The ethical need to give legitimacy to the voices of older adults with dementia in long-term care

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ABSTRACT

The objective of this thesis is to create a research protocol that can be readily used to give legitimacy to the voices of the older adults by collecting the perspectives and impressions from residents with dementia in long-term care about the value of their communications. Older persons with dementia, many of whom reside in long-term care, make up a significant proportion of the rapidly expanding older adult population in Quebec and Canada. Problems in comprehension, word finding, and short-term memory loss can arise from dementia and may impede effective communication between patients and health care professionals. Recent studies have provided evidence that communications from older adults with dementia are not being valued and have described how research can be inclusive of the participant voice. A literature review revealed that little is known regarding the subjective perspectives of those with dementia. Three ethical perspectives provide lenses through which this gap in the literature can be addressed, taking into consideration the role which stigma has played in deteriorating the autonomy of older adults with dementia. The ethics of conducting research with persons with dementia to fill this gap are investigated in a general sense, with respect to harm prevention and supporting inclusion. Relevant qualitative approaches as well as realistic objectives and outcomes of various types of qualitative research methods involving older adults with dementia are discussed, carefully considering benefits, limitations, and risks. Pertinent components of research protocols are carefully discussed, bearing in mind the research objective. Anticipated and foreseeable risks and benefits for the target population are considered to satisfy and value respect for human dignity through three main research ethics principles: respect for persons, concern for welfare, and justice. A detailed template protocol is provided - carefully structured to be inclusive of older adults with dementia in long-term care to give legitimacy to their voice. Considering the awful truth of the devastating state of care in the long-term care environment as revealed by the COVID-19 pandemic, there is urgency and value to be widely inclusive of these perspectives. The proposed study can be readily adapted and used broadly and would be an important first step in addressing the issue of loss of voice of those with dementia in long-term care.

ABRÉGÉ

L'objectif de cette thèse est de créer un protocole de recherche qui peut être facilement utilisé pour donner une légitimité aux voix des personnes âgées en recueillant les points de vue et les impressions des résidents en soins de longue durée atteints de démence sur la valeur de leurs communications. Les personnes âgées atteintes de démence, dont beaucoup résident dans des établissements de soins de longue durée, représentent une proportion importante de la population d'adultes âgés en croissance rapide au Québec et au Canada. Des problèmes de compréhension, de recherche de mots et de perte de mémoire à court terme peuvent résulter de la démence et peuvent entraver une communication efficace entre les patients et les professionnels de la santé. Des études récentes ont fourni des preuves que les communications des personnes âgées atteintes de démence ne sont pas valorisées et ont décrit comment la recherche peut inclure la voix des participants. Une revue de la littérature a révélé un manque de connaissance sur les perspectives subjectives des personnes atteintes de démence. Trois perspectives éthiques fournissent des lentilles à travers lesquelles cette lacune dans la littérature peut être abordée, en tenant compte du rôle que la stigmatisation a joué dans la détérioration de l'autonomie des personnes âgées atteintes de démence. L'éthique de mener des recherches avec des personnes atteintes de démence pour combler cette lacune est étudiée dans un sens général, en ce qui concerne la prévention des préjudices et le soutien à l'inclusion. Les approches qualitatives pertinentes ainsi que les objectifs et les résultats réalistes de divers types de méthodes de recherche qualitative impliquant des personnes âgées atteintes de démence sont discutés, en tenant compte des avantages, des limites, et des risques. Les composantes pertinentes des protocoles de recherche sont discutées, en gardant à l'esprit l'objectif de la recherche. Les risques et bénéfices anticipés et prévisibles pour la population cible sont considérés comme satisfaisant et valorisant le respect de la dignité humaine à travers trois grands principes éthiques de la recherche: le respect des personnes, le souci du bien-être, et la justice. Un modèle de protocole détaillé est fourni - soigneusement structuré pour inclure les personnes âgées en soins de longue durée atteintes de démence afin de donner une légitimité à leur voix. Compte tenu de la terrible réalité de l'état dévastateur des soins dans l'environnement des soins de longue durée révélé par la pandémie de COVID-19, il est urgent et utile d'inclure largement ces perspectives. L'étude proposée peut être facilement adaptée et utilisée à grande échelle et constituerait une première étape importante dans la résolution du problème de la perte de voix des personnes atteintes de démence dans les soins de longue durée.

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LIST OF ABBREVIATIONS AND ACRONYMS

The list below defines abbreviations and acronyms that are used throughout the thesis.

Abbreviations	Meaning
AD	Alzheimer’s disease
AERS	Apparent Emotion Rating Scale
AHSSS	Act Respecting Health Services and Social Services
BASQID	Bath Assessment of Subjective Quality of Life in Dementia
CCRF	Canadian Charter of Rights and Freedoms
CCQ	Civil Code of Quebec
CHA	Canada Health Act
CHSLD	Centre d'hébergement et de soins de longue durée
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes of Health Research
CNOT	Caring Nurse Observation Tool
CORTE	COnsent, Responses, Tell the story, End on a high
DCM	Dementia Care Mapping
ETRS	Emotional Tone Rating Scale
HCP	Health Care Professional
INESSS	Institut national d’excellence en sante et en services sociaux
INSPQ	Institut National de Sante Publique du Quebec
LTCH	Long-Term Care Homes
LTCHA	Ontario Long Term Care Homes Act
MECQ-LTC	Montreal Evaluation of Communication Questionnaire for use in Long-term Care
MMSE	Mini–Mental State Examination
MoCA	Montreal Cognitive Assessment
NARS-MFS	Memory Awareness Rating Scale – Memory Functioning Scale
OPSWA	Ontario Personal Support Workers Association’s Code of Conduct
PAR	Participatory action research
PHA	Public Health Act (Quebec)
PCC	Person-centered care
QCRF	Quebec Charter of Human Rights and Freedoms
QoL-AD	Quality of Life in Alzheimer's disease scale
TCPS 2	Tri-Council Policy Statement 2
WHO	World Health Organization

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CONTRIBUTION OF AUTHORS

All sections are authored by Jaclyn Chabot, including all Chapters, Tables, Appendices, and Figures. Thesis supervisor, Dr. Carolyn Ells, provided editorial help on all sections.

Appendix 4 (Participant Informed Consent Form) was drafted based on a site-specific template.

While he did not contribute to the actual thesis (writing or editing), the Research Advisor (Jim Mann) provided a wealth of advice and helped refine the approach for interviews and the re-wording of questions for the Semi-Structured Interview Guide.

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CHAPTER 1 – INTRODUCTION

1.1 DEMENTIA & LONG-TERM CARE IN QUEBEC

OLDER ADULTS & LONG-TERM CARE

Canada's seniors' population begins at age 65 (CIHI, 2021) – the age at which Old Age Security pension begins (Government of Canada, 2021). Though the definition of 'senior' is debated, according to the *Oxford Canadian Dictionary*, a senior citizen is "an elderly person, especially a person over 65" and 'elderly' is "rather old; past middle age" (Turcotte & Schellenberg, 2007, para. 5). The number of older adults aged 65+ increased by 18.3% from 2016 to 2021, the second largest increase in 75 years (Statistics Canada, 2022). Over the next 20 years, the seniors' population is expected to grow by 68%, and the population of older seniors, aged 75+, is expected to more than double (CIHI, 2021). The province of Quebec has been noted as one of the fastest aging populations in the world (Charpentier & Soulieres, 2013). In 1995, it was estimated that 5% of the older population lived in Long-Term Care Homes (LTCH), where a significant proportion - up to ninety percent - of residents have communication impairments, including dementia (Le Dorze, 2000; Dong *et al.*, 2014). Long-term care may include skilled nursing homes, assisted living, or any type of residential or care home where residents live on site; demand for these services is only increasing (Li & Porock, 2014).

DEMENTIA

Dementia - from Latin, meaning 'out of the mind' - is an overarching term for symptoms affecting the brain (Alzheimer Society, 2019). It is a syndrome characterized by progressive and chronic decline in both cognition and function. The medical term dementia specifically means brain failure or the inability of the brain to function normally, and "refers to a loss of intellectual ability sufficient to interfere with the person's daily activities and social or occupational life" (Harrigan, 2010, p. 5). Dementia should be understood as an interplay between neurological impairment and psychosocial factors including health, individual psychology, and the environment - which is greatly influenced by social context (Fazio *et al*., 2018, Terada *et al*., 2013).

