Beck & Vogelpohl, 1995; Janes et al., 2008), and lack of organizational leadership (n=1; 12.5%) (Bolmsjö et al., 2006).

Procedural issues involve the method of care delivery; the day-to-day activities or practices that are involved in the provision of direct care to residents. These include the interactions between nursing staff and residents, and conditions that impact these interactions, such as family members, working conditions and other members of the care team. Sixteen process barriers were identified across fifteen articles which justified nursing staffs' denial of residents' self-determination. Eight articles identified a process issue related to nursing staffs' desire to protect residents from harm (50.0%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Di Napoli et al., 2013; Hertogh et al., 2004; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997), while six identified respecting family wishes (40.0%) (Beck & Vogelpohl, 1995; Ehrenfeld et al., 1997; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996). Five (35.7%) articles identified protecting other residents (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Ehrenfeld et al., 1997; Tarzia et al., 2015) and adherence with routines (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Janes et al., 2008)

as barriers to residents' self-determination. Other conditions cited as warranting the denial of residents' self-determination were being unfamiliar with residents (n=4; 26.7%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Woodrow, 1996), a need to uphold professional responsibilities (n=4; 26.7%) (Di Napoli et al., 2013; Karlsson et al., 2000; Spielman, 1997; Woodrow, 1996), workload demands (n=4; 26.7%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Janes et al., 2008; Tarzia et al., 2015), inability to communicate effectively with residents (n=4; 26.7%)(Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Clarke & Davey, 2004; Spielman, 1997), resident compliance (n=3; 20.0%) (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Young & Unger, 2016), assuming residents lack capacity to self-determine (n=3; 20.0%) (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Greenwood, 2007), and doing what other staff do (n=2; 13.3%) (Karlsson et al., 2000; Young & Unger, 2016). The remaining conditions are each cited in one article apiece (n=1; 6.7%).

Review question 4

What language do nursing staff use to talk about self-determination?

The literature described nursing staff members' struggles to negotiate self-determination with residents in four main ways: 1) through the language of competency/capacity assessments (Table 7 and 8); 2) through the language of risk management (Table 9 and 10); 3) through the language of outside influences and balancing competing demands (Table 11 and 12); and 4) through the language of applying ethical ideals to real life situations (Table 13 and 14).

Competency/capacity assessments

Competency is a medico-legal determination about global cognitive function, which is typically provided by a judge in consultation with a physician regarding whether or not a resident's mental capacity limits their ability to make medical and legal decisions for themselves (Darby & Dickerson, 2017). Capacity is much more specific to particular decisions and tasks, and was described as an ongoing and relational process in the literature reviewed (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; Janes et al., 2008; Spielman, 1997; Tarzia et al., 2015; Young & Unger, 2016). Formal assessments of competency are often important in determining a diagnosis of cognitive impairment and useful in determining if a resident was competent to make medical and legal decisions (Hegde & Ellajosyula, 2016); nevertheless, five articles (35.7%) described this process as doing little to guide nursing staff in day-to-day interactions with residents (Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Hertogh et al., 2004; Spielman, 1997; Woodrow, 1996). In their day-to-day interactions, nursing staff were described as continually assessing residents' capacity to perform various tasks and make decisions about personal care.

As reflected in Table 7, 14 articles (82.4%) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; Eisenmann et al., 2016; Greenwood, 2007; Janes et al., 2008; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996; Young & Unger, 2016) used the language of capacity assessments to describe the challenges nursing staffs' experience in negotiating self-determination with residents. The most

common challenges associated with assessing capacity were difficulty interpreting residents' wishes due to communication challenges (n=6; 42.9%) (Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; Eisenmann et al., 2016; Greenwood, 2007; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996; Young & Unger, 2016), followed by inconsistent methods of assessment (n= 5; 35.7%) (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Di Napoli et al., 2013; Janes et al., 2008; Spielman, 1997), and relating to residents based on a dementia label rather than truly assessing capacity (n= 5; 35.7%) (Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Dewing, 1999; Greenwood, 2007; Woodrow, 1996). Articles also described challenges relating to unpredictability and residents' frequently shifting capacities (n= 3; 21.4%) (Behrens et al., 2018; Janes et al., 2008; Johansson et al., 2009), the importance of getting to know residents before assessing capacity (n=3; 21.4%)(Clarke & Davey, 2004; Tarzia et al., 2015; Woodrow, 1996), and misattributing signs of acute illness as signs of decreasing mental capacity (n=1; 21.4%) (Spielman, 1997).

Table 7

Capacity Assessment Language Used to Describe Challenges Nursing Staffs' Experiences Negotiating Self-Determination (n=14)

	Difficulty interpreting residents' wishes	Inconsistent methods of assessment	Relating based on a label rather than a capacity assessment	Unpredictability/ residents' shifting capacities	Importance of getting to know residents	Mis-attributing signs of acute illness
Beck et al. 1995	X	X	X			
Behrens et al. 2018				X		
Bolmsjo et al. 2006	X		X			

Clarke & Davey 2004	X	X			X	
Dewing 1999			X			
Di Napoli et al. 2013		X				
Johansson 2009	X			X		
Eisenmann et al., 2016	X					
Greenwood 2007			X			
Janes 2008		X		X		
Spielman 1997		X				X
Tarzia et al. 2015					X	
Woodrow 2016	X		X		X	
Young & Unger 2016	X					
TOTAL %(n)	n=6 (42.9 %)	n=5 (35.7%)	n=5 (35.7%)	n=3 (21.4%)	n=3 (21.4%)	n=1 (7.1%)

Table 8

Capacity Assessment Language by Article

Category	Language
Inconsistent methods of assessment	<p>“Through a variety of means, including legal and social, we must try to determine the extent of mental incompetence accompanying cognitive impairment” (Beck & Vogelpohl, 1995, p. 52)</p> <p>“Capacity is an abstract concept representing a normative process and, generally, standards of evaluating capacity are not rigorous” (Clarke & Davey, 2004, p. 18)</p> <p>“Sexuality among NH residents with dementia remains an extremely sensitive topic, particularly because national guidelines do not exist for determining sexual consent capacity among severely demented residents... NH staff can become preoccupied with dementia patients’ ability (or inability) to consent to sexual activity” (Di Napoli et al., 2013, pp. 1089-1090)</p> <p>“Because of the perceived uncertain nature of their work, participants did not plan in advance how they would use knowledge about person-centered care” (Janes et al., 2008, p. 17)</p> <p>“Even persons with diminished capacity are able to make some informed decisions about their healthcare choices. In long-term care the APN is required to ensure that residents, whether competent or incompetent, be involved in the decision-making process to the extent that their abilities allow” (Spielman, 1997, p. 379)</p>
Difficulty interpreting wishes	<p>“... the inability of cognitively impaired residents to clearly articulate their own wishes further complicates the situation” (Beck & Vogelpohl, 1995, p. 54)</p> <p>“...as residents’ cognitive abilities gradually decrease, their wishes may be difficult to interpret” (Bolmsjö et al., 2006, p. 341)</p> <p>“...it is often unclear when, in the course of a dementing illness, individuals are no longer able to provide reliable reports about their own quality of life and, by implication, make rational decisions” (Clarke & Davey, 2004, p. 18)</p>

	<p>“The informants experienced special problems related to caring and the increased risk of falling when residents with dementia have insufficient ability to express their needs and call for help. They could not always communicate ‘the right thing’, and the staff could not understand what they meant” (Johansson et al., 2009, p. 67)</p> <p>“In the advanced stage of the disease, significant loss of speech often restricts affected persons in their ability to properly articulate their needs and wishes verbally” (Eisenmann et al., 2016)</p> <p>“To empower an institutionalised resident who has limited communication abilities because of problems such as dysphasia and dementia is obviously difficult” (Woodrow, 1996, p. 503)</p> <p>“Individuals who lack the capacity for fully informed consent for treatment... are not able to express their choices, but they are still owed the same high standard of quality medical care as those who can speak for themselves” (Young & Unger, 2016, pp. 294–295)</p>
Unpredictability	<p>“The IDHCP team’s concerns about Mr. H’s cognitive abilities are eased by his consistent and reasonable decisions for care since coming to the NH” (Behrens et al., 2018, p. 13)</p> <p>“The right to be protected and not exposed to injury focuses on the residents’ reduced ability to judge everyday situations or their own capacity” (Johansson et al., 2009, p. 65)</p> <p>“The <i>game of chance</i> represents the uncertainties inherent in dementia care practice. It relates to the changeable moods and behaviors of residents as well as the variability with which they respond to caregiver actions” (Janes et al., 2008, p. 17)</p>
Relating based on diagnosis	<p>“Caregivers may not recognize the heterogeneity of cognitively impaired elders and may assume that all of them have the same cognitive deficits” (Beck & Vogelpohl, 1995, p. 46)</p> <p>“...it is essential to allow them to take part in decision-making about their care as long as possible and not deem them incompetent in all respects” (Bolmsjö et al., 2006, p. 341)</p> <p>“Nurses who believe in personhood will centre their practice around it. They will respect people with dementia as people first and foremost, seeing beyond the label and traditional stereotypes” (Dewing, 1999, p. 588)</p> <p>“Labels like ‘dementia’ are shown to strongly influence the way that a person is experienced, hindering and often preventing the possibility of relating to another person as a separate and autonomous individual” (Greenwood, 2007, p. 224)</p> <p>When acute disease processes are replaced by chronic dependency, medical labels remain. People see themselves and others in terms of these labels, not as individuals (Woodrow, 1996, p. 504)</p>

Getting to know the resident	<p>“Staff perceived that with only a little effort on their part, decision making could be facilitated, and many emphasized the importance of getting to know the individual with dementia and learning his/her likes and dislikes” (Tarzia et al., 2015, p. 289)</p> <p>“Results imply that aged care workers are making capacity assessments about residents’ personal care abilities without any detailed knowledge, information and updates from medical staff, or even personal exploration, in the course of their work” (Clarke & Davey, 2004, p. 22)</p>
Misattributing signs	<p>“An effective practitioner in long-term care must be able to differentiate behaviors caused by physiologic needs versus a symptom of the dementia process” (Spielman, 1997, p. 376)</p>

Risk Management

The language of risk management was also used to describe the challenges of negotiating self-determination with residents with cognitive impairments. As per Table 9, seven articles (Behrens et al., 2018; Bolmsjö et al., 2006; Ehrenfeld et al., 1997; Greenwood, 2007; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997) discussed these challenges in terms of risk and risk management. The articles described the challenges in terms of: the professional difficulties of ‘taking the risk’ and allowing a resident to self-determine (n=4; 23.5%) (Bolmsjö et al., 2006; Greenwood, 2007; Karlsson et al., 2000; Spielman, 1997); lacking appropriate understanding of the evidence behind risk management interventions (n=3; 17.6%) (Behrens et al., 2018; Bolmsjö et al., 2006; Johansson et al., 2009); practicing in a risk averse culture (n=2; 11.8%) (Behrens et al., 2018; Ehrenfeld et al., 1997); and finally, having to balance the negative impacts of the risk with the right to live at risk (n=1; 5.9%) (Johansson et al., 2009).

Table 9

Risk Management Language Used to Describe Challenges Nursing Staffs’ Experience Negotiating Self-Determination (n=7)

	Taking the risk	Understanding evidence	Risk averse culture	Balancing risk and rights
Behrens et al. 2018		X	X	

Bolmsjo et al. 2006	X	X		
Ehrenfeld et al. 1999			X	
Greenwood 2007	X			
Johansson et al.		X		X
Karlsson 2000	X			
Spielman 1997	X			
Total n (%)	n=4 (57.1%)	n=3 (42.9%)	n=2 (28.6%)	n=1 (14.3%)

Table 10

Risk Management Language by Article

Categories	Language
Practicing in a risk averse culture	<p>“Staff are working in culture of surplus safety (i.e. a culture of maximizing risk avoidance at the expense of independence and self-direction)... Risk aversion on the part of regulators, NH administrators and staff, and family members has the potential to marginalize older adults who these stakeholders intend to protect from harm” (Behrens et al., 2018, p. 12)</p> <p>“The autonomy and privacy of patients must be safe-guarded and their needs satisfied. At the same time, the moral norms of the institution must be maintained and the safety of the patient population ensured” (Ehrenfeld et al., 1997, p. 257)</p>
Balancing the right to protection versus the right to live at risk	<p>“The main category ‘Balancing integrity and autonomy vs. risk of falling’ encompasses an ethical dilemma by which the residents’ integrity and right to self-determination are placed in contrast to their right to protect from, and avoid the risk of fall and physical injury” (Johansson et al., 2009, p. 65)</p>
Understanding the evidence behind risk management interventions	<p>“... in order to avoid persons requiring care suffering greater risks than necessary, the measures used should as far as possible be evidence based” (Bolmsjö et al., 2006, p. 345)</p> <p>“NH staff need evidence-based protocols to guide efforts in honoring preferred choices of residents, especially those that are perceived to be risky” (Behrens et al., 2018, p. 11)</p> <p>“According to the informants, it is important to always be one step ahead to prevent any incidents... However, overly intrusive observation and control on the staffs’ part could irritate and provoke risk behavior” (Johansson et al., 2009, p. 66)</p>
Taking the risk	<p>“The decision to keep Rodney at our home, to take the risk with him, appeared to me to be based on the insight given to me by glimpsing the non-intentional and allowing this to inform my decision” (Greenwood, 2007, p. 231)</p> <p>“[Participants] used arguments [to justify removing a physical restraint] such as: ‘Sometimes you must take the risk, even though you know that the patient might fall; it is not possible to prevent everything’” (Karlsson et al., 2000, p. 845)</p>

	<p>These staff members need to learn to allow residents to take risks- this is their right. To allow a resident to take a risk, staff then need to re-evaluate their notions of good care. Is good care keeping the resident safe, even if it creates distress in the resident? (Spielman, 1997, p. 378)</p> <p>“In their role as carers they will have to accept a certain level of worry if that is required in order not to restrict Mary more than necessary” (Bolmsjö et al., 2006, p. 345)</p>
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Competing Demands

Most of the articles discussed nursing staffs’ negotiations of self-determination with residents within the context of organizational policies and procedures, health and safety requirements, human rights laws, and various government and professional mandates specific to the region of practice, and the rights of other residents (n=13; 76.5%) (see Table 11) (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; M. Ehrenfeld et al., 1997; Hertogh et al., 2004; Janes et al., 2008; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Young & Unger, 2016).

When discussing the challenges of negotiating self-determination in nursing homes in these terms, the majority of the authors expressed nursing staffs’ challenges using the language of balancing an organizational, professional, or legal mandate with real life concerns (n=9; 69.2%) (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; M. Ehrenfeld et al., 1997; Hertogh et al., 2004; Janes et al., 2008; Spielman, 1997; Tarzia et al., 2015). They described challenges arising because a mandate in policy, law, or organizational value did not account for the complex reality of caring for an individual living with cognitive impairment. They also described challenges that arise due to nursing staffs’ fears of professional and legal sanctions such as malpractice, disciplinary hearings, and loss of licensure (n=5;

38.5%) (Behrens et al., 2018; Hertogh et al., 2004; Karlsson et al., 2000; Tarzia et al., 2015; Young & Unger, 2016). Two articles described the challenge in terms of nursing staffs’ need to balance their duty to empower with their duty to protect other residents who might be harmed by residents’ choices (n=2; 15.4%) (Bolmsjö et al., 2006; Karlsson et al., 2000).

Table 11

Competing Demands Language Used to Describe Challenges Nursing Staffs’ Experience Negotiating Self-Determination (n=13)

	Policy does not account for complexity of real life	Fears of professional sanctions	Residents’ competing needs
Beck & Vogelpohl, 1995	X		
Behrens et al. 2018		X	
Bolmsjo et al. 2006			X
Clarke & Davey 2004	X		
Dewing 1999	X		
Di Napoli et al. 2013	X		
Ehrenfeld et al. 1999	X		
Hertogh et al. 2004	X	X	
Janes et al. 2008	X		
Karlsson 2000		X	X
Spielman 19997	X		
Tarzia et al. 2012	X	X	
Young & Unger 2016		X	
Total n (%)	n=9 (69.2%)	n=5 (38.5%)	n=2 (15.4%)

Table 12

Competing Demands Language by Article

Categories	Language
Policy/law/care practice do not account for the complexity of real life	<p>“Although OBRA mandates that we respect the rights and autonomy of residents, OBRA regulations provide few clues to resolving the dilemmas that arise when this mandate is applied to cognitively impaired individuals” (Beck & Vogelpohl, 1995, p. 44)</p> <p>“...these results suggest that mechanisms to maintain autonomy and protect the rights of residents with dementia are not always operating” (Clarke & Davey, 2004, p. 22)</p>

	<p>“...any decisions or actions must have at their centre the desire to maintain or improve that patient’s social well-being or personhood. This is not an easy task in any care setting” (Dewing, 1999, p. 587)</p> <p>“Sexuality among NH residents with dementia remains an extremely sensitive topic, particularly because national guidelines do not exist for determining sexual consent capacity among severely demented residents” (Di Napoli et al. 2016, pg. 1089)</p> <p>“The autonomy and privacy of patients must be safeguarded and their needs satisfied. At the same time, the moral norms of the institution must be maintained and the safety of the patient population ensured” (Ehrenfeld et al., 1999, p. 257)</p> <p>“In this respect, the psychogeriatric care policy follows a path that seems to be opposite to the direction that is indicated in current health care ethics” (Hertogh et al., 2004, p. 1681)</p> <p>“Knowledge about person-centered care does not unequivocally work in every practice moment by virtue of the variability and unpredictability inherent in dementia care practice” (Di Napoli et al., 2013, p. 12)</p> <p>“When considering a resident's ethical rights, legal implications must also be considered. Determination of a person's competency in decision making is a legal issue” (Spielman, 1997, p. 397)</p> <p>“Staff members who participated in the current study described themselves as having to “work within the system” when it came to decision making for individuals with dementia” (Tarzia et al., 2015, p. 288)</p>
<p>Fear of professional sanctions and reliance on outside authority</p>	<p>“However, NH care providers report difficulty in responding to some choices, fearing that negative health outcomes for the resident may result in regulatory sanctions and/or the threat of malpractice litigation” (Behrens et al., 2018, p. 12)</p> <p>“In the end, the doctor and the psychologist were asked to arbitrate: they had to decide what was the correct code of practice in this situation” (Hertogh et al., 2004, p. 1069)</p> <p>“It is suggested that a culture of fear may surround CAM as, lacking guidelines, staff may be fearful of litigation and so practice it in secrecy” (Young & Unger, 2016, p. 291)</p> <p>“Four nurses claimed that the use of a restraint demands a prescription by a physician, which means that they are obligated to use it” (Karlsson et al., 2000, p. 847)</p> <p>“Family members often had their own views about what the individual with dementia should or should not be doing, and staff felt obliged to accommodate them even when it contravened what the resident wanted” (Tarzia et al., 2015, p. 288)</p>
<p>Residents’ competing needs</p>	<p>“Nurses are still at risk of making decisions that are not in the best interest of the person in question, since they will also have to balance this with the best interest of other persons in their care” (Bolmsjo et al., 2006, p. 341)</p>

	<p>“Nursing staff must also balance the best interests of one patient with responsibilities to other patients, families, colleagues and the employing institution” (Hertogh et al., 2004, p. 1681)</p>
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Ethical Ideals to Real Life Situations

Self-determination was rarely discussed as such in the literature identified in this scoping review. Instead, it was discussed indirectly through terms like freedom of movement (Greenwood, 2007; Janes et al., 2008), self-governance, (Clarke & Davey, 2004; Di Napoli et al., 2013; Tarzia et al., 2015; Young & Unger, 2016), and as the essential human right to act autonomously (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Di Napoli et al., 2013; M. Ehrenfeld et al., 1997; Hertogh et al., 2004; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015). In particular, the melding of the language of ‘autonomy’ and ‘self-determination’ facilitated a discussion of the challenges in negotiating self-determination in terms of bioethical principles of autonomy, beneficence, and non-maleficence (Beauchamp & Childress, 2012). Ten articles (58.8%) used the language of bioethics and ethical principles to describe the challenges nursing staff experience negotiating self-determination with residents with cognitive impairments in nursing homes. The most common language used was that of being caught between two principles (n=9; 90%) (Bolmsjö et al., 2006; Dewing, 1999; Di Napoli et al., 2013; Hertogh et al., 2004; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997; Woodrow, 1996; Young & Unger, 2016). One article focused on finding alternatives to the language of ethical dilemmas, offering the language of “autonomy-promoting paternalism” as a way to bring two seemingly disparate concepts together (Beck &

Vogelpohl, 1995, p. 51). Another article focused on role uncertainty and the moral/ethical distress nursing staff experience when they are unsure of their role in decision-making (Bolmsjö et al., 2006).

Table 13

Ethical Dilemma Language Used to Describe Challenges Nursing Staff Experience Negotiating Self-Determination (n=10)

	Caught between two principles	Finding alternatives	Role uncertainty
Beck & Vogelpohl 1995		X	
Bolmsjo et al. 2006	X		X
Dewing 1999	X		
Di Napoli et al. 2013	X		
Hertogh et al. 2004	X		
Johansson et al. 2009	X		
Karlsson et al. 2000	X		
Spielman 1997	X		
Young & Unger 2006	X		
Woodrow 1996	X		
Total n (%)	n=9 (90%)	n=1 (10%)	n=1 (10%)

Table 14

Ethical Dilemmas Language by Article

Categories	Language
Caught between two principles	<p>“First, there is a need to respect the self-determination of the concerned parties, meaning that, only reluctantly and with strong reasons, should care be forced on a person with dementia” (Bolmsjö et al., 2006, p. 345)</p> <p>“In addition, sexual behavior between two cognitively impaired residents poses a dilemma for NH staff response; specifically, whether to prioritize the autonomous behavior of the individual or the practice ethic of beneficence” (Di Napoli et al., 2013, p. 1090)</p> <p>“...tension can develop between the moral principle of perception-oriented care and the moral obligation of caregivers resulting from the principle of respect for autonomy, such as the right to be informed about one’s situation” (Hertogh et al., 2004, p. 1686)</p> <p>“The result showed a complex picture grounded in the ethical dilemma personnel face when, in the course of providing care, they must choose between residents’ safety and their rights to integrity and autonomy” (Johansson et al., 2009, p. 69)</p> <p>“The use of physical restraints in nursing practice has been reported as posing an ethical dilemma for nursing staff, who often express a conflict</p>

	<p>between the patient’s right to self-determination and their own responsibility for doing what they believe is best for her/him” (Karlsson et al., 2000, p. 843)</p> <p>“Nurses pride themselves on treating patients as individuals, regardless of their medical condition or diagnosis.... Working with people who have dementia may, however, challenge nurses’ pragmatic, ethical and philosophical beliefs” (Dewing, 1999, p. 585)</p> <p>“The ethical dilemma faced when a demented resident of a long-term care facility refuses treatment concerns the demented person's autonomy versus the ethical principle of beneficence” (Spielman, 1997, p. 376)</p> <p>“Ethical discernment regarding CAM involves balancing beneficence and nonmaleficence, measuring these against respecting personal autonomy, and taking into account the broadest societal conceptions of justice” (Young & Unger, 2016, p. 295)</p> <p>“Moral duties to promote autonomy through informed consent may contradict professional duties to promote and safeguard patient well-being. But respect for autonomy need not be absolute” (Woodrow, 1996, p. 502)</p>
Finding alternatives	<p>“Usually we perceive autonomy and paternalism as opposite ends of the spectrum of care. However, we may need to embrace a philosophy of autonomy-promoting paternalism, in which the caregiver allows maximum independence while protecting the cognitively impaired resident from harm” (Beck & Vogelpohl, 1995, p. 51)</p>
Role uncertainty	<p>“...seeing needs that cannot be fulfilled and being unclear about where the responsibilities of nurses end [is] likely to create tensions that may result in moral distress” (Bolmsjö et al., 2006, p. 345)</p>

In the next section I discuss the review findings as a whole, and I highlight some of the theoretical issues that emerged through analysis of the literature. Following this I provide a number of specific recommendations for practice change at the partner organization that are directed by the findings from this review.