Many diseases can cause dementia, such as Alzheimer's disease (AD), vascular dementia, Lewy Body disease, frontotemporal dementia, and Creutzfeldt-Jakob disease (Alzheimer Society, 2019). Dementia currently has no cure and is a degenerative terminal condition, thus people with dementia tend to move through clinical stages as they progress through their disease, requiring a greater level of care as they progress (Alzheimer Association, 2022; Alzheimer Society, 2019;

Harrigan, 2010). While the disease continually progresses, the changes caused by dementia do not occur in a linear fashion but vary from person to person (Fazio *et al.,* 2018). Symptoms from the varying diseases causing dementia include memory loss, difficulties with thinking, problem-solving, and language, which can be accompanied by mood or behavioural changes such as agitation, suspiciousness, delusions, and hallucinations (Alzheimer Society, 2019; Harrigan, 2010). Higher brain functions eventually become impaired to the point that daily activities are impacted (Harrigan, 2010). Additional vulnerabilities of persons with AD include problems in cognition that span memory, language, attention, perception, and motor skills (including loss of attention) as well as problems with perceptual skills which can hinder driving, reading, and dressing (Harrigan, 2010). Those with early-stage dementia have mild impairment and are still able to describe experiences as well as to plan and direct their own care. Middle-stage dementia is the longest stage, lasting for many years, and is characterized by a greater decline in cognitive and functional abilities, requiring increasing assistance in many daily tasks, and a peak in behavioural and psychological symptoms (Alzheimer Association, 2022; Harrigan, 2010). In middle stage, damage to the brain makes routine tasks and verbal expression difficult, which may lead to frustration, anger, and unexpected behaviours (Alzheimer Association, 2022). Neuropsychiatric symptoms include depression, boredom, loneliness, anxiety, irritability, repetitive behaviors, sleep changes, physical and verbal outbursts, and wandering, which makes leaving these people alone difficult or dangerous (Alzheimer Association, 2022; Li & Porock, 2014). While psychotropic drugs may be used to control them, these symptoms are hard to manage, the drugs have side effects, and lack of effective management requires people to move in with relatives or be institutionalized into long-term care (Kim & Park, 2017). Late-stage dementia and nearing end of life requires significant constant assistance (Harrigan, 2010). Thus, the probability of needing to move to a long-term care home (LTCH) is significantly increased with dementia.

Older adults with dementia experience worsening problems with effective communication. Those with AD gradually lose speech abilities and struggle to find words, to express thoughts, to follow conversations, and have increasing difficulty understanding others (Alzheimer Association, 2022). Of those diagnosed with AD, 85-95% have memory deficits and language and communication disturbances (Orange *et al*., 1994). During the middle stages of AD, communication changes include trouble finding the right word, repeating questions, losing a train of thought, reverting to a native language, and increased reliance on non-verbal communication

(Alzheimer Association, 2022; Harrigan, 2010). Persons with dementia are aware of their limitations and try to compensate for their difficulties to come up with correct answers and assert their autonomy (Orange *et al*., 1994). For example, their use of humor demonstrates their ability to be a productive member in an interaction; creative metaphors act as a different way to show understanding in conversation. While it has been recognized that identifying the unique language, communication, and speech features of AD is critical to establishing effective channels of communication with people having dementia, there has been limited success in attempts to improve AD communication (Orange *et al*., 1994). The problems with comprehension, word finding, and short-term memory loss which arise from dementia (Blair *et al*., 2007) may impede effective communication between health care professionals (HCPs) and persons with dementia (Dooley *et al*., 2015).

COMMUNICATION

> "Communication is the means by which people maintain interpersonal attachments. Such attachments underpin wellbeing and personhood." (Ward *et al*., 2008, p. 646)

Communication is multifaceted and complex. Communication acts encompass both receiving and expressing – it is an interaction between persons (Le Dorze *et al*., 2000). While focus is often on the verbal portion of communication, patient communication should be understood as an exchange of ideas including not only spoken words but also written, signed, and other non-verbal silent forms (Orange *et al*., 1994). Communication has been described as central to both the maintenance of personhood and as a vital component of high-quality person-centered care (Savundranayagam *et al*., 2016; Williams *et al*., 2012). Failure to value communications can cause harm and suffering due to loss of autonomy (Burchardt, 2004; Entwistle *et al.*, 2010). Since the consequences of not addressing the issue are dire, there is a growing desire to "understand the significance of communication from the patient's perspective" (Entwistle *et al.*, 2010, p. 744).

DEMENTIA & COMMUNICATION

> When a person is labelled 'unable to communicate' they are denied the right to a relationship with the world they inhabit." (Ward *et al.*, 2008, p. 646)

Problems with communications may be perilous to older adults with dementia. At a certain point in disease progression, articulation and understanding may make expressing care needs difficult (Kim & Park, 2017). Seventy-four percent of family caregivers noted communication difficulties as the cause of frustration and "catastrophic" reactions for older adults with AD (Orange *et al.*, 1994, p. 1164). Even for those in long-term care who have less severe language impairments, "residents with dementia appear less capable, in the eyes of their nurses, to express and understand communication acts" (Le Dorze *et al.*, 2000, p. 33). For persons with dementia, communicating can be a means for both constructing and preserving self and identity (Vittoria, 1998), and may occur without words (Oldfield, 2021). There is evidence that those with dementia, regardless of the severity of their impairment, are aware of their cognitive limitations and they seek out and establish ways to compensate for their difficulties, to come up with correct answers, and to maintain a relationship with the world they inhabit (Dooley *et al.*, 2015; Ward *et al.*, 2008). Not only do persons with dementia retain the need for and ability to have meaningful communication, but they also require effective communication between themselves and those caring for them to meet their care and social needs (Savundranayagam *et al*., 2016). A vast array of problems, feelings, and needs may be intertwined with their communication difficulties (Olthof-Nefkens *et al*., 2021). Yet, studies have claimed that AD patient communications seem empty or lacking in meaning particularly due to their speaking in circles or having problems with word finding (Orange *et al.*, 1994). Difficulties encountered in the communications of cognitively impaired persons become problematic when those difficulties cause their communications to be ignored or denied, no longer listened to or considered relevant, or are not valued by the very people they are dependent on for care. Unfortunately, condescension, stigma, and a lack of person-centered communication are all too common in LTCHs, and these attitudes and behaviours by HCPs challenge the residents' understanding of self as well as their personhood, risking harmful consequences on their wellbeing (Williams *et al*., 2012). Among the older adults with dementia, poor efforts to value communication have been linked with negative resident behaviours and have been found to have a negative impact their quality of life (Savundranayagam *et al*., 2016; Williams *et al*., 2012). As such, it has been found that "communication that fails to support autonomy and well-being of older adults leads to outcomes that are incongruent with quality care" (Williams *et al*., 2012, p. 378). If these problems in communication have been found to fragment autonomy and collapse care, such problems may border on elder abuse.

ELDER ABUSE - WIDESPREAD ISSUES KNOWN FOR YEARS IN QUEBEC

Elder abuse has been recognized internationally for some time. Institutional problems recognized by the World Health Organization (WHO) as leading to elder abuse include: low standards for health care, welfare services, and care facilities for older persons; overworked and poorly trained and remunerated staff; a deficient physical environment; and institution-centric rather than resident-centric policies (WHO, 2020). In all Canadian communities, there is a recognized need for solutions to the recurring abuse and neglect of older adults, solutions that will "require the coordinated efforts of society at large" (Harrigan, 2010, p. 38).

Nurses in Quebec have called attention to elder abuse and victimization in both privately run residences and public long-term care hospitals in the province for many years (CBC, 2000). Investigations carried out in 49 hospitals and 38 residences in Quebec between 1995 and 1999 found that a lack of nurses - particularly at night when the ratio was one nurse per 200 patients - was commonplace. The Quebec Order of Nurses found that older people could not get sufficient care, were subject to physical and verbal abuse, and were not treated with respect. Since the nurses' study in 2000, patients' rights groups and other supporters of older persons have been pushing the Quebec Health Minister to spend more money on Quebec's 143 nursing homes (CBC, 2000). They were also lobbying for increased staffing levels at older care facilities and for emergency room doctors to be required to report suspicious injuries (CBC, 2000).

In 2015, the Canadian Department of Justice found that on top of insufficient staffing and inadequate training, work-related stress and burnout contributed to abuse in long-term care facilities (Pugliese, 2020). An Ontario study had found that close to a third of more than 1,600 nurses and nursing assistants in LTCHs had themselves witnessed rough handling of patients, staff verbally abusing patients by yelling or swearing at them, and embarrassing comments being made to patients (Pugliese, 2020). However, if caring for persons with dementia requires education regarding strategies and particular approaches for the various behaviors and psychological symptoms (Harrigan, 2010), in situations involving organizational neglect as well as untrained personnel, failure and harm is simply inevitable.

> "...Because older victims usually have fewer support systems and reserves – physical, psychological, and economic – the impact of abuse and neglect is magnified, and a single incident of mistreatment is more likely to trigger a downward spiral leading to loss of independence, serious complicating illness, and even death." (Dyer *et al.*, 2003, p.340)

According to a WHO fact sheet, rates of elder abuse are high in institutions such as nursing homes and long-term care facilities, where in 2020 two out of three staff self-reported having committed abuse in the past year (WHO, 2020). While abuse is traditionally thought of as physical or sexual harms, it also includes psychological harms and neglect, whether intentional or unintentional, that result in unnecessary suffering, violation of human rights, serious loss of dignity and respect, and/or decreased quality of life (WHO, 2020; Harrigan, 2010). The WHO defines abuse in the context of older adults as a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, and which causes harm or distress to an older person (WHO, 2020). Only one in 24 cases of elder abuse is reported, partially because older people are often afraid to report cases of abuse; as a result, prevalence rates are usually underestimated (WHO, 2020). Elder abuse is predicted to increase since many countries are experiencing rapidly ageing populations (WHO, 2020).

Numerous possible socio-cultural factors further worsen risks of elder abuse in specific communities (WHO, 2020). In institutions, abusive acts may include deprivation of dignity (leaving residents soiled, for example) and restriction of autonomous choices over daily affairs and emotional inattention and abuse (WHO, 2020). Risks at the individual level are magnified for victims having poorer mental health (WHO, 2020).

Several relevant hypotheses of elder abuse have been elaborated. Situational Theory or Caregiver Stress argues that caregiver's incumbrances multiply and overcome their capacity to meet needs; their stress overtakes the situation (Harrigan, 2010). Isolation Theory suggests that elder mistreatment may occur because of a person's diminishing social circle, which occurs with dementia (Harrigan, 2010). Finally, Political Economic Theory addresses challenges, such as those arising from ageism and stigma, faced by older adults when they lose their autonomous role in society (Harrigan, 2010).

ABUSE - HEIGHTENED RISK WITH DEMENTIA IN LTC

Evidence overwhelmingly points to older residents living in long-term care environments, of whom the majority have dementia, being particularly prone to abuse and neglect. Middle stage dementia seems to be the stage most at risk of abuse, since it is the peak of symptoms (Dong *et al.*, 2014; Harrigan, 2010; Le Dorze, 2000;). Dementia, like elder abuse, is common but under-diagnosed and under-reported (Harrigan, 2010; Dong *et al.*, 2014). Identification of elder abuse becomes even more difficult when abused persons have impaired ability to communicate, lack decisional capacity, have disinhibited behavior exacerbating the cycle of violence, or have concurrent depression (Harrigan, 2010). They may also display common signs of or reactions to abuse which are indistinguishable from dementia symptoms themselves, such as a withdrawal from communication or increased dependence on others (Dong *et al.*, 2014). Literature also points to persons with dementia being at greater risk for abuse due to their being undervalued (Harrigan, 2010). Furthermore, residents may be unaware that they were abused or neglected (Harrigan, 2010), or may not want to speak out of fear of retaliation or loss of support (Dong *et al.*, 2014). Therefore, the signs of abuse or neglect may be unspecific, subtle, or vague.

Persons in LTCHs are further socially isolated, interacting mainly (or only) with caregivers and other older persons. Denying older adults with dementia their own voice has been described not only as abusive itself but also as a crucial component of sexual and physical abuse within the context of a study of the experience of abuse (Swain *et al.,* 1998). Older adults living with dementia are not only vulnerable to abuse by people who are close to them, but they are also vulnerable to being taken advantage of (Alzheimer Society, 2021). Isolation increases with the decline of physical or mental capacity, or through the loss of friends and family members (WHO, 2020). Due to their cognitive impairments, the increasing dependence on caregivers, and the loss of social support, older adults with dementia are put at heightened risk of various forms of abuse (Dong *et al.,* 2014). Providing care becomes more challenging as dementia progresses (Alzheimer Society, 2021), and records as far back as the 1980's reveal that nurses' treatment of residents has been insensitive, infantilizing, and abusive – contributing to loss of self rather than its preservation (Vittoria, 1998). Caregivers' risk factors for abuse include limited knowledge of dementia (resulting in stigma), high stress levels, depression, and lack of support or counseling (Alzheimer Society, 2021). In many cases elder abuse, mistreatment, or neglect may be unintentional; when caregivers are pushed beyond their competencies, they may not mean to be abusive or negligent of care or needs (Alzheimer Society, 2021). Regardless of intent, institutionalized care studies since 1961 have described the relationships between staff and residents with dementia as adversarial, resulting in devaluing of self (Vittoria, 1998).

DIGNITY - A BASIC HUMAN RIGHT TO MAINTAIN IN LTC

Every person in Canada has the right to life, security, and liberty as well as the right to not be deprived of these, according to the Canadian Charter of Rights and Freedoms (CCRF, ss.7). Those in long-term care are not to be disadvantaged, having just as much right to legal protection and benefits as any person (CCRF, ss.15). Similarly, the Quebec Charter of Human Rights and Freedoms (QCRF) states that every person has the right to life and to the protection of their dignity as well as to full and equal recognition and to autonomy, that is, to exercise their rights without distinction, exclusion, or preference including with respect to any handicaps (QCRF s.1,4, 10). Older adults with dementia live with symptoms and limitations which threaten their ability to live a normal life and maintain their dignity (Kim & Park, 2017). The right to autonomy and to protection against unwanted interference is contained in the CCRF s.7, QCRF s.1, and in the Civil Code of Quebec (CCQ) ss. 3 and 10. When it comes to those who may have lost their autonomy, attention to these rights should be even more important, especially where problems exist in the system providing care for those who cannot care for themselves, who are mostly or totally reliant on others for their care.

RESIDENTS' PERSPECTIVES – A KNOWLEDGE GAP

Many strategies have been implemented to attempt to prevent, take action against, and mitigate the consequences of elder abuse. Institutions have employed awareness campaigns, screening programs, caregiver support interventions, care policies, or dementia specific caregiver training; however, evidence of their effectiveness is limited (WHO, 2020; Harrigan, 2010). Caregivers have been supported with education and training regarding the clinical course of dementia and the anticipated needs of the care recipient, and have been provided with treatment for caregiver depression to help prevent abuse (Harrigan, 2010). While caregivers' and the general public's perspectives on various elder abuses are abundant (Harrigan, 2010), few patient-perspective studies have been conducted. Charpentier and Souliéres (2013) presented the residents' own perspective of abuse and neglect in Quebec LTCHs through a constructivist approach to empowerment using semi-structured interviews with 20 residents. Harsh images of abuse presented by the media only trivialized residents' own perceptions of disrespectful and violent acts committed against them (Charpentier & Souliéres, 2013). Though it could be a generational issue, residents tended to perceive abuse as limited to solely physical acts – not categorizing verbal or psychological abuses, neglect, or fundamental violations of their rights as *abuse*. Nevertheless, it was clear that their residence never felt like home to them; they were constantly on their guard, striving to do or say the right thing to not jeopardize their care (Charpentier & Souliéres, 2013).

Valuing communications in long-term care positively impacts residents. Though focused on cognitively intact residents, a small (n=6) phenomenological narrative method study using semi-structured interviews concluded that information gained when nurses listened to residents could improve their lives and "dignify them as individuals" (Iwasiw *et al.*, 2003, p. 52). Little is known however, regarding how those with dementia feel about their own communications with respect to whether they feel listened to or not by their caregivers, and regarding their opinions on how that affects their wellbeing, either positively or negatively.

> "Since the concept of elder abuse was first raised in the seminal paper about 'granny battering', numerous studies have attempted to measure its prevalence."
> (Selwood *et al*., 2007, p. 1009)

Obtaining first-hand perspectives from people with cognitive impairments, though challenging, is not impossible (Dong *et al.,* 2014). Two studies investigated abuses using communications from cognitively impaired adults in LTCHs. Residents freely communicated and voiced their concerns about their experiences in a nursing home in the study of older adults with Korsakoff's syndrome (van den Hooff & Goossensen, 2015). Through focused conversation, residents provided "a window into their inner world" (van den Hooff & Goossensen, 2015, p. 383), and were found to have some knowledge of their condition, despite their understanding differing from that of a physician. In their qualitative study of adults with intellectual disability, Wullink *et al.*, (2009) similarly allowed residents to create their own narratives, which were shared in a group meeting. Residents expressed dissatisfaction, indicating how doctor-patient communications themselves were damaging and hurtful. The residents went further by giving recommendations on how communications could be improved (Wullink *et al.*, 2009).

Few studies exclusively focus on selective types of elder abuse (Dong *et al.,* 2014); studies examining dementia residents' understanding of how care workers value their communications would provide valuable insights. Residents' perceptions could be an invaluable tool since it is evident from the limited available studies that not all patient needs were fully met, which resulted in physical and mental distress and suffering.

Indeed, the WHO advises that further resident perspective studies are urgently needed (2020) to learn what the truth is regarding potential elder abuses via reporting by older adults themselves, which can then help drive meaningful changes in how older adults in long-term care are treated.