Discussion

Seventeen articles were identified that explored nursing provisions for self-determination with residents with cognitive impairments living in nursing homes. Each highlighted the idealized expectation that residents’ have the right to self-determine, alongside the reality that this ideal is incredibly complex to manifest in

practice. While self-determination is a basic human right—identified as such in the *United Nations Convention on the Rights of Persons with Disabilities* (Dickey, 2006)—actualizing this principle in the day-to-day care of residents with cognitive impairments is challenging. As Bolmsjo et al. note, a focus on residents’ rights to self-determine

...does not imply a right for people with dementia to do whatever they like, but rather a right to decide and choose between the alternatives that can be offered, since there are other factors that also need to be taken into account (2006, p. 345)

Process factors such as the resident’s safety, worker safety, the safety of other residents, and structural factors like policies and procedures must be considered. As noted in this review, nursing staff are not free to let residents choose as they might like in all circumstances, given the realities of institutional standards, negligence and malpractice laws, and professional obligations to protect vulnerable residents.

The broader theoretical (Bentwich et al., 2017; Bollig et al., 2016; Collier, 1998; Moody, 2003; Preshaw et al., 2016) literature and much of the literature included in this review (Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Dewing, 1999; Di Napoli et al., 2013; Hertogh et al., 2004; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997; Woodrow, 1996; Young & Unger, 2016) about self-determination and cognitive impairment has centered around a debate over the most appropriate ranking of Beauchamp and Childress’ (2012) bioethical principles of autonomy and beneficence. In caring for residents with cognitive impairments who wish to make choices that put them at risk, the nursing staff member’s struggle is often reduced to a choice between supporting autonomy and practicing beneficently.

Practitioners are portrayed as encountering an ethical dilemma in the ranking of these principles and seem to divide sharply on the issue (Moody, 2003; Nicholls & Clayton, 2002). A debate piece by Nicholls and Clayton (2002) demonstrates the reasoning behind both sides of this argument. Nicholls highlights the ways that those in favor of restricting autonomy for the sake of beneficence justify this decision by arguing that it is more important to substantially benefit a resident or help them avoid harm than it is to support their independent decision-making. Clayton presents the perspective of many who favor autonomy and justify promoting it in the face of risk, even for residents who may not understand the full weight of these risks. There are notably few who embrace either view wholeheartedly, though, and the challenge of promoting autonomy while doing good appears much more complex than the theoretical literature currently allows (Beck & Vogelpohl, 1995). In the literature included in this review, nursing staff who are unable to take either side were positioned as experiencing an everyday ethical dilemma (Beck & Vogelpohl, 1995; Bolmsjö et al., 2006; Dewing, 1999; Di Napoli et al., 2013; Hertogh et al., 2004; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997; Woodrow, 1996; Young & Unger, 2016). In spite of these dilemmas, nursing staff were also shown continuing to act and provide care. In mapping the literature about nursing provisions during that care, a more complex understanding of nursing staffs' roles emerged. The nursing staff member's role emerged as a complex mixture of investigator, advocate, protector, and assessor in supporting residents to make their own choices.

Role of Investigator

The first review question asked about the role of self-determination in the provision of everyday nursing care, and nursing staffs' role as skilled investigators

emerged as critical to this challenge. Nursing staff were described as looking for clues about residents' wishes in life stories (Karlsson et al., 2000), facial cues (Woodrow, 1996), vocalizations (Eisenmann et al., 2016; Hertogh et al., 2004; Woodrow, 1996), family's requests (Beck & Vogelpohl, 1995), and many more (Bolmsjö et al., 2006). Nursing staff described their unique capacity to discern and interpret residents' cues based on their knowledge of the individual resident, their knowledge of the typical disease process, and their knowledge of the family (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Hertogh et al., 2004; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996).

Frontline nursing staff were identified as skilled investigators with unique capacities to discern residents' wishes with unique skill in responding to residents' wishes with compassion and respect (Beck & Vogelpohl, 1995; Ehrenfeld et al., 1997; Eisenmann et al., 2016; Hertogh et al., 2004; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996). Appropriate training in positive communication and person-centered care particularly improved unregulated staff members' investigative skills because such training tended to focus on the adage that all behavior has meaning (Clarke & Davey, 2004; Tarzia et al., 2015; Janes et al., 2008). This kind of training orients staff toward investigative work to understand the meaning behind responsive and resistive behaviors (Janes et al., 2008). Nevertheless, unregulated staff were also identified as lacking the capacity to respond to these behaviors and residents' desires in innovative and thoughtful ways (Clarke & Davey, 2004; Tarzia et al., 2015; Janes et al., 2008). While they were respectful and compassionate, decision-making skills decreased as complexity of the situation

increased. Particularly, unregulated nursing staff without formal education at the baccalaureate level were identified as lacking the critical thinking skills required to consider and make decisions about complex resident circumstances related to self-determination (Clarke & Davey, 2004; Janes et al., 2008; Spielman, 1997; Tarzia et al., 2015). Unregulated care workers were troubled by situations where residents refused care that they deemed necessary to support safety, health, and dignity. As Spielman (1997) notes: “the skillful practitioner knows how to help a resident who is refusing care by redirecting, diverting, or returning at a later time. A smile, hug, patience, and humor are imperative” (p. 376). Spielman (1997) and Greenwood (2007) identified Registered Nurses (and particularly advanced practice nurses) as the practitioners best suited to the unique role of facilitating self-determination with residents with cognitive impairments.

Role of Advocate

The nursing staff member’s role as advocate emerged through an analysis of the literature in relation to the second review question, about nursing staffs’ strategies to support self-determination. Nursing staff negotiated self-determination by striking a balance between residents’ past and present preferences (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Dewing, 1999), interdisciplinary team members’ preferences (Behrens et al., 2018; Bolmsjö et al., 2006; Hertogh et al., 2004; Karlsson et al., 2000; Spielman, 1997; Young & Unger, 2016), family wishes (Beck & Vogelpohl, 1995; Behrens et al., 2018; Tarzia et al., 2015), and organizational demands (Beck & Vogelpohl, 1995; Behrens et al., 2018; Karlsson et al., 2000; Tarzia et al., 2015; Woodrow, 1996). The nursing staff member’s role as

advocate was driven by professional and institutional standards, as well as nursing staff members' own moral convictions about residents' rights. This insight gave rise to the practice recommendation to include RAs in documentation about care plan variations at LLV, in the hopes of expanding the dialogue to include more frontline care providers.

Role of Protector

Nursing staffs' self-appointed role as protector emerged in response to question three, which explored the barriers to enacting self-determination. While nursing staff often cited structural issues as the strongest impediment to empowering residents, the most common reason that nursing staff offered for limiting self-determination was a process issue: their desire to protect the resident from harm (Beck & Vogelpohl, 1995; Behrens et al., 2018; Di Napoli et al., 2013; Greenwood, 2007; Hertogh et al., 2004; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997). While organizational factors such as lack of staff continuity (Beck & Vogelpohl, 1995; Tarzia et al., 2015) and institutional policies and procedures (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Hertogh et al., 2004; Tarzia et al., 2015) were often cited as reasons for restricting autonomy, nursing staff most frequently referred to their desire to protect vulnerable residents from physical harm as the reason why they opted to restrict autonomy. People with cognitive impairments were understood as constantly at risk of making seemingly unwise decisions that jeopardized their physical health, as a result of their disease process. The nursing role of protector emerged as an attempt to mitigate that risk and ensure physical safety.

Role of Assessor

In relation to the fourth question, which explored the language used to describe challenges with self-determination, the nursing staff member's role as assessor emerged. Nursing staff members in the literature described their role as assessors of capacity (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; Eisenmann et al., 2016; Greenwood, 2007; Janes et al., 2008; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996; Young & Unger, 2016), risk (Bolmsjö et al., 2006; Ehrenfeld et al., 1997; Greenwood, 2007; Hertogh et al., 2004; Johansson et al., 2009; Karlsson et al., 2000; Spielman, 1997), institutional priorities (Beck & Vogelpohl, 1995; Behrens et al., 2018, 2018; Clarke & Davey, 2004; Dewing, 1999; Di Napoli et al., 2013; Hertogh et al., 2004; Janes et al., 2008; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Young & Unger, 2016), and their own values (Dewing, 1999; Di Napoli et al., 2013; M. Ehrenfeld et al., 1997; Hertogh et al., 2004; Janes et al., 2008; Tarzia et al., 2015).

Autonomy and Self-Determination

Particularly interesting in this review and in nursing staff members' vocalizations was the slippage between the concepts of autonomy and self-determination. 'Self-determination' is frequently used interchangeably with 'autonomy' in the broader literature on ethics (e.g. Hagger et al., 2014), even though the etymology of the two concepts are actually quite different. This may be due, in part, to popular theories of self-determination that began emerging in the 1970s. Self-

determination theory (SDT) and the sub-theories it has generated were originally developed by Deci and Ryan (1985), and they have been updated and empirically tested in many contexts (Kietzman et al., 2013; Kinnafick et al., 2014). SDT is a popular grand theory of human motivation, emphasizing the intrinsic and extrinsic rewards of particular behaviors (Kietzman et al., 2013). Autonomous motivation is central to the theory, and it is defined as motivation to engage in behaviors because they are “consistent with and endorsed by the self” (Jang et al., 2009, p. 644). Autonomously motivated behaviors are driven by understandings of an activity’s values and the ways those values align with the individual’s sense of self. Self-determination in decision-making is the ultimate goal; the ability to act and decide according to one’s internal sense of self, value, and reward in order to control the course of one’s life (Deci & Ryan, 2008).