QUEBEC - A WORSENING SITUATION

There have been long-standing problems with the system put in place to deliver health care to older persons in Quebec, especially concerning those who are no longer able to care for themselves autonomously. In fact, constraints such as poor wages, understaffing, staffing burnout, and excessive paperwork have been reported since 1975 (Vittoria, 1998) – and not much has seemed to change in 47 years! Though these issues were known to exist years before the COVID-19 pandemic hit, they were heightened and brought to the forefront by the death and suffering that resulted from COVID-19 and the effects of the pandemic. The pandemic brought to light several problems in public and private long-term care homes where older citizens are cared for: insufficient staffing, lack of a stable staff dedicated to an institution, organizational deficiencies such as poor training, and difficulties in retaining the staff because of low wages and difficult work conditions (considering the significant needs of the patients). These factors could all contribute to how healthcare workers give value the communications of older adults with dementia.

When organizations are negligent to begin with, that lack of structure have devastating results, as we saw in Quebec at the beginning of the COVID-19 pandemic. After an investigation into one of the province’s hardest-hit long-term care homes, a report concluded that residents at the private LTCH (in Quebec referred to as CHSLDs - centre d'hébergement et de soins de longue durée or long-term care and housing center) known as Herron Residence in Montreal were victims of “organizational negligence” (Olson & Shingler, 2020, para. 1). Though the Premier had initially accused staff of abandoning the residence and its residents, documentation actually proved that the majority of absentee staff were either waiting to be tested for COVID-19 or were already sick (McKenna, 2020). The minister responsible for seniors pointed out that “the pandemic alone (did) not justify what happened” (Olson & Shingler, 2020, para. 21). Had management at the private seniors' home properly understood their responsibilities and used their resources, the situation would not have been as devastating as it was (Olson & Shingler, 2020). By the time local health authorities had finally arrived at Herron, only three employees were caring for 133 residents, and the facility “was filled with a ‘nauseating odour of urine and feces’ and unwashed dishes” (Olson & Shingler, 2020, para. 4). The report into CHSLD Herron had found that staffing shortages and a high turnover rate had left the residence vulnerable when the pandemic struck. The fact that the home had four different nursing directors over three years, and that just before the pandemic numerous employees had quit and a management position was vacant (Olson & Shingler, 2020), is a strong indication of financial and managerial neglect. Similar problems were reported in public homes, such as Sainte-Dorothée, hence it was reported that the problems were representative of those facing the entire network of CHSLDs (Olson & Shingler, 2020).

Sparked by the outbreaks of COVID-19 at seniors' residences and long-term care homes in Quebec, reports of alleged neglect and mistreatment continued to pour in. That same spring of 2020, when nearly 1,700 members of the Canadian Forces were deployed to help overworked staff at 25 LTCHs in Quebec and five in Ontario, military personnel revealed cases of alleged elder abuse and neglect (Pugliese, 2020). At the Manoir Liverpool near Quebec City, it was recently found that over a period of five years residents had been underfed, infrequently bathed, and given expired medication (Grant *et al*., 2021). Physical and organizational mistreatment were both identified, and the Quebec Seniors' Minister stressed that all LTCHs had "a legal responsibility for the services that they give directly to the population or through resources" (Grant *et al*., 2021, para. 11). The minister underlined the need for a shift in the way the province takes care of its elderly and disabled populations and beseeched those working in the system to speak up: "People have to call out situations when it's going bad, we cannot just close our eyes, close our ears and not take care of these vulnerable people" (Grant *et al*., 2021, para. 23). This, however, is something easier said than done. It can be terrifying for staff to speak out and report wrongdoings. After detailing the chaos and horrible conditions patients were left in during the COVID crisis of spring 2020 at Herron Residence in Montreal, the staff member who initially spoke out used a pseudonym out of fear and concern for professional repercussions (McKenna, 2020). When CBC obtained copies of work schedules that revealed daily staff shortages, the four other patient attendants who verified that fact also withheld their identities out of fear for their jobs (McKenna, 2020). Those staff further revealed the awful truth that over a period of 8 days following an email where the owner assured families of appropriate safety measures and monitoring of their residents, there were in fact only three patient attendants working on a shift. CBC News noted that there should have been 22 patient attendants on a day shift, 16 through the evening, and another five attendants overnight for an institution of that size (McKenna, 2020).

GOVERNMENTAL OVERSIGHT & ACCOUNTABILITY - INSIGHTS GROUNDED IN THE CANADIAN CHARTER OF RIGHTS AND FREEDOMS AND THE QUEBEC CHARTER OF HUMAN RIGHTS AND FREEDOMS

Van den Hoof and Goossensen (2015) accurately point out that the real cause for concern may lie at the health policy level: "healthcare professionals are tied to specific healthcare legislation, institutional regulations, general nursing home rules and team appointments, which might hinder them to be sensitive to the particularity of situations and patients" (p. 385). Perhaps breaking from rules is necessary when harm is being done - indeed, van den Hoof and Goossensen support deviations from dysfunctional and dehumanizing rules (2015). In Quebec, and perhaps all of Canada, HCPs do not seem to be provided enough time within the current framework to be able to invest in appropriate listening for each patient.

A health care system that balances safety, caring, and effectiveness is the best way to ensure high quality care (CPSO, 2007, p.14). The LTCH environment in Canada does not seem optimal since the current environment is lacking sufficient safety and effectiveness (Sibbald & Stanbrook, 2016) and therefore is incapable of delivering high quality care. LTCHs often must manage care within the confines of poor funding – having budgets that are often greatly insufficient to meet the standards of ideal care (Sherwin & Winsby, 2010). The result of this environment is heavy workloads, fatigue, poor equipment - or lack thereof - and inadequate training, all of which contribute to an unsafe living environment (Sherwin & Winsby, 2010). A particular aim of healthcare rights is to improve the health of the most vulnerable however Canadian courts have been slow to act (Thomas & Flood, 2015, p. 77), particularly when it comes to LTCH residents, who seem an obvious and large group of vulnerable persons. The government has allowed such deterioration of the public health system that human rights are being violated (Sibbald & Stanbrook, 2016). For example, Canada does not currently have federal laws that make reporting elder abuses mandatory and leaves the provinces to handle elder abuse (CMPA, 2016). Follow-through with the application of serious consequences for poor treatment of older persons seems to be somewhat lacking in Canada, perhaps due to a shortsighted understanding what constitutes poor treatment. Further, in October 2020 it was publicized that 85% of nursing homes in Ontario were repeatedly breaking the law with virtually no consequences (Pedersen *et al*., 2020). The Quebec Seniors' Minister has recently voiced hope that Quebec would review its laws on abuse and neglect and impose harsher penalties (Grant *et al*., 2021).

While it was claimed that the reports obtained in Quebec would be used to improve care for seniors in CHSLDs during the pandemic, it remains unclear whether this will be enough to protect older persons outside of a pandemic situation. The Institut National de Sante Publique du Quebec (INSPQ) released a detailed report in 2019 drawing attention to the risks and consequences of mistreating older adults in Quebec, outlining prevention methods, policy, and program directions, specifically highlighting prevention activities for residential facilities, and making best practice recommendations (Beaulieu *et al*., 2019). This did not, however, prevent the disasters that occurred only one year later during the first wave of the COVID-19 pandemic. Following the results of investigations into both private and public LTCHs during the pandemic, the government claimed it would make efforts to improve the situation (Olson & Shingler, 2020). In the throne speech of summer 2020, the government pledged to establish national standards for LTCHs and to amend the Criminal Code to penalize those who neglect seniors in their care and put them in danger (Olson & Shingler, 2020). The federal government did receive proposals from an independent, not for profit organization (the Health Standards Organization) for new 'post-pandemic' standards in early 2022 which recommend new national standards to give residents in long-term care more autonomy and control over their lives (Roman, 2022). Furthermore, the new standards would compel LTCHs to provide evidence of sufficient staffing through legislation that would reflect jurisdictional responsibilities since provinces and territories have jurisdiction over long-term care (Roman, 2022). However, it remains to be seen whether promises will come to fruition and elicit meaningful change. During the last few decades, provinces have seen major funding cuts that have detrimentally affected abuse of older persons (Harrigan, 2010), and so even if laws are changed and national standards published, difficulties in obtaining appropriate assistance and support services may remain even after authorities intervene in cases of abuse.

The solution to allocating sufficient time to listen may be to increase personnel – a governmental issue. A Montreal emergency nurse's comments from the spring of 2020 revealed the stress, exhaustion, and overworked environment at that time: "we are lacking support, we are lacking equipment, we are lacking personnel" (Mackenzie & Gilmour, 2020, para. 5). She continued, "those three factors alone play a tremendous impact on the service we provide and the care that we give." A patient advocate noted, "you cannot hold the system…the way they are handling it right now. Something's going to happen, and it will be tragic" (Mackenzie & Gilmour, 2020, para. 9). In an interview with the CBC, Dr. Samir Sinha, the director of health policy research and co-chair at the National Institute on Ageing shared that a study by the Canadian Institute for Health Information (CIHI) revealed that countries with better funded long-term care vastly outperformed Canada - where Quebec and Ontario fared worst - when it came to deaths in LTCHs during the pandemic, starkly revealing how much is lacking in our system (Ireton, 2021). Without better organization and support, mistakes can continue to be made which become costlier in the long run.

Both the federal and provincial governments have a duty to oversee public health in care homes under the purview of medical services (Constitution of Canada (ss.92(7)). If a legislative framework gives the government power to act in the public interest, its duty is to the public as a whole (Hardcastle, p.12). LTCHs are a significant grouping of the public, and their residents also have a right to life and wellbeing (CCRF ss.7,15; QCRF s.1,4,10). However, when LTCHs were removed from the physical hospitals they were left with only minimal federal oversight since federal funding is centered around the hospital setting. LTCHs are required to report serious issues to government or regulatory agencies to ensure external oversight and put onus on the State to assess patient safety and foresee harm (AHSSS, ss 183.1-183.2., 431(6.2)). Yet, since provincial reporting is optional, the federal government actually receives little for review (Sibbald & Stanbrook, 2016). Under-reporting and non-disclosure of harm similarly persists in the courts (Gilmour, 2006, p.27), consequently, the federal government is likely largely unaware of the conditions in LTCHs. The Public Health Act (PHA) of Quebec gives public health authorities the right to monitor (PHA, ss.2); the provincial government could be liable for negligence with respect to the grim LTCH outcomes where authorities had “power to take action where the health of the population is threatened” (PHA, ss.2) and did nothing for a significant subset of the population. The Supreme Court of Canada has suggested that the government’s legal duty to act in the public interest may include a “statutory obligation” for systemic misconduct “particularly serious in nature” (Hardcastle, 2012, p.16), such as that encountered in LTCHs.

Both Charters could be invoked to shape health care delivery by forcing changes in legislation and courts could lobby for a systemic change to LTCH funding to achieve safer care (Gilmour, 2006, p.v). Alternatively, the Supreme Court of Canada could pressure the government to update the Canada Health Act (CHA), allowing provinces to decide how federal money is spent (Flood & Choudhry, 2002, pg.v), which could increase funding and staffing to LTCHs. When reviewing policies that negate duty, judges only consider implementation of decisions, not policies themselves (Hardcastle, 2012, p.11), and while the state may be granted immunity from policy decisions, it does not have immunity regarding their operation (Hardcastle, 2012, p.13,14). In LTCHs, the requirements of the CHA were not respected, failing to meet the needs of residents. The seriousness of the violation was exacerbated because the very system residents relied on for their wellbeing left them more vulnerable (Gilmour, 2006, p.v). Indeed, the province assumed greater duty of care through its increasingly active role in healthcare management and resource allocation thereby opening itself to greater liability vis-à-vis organizational mismanagement

(Hardcastle, 2012, p.1, 15). Despite the evidence, courts have been reluctant to impose liability for governmental decisions “made in the face of competing interests and limited budgets” (Hardcastle, 2012, p.14).

THESIS INTENTS

Instead of relying solely on legal methods for change, in this thesis I advance an argument that participatory resident-perspective qualitative studies could provide valuable insights to help drive change in the LTCH environment. Following this introductory chapter that motivates the thesis project, Chapter two reports findings from the literature and introduces three moral theories (Person-Centered Care, Care Ethics, and Narrative Ethics) to be employed as helpful lenses. The role of stigma and the nature of autonomy for older adults with dementia are discussed, as is the importance of examining risks before developing research protocols.

Chapter three discusses relevant qualitative approaches for involving older adults with dementia in research. The importance of including these stakeholders’ voices as well as the harms and consequences which could occur by not being inclusive of them in the very research meant to help them are discussed. A review of the benefits, limitations, and risks of various qualitative research methods with persons with dementia reveal what can realistically be achieved through each different type of research study. Each component of a research study is carefully discussed, first acknowledging an ethical stance which bears in mind anticipated and foreseeable risks and benefits to satisfy and value respect for human dignity through three main research ethics principles: respect for persons, concern for welfare, and justice.

Chapter four details key parts of a template protocol, for a small qualitative resident-perspective study that is structured to be inclusive of older adults with dementia in long-term care to give legitimacy to their voice, by helping to uncover their subjective truths about the value their communication acts hold with and for others, as well as themselves.

By giving legitimacy to voices of older adults with dementia who are living there right now, insights into their lived realities may prove instrumental to direct and shape action for change.

THESIS RESEARCH QUESTION

To explore ethical considerations and potential qualitative research methodologies to provide possible solutions to the gap in the research to involve older adults with dementia living in long-term care, towards the goal of giving legitimacy to the voices of older adults with dementia and to value and hear their perspectives and impressions.

THESIS OBJECTIVE

To create a research protocol that can be readily used to give legitimacy to the voices of the older adults by collecting the perspectives and impressions from residents with dementia in long-term care about the value of their communications.

1.2 THEORETICAL FRAMEWORK

On the surface, harms (such as loss of autonomy or dignity) resulting from ignoring voices and de-valuing communications may seem too obvious a wrong to elaborate in a thesis. Historically, bioethics has not concerned itself with obvious wrongs, however bioethics' silence on these matters has been criticized (Ayeh, 2015). It's becoming increasingly important to bring attention to issues and employ activism when obvious and grievous wrongdoings go unnoticed (Draper, 2019) or are unresolved. Bioethics should not simply focus on new, cutting-edge topics (Ayeh, 2015; Draper, 2019); rather when something seems so simple and obviously wrong, bioethics has a great responsibility to help bring these issues to light to provide ethical insights and guidance towards a resolution of those wrongs.

It is important to create a solid ethical foundation of understanding before attempting to address these issues. The major ethical frameworks relevant to the need to give legitimacy to the voices of older adults with dementia in long-term care are largely decisional and care centric. Older adults in LTCHs experience a real and steady loss of both independence and autonomy (Sherwin & Winsby, 2010). From a bioethics perspective, individuals' ability to control their own healthcare decisions must be enabled to empower them and thereby uphold respect for individual autonomy (Durochers *et al.*, 2019; Sherwin & Winsby, 2011). Highly pertinent to this research endeavor are three ethical frameworks: person-centered care, care ethics, and narrative ethics.

Person-centered care (PCC) really lies at the heart of care, thereby serving as a grounding theoretical framework. PCC is enabling for older persons, preserves their dignity, and is being adopted within the healthcare domain. As a relational framework, PCC emphasizes maintaining connections through effective communication and relationships (Fazio *et al.*, 2018, Kitwood, 1997), prioritizes maintaining identities to uphold dignity (Li & Porock, 2014), and enables and promotes personhood and wellbeing (Cooney & O’Shea, 2019). While not explicitly referring to PCC, both the Ontario Long Term Care Homes Act (LTCHA, 2007) and the Ontario Personal Support Workers Association’s Code of Conduct (OPSWA, 2022) have adopted numerous aspects of PCC to uphold for residents: respect for residents’ dignity; their right to exercise the rights of a citizen; their right to have their participation in decision-making respected; their right to full participation in all aspects of their care and care plan; and their right to express concerns and recommend changes in policies and services. PCC is being further developed and implemented for people with dementia (Cooney & O’Shea, 2019; Fazio *et al*., 2018; Kim & Park, 2017; Terada *et al*., 2013).

While PCC enriches the outset of this research, the philosophies of care ethics and narrative ethics are also connected and reach beyond health care, deeper into ethical theory. Care ethics relates to ethical principles of beneficence, non-maleficence, duty to provide care, and justice. It expands on the moral significance of relationships and dependencies, allowing a person to flourish by being attuned to the other’s position as they express it. Narrative ethics further reveal truths and insights into patients lived situations and care received, while attending to human dignity by affirming a person’s reality.

Decisional themes affected by old age and illness include autonomy, decisional capacity, and surrogate appropriateness – the latter of which is also relational and touches on trust, paternalism, and power imbalance, which in turn are all impacted by stigma and ageism. When considering decisional themes of autonomy and stigma, these are best viewed from a relational autonomy lens rather than through a traditional perspective of autonomy to take into account each individual’s circumstance.

Though resident communications can be a starting point to addressing key issues of autonomy, justice, and beneficence as they affect residents, these bioethical principles must first be well understood in their own right to appreciate their relevance and will be discussed further in chapter two.

1.3 PERSONAL LOCATION

My hypothesis is largely influenced by my personal location. Combined experiences of working in long-term care as a teen, experiencing the gradual cognitive decline of my father, and more recently coming to the aid of an emergency situation in an LTCH sensitized me to potential issues.