Within this theory, the capacity to evaluate how an activity aligns with internal values and one’s sense of self is dependent upon reflexivity, intellect, and cognition (Deci & Ryan, 2008). In order to self-determine, SDT holds that individuals must be able to reflect, integrate, and make rational choices that are consistent with an internal self (Jang et al., 2009). SDT’s hyper-focus on rationality and reflexive thought makes it complicated to apply to care of people with cognitive impairments. Indeed, it is in attempting to apply it to these contexts that we can begin to see the bias in this theory toward Western values of rationality. As Dewing (1999) notes, “rationality is highly valued in Western cultures, and in normative philosophical theories the presence of rationality is a necessary condition for personhood” (p. 585). In linking self-determination so strictly to autonomous

motivation, SDT does little to help us understand the lives and personhood of people with cognitive impairments who are almost certainly not motivated by reflexive insights consistently. Neither, though, can it be said that people with cognitive impairments are strictly motivated by external rewards. Unlinking autonomy from self-determination is foundational to the project of beginning to value people apart from their intellectual contributions to the world.

The distinctiveness of each concept is critical to understanding nursing staff members' provisions for self-determination. 'Self-determination' was a concept mobilized by countries and groups oppressed by foreign rule (Erez, 2007; Thurer & Burri, 2018). The meaning of self-determination as the right to self-govern as a nation has given way to use of the term to describe the right of vulnerable groups and individuals to determine what occurs to their bodies (Erez, 2007). Autonomy is a core ethical principle that evolved from the premise that people are endowed with an *internal capacity* to make the right (or most moral) decision (Christman, 2018; Stoljar, 2018)). In contrast, self-determination emerged as a core principle in international human rights, in response to oppressive conditions that constrained individual choices. The right to self-determine is the right to self-govern and decide what to do with one's own body, while autonomy is the internal capacity to determine what is best for oneself according to internal standards of what constitutes a good life (Kalis et al., 2004). Ideally, one's right to make decisions links with the capacity to make informed decisions. In these circumstances, supporting self-determination involves providing appropriate information and empowering people in their decision-making (Grad et al., 2017). In the care of people with cognitive impairments, though, this connection becomes increasingly complex. Residents might be endowed with the

right to self-determine by legal and institutional mandates (Beck & Vogelpohl, 1995; Behrens et al., 2018; Hertogh et al., 2004; Karlsson et al., 2000; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996), and yet their strong internal capacities to decide what is best for themselves is debatable (Beck & Vogelpohl, 1995; Behrens et al., 2018; Bolmsjö et al., 2006; Dewing, 1999; Di Napoli et al., 2013; Greenwood, 2007; Janes et al., 2008; Johansson et al., 2009; Spielman, 1997; Tarzia et al., 2015; Woodrow, 1996; Young & Unger, 2016). In many ways, nursing provisions for self-determination rely on nursing staff members' understandings of autonomy and cognitive impairment.

Personhood

Nursing staff who care for residents with cognitive impairments become enmeshed in philosophical debates about different forms of autonomy and related concepts of personhood that (often unwittingly) structure their care and approaches to self-determination. Moody (2003) identifies two types of autonomy relevant to healthcare professionals in the care of people with later-in-life cognitive impairments: contemporaneous autonomy and precedent autonomy. These terms, also popular in the legal literature about consent and impairment (e.g. de Kort et al., 2017), are the backdrop against which nursing staff practice in the context of cognitive impairment. In their daily efforts to promote self-determination, nursing staff struggle with questions around whether or not they should respect the preferences of the person as they used to be—as reported by their families, advance care plans, and life stories—or the preferences of the person standing in front of them here and now. If, for example, a residents' refusal of life-saving medication (contemporaneous autonomy) collides with a previously known desire to extend life at all costs (precedent

autonomy), which preference is prioritized? Nursing staff can be understood as respecting and supporting self-determination when they accept the resident's current wishes (Dewing, 1999; Janes et al., 2008), but they can also be understood as supporting self-determination when they provide care in accordance with past preferences (even when that care conflicts with currently expressed desires) (Behrens et al., 2018; Moody, 2003).

This debate dovetails into nursing staff members' underlying beliefs about personhood and dementia. Which self—the 'then self' of precedent autonomy or the 'now self' of contemporaneous autonomy—ought to make determinations? Taking this one step further still, are those selves the same? That is, does selfhood remain stable across the lifespan, or does it ebb and flow with disease progression and external input? This debate is ongoing in the literature. For some nursing theorists and researchers, the notion of stable and enduring self-hood is problematic for its hyper-focus on rationality and conscious reflection (Dewing, 1999). For example, in their interviews with children of people with early-onset dementia, Sikes and Hall highlight the problems with what they call the "'still' narrative" (Sikes & Hall, 2018, p. 181). Their participants took little comfort in the idea that their parent was 'still' the same person, and indeed experienced their parents and their relationships with them quite differently than they did prior to the onset of symptoms. They note that it is both limiting and unrealistic to "lock people and their family and friends who are living with dementia into how things were pre-diagnosis" (Sikes & Hall, 2018, p. 193). The dominant message that the people have one immutable and unchanging self, and that people make decisions, learn, and grow in an effort to maintain psychological continuity, did not sit well with participants. Sikes and Hall (2018)

note that the 'still' narrative can be distressing for support people, whose loved ones might have become aggressive or sexually uninhibited as a result of their disease process.

To insist that someone is 'still' the same person is, in many cases, experienced as a discounting of the significant loss, resilience, and coping strategies that accompany life with a dementia diagnosis (Clare, 2002). There is, however, evidence that supports the perspective of an enduring self. In their systematic review of qualitative studies of subjective experiences of self-hood in dementia, Caddell and Clare (2010) analyzed a number of articles that reported evidence of an enduring, preserved sense of self in all stages of dementia. They also note that, while studies found evidence of a preserved self, they also highlighted people's abilities to "reflect on new self attributes which had arisen from the onset of dementia, such as problems with speech and memory" (Caddell & Clare, 2010, p. 115).

Nursing staff become entangled in these debates through their care of people with cognitive impairments, whether or not they are consciously aware of this (Dewing, 1999). The language nursing staff have at their disposal to describe their challenges working with people with cognitive impairments limits their ability to engage in the deeper, reflexive, philosophical work of determining what makes a person a person and how this view influences their decision-making with people with cognitive impairments. Characterizing nursing staff members' struggles in terms of ethical dilemmas, without insight into the deeper values and philosophical questions that drive nursing staffs' responses, reduces their work to a struggle between professional obligation (beneficence) and personal values (autonomy). While the literature in this scoping review does rely on this dichotomy at times, it also clearly

demonstrates that nursing provisions for self-determination are more complex than the language of dilemmas allows, and that nursing staff require new language to frame their discussions and understand their roles.

Education and Training

A critical approach to self-determination, grounded in the philosophical literature about selfhood and autonomy, is hampered by the limited educational preparation of most frontline staff in nursing homes. Most staff are unregulated care providers whose training is focused on the proper completion of physical tasks such as bathing, dressing, and toileting (Chamberlain et al., 2019; Estabrooks et al., 2015). This training infrequently allows for sufficient reflexive thought and discussion about deeper issues of personhood and autonomy which influence nursing provisions for self-determination (Janes et al., 2008). Even in baccalaureate programs, there is limited emphasis on ethical practice specifically with people with cognitive impairments (Surr et al., 2017). Even when this training is provided later, on-the-job, it rarely addresses the deeper philosophical questions about which nursing staff need to be reflexive in order to develop critical insights into their practice (Greenwood, 2007).

When nursing staff members' struggles to support self-determination are characterized as ethical dilemmas it is little wonder why nursing staff seem to be erring on the side of safety and risk aversion in most cases (Karlsson et al., 2000). While the ethical principles of beneficence and autonomy are equally rated theoretically, (Beauchamp & Childress, 2012) in practice the very real pressures of legal, medical, and professional standards and personal values weigh heavily on nursing staff. (Johansson et al., 2009) The language of bioethics alone might be

insufficient to support nursing staff in their work. In order to provide truly person-centered care, as the WHO recommends (2016), nursing staff need to be supported in having these kinds of conversations on the job and during their educational preparation.

Strengths and Limitations

The final number of studies included in this review was just seventeen. Although many articles discussed the topic of self-determination of people with cognitive impairments, only a small number of those articles discussed nursing provisions exclusively and focused specifically on nursing homes. In many cases, literature included nursing staff with other allied health care professionals and focused on care in several different settings. This melding of participant groups and locations made it challenging to distinguish nursing perspectives in nursing homes from others. In excluding these articles, the reviewers acknowledge that important perspectives might have been lost; nevertheless, it was considered important to look exclusively at nursing provisions because nursing staffs' experiences with residents is dramatically different from the experiences of allied health professionals such as physiotherapists and recreational therapists. Similarly, nursing homes are culturally quite different from acute care facilities and nursing provisions in this locale were considered sufficiently different from those enacted in other locations to focus exclusively on nursing homes. The articles came from eight different countries around the world, reflecting the global nature of this challenge, and were published from 1995 to 2018, reflecting the ongoing nature of this challenge. A limitation of the review was that every instance of cognitive impairment identified was related to a

dementia. No articles were returned that focused on life-long cognitive impairments. Even though we tried to be as inclusive as possible with the synonyms included in our search strategy to describe cognitive impairment and self-determination, it is possible that some terms remained unidentified. Only studies published in English were included, which may have resulted in some studies being missed. Finally, no critical appraisal of article quality was conducted which may limit the strength of recommendations derived from this study.

Conclusion

This review mapped the literature on nursing provisions for self-determination in residential care of people with cognitive impairments. The mapped literature highlighted the importance of the nursing role in promoting residents' self-determination and highlighted the complexity of nursing staffs' practices with these residents. Nursing staff members emerged as investigators, advocates, protectors, and assessors. The complexity of this role indicates that nursing staff need to engage in deeper, reflexive conversations about self-determination, autonomy, selfhood and cognitive impairments. These conversations will open up possibilities for better understanding their role in the care of people living with a dementia (Chamberlain et al., 2019).

This analysis is the result of a systematic search of the literature and a rigorous analysis that was guided by the JBI procedures for scoping reviews (Peters et al., 2017). The findings from this work can therefore help serve as a basis for the following practice recommendations for the community partner for this report.

Recommendations

LLV is an explicitly person-centered facility, with a vision and guiding philosophy that centers around mutually beneficial care (Planetree, 2018b). LLV emphasizes the importance of resident *and* staff wellness, which positions it well to implement changes that might further nursing staffs' abilities to support residents' self-determination and/or constrain it with appropriate evidence and ethics-based reasoning. Self-determination is mandated by PCC policies at LLV, but the literature supports that LLV could benefit from further solidification of this mandate. Janes et al. (2008) note the challenges frontline nursing staff experience as they try to implement PCC policies in practice, and they emphasize the many ways that educational programming idealizes everyday nursing practice and fails to consider the complexities of day-to-day care. The literature indicates that self-determination is facilitated when it is mandated *and* staff possess the skills to discern residents' wishes and facilitate complicated conversations with families. Frontline nursing staffs' role in bridging the gap between mandated philosophies and practice impossibility through skilled investigation was revealed through analysis of the first review question. These insights formed the basis for the creation of the following practice

recommendations for LLV regarding supporting self-determination of people with cognitive impairments:

1. Advance care planning should be done with all residents and their families when they are first admitted to the facility.

Advance care plans are often heralded as the pinnacle of PCC with people with late-onset cognitive impairments like those caused by Alzheimer’s Disease (Ampe et al., 2017; Canadian Medical Protective Association, 2019; Motley, 2013; Sævareid et al., 2019). They often serve as the basis for legal documents (Advance Directives) which enshrine residents’ choices in writing, to be enacted once they are no longer capable of deciding for themselves. This has led to a great deal of disagreement in practice, where healthcare providers must balance respecting the preferences of the person as they *used to be*—as outlined in the advance care plan—and the needs and preferences of the person standing in front of the HCP *here and now*. The ethics of supporting a resident as they are now by following guidelines that were established by a person who had not yet experienced their current state can be questionable (Mariani et al., 2017; Moody, 2003; Smith et al., 2013). It is critical, then, that advance care plans be undertaken a bit differently in the context of residents with cognitive impairments at LLV.