Observing and listening to what they were saying with words or actions awakened concern. Despite their limitations, these people seemed to be trying to communicate in their own ways within the bounds of their own abilities – but they often didn't seem to be understood by those they were trying desperately to communicate with. A question began to formulate in my mind: are older adults with cognitive decline trying to communicate and not being heard? Thus, my positionality in this research is that I anticipate older adults with cognitive impairments may be trying to communicate unwellness and their communications go unnoticed, unheard, or ignored (possibly due to assumptions about their illness), which may be resulting in some form of elder abuse, neglect, or other form of harm.

My 85-year-old father has been losing more of his memory every year – it is frustrating to him as well as to me and my two sisters. We have encountered issues on several occasions where healthcare teams misunderstood him and vice versa - which has had devastating consequences on our intra-family relationships. As a teen staff member, I was surprised by the conditions and the treatment of residents I witnessed in a LTCH in Ontario. Recently, as a volunteer during the COVID crisis in Spring 2020 at the Herron Residence CHSLD, my attention again was drawn to the notion that perhaps older adults with cognitive impairments may be trying to communicate *unwellness* – but it may be going unnoticed, unheard, or intentionally ignored – or – even worse, they may be frightened to share how they feel, out of concern of jeopardizing their care (Charpentier & Souliéres, 2013). A few firsthand accounts I received from residents revealed such a history when they shared things such as "I have no one to tell, they are all on the same side and don't listen to me" or "there is no one I can trust here". If true, this lack of attention to their communications, or the suppression and denial of their voices, could be a form of abuse itself (Swain *et al.*, 1998), albeit a hidden one:

> "There are inherent difficulties in studying elder abuse since it is a hidden offence, often perpetrated against vulnerable people, many with memory impairment, by those on whom they depend." (Selwood *et al.*, 2007, p. 1009)

Residents' own perceptions have proven an invaluable tool for investigating levels of elder abuse, particularly since it has become evident from their firsthand accounts that residents' needs are not all fully met, resulting in physical and mental distress and suffering (Wullink *et al.*, 2009; Charpentier & Souliéres, 2013; van den Hooff & Goossensen, 2015).

There are multiple areas of focus for prevention of harm, including raising awareness, supporting caregivers with education, treating depression, and providing training regarding the clinical course of dementia as well as the anticipated needs of the care recipients (Harrigan, 2010). However, I argue further resident perspective studies are needed, so that through self-reporting by older adults, their truths can shed light on the current state of wellness in long-term care institutions (WHO, 2020).

It is not clear how those with dementia feel about their own communications within their LTCH experience, whether they feel they are listened to or not, and if they feel that affects their wellbeing. Few studies exclusively focus on selective types of elder abuse (Dong *et al.*, 2014). It remains to be seen whether practices such as ignoring or de-valuing communication are commonplace, and whether these play a role in diminishing wellbeing or can be considered abusive. Also, could de-legitimizing communications be driven in part by assumptions or stigmas surrounding an illness such as dementia. Therefore, I've remained curious about how those with dementia feel about their own communications within their LTCH experience, whether they feel they are listened to or not, and if they feel that affects their wellbeing. If these groups' communications are de-valued, this should act as a red flag for potential harms. Whether a person's communication makes logical sense or not may be beside the point when there is a palpable emotion behind it that can be understood, such as anger, frustration, or sadness — all of which point to non-thriving. How caregivers value such communications may in turn affect the care people with dementia receive from them. Studies examining residents' understanding of how care workers' value their communications and what effect residents feel it has on their wellbeing would provide valuable insights.

CHAPTER 2 – LITERATURE REVIEW

This chapter reports findings from the literature. Few subjective perspective studies involving older adults with dementia as participants were found. Even more sparse are studies seeking to give voice to the subjective perspectives of older adults with dementia regarding how they feel their communications are valued by those who care for them. To ground the research in ethical perspectives, three moral theories provide helpful lenses through which to address this concern. Pursuant to understanding the ethical theories, stigma must be evaluated for the role it has played in deteriorating the autonomy of older adults with dementia. Furthermore, the nature of autonomy must be understood through a relational lens rather than through a traditional one. Finally, when commencing research giving voice to others, risks involved in speaking for others should be well understood to avoid supplanting the participant's voice.

2.1 METHOD

An in-depth literature review was conducted relating to concepts of residents in long-term care with dementia and their communications. While the review was not exhaustive, literature on the subject was found to be sparse. The bulk of the research was focused on ethical considerations for involving people with dementia in research.

The below search criteria were developed to begin the literature review process. The papers obtained from the initial searches through June to August of 2021 led to deeper review of sub-referenced and related literature. This included but was not limited to research study approaches for, qualitative methodologies for, and advice to new researchers for *the inclusion of the voices and perspectives of people with dementia.*

Primary term: Communication

Dementia (cognitive impairment, mild or moderate; Alzheimer; Stigma/tized; Assumptions or negative assumptions, Dysfunctional beliefs, Negative social attitude, Marginalized) + Communication (exchange of ideas, listen*, empowerment, satisfaction, misunderstood, Nonverbal, meaning, identity or loss of identity, good or bad, deterioration or improve(d) skills, valid or non-valid, value or de-valued, ignored, denied, Subjective experience, Patient experience or knowledge or perspective, resident or lived experience, identity, firsthand account) + qualitative study (phenomenology, critical theory, hermeneutics) + qualitative tools (Participant observation, Interviews, Focus group, Interview schedule, Questionnaire) + ethics (care ethics, ethics of care, narrative ethics, thriving, non-thriving, epistemic injustice)

Other relevant terms:

a. Quebec
b. Long-term care, institutional setting(s), CHSLD, support group
c. Community-based care
d. policy

Secondary or sub- objectives: how do the above relate to quality of older adult care?

Sample literature search: Older adult (Elderly, aged, aging, resident, patient) + Care (Good or bad, positive or negative, intentional or unintentional, harm, neglect, abuse, elder abuse, underreported, Patient centered and Individual needs, Preferences, dissatisfaction, quality, life and health outcomes, healthcare)

An initial search in the McGill Library catalogue for background resources did not yield many results. In HaPI (on Ovid Online), different approaches included limiting communication* to the title field and then limiting to "primary sources".

1) Advanced search: Title field: communication*

   AND

   Title field: dementia

2) Keyword: communication*

   AND

   Keyword: dementia

Google Scholar searches provided a more comprehensive search of the literature.

1) This is an example of a five-concept search: dementia + comm + LTC + validity + very precise instrument terms: dementia|alzheimer communication|voice|interaction |conversation "long term care"|institutional|"homes for the aged"|"residential care" validity|reliability "qualitative instrument"|"interview guide"|"interview schedule"
2) Three-concept, precise search: dementia + interview guide + patient experience in the title field only: dementia|alzheimer "interview schedule"|"interview guide" intitle:"patient experience"

2.2 FEW SUBJECTIVE PERSPECTIVE STUDIES INVOLVING OLDER ADULTS WITH DEMENTIA

While numerous perspectives are available from healthcare staff and other caregivers regarding how to be inclusive of the voices of older adults with dementia (*e.g.,* Orange *et al*., 1994; Vittoria, 1998; van den Hooff & Goossensen, 2015; Entwistle *et al*., 2010; Wullink *et al*., 2009; Cooney *et al*., 2013; Savundranayagam *et al*., 2016), and despite recent advances in the promotion and number of patient-perspective studies advocating for the inclusion of their voices (*e.g.,* McKillop & Wilkinson, 2004; Sherratt *et al.*, 2007; Murphy *et al.*, 2015; Oldfield, 2021), the fact remains that comparably few studies exist to reveal the subjective experiences of older adults with dementia regarding how they feel their communications are valued by those who care for them. The reason for this seems to be largely due to stereotypes and stigma which remain a barrier that few scholars are willing to overcome to explore new possibilities for positive, meaningful, and impactful collaboration with persons with dementia (Mann & Hung, 2019).

Efforts have been made to improve and measure changes in quality of life for people with dementia. For example, studies have developed tools that attempt to measure and rate person-centered communication. Cossette and Forbes (2012) developed an observational tool in Montreal that would be sensitive to the more non-verbal patient population (Caring Nurse Observation Tool - CNOT). The Emotional Tone Rating Scale (ETRS) was developed as a communication rating tool, to measure “underlying affective qualities of communication” - care, respect, and control - with older residents in LTCHs (Williams *et al*., 2012, p. 377). Self-reporting quality of life measures have been specifically developed for those with dementia. The Quality of Life in Alzheimer's disease scale (QoL-AD) is a 13-item scale given during an interview (Woods *et al*., 2014). The NARS-MFS (Memory Awareness Rating Scale – Memory Functioning Scale) reveals differences between the rating of a person’s memory function as it is perceived from that person versus their carer, and the Bath Assessment of Subjective Quality of Life in Dementia (BASQID) has proven not very useful in concert with the NARS-MFS, since people having less awareness of their own disease score quite well, which does not align with their carers’ perceptions and assumptions (Woods *et al*., 2014). Dementia Care Mapping (DCM) is an observational assessment tool to evaluate well-being, and the Apparent Emotion Rating Scale (AERS) records how many affective states (pleasure, anger, anxiety, depression, interest and contentment) occur within a defined period of time (McKee *et al*., 2002). These are just a few of the available tools; the list is not exhaustive.