Sudore and Fried (2010) contend that healthcare providers need to shift the focus of advance care planning. HCPs need to shift the conversation away from making “premature decisions based on incomplete information, to preparing them and their surrogates for the types of decisions and conflicts they may encounter when

[clinicians] have to make in-the-moment decisions” (p. 256). This includes working with people with cognitive impairments where they are *now* and uncovering and respecting their values as they are currently expressed. Advance care planning becomes, then, a discussion of values and ideas of what constitutes a good life (Kalis et al., 2004) rather than an explicit plan for what might happen during an unforeseen illness.

The resident should be involved in this process as much as possible, and their quality of life prioritized based on their own vocalizations about their care (Dewing, 1999). Considering that substitute decisions makers often make decisions based on their perceptions of the resident rather than the residents’ own previously expressed wishes (Cresp et al., 2018), SDMs should be provided with education on dementia and the Registered Nurse in charge of the unit should facilitate discussions that help SDMs differentiate between their goals and the goals of the resident. LLV currently provides families with a number of information packets and pamphlets about the roles and responsibilities of residents and staff. I recommend preparing an informational pamphlet about substitute decision making in dementia, which can help families understand their role more critically. A discussion of values that involves the resident directly in these discussions whenever possible will help HCPs and families identify current values and how they compare with previously held values. HCPs will need to facilitate discussions with SDMs about the residents’ values and why they might have changed as disease and/or impairment has progressed. This focus on values rather than the concrete plans for how things will progress opens up conversations about the

resident's changing condition and might help SDMs connect more deeply with the residents' actual values.

Advance care plans should be revisited every three months and/or after any life-altering medical events, and should continue to focus on the residents' values (Ampe et al., 2017). Additionally, this planning would ideally be undertaken with a Registered Nurse or licensed HCP in light of the judgement in much of the literature that unregulated care workers are unlikely to possess the skills required to discern resident's wishes. Skilled investigators are required for this process.

2. Audits should be completed regularly to ensure compliance with and fidelity to the residents' care plans

Care plans are required in all licensed nursing homes in New Brunswick. According to regulations under New Brunswick's *Nursing Home Act*, each resident must have an individualized, comprehensive current care plan that is developed on admission and reviewed at least annually (Department of Social Development, 2019). While care plan review occurs at least this frequently (and typically more often) at LLV, I recommend audits not only to ensure care plans are updated but that frontline nursing staff are honouring these care plans in their everyday work (Behrens et al., 2018). If an element of the care plan is not being honoured, this would necessitate a discussion about the care plan and/or staff education to address knowledge deficits and issues with staff approach. A Registered Nurse should complete these audits,

given the finding that unregulated care staff may struggle as complexity of issues increases.

3. Unregulated care workers should be granted access to computer charting and should be encouraged to document changes in resident condition and care challenges in the focus notes.

Following up on the previous recommendation for care planning audits, I also recommend providing opportunities for frontline nursing staff to share their concerns about resident care, staff safety, and approaches to care that are not working well in the interdisciplinary progress record. At present, only RNs and LPNs complete focus charting on residents. As the majority of hands-on care is provided by unregulated care workers at LLV and at nursing homes more generally, audits for fidelity to care plans and identification of challenges to enacting plans would be facilitated if resident attendants (RAs) were encouraged to document changes in the resident's record directly. This may also have the added benefit of demonstrating appreciation for the work of RAs, and respect for their knowledge of the resident. This kind of support and respect was identified as a major facilitator of staffs' positive outlook and desire to support residents to make their own choices (Beck & Vogelpohl, 1995; Clarke & Davey, 2004; Janes et al., 2008). Staff who receive appropriate dementia-specific education, work consistent schedules, are adequately praised, and understand institutional priorities around self-determination may be better able to think critically about the care they provide.

4. A forum should be established for staff to discuss their concerns about resident care and safety.

Much like the recommendation to facilitate the documentation of concerns in the residents' health care record, this recommendation focuses on providing a formal but accessible way for staff to raise concerns about safety and to have those addressed systematically rather than piecemeal in the moment. This process might look like regular, formal care plan meetings between the RNs and the assigned RAs to seek input from RAs about their experiences enacting the care plan. At present the RNs from each house at LLV meet in the mornings to discuss challenges and seek input from the RNs of other houses. When a practice challenge arises that directly involves one of the residents, the RA regularly assigned to that resident might be invited to attend this meeting and provide a short, real-time update on the concern. A care plan discrepancy form might also be useful, if it is completed by the direct care provider and shared with the Director of Care or RN for each house. Such a document might form the basis for future conversations about the care plan and might improve accountability for care plan fidelity.

5. Building on policies of least restraint, LLV should explore less restrictive restraints such as seatbelt alarms and dementia surveillance technology on all houses

Under the Nursing Home Act in New Brunswick, LLV is required to have a written policy of least restraint and a physician's or Nurse Practitioner's order for their use (Department of Social Development, 2019). While LLV has an undeniably low restraint usage rate (both chemical and physical) (A. Connor, personal communication, February 13, 2020), this practice persists for the safety of residents in some cases. Restraint use can impact residents' mental and physical health (e.g. can lead to increased frustration, feelings of powerlessness, pressure sores, and muscle wasting related to inactivity) (Alzheimer Society of Canada, 2017). Pin

restraints, tray tables, and anti-wandering systems are some examples of what is currently in place at LLV. It would be beneficial if each of LLV's facilities were equipped with surveillance technology that would enable residents with cognitive impairments to move about independently in their rooms and hallways with remote supervision. Dementia surveillance technologies can involve motion detectors, GPS tracking, audio monitoring, personal alarms and more (Vermeer et al., 2019). Residents across all of LLV's houses live with cognitive impairments and may benefit from passive surveillance as opposed to active restraint.

6. Policy should be developed around covert administration of medication

Covert administration of medications (CAM) is defined as the administration of any medication in a disguised format such as mixed in food or drinks (Care Quality Commission, 2020). While this practice is often done with benevolent intentions, covert medication administration carries significant risks including breaking a resident's trust with prepared food if the practice is uncovered, changing the mechanism of action of a medication depending upon the food it is mixed with, and more generally risking the trusting relationship between the resident and care provider. As Young & Unger (2016) note:

The practice of CAM is often secretive. It is decided upon by nursing staff alone, and not discussed with colleagues, recorded, or monitored. It is suggested that a culture of fear may surround CAM as, lacking guidelines, staff may be fearful of litigation and so practice it in secrecy. (p. 291)

A lack of guidelines around CAM can amplify nurses' fears of professional sanction and litigation. In order to increase transparency around the practice and in order to advocate for its judicious use, a policy about CAM should be developed. Such a policy would ideally outline how decisions will be made regarding the resident's best interest and medication administration, and these decisions should consider the significant risk of this practice. These decisions should not be made lightly, without interdisciplinary discussion and collaboration with the resident's SDM. A policy would also ideally require consult with pharmacists regarding appropriate food/drink to mitigate the risk of altering the mechanism of action of a medication. Covert medication administration directives should be reviewed at least every three months, to ensure continued appropriateness. Additionally, all medications given covertly should be documented as such and the medium for mixing should be indicated each time so that this practice might be audited in the future.

7. Policies should be developed on the right to live at risk, and waivers of risk should be created for signature by the resident and/or the SDM to protect staff and ensure that residents' rights are protected.

Frontline nursing staff often consider their roles to be protective in nature, and they struggle to provide for residents' self-determination when the residents' safety (or the safety of others) is at stake. They may also fear professional sanctions, and understandably struggle with taking risks that might put the resident or others in danger. It is, however, in taking these risks that Greenwood (2007) describes truly coming to know a resident and the meaning behind their behaviors.

The right to live at risk is often denied to older adults (Danda, 2019), and this is particularly challenging for older adults with cognitive impairments who may

have lived very differently before institutionalization. For example, Greenwood (2007) draws on an example of an older adults whose joy in life was directly connected to solitary walks outdoors in spite of cognitive and physical impairments. To deny this resident free access to the outdoors, even if it was for the benevolent reasons of his safety, was tantamount to imprisoning him. Residents and their SDMs have a right to request 'risky' care if the impacts of risk prevention are too large and the 'risky' care will significantly improve the resident's quality of life. Nevertheless, staff require protection in the event that administered treatments and actions lead to adverse events. Waivers of risk, such as those used by the Regional Health Authority (Horizon Health), might serve to protect staff while simultaneously ensuring that residents' rights and preferences are not eclipsed by staffs' desire to protect residents and themselves against litigation. In combination with a larger risk mitigation strategy, policies and procedures around acceptable and unacceptable risk ought to be in place to guide frontline staff.

8. An ethics committee could be formed to address ethical and moral issues that arise in the delivery of care.

In their discussion of sexuality in nursing, Ehrenfeld et al. (1997) described the formation of an ethics committee to formally discuss ethical and moral issues that arise in the care of residents with sexually disinhibited behaviors. Additionally, Spielman (1997) and Bolmsjo et al. (2006) propose models for working through everyday ethical dilemmas that could be used by such a committee to guide decisions. Using a developed model would ensure that all sides of the issue are addressed judiciously and would allow opportunity for concrete decision-making to flow from meetings. I would strongly encourage such a committee meet regularly, rather than on

an as needed basis, and would encourage the discussion of recurrent routine issues such as a desire to walk unaccompanied as well as larger issues such as the desire to engage in sexual activity with another resident. The composition of this committee should include at least one resident and/or a representative, and it would ideally be reflective of LLV's staff model (60% RAs, 20% LPNs, 15% RNs) in order to ensure that the staff actually providing the care have an opportunity to work through the ethical challenges. This committee might be ideally positioned to engage reports from the staff forum for the discussion of ethical challenges that I recommended in response to review questions two and three. Such a committee would ideally be facilitated by a Registered Nurse, given the finding that unregulated care workers may struggle as complexity of situations increases.

9. Regular education and training on self-determination/ethics.

At present, LLV provides a number of education and training opportunities for staff. On first hire, all staff engage in training in *Gentle Persuasive Approaches* (GPA). GPA is a unique, person-centered dementia care education program that prepares frontline staff for respectful interactions with people with dementia. It is rooted in the understanding that all behavior has meaning and that even challenging behaviors (termed responsive behaviors) express an unmet need (Smith & Buckwalter, 2005). Part of the training program focuses on communication strategies to “prevent, recognize, defuse and respond effectively and safely to responsive behaviors” (Advanced Gerontological Education, 2019). The program aims to provide caregivers with the skills they might need to detect the meanings behind responsive behaviors. While the program is relatively new, compelling evidence exists for its usefulness in practice (Hung et al., 2019). This is an excellent step in

supporting staff to respect residents' choices and promote their appreciation for the importance of self-determination. In spite of this, RAs and other staff would benefit from training opportunities specifically related to self-determination and ethics.

Training on persuasive approaches is important, but RAs might benefit from specific training on the potentially detrimental impacts of restricting freedom and specific training on ethical models that can help them solve seemingly unsolvable dilemmas in practice.

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Appendix I Search Strategy

CINAHL – Searched January 22, 2020.

Search Term(s)	Results
1. MH “Consent+”	17,606
2. MH “Self-Management”	550
3. MH “Patient Autonomy”	6,131
4. MH “Decision Making, Patient+”	16,508
5. TI consent* OR AB consent*	28,594
6. TI autonom* OR AB autonom*	29,874
7. TI self-determin* OR AB self-determin*	3,344
8. TI self-manag* OR AB self-manag*	13,089
9. TI “decision making” OR AB “decision making”	53,605
10. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9	145,111
11. MH “Nurses+”	204,849
12. MH “Nursing Home Personnel”	3,582
13. TI nurs* OR AB nurs*	480,427
14. S11 OR S12 OR S13	563,455
15. MH “Dementia+”	65,352
16. MH “Alzheimer’s Disease”	28,871
17. TI alzheimer* OR AB Alzheimer*	30,610
18. TI dementia OR dementia	45,904
19. TI cognit* N2 impair* OR AB cognit* N2 impair*	24,951
20. TI cognit* N2 declin* OR AB cognit* N2 declin*	8,540
21. TI cognit* N2 dysfunc* OR AB cognit* N2 dysfunc*	3,691
22. TI loss N2 memor* OR AB loss N2 memor*	1,462
23. TI memor* N2 impair* OR AB memor* N2 impair*	3,778
24. S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23	105,307
25. S10 AND S14 AND S24	789
26. S10 AND S14 AND S24; Limits: 19910101-20201231, English	746

Embase – searched January 29, 2020.

Search Term(s)	Results
1. ‘informed consent’/exp	104,798
2. ‘patient autonomy’/exp	5,485
3. ‘patient decision making’/exp	9,813
4. consent* :ti,ab,kw	155,926
5. autonom*:ti,ab,kw	173,115

6. 'self-determin*':ti,ab,kw	6,128
7. 'self-manag*':ti,ab,kw	27,921
8. 'decision making':ti,ab,kw	178,340
9. #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8	566,394
10. 'nurse'/exp	175,699
11. 'nursing home personnel'/exp	651
12. nurs*:ti,ab,kw	530,519
13. #10 OR #11 OR #12	576,437
14. 'dementia'/exp	352,930
15. alzheimer*:ti,ab,kw	201,627
16. dementia:ti,ab,kw	158,218
17. (cognit* NEAR/2 impair*):ti,ab,kw	111,631
18. (cognit*NEAR/2 declin*):ti,ab,kw	37,345
19. (cognit* NEAR/2 dysfunc*):ti,ab,kw	24,430
20. (memor NEAR/2 loss):ti,ab,kw	7,778
21. (memor* NEAR/2 impair*):ti,ab,kw	26,638
22. #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21	508,824
23. #9 AND #13 AND #22	1,326
24. #23 AND (1995:py OR 1996:py OR 1997:py OR 1998:py OR 1999:py OR 2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py or 2019:py OR 2020:py)	1,285
25. #23 AND (1995:py OR 1996:py OR 1997:py OR 1998:py OR 1999:py OR 2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py or 2019:py OR 2020:py) AND [english]/lim	1,197

ERIC (EBSCO) – searched January 29, 2020

Search Term(s)	Results
1. DE “Decision Making” OR DE “Participative Decision Making”	38,418
2. TI consent* OR AB consent*	2,502
3. TI autonom* OR AB autonom*	14,136
4. TI self-determin* OR AB self-determin*	3,432
5. TI self-manag* OR AB self-manag*	1,773
6. TI “decision making” OR AB “decision making”	31,370
7. S1 OR S2 OR S3 OR S4 OR S5 OR S6	72,985
8. DE “Nurses” OR DE “School Nurses”	4,512
9. DE “Nursing Homes”	1,234
10. TI nurs* OR AB nurs*	16,015

11. S8 OR S9 OR S10	16, 652
12. DE “Dementia” OR DE “Alzheimers Disease”	1,148
13. TI dementia OR AB dementia	897
14. TI alzheimer* OR AB alzheimer*	674
15. TI cognit* N2 impair* OR AB cognit* N2 impair*	827
16. TI cognit* N2 declin* OR AB cognit* N2 declin*	157
17. TI cognit* N2 dysfunc* OR AB cognit N2 dysfunc*	120
18. TI loss N2 memor* OR AB loss N2 memor*	114
19. TI memor* N2 impair* OR AB memor* N2 impair*	444
20. S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19	2,749
21. S7 AND S11 AND S20	15
22. S7 AND S11 AND S20, limits 1995-01-01-present, English	12

Ovid MEDLINE(R) (ALL) – searched February 5, 2020

Search Term(s)	Results
1. exp Informed Consent/	40,990
2. exp Self-Management/	2,185
3. exp Personal Autonomy/	16,966
4. exp Decision Making/	201,223
5. consent*.tw.	77,569
6. autonom*.tw.	131,995
7. self-manag*.tw.	19,555
8. self-determin*.tw.	5,223
9. “decision making”.tw.	131,467
10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9	536,155
11. exp Nurses/	88,019
12. exp Nursing Homes/	39,122
13. nurs*.tw.	451,057
14. 11 or 12 or 13	500,637
15. exp Dementia/	164,836
16. alzheimer*.tw.	144,381
17. dementia.tw.	106,375
18. (cognit* adj2 dysfunc*).tw.	15,968
19. (cognit* adj2 impair*).tw.	72,679
20. (cognit* adj2 declin*).tw.	24,423
21. (memor* adj2 loss).tw.	5,291
22. (memor* adj2 impair*).tw.	19,883
23. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22	325,202
24. 10 and 14 and 23	1147
25. limit 24 to (english language and yr=”1995-Current”)	908

ProQuest Dissertations & Theses Global – Searched April 22, 2020

(ti(nurs*) OR ab(nurs)) AND ((ti(dementia) OR ab(dementia)) OR (ti(alzheimer*) OR ab(alzheimer*)) OR (ti(cognit* NEAR/2 impair*) OR ab(cognit* NEAR/2 impair*)) OR (ti(cognit* NEAR/2 declin*) OR ab(cognit* NEAR/2 declin*)) OR (ti(cognit* NEAR/2 dysfunc*) OR ab(cognit* NEAR/2 dysfunc*)) OR (ti(loss NEAR/2 memor*) OR ab(loss NEAR/2 memor*))) AND ((ti(consent*) OR ab(consent*)) OR (ti(autonom*) OR ab(autonom*)) OR (ti(self-determin*) OR ab(self-determin*)) OR (ti(self-manag*) OR ab(self-manag*)) OR (ti("decision making") OR ab("decision making"))))

Limits: 1995-present, English.

ProQuest Nursing & Allied Health Database – Searched April 22, 2020

(ti(nurs*) OR ab(nurs)) AND ((ti(dementia) OR ab(dementia)) OR (ti(alzheimer*) OR ab(alzheimer*)) OR (ti(cognit* NEAR/2 impair*) OR ab(cognit* NEAR/2 impair*)) OR (ti(cognit* NEAR/2 declin*) OR ab(cognit* NEAR/2 declin*)) OR (ti(cognit* NEAR/2 dysfunc*) OR ab(cognit* NEAR/2 dysfunc*)) OR (ti(loss NEAR/2 memor*) OR ab(loss NEAR/2 memor*))) AND ((ti(consent*) OR ab(consent*)) OR (ti(autonom*) OR ab(autonom*)) OR (ti(self-determin*) OR ab(self-determin*)) OR (ti(self-manag*) OR ab(self-manag*)) OR (ti("decision making") OR ab("decision making"))))

Limits: 1995-present, English.

Appendix II

Excluded with reasons

Can elderly individuals with dementia consent to sexual contact? (2015). *Victimization of the Elderly & Disabled*, 18(3), 37-38.

<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=110225424&site=ehost-live>

Exclusion reason: Wrong setting

To restrain or not to restrain? (2019). *Alberta RN*, 74(4), 16-16.

<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=135020905&site=ehost-live>

Exclusion reason: Wrong phenomena

Ackerman, T. F. (1996). The moral implications of medical uncertainty: tube feeding demented patients... tube feeding the demented nursing home resident. *Journal of the American Geriatrics Society*, 44 (10), 1265-1267.

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Exclusion reason: Wrong phenomena

Adams, T. (2010). The applicability of a recovery approach to nursing people with dementia. *International Journal of Nursing Studies*, 47(5), 626-634.

<https://doi.org/10.1016/j.ijnurstu.2009.10.003>

Exclusion reason: Wrong setting

Amella, E. J. (1997). *Amount of food consumed by elderly nursing home residents with dementia as a function of the quality of the reciprocal relationship between nurse aide caregivers and residents, caregivers' power and empathy* New York University.

<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=109873877&site=ehost-live>

Exclusion reason: Wrong phenomena

Aselage, M. (2011). Commentary on Lopez R, Amella E, Mitchell S & Strumpf N (2010) nurses' perspectives on feeding decisions for nursing home residents with advanced

dementia. *Journal of Clinical Nursing*, 20(5-6), 911-912.

<https://doi.org/10.1111/j.1365-2702.2010.03615.x>

Exclusion reason: Wrong phenomena

Ballard, C. (2010). Video decision support affects patients' care choices in dementia care planning. *Evidence Based Mental Health*, 13(1), 12-12.

<https://doi.org/10.1136/ebmh.13.1.12>

Exclusion reason: Wrong setting

Barnes, I. (2003). The resident nobody wants. *Canadian Nursing Home*, 14(2), 19-25.

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Exclusion reason: Wrong phenomena

Batchelor-Aselage, M., Amella, E., Zapka, J., Mueller, M., & Beck, C. (2014). Research with Dementia Patients in the Nursing Home Setting: A Protocol for Informed Consent and Assent. *IRB: Ethics & Human Research*, 36(2), 14-19.

<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=107899855&site=ehost-live>

Exclusion reason: Wrong population

Ben Natan, M., Akrish, O., Zaltkina, B., & Noy, R. H. (2010). Physically restraining elder residents of long-term care facilities from a nurses' perspective. *International Journal of Nursing Practice*, 16(5), 499-507. <https://doi.org/10.1111/j.1440-172X.2010.01875.x>

Exclusion reason: Wrong phenomena

Bentwich, M. E., Dickman, N., & Oberman, A. (2017). Dignity and autonomy in the care for patients with dementia: Differences among formal caretakers of varied cultural backgrounds and their meaning. *Archives of Gerontology & Geriatrics*, 70, 19-27.