Specifically on the topic of communication, there is significant literature on communication issues of older adults with dementia from the objective perspectives of healthcare staff and other caregivers. Communication challenges encountered by physicians included the inability to “get the person [with AD] to understand the reasons for a minor change in medication" which sometimes actually resulted from physicians themselves explaining in too much detail (Orange *et al.*, 1994, p. 1163). The author suggested that nothing could be done from the patient perspective, but that the physicians, family, and caregivers could work on improving their strategies "to optimize the patient's residual skills" (Orange *et al.*, 1994, p. 1163). In an observational study focused on communication, a select group of nurses' assistants assumed that there are "surviving selves" in Alzheimer's residents, and their central mission was 'to preserve, protect, support, and engage these selves' (Vittoria, 1998, pp. 105, 92). For those with Korsakoff's syndrome (a chronic memory disorder), it is often understood by HCPs that information given by them "might be mistaken, invented and even not true" (van den Hooff & Goossensen, 2015, p. 377). Studies sometimes involving patient participants have attempted to improve communications in the population of people with dementia. A focus on improving valuing of vulnerable patient communiques, particularly where it seems unlikely that improvements can be achieved from the patients themselves, has been described by physicians (Wullink *et al*., 2009). Similarly, HCPs have been presented with strategies to encourage them to develop better individualized care for patients by reviewing changes in patient language, communication, and speech (Orange *et al*., 1994). In their report on eight hospitals looking at favourable practices being used for patient-centered communications in vulnerable populations, Wynia and Matiasek (2006) pointed to specific strategies which improved patient satisfaction, observance of medical advice, and health outcomes. Recognizing the need to improve care for people with dementia in long-term care, Cooney *et al*. (2013) developed a structured education program for nurses and caregivers based upon reminiscence (facilitating the residents to talk or think about their past) that had been found to improve quality of life through its focus on preserved abilities and generating a sense of achievement, mastery, and self-esteem. In a 12-week study aiming to identify person-centered communication between caregivers and residents with dementia in LTCHs, conversations were recorded by long-term care staff during routine tasks (Savundranayagam *et al*., 2016). A correlation was found between person-centered communication and positive reactions, whereas missed opportunities were linked with negative reactions (Savundranayagam *et al*., 2016).

More recently, there has been movement in support of inclusive research, and tips are surfacing on how to conduct such studies properly. A number of advice papers as well as preliminary studies describe how to be inclusive of the subjective voices of older adults and people with dementia in research. In 2002, Bartlett and Martin heralded the change in power structures: the challenge that stood against objectifying persons with dementia, and the transition to a more popular promotion of understanding their own experiences. James McKillop, a person with dementia in the United Kingdom (UK), co-wrote a groundbreaking article in 2004 to instruct researchers on how best to interview a person with dementia, since until then the perspective of the person with dementia had been entirely missing on the subject (McKillop & Wilkinson, 2004). Sherratt *et al.* (2007) brought attention to some of the ethical and legal issues of inclusion and exclusion, drawing attention to the importance of being inclusive of all, irrespective of matching the level of complexity of a study with the capacity of the participants – a process they felt to be discriminatory. Strategies for maximizing the inclusion of people with dementia in qualitative research were transcribed into a guide called CORTE outlining how to gain COnsent, to maximize Responses, to Tell the story, and to End on a high, leaving the participant feeling positive about their contribution (Murphy *et al.*, 2015). In their focused literature review of in-depth interviews with people with dementia, Cridland *et al.* (2016), identified challenges to both researchers and participants, discussed interview guide preparation, and gave recommendations for the self-care of the researcher and health of the participant. In their 2019 paper following an action research project involving people with dementia as experts of lived experiences to co-develop knowledge for change, Mann (Dementia Advocate and this study's Research Advisor) and Hung offered practical tips to researchers working with people with dementia and drew attention to a range of ethical responsibilities. They challenged the perceived need for protection of the vulnerable (which they noted was perhaps reflective of prejudices towards a marginalized group seen as less competent), stating that "'everyday ethics' recognizes that a better understanding of protection requires the engagement of the patients' perspective" (Mann & Hung, 2019, p. 583). Margaret Oldfield, a social scientist and disability scholar, points to the discrimination of viewing dementia as only a medical diagnosis, leaving people devalued and infantilized and left out of decisions concerning their own livelihood (Oldfield, 2021). Like Mann and Hung, Oldfield points to the agency people with dementia have shown through resisting the "exercises of power over them" and expresses disbelief that despite how far research has come, caregivers are still asked to speak for people with dementia – even for those who are fully capable of articulating for themselves (Oldfield, 2021, p. 1). They point out that even though all qualitative research about disability should include participants with lived experience, sadly people with dementia are rarely invited by researchers to participate, and they applaud critical disabilities studies for having led the way for being inclusive of persons with dementia (Oldfield, 2021).

A few studies are beginning to give ear to older adults with dementia to share their perspectives. In one study patients with dementia gave their perspectives on both the supportive and unsupportive aspects of the hospital environment (Hung *et al.*, 2017). Their voicing of how those aspects affected both their well-being and their experience of care revealed that 'little things matter' a great deal to them. They intimated that hospital environments should enable independence, provide safety, support social interaction, and be a place of respect (Hung *et al.*, 2017). Scheffelaar *et al.* (2020) involved long-term care residents as co-researchers to help identify the two best instruments to monitor quality of care relationships from the residents' perspectives.

While there is some evidence in the literature that older adults with dementia feel their communications are not valued and that HCPs may not always be attentive to them, only a handful of studies are from the participants' own perspectives, most of which address people with cognitive impairment or intellectual disability and not dementia. For example, persons with intellectual disabilities voiced they felt harmed and want HCPs to speak respectfully, not shout, explain properly, treat them with deference, listen, communicate when they do not understand the patient, and allow enough time for proper communicating during visits (Lacono & Johnson, 2004; Lennox *et al*., 1997; Lennox, 2005). A study with patients with Korsakoff's syndrome found that valuing patients' unique knowledge via the complexity and richness of their different views could yield a more humane response to their individual needs (van den Hooff & Goossensen, 2015). Their in-depth and open-ended interview approach, beginning with the simple question: "Can you tell me something about your experiences in the nursing home?" (p. 379), allowed for free and individualized responses and kept the interviews more like casual conversations, though with a focused nature (the interviewer was allowed to ask spontaneous follow up questions). The participants revealed their own impressions of what good care should look like: "care experienced as good care by the patient" (van den Hooff & Goossensen, 2015, p. 383). People with intellectual disabilities revealed things they liked and did not like from their own doctor-patient meetings, and together created a substantial list of preferences on what the doctor should do during communications with them (Wullink *et al.*, 2009). The authors noted that it was the first study of its kind where communication preferences were sought out from persons with intellectual disabilities themselves.

A qualitative study of French older patients with dementia explored the conditions of the residents' decision-making in home health care settings (Tyrrell *et al.* 2006). When the authors investigated how involved participants were in making decisions pertaining to their own care, they found that dementia patients felt unheard by their care takers and in most cases had not been permitted to even express their views (Tyrrell *et al.,* 2006). In the UK, researchers explored the patterns of communication in residential dementia care (Ward *et al.*, 2008), and learned that not only are people with dementia capable of communicating, but they also put a lot of effort into trying to engage with those around them. Despite their earnest attempts, they are excluded from decision making regarding their care, which the authors find discriminatory. Olthof-Nefkens *et al.* (2021), worked in concert with persons with dementia and their caregivers to build a questionnaire that measures the "experienced communication" of persons with dementia and of their caregivers (p. 1). The qualitative study with elements of participatory research involved face to face interviews with a speech language therapist who had expertise in working with communicatively impaired older adults. Their final tool was aimed at detecting changes in the experienced communication of the older adults with dementia, using a questionnaire for the person with dementia alongside a separate questionnaire for the caregiver (Olthof-Nefkens *et al.*, 2021). *In their voices: Identity preservation and experiences of Alzheimer's disease* presented rich and diverse subjective perspectives of how those with dementia were impacted upon being diagnosed with early AD, and how, despite the assumptions and stigmas surrounding the disease, they resolutely managed their interactions to both preserve themselves and make sense of their lives (Beard, 2004). More studies are needed to give legitimacy to the voices of older adults with dementia in this domain – to value and to give ear to their perspectives and impressions.

2.3 ETHICAL LENSES – PERSON-CENTERED CARE, CARE ETHICS, & NARRATIVE ETHICS

Involving older adults with dementia in research requires a solid ethical foundation before embarking into analyzing research methodologies and approaches. Carl Elliot points out that one of the most alarming things about trying to solve ethical problems is learning of the many different ways to do it (1992). That said, Elliot provides a starting point with respect to the communication problem at hand. Elliot points out that as a patient's story unfolds, the perceptions of their goals, values, and wishes can change. He points to communication from the patient as being central to their shifting story (Elliot, 1992). Thus, resident communication should be the starting point for addressing key issues of autonomy, justice, and beneficence as they affect residents. When vulnerable adults are cognitively impaired, the risk of their voices being unheard is particularly concerning. Elliot notes that moral differences are best settled by *becoming more like each other* (1992): seeing and helping people at their level. The employment of three moral theories provides helpful lenses through which to address such communication concerns: person-centered care, care ethics, and narrative ethics.

PERSON-CENTERED CARE

Person-Centered Care is a relational theoretical framework, lying at the heart of care, and provides an ideal starting point to begin seeing and helping others at their level. Also known as patient-centered care, PCC has recently gained popularity as a theoretical framework being used in LTCHs. While the province of Ontario has already adopted PCC approaches in long-term care and with respect to its support workers (LTCHA, 2007; OPSWA, 2022), patient-rights groups have been long calling on Quebec to follow suit and adopt a law to establish provincial standards for the public LTCHs (Derfel, 2019). PCC is a high-quality sociopsychological interpersonal care approach that grew from Carl Rogers' person-centered therapy and client-centered counseling (Kim & Park, 2017; Li & Porock, 2014). The goal was to provide a safe psychological environment to recognize the individuality of the patient in relation to those who care for them and to help provide the patient with greater self-awareness to help fulfill their potential (Kim & Park, 2017; Li & Porock, 2014). The focus of this philosophy of care model is not on adherence to rules (Li & Porock, 2014), rather, PCC works with the needs of the individual and requires interpersonal relationships to know the person (Fazio *et al*., 2018). While a universal definition of PCC does not yet exist, common themes include: "striving to maintain personhood in spite of declining cognitive ability, collecting and using personal experiences of life and relationships to visualize care in the environment, prioritizing relationships as much as care tasks, and involving family members in care and offering shared decision making" (Terada *et al*., 2013, p. 104). According to the United States Institute of Medicine (2001, p. 71), "patient-centered encompasses qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient." The Institute recognizes six dimensions of PCC: "(1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support—relieving fear and anxiety; and (6) involvement of family and friends." (Institute of Medicine, 2001, pg.72). An extensive literature review for definitions of PCC found respect and value, dignity, and self-determination among the six predominant domains - all of which contribute to respect for personal choice and autonomy (Fazio *et al*., 2018).

PCC has gained traction in dementia care and is considered very important, if not essential, to dementia care (Fazio *et al*.¸2018; Terada *et al*., 2013). The concept of being person-centered in dementia care was first realized in the 1980s, after Kitwood beheld the horrors of dehumanizing care in traditionally run facilities and rejected such rigid treatment of disease which was the standard medical approach of that time (Fazio *et al*., 2018; Kitwood, 1997; Li & Porock, 2014). Kitwood integrated ideas and ways of working that emphasized communication and relationships and found “that the environment has as much effect on the brain as the brain has on a person's abilities” (Fazio *et al*., 2018, p. S10). Priority is placed on sustaining the identities of older adults, thereby supporting their dignity (Li & Porock, 2014). PCC aims to enable people with dementia to exercise choice, use their abilities, express their feelings, and develop and maintain relationships (Kitwood, 1997). Through a PCC lens, dementia patients are seen to ultimately need love, from which five other needs branch: comfort, attachment, inclusion, occupation, and identity (Fazio *et al*., 2018). Notably, effective communication is highlighted as central to taking the perspective of the person with dementia (Fazio *et al*., 2018).

There is evidence of PCC being developed and implemented in LTCHs for people with dementia. It has been noted that for many of those with dementia in LTCHs, their current lived experience is not person-centered (Cooney & O’Shea, 2019). Early research into PCC provided promising measurable results including improved quality of life, decreased agitation, improved sleep patterns and maintenance of self-esteem (Fazio *et al*., 2018). A systematic literature review and meta-analysis of 19 published clinical trials involving a total of 3,985 participants found that PCC implementation in LTCHs improved quality of life and reduced neuropsychiatric symptoms, agitation, and depression (Kim & Park, 2017). This result correlated with participants being engaged in activities that personally interested them – which required being attentive to their communications regarding personal preferences and interests. Studies also indicate improvement in staff working conditions (Fazio *et al*., 2018). People with dementia can remain connected with their families, friends, and communities (Cooney & O’Shea, 2019) via sharing life experiences through conversation, which has been shown to promote personhood and wellbeing.

Self and selfhood consist of more than just memory and lie at the heart of this care method (Fazio *et al*., 2018). Personhood has been described as "a socially based understanding of a human being in relation with others" (Cooney & O'Shea, 2019, p. 2732). Affirming personhood fills the need for recognition, respect, and trust (Fazio *et al*., 2018). Unmet psychological needs, including isolation, are acknowledged as potential catalysts for behavioral symptoms or neuropsychiatric symptoms in people with dementia (Kim & Park, 2017). Due to dysfunctional social interactions rather than disease itself, these persons may have lost aspects of selfhood (Fazio *et al*., 2018). For example, loss of self is caused not by the disease itself, but rather through the treatment and assumptions of others (Cooney & O'Shea, 2019). Busy caregivers working in stressful environments have been singled out for considering those with dementia as personless, due to losing sight of the person living in the "new lifeworld of dementia" (Cooney & O'Shea, 2019, p. 2732). Despite significant cognitive impairment, persons with dementia can have "intact manifestations of selfhood" (Fazio *et al*., 2018, p. S11), which PCC helps to recognize and maintain (Kim & Park, 2017). The person with dementia is ever in some "state of relative well-being or ill-being", and PCC relationship are mutually respect, recognizing, and trusting – all of which affirm and ensure personhood (Fazio *et al*.,2018, p. S11). An integral part of delivering true person-centered care for those with dementia is incorporating their life story into their care plan to enable choice, use of abilities, expression of feelings, and fostering of relationships (Cooney & O'Shea, 2019).

NARRATIVE ETHICS

If resident communications should be the starting point for addressing key issues of autonomy, justice, and beneficence, narrative ethics can provide further guidance for revealing truths of patients lived situations. By studying narratives consisting of communication from those with cognitive impairments, Brody and Clark (2014) gained insights to better understand patient illness and the health care they had received. Stories are inherent to human existence and as such are essential to our lives in society (Brody and Clark, 2014). A person's narrative gives them an identity; when their cognition declines, a person with dementia may lose this sense of continuity with their past and they may need help from others to hold on to their story (Fazio *et al.,* 2018). For a person with dementia, sustaining their life story helps preserve their sense of self (Cooney & O'Shea, 2019). Expressing one's own narrative comes from a deep desire to be listened to, and stories are inherently derived from a person's own moral baselines (Brody and Clark, 2014) - fashioned from events and narratives encountered throughout life. Narratives are therefore relevant, *whether true or not.* They illuminate the importance of better valuing communications from vulnerable adults with cognitive impairments and can shed light on the care they have received.

When we prevent or discredit a narrative, we refuse to enter into a dialogue that takes seriously the perspective, experiences, uniqueness, and sense of self of the other person. Healthcare professionals have been known to disregard communications because they are objectively not true, which only drives confusion, anger, and aggressive behavior in adults with cognitive impairments (van den Hooff and Goossensen, 2015). Brody and Clark (2014) point out that "we tell ourselves stories in order to live" (p. S8), that stories are central to our lives, and that narratives make the earth livable – thus, our own narratives are also essential to our lives. In cases where cognitively impaired residents are denied their own voices in their own stories, they are essentially cut off from their very selves. In *The Moral Irrelevance of Equality* (2000), Frankfurt describes the fallout of being denied one's own narrative very clearly:

> "it can be extremely disturbing to a person to feel that he is being treated as though he were something other than what he quite plainly is… despite calling for attention as loudly and as clearly as possible, *he cannot make his voice heard*… terrible anger and terrible anxiety may be aroused… (when) *what he manifestly and undeniably is just does not count, and… he cannot gain simple recognition of what is no more than the plain truth about himself*" (pg. 102, emphasis added)

Such a profound loss of self-narrative threatens a person's very reality - since "there is a morally