<https://doi.org/10.1016/j.archger.2016.12.003>

Exclusion reason: Wrong phenomena

Bentwich, M. E., Dickman, N., & Oberman, A. (2018). Autonomy and dignity of patients with dementia: Perceptions of multicultural caretakers. *Nursing Ethics*, 25(1), 37-53. <https://doi.org/10.1177/0969733016642625>

Exclusion reason: Wrong population

Bentwich, M. E., Dickman, N., & Oberman, A. (2018). Human dignity and autonomy in the care for patients with dementia: differences among formal caretakers from various cultural backgrounds. *Ethnicity & Health, 23*(2), 121-141.
<https://doi.org/10.1080/13557858.2016.1246519>

Exclusion reason: Wrong population

Berghmans, R. L. P. (2010). Dementia and end-of-life decisions: Ethical issues - A perspective from the Netherlands. In (Vol. 45, pp. 401-420). Springer Science + Business Media. https://doi.org/10.1007/978-90-481-8721-8_24

Exclusion reason: Wrong population

Bishop, C., & Chau, D. (2011). What Is Our Ethical Duty to Malingerers? *Annals of Long Term Care, 19*(11), 36-40.
<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=108207216&site=ehost-live>

Exclusion reason: Wrong population

Black, K., & Osman, H. (2005). Concerned about client decision-making capacity? Considerations for practice. *Care Management Journals, 6*(2), 50-55.
<https://doi.org/10.1891/cmaj.6.2.50>

Exclusion reason: Wrong population

Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. *Nursing Ethics, 23*(2), 142-153. doi.org/10.1177/0969733014557719

Exclusion reason: Wrong population

Christenson, J. (2019). An Ethical Discussion on Voluntarily Stopping Eating and Drinking by Proxy Decision Maker or by Advance Directive. *Journal of Hospice & Palliative Nursing, 21*(3), 188-192. doi.org/10.1097/NJH.0000000000000557

Exclusion reason: Wrong phenomena

Cohen-Mansfield, J., & Bester, A. (2006). Flexibility as a Management Principle in Dementia Care: The Adards Example. *The Gerontologist, 46*(4), 540-544.
<https://doi.org/10.1093/geront/46.4.540>

Exclusion reason: Wrong phenomena

Cohen-Mansfield, J., & Lipson, S. (2003). Medical decision-making around the time of death of cognitively impaired nursing home residents: a pilot study. *Omega: Journal of Death & Dying*, 48(2), 103-114.
<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=106571564&site=ehost-live>

Exclusion reason: Wrong phenomena

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Exclusion reason: Wrong phenomena

Crack, J., & Crack, G. (2007). Promoting quality care for older people in meal management: whose responsibility is it? *Australian Journal of Advanced Nursing*, 25(1), 85-89.
<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=105916936&site=ehost-live>

Exclusion reason: Wrong phenomena

Cutcliffe, J., & Milton, J. (1996). In Defence of Telling Lies to Cognitively Impaired Elderly Patients. *International Journal of Geriatric Psychiatry*, 11(12), 1117-1118.
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Exclusion reason: Wrong setting

Davies, S., Ellis, L., & Laker, S. (2000). Promoting autonomy and independence for older people within nursing practice: an observational study. *Journal of Clinical Nursing*, 9(1), 127-136. <https://doi.org/10.1046/j.1365-2702.2000.00348.x>

Exclusion reason: Wrong setting

Day, L., Drought, T., & Davis, A. J. (1995). Principle-based ethics and nurses' attitudes towards artificial feeding. *Journal of Advanced Nursing*, 21(2), 295-298.
<https://doi.org/10.1111/j.1365-2648.1995.tb02525.x>

Exclusion reason: Wrong setting

Doll, G. M. (2013). Sexuality in Nursing Homes. *Journal of Gerontological Nursing*, 39(7), 30-37. <https://doi.org/10.3928/00989134-20130418-01>

Exclusion reason: Wrong population

Dreyer, A., Førde, R., & Nortvedt, P. (2010). Life-prolonging treatment in nursing homes: how do physicians and nurses describe and justify their own practice? *Journal of Medical Ethics*, 36(7), 396-400. <https://doi.org/10.1136/jme.2010.036244>

Exclusion reason: Wrong population

Dröes, R., Boelens-Van Der Knoop, E. C. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., Hoogeveen, F., De Lange, J., & Schölzel-Dorenbos, C. J. M. (2006). Quality of life in dementia in perspective: an explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, 5(4), 533-558.

<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=106146193&site=ehost-live>

Exclusion reason: Wrong setting

Duffin, C. (2007). Empowering and protecting adults who have impaired mental capacity. *Nursing Standard*, 21(30), 12-13.

<http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=aph&AN=24806461&site=ehost-live>

Exclusion reason: Wrong setting

Egede-Nissen, V., Sellevold, G. S., Jakobsen, R., & Sørli, V. (2017). Ethical and cultural striving: Lived experiences of minority nurses in dementia care. *Nursing Ethics*, 24(6), 752-766. doi.org/10.1177/0969733015624489

Exclusion reason: Wrong population

Enes, S. P. D., & de Vries, K. (2004). A survey of ethical issues experienced by nurses caring for terminally ill elderly people. *Nursing Ethics*, 11(2), 150-164. doi.org/10.1191/0969733004ne680oa

Exclusion reason: Wrong setting

Evans, E. A., Perkins, E., Clarke, P., Haines, A., Baldwin, A., & Whittington, R. (2018). Care home manager attitudes to balancing risk and autonomy for residents with

dementia. *Aging & Mental Health*, 22(2), 261-269.

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Exclusion reason: Wrong population

Fetherstonhaugh, D., Tarzia, L., Bauer, M., Nay, R., & Beattie, E. (2016). "The Red Dress or the Blue?". *Journal of Applied Gerontology*, 35(2), 209-226.

<https://doi.org/10.1177/0733464814531089>

Exclusion reason: Wrong population

Fukui, S., Okada, S., Nishimoto, Y., Nelson-Becker, H. B., Fukui, S., Okada, S., Nishimoto, Y., & Nelson-Becker, H. B. (2011). The repeated appeal to return home in older adults with dementia: developing a model for practice. *Journal of Cross-Cultural Gerontology*, 26(1), 39-54. doi.org/10.1007/s10823-010-9133-7

Exclusion reason: Wrong phenomena

Gastmans, C. (2014). Sexual expression in nursing homes: A neglected nursing ethics issue. *Nursing Ethics*, 21(5), 505-506. doi.org/10.1177/0969733014531530

Exclusion reason: Wrong phenomena

Gjødsbøl, I. M., Koch, L., & Svendsen, M. N. (2017). Resisting decay: On disposal, valuation, and care in a dementia nursing home in Denmark. *Social Science & Medicine*, 184, 116-123. doi.org/10.1016/j.socscimed.2017.05.022

Exclusion reason: Wrong phenomena

Godwin, B., & Poland, F. (2015). Bedlam or bliss? Recognising the emotional self-experience of people with moderate to advanced dementia in residential and nursing care. *Quality in Ageing & Older Adults*, 16(4), 235-248.

doi.org/10.1108/QAOA-08-2015-0038

Exclusion reason: Wrong population

Gozalo, P., Prakash, S., Qato, D. M., Sloane, P. D., & Mor, V. (2014). Effect of the bathing without a battle training intervention on bathing-associated physical and verbal outcomes in nursing home residents with dementia: A randomized crossover diffusion study. *Journal of the American Geriatrics Society*, 62(5), 797-804.

doi.org/10.1111/jgs.12777

Exclusion reason: Wrong phenomena

Grebe, R. V. (2007). Informed consent for patients with cognitive impairment. *Nurse Practitioner*, 32(12), 39-44.

Exclusion reason: Wrong phenomena

Groen-Van De Ven, L., Smits, C., De Graaff, F., Span, M., Eefsting, J., Jukema, J., & Vernooij-Dassen, M. (2017). Involvement of people with dementia in making decisions about their lives: A qualitative study that appraises shared decision-making concerning daycare. *BMJ Open*, 7(11). doi.org/10.1136/bmjopen-2017-018337

Exclusion reason: Wrong setting

Hallberg, I. R., Holst, G., Nordmark, Å., & Edberg, A.-K. (1995). Cooperation during morning care between nurses and severely demented institutionalized patients. *Clinical Nursing Research*, 4(1), 78-104. doi.org/10.1177/105477389500400108

Exclusion reason: Wrong setting

Hammar, L. M., Swall, A., & Meranius, M. S. (2016). Ethical aspects of caregivers' experience with persons with dementia at mealtimes. *Nursing Ethics*, 23(6), 624-635. doi.org/https://dx.doi.org/10.1177/0969733015580812

Exclusion reason: Wrong phenomena

Higgins, A., Barker, P., & Begley, C. M. (2005). Hypersexuality and dementia: dealing with inappropriate sexual expression. *British Journal of Nursing*, 13(22), 1330-1334.

Exclusion reason: Wrong phenomena

Hope, T. (2009). Ethical dilemmas in the care of people with dementia. *British Journal of Community Nursing*, 14(12), 548-550.

Exclusion reason: Wrong population

Hradcova, D. (2017). Relational approach to ethics and quality improvement in institutional care for people with dementia. *Annals of Palliative Medicine*, 6(4), 319-326. doi.org/https://dx.doi.org/10.21037/apm.2017.06.20

Exclusion reason: Wrong phenomena

Hung, L., Chaudhury, H., & Rust, T. (2016). The effect of dining room physical environmental renovations on person-centered care practice and residents' dining

experiences in long-term care facilities. *Journal of Applied Gerontology*, 35(12), 1279-1301. <https://doi.org/10.1177/0733464815574094>

Exclusion reason: Wrong phenomena

Hurley, A. C., Volicer, L., Rempusheski, V. F., & Fry, S. T. (1995). Reaching consensus: the process of recommending treatment decisions for Alzheimer's patients. *Advances in Nursing Science*, 18(2), 33-43.

Exclusion reason: Wrong phenomena

Jablonski, R. A. (2003). *Making the decision to transfer an elder from the nursing home to the emergency department: the experience of key decision makers. Doctoral Dissertation, University of Virginia.*
<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=109841946&site=ehost-live>

Exclusion reason: Wrong phenomena

Jakobsen, R., & Sorlie, V. (2016). Ethical challenges: Trust and leadership in dementia care. *Nursing Ethics*, 23(6), 636-645.
[doi.org/https://dx.doi.org/10.1177/0969733015580810](https://doi.org/10.1177/0969733015580810)

Exclusion reason: Wrong phenomena

Jakobsen, R., & Sørli, V. (2010). Dignity of older people in a nursing home: narratives of care providers. *Nursing Ethics*, 17(3), 289-300.
doi.org/10.1177/0969733009355375

Exclusion reason: Wrong population

Jansson, L., Norberg, A., Sandman, P., & Astrom, G. (1995). When the severely ill elderly patient refuses food: ethical reasoning among nurses. *International Journal of Nursing Studies*, 32(1), 68-78.

Exclusion reason: Wrong setting

Kala, A. K. (2012). Covert medication; The last option: A case for taking it out of the closet and using it selectively. *Indian Journal of Psychiatry*, 54(3), 257-265.
doi.org/10.4103/0019-5545.102427

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Appendix III

Data extraction tool

Paper /Source characteristics	
Author(s)/Organization	
Year of publication	
Country of origin	
Type of research/paper	
Description of participants	
Description/measure of self-determination	
Role of self-determination	

Nurse activity and/or response to self-determination	
Nurse experiences with self-determination	
Outcome	

Appendix IV

Characteristics of Included Articles

Source	Study/Article Characteristics	Setting/ Country of Origin	Article/Study Aim	Definition of self-determination	Specific context for discussion of self-determination	Description of person-centered care	Description of autonomy	Nursing actions that enhance self-determination	Nursing actions that inhibit self-determination
Beck & Vogelpohl, 1995	General discussion	Long-term care facilities in the United States	Explore the day-to-day issues associated with autonomy and cognitive impairment in RACFs	Not defined. Used synonymously with autonomy; right to make decisions depending on capacity	General	Not discussed.	Mental capacity fluctuates from situation to situation. Autonomy in contexts of cognitive impairment is best measured by residents' perceptions of quality of life and sense of dignity.	Communication strategies and supportive approaches to care enhance autonomy. Authors encourage "autonomy-promoting paternalism" (p. 52), which involves simultaneously maximizing independence and protecting from risk.	-Assuming all cognitively impaired elders cannot express their needs -Assuming that skills that are lost with disease progression cannot be regained - Task-centered care approach - Restrictive, routine-focused organizational regulations/policies
Behrens et al., 2018	Case study	One nursing home in the United States	Demonstrate the use of the Rothschild Care Planning Process, to systematically plan care that better honours the choices of residents with dementia	The right to make one's own decisions; used synonymously with autonomy	Unaccompanied walks outside	A regulatory requirement that ensures NH residents have control and support in making their own decisions	Capacity to make one's own (good) choices, which may be limited by dementia and other brain injuries	Decisions can be honoured in ways that mitigate risk using the Rothschild approach. Nurses enhance residents' decision-making abilities by: -Proactively minimizing risks while still	-Minimal education levels of frontline staff -Practicing in a culture of surplus safety/intensive risk avoidance

								honouring preferences -Developing a plan of care with the interdisciplinary team and the resident, using a standardized approach (central to PCC) -Involving frontline staff in care planning	
Bolmsjö et al., 2006	General discussion	Nursing homes in Sweden	Demonstrate the application of Sandman's teleological model for analysis of ethical challenges in dementia care	A common human value; the right to decide between alternatives for oneself.	Lasting challenges; challenges for which it is difficult to find a solution	Not discussed.	Capacity to self-determine; if this capacity is no longer evident, it is important to consider the person's known will when they were competent	In order to advocate for patients, nurses need to reason in structured, systematic ways; they must have ethical competence. Sandman's model can assist nurses in everyday decision-making in dementia care.	-Structural constraints impact nurses' abilities to practice ethically (e.g. resource restrictions; leadership; care culture) - Only in situations with "strong reasons" should self-determination be overridden and care forced on people (p. 344)
Clarke & Davey, 2004	Participant observation and interviews with 14 formal caregivers	Four high care residential facilities in Australia	Observe how caregivers' communication strategies might impact the decision-making capacities of clients with dementia	Term not used directly.	Personal care	Task-centered nursing styles undermine the decision-making capacities of people with dementia	Capacity to make decisions; independence and decision-making power are often denied to people with dementia who are capable of some types of autonomous decision-making	Caregivers conduct ongoing capacity assessments during personal care. Caregivers with more positive communication strategies tended to enhance residents' autonomy and human right to make choices	-Attention to physical well-being and procedures, without adequate involvement of the resident -Communication that discourages decision-making, such as demeaning and depersonalizing discussions

Di Napoli et al., 2013	Initial questionnaire with 100 formal caregivers, an educational intervention, and then focus groups	Three nursing homes in Alabama	Describe staff attitudes toward sexual expression between residents	Term not used. Focuses on autonomy and right to make decisions depending on capacity	Sexual relationships between residents	Protecting residents from the consequences of their own decisions regarding sexual expression may interfere with provision of resident-centered care	Not defined. A dementia diagnosis does not necessarily preclude capacity to consent to sexual activity.	-Staff believed that nursing home policies on management of sexual expression would better enable them balance resident safety and autonomy	-Restriction of sexual behavior on the basis of personal beliefs (e.g. negative views of sexuality in older adulthood) -Ad hoc application of criteria for sexual expression
Dewing, 1999	Theoretical discussion	United States	Describe links between intellect and value in Western cultures, and impact of these links on dementia care	Term not used. Focuses on autonomy, personhood, choice.	General discussion.	Maintaining the personhood of a person with dementia; respecting individuality; entering into trusting therapeutic relationships	Not defined.	-Person-centered approaches	-Hyper-focus on intellect
Ehrenfeld et al., 1999	Thematic analysis of focus group discussions; presentation of systematized decision-making tool	Eight psychogeriatric wards in Israel, for whom the research team served as professional consultants	Discuss the challenges that nurses encountered regarding the sexual expression of residents, and describe the decision-making process of the study team in relation to these challenges	Term not used.	Sexual expression	Not discussed directly. At a policy level, the authors recommend emphasizing holistic approaches to care and improving accommodations to ensure patient privacy	Not defined; autonomy discussed as a right; must be safeguarded by dementia care nurses	-Using a systematized process to decision-making in ethically challenging situations (such as the worksheet used in this study). -Assessing solutions to issues with sexual expression on a case-by-case basis	-Overreacting -Treating patients like children -Adherence to “traditional social values” (p. 256) -Lack of theoretical knowledge about sexuality and dementia
Greenwood, 2007	Theoretical discussion with actual case exemplar from practice	Nursing home in the United Kingdom	Apply Levinas’ theory of the ‘non-intentional’ to a practice situation in a	Term not used.	Unaccompanied walk outside	PCC was an importance response to traditional models of care, but it is inevitably based	Not defined; used synonymously with “separate” (p. 224)	-Limiting, as much as possible, pre-understandings of the patient; allowing for moments which	-Caregivers often make decisions based on their own assumptions and associations about dementia, rather than

			nursing home in the UK			on the care provider's assumptions about who the client is. PCC approaches to care "define and systematize," and consequently inhibit nursing practice (p. 230).		help nurses recognize that a patient is other than how nurses perceive them	in relationship with people with dementia - The label of 'dementia' often prevents the recognition of a person as an autonomous being, leading to depersonalized care and an inability to relate to the person with dementia
Hertogh et al., 2004	Ethnographic fieldwork	Two nursing homes in the Netherlands	Highlight the shortcomings of the ethical principle of autonomy in dementia care; promote a perception-oriented approach to care.	Term not used.	Deceit in dementia care (e.g. use of fake money, hiding medications, lying about the whereabouts of a loved one)	Authors describe "perception-oriented care," (p. 1692) which aims to improve QOL in dementia by supporting the patient's subjective perceptions of reality.	Discussed in terms of right to be informed. Described as a common ethical principle that is insufficient for guiding dementia care	-"Linking up with" patients' subjective worlds (p. 1690); perception-oriented care demonstrates respect for the subjective realities of the person with dementia and does not prioritize the caregiver's reality.	-Routine reactions and answers to complex questions (usually provided due to time constraints)
Janes et al., 2008	Qualitative interviews with 20 unregulated care workers; grounded theory study	Eight long-term care facilities that provided staff with PCC training in Canada	Develop a mid-range theory about how unregulated care workers in dementia care use knowledge about PCC practices in their everyday care	Not defined. Discussed in combination with independent functioning.	Personal care	A PCC approach is best practice for dementia care; focuses on full range of psychosocial needs and involves close relationships between care providers and residents	Not discussed.	Participants experience a tension between what they know is best practice (rooted in PCC) and what they are able to do in the moment. Their process for resolving this tension is reflected in the theory of "figuring it out in the moment"	

								modeled in this paper.	
Johansson et al., 2009	Qualitative interviews with 10 nurses and 18 nursing assistants; phenomenological approach	Ten nursing homes across Sweden and Norway	Explore factors that promote or reduce falls in older adults with dementia, and to explore participants' experiences of caring for people with dementia who are at risk of falling	Described as a right for people with dementia, which is often in contrast to the person's right to protection. Used synonymously with autonomy	Falls	Not discussed.	Not defined. Autonomy and safety are often at odds in dementia care. Reducing falls requires a systematic identification of risk factors	Not discussed	Not discussed
Karlsson et al., 2000	Mixed methods; case vignette followed by semi-structured oral interviews and a survey with 30 RNs	Two nursing homes in Sweden	Explore nurses' reasoning around use of physical restraints, and to investigate the relationship between attitudes toward restraints and decisions made in practice	Described as a right; a minority of nurses felt that restraints violated patients' rights to self-determine.	Physical restraints	Not defined directly; authors do note that facilities with least restraint policies usually do not experience higher fall/injury rates and that such policies are based on holistic philosophies.	Defined as "the patient's own will" (p. 848), which often conflict with their best interests in dementia care	-Willingness to take risks -Viewing responsive behaviors (i.e. refusal of restraints) as meaningful and indicative of a patient's desire for liberty	Nurses felt limited in their ability to act autonomously with regard to restraints in dementia care. Many nurses preferred to rely on direction from physicians, management/ organizational policy, and families regarding use of restraints.
Eisenmann et al., 2016	Participant observation of one resident and focus groups with caregivers and family members	One nursing home in Germany	Analyzing the needs of people with severe dementia, through case study	Expression of intention; giving consent to daily activities; influencing situations and being heard	Personal care	Not defined; described as widely used but challenging as dementia becomes more severe	Term not used	-Listening to verbal and non-verbal cues of assent/discomfort -Minimizing external stimuli	-Proceeding with care when residents express displeasure/discomfort
Spielman, 1997	General discussion	Long-term care in the United States	Apply Fry's ethical decision-making model to a case exemplar, to demonstrate how a moral compromise	Described as a basic human right; used synonymously with autonomy.	Decision-making	Not discussed explicitly; author notes that caregivers define personhood/selfhood in unique ways, which	Autonomy is defined as the right to make one's own decisions; used synonymously with self-determination	Using Fry's decision-making model, nurses can reach a moral compromise in situations where values of autonomy and	Not discussed.

			might be reached in ethical dilemmas in dementia care			influences their care for people with dementia		beneficence/non-maleficence conflict.	
Tarzia et al., 2015	Grounded Theory	Fourteen RACFs in Australia	Use normalization process theory to discover why health care interventions or behaviours may not become embedded into routine practices. The study was done within the context of person-centered care	Not defined	Barriers to decision-making. General discussion; did not focus on specific decisions.	Priority given to residents. Residents should be supported in his or her choices and have the right to make decisions.	Used synonymously with independence, self-determination freedom, self-governance. Resident ability to make their own decisions.	Not discussed	-Having the time to wait for residents to make decisions -Schedules in the RACF do not allow residents to do what they want when they want it. -Staff shortages and reliance on casual staff who are unfamiliar with residents. -Obligation to do what families ask even when they know if differs from what residents want. -Communal living-residents' choices may negatively impact other residents. -No policies to support nurses actions/lack of education around existing policies
Woodrow, 1996	General discussion	Continuing care in England	Discuss Fawcett's four constructs of nursing care.	Not defined	Discussed within the context of autonomy.	Not defined	Not defined	- Providing simple choices -Involving family -Exploring and expecting any known preferences. -Using residents' remaining communication abilities (non verbal,	Not discussed

								behaviour) to identify preferences.	
Young & Unger, 2016	General discussion	Nursing homes in Canada	To discuss the ethical issues involved in covert administration of medications	Not defined	Covert medication administration	Not discussed	Autonomy is embedded in individuals choices to take medications. This is never explicitly defined	-Conducting a harm/benefit analysis. -Involving substitute decision makers in the decisions -Consulting a patient advocate. -Professional guidelines	-Limited guidelines from professional bodies and healthcare organizations to guide covert medication administration

Legend: RACF= residential aged care facility; PCC= person-centered care

Curriculum Vitae

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Education

Master of Nursing (c), University of New Brunswick, September 2019-present

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Publications

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Awards

2020/9 NANB Nursing Award - 10,000 (Canadian dollar) Canadian Nurses' Federation

2020/9 Alzheimer Society of NB/Dr. Jed B. Sutherland Bursary - 1,000 (Canadian dollar)

2020/9 Cutler Nursing Scholarship - 8,000 (Canadian dollar) University of New Brunswick

2019/9 Cutler Nursing Scholarship - 8,000 (Canadian dollar) University of New Brunswick

2019/9 Alzheimer Society of NB/Dr. Jed B. Sutherland Bursary - 1,000 (Canadian dollar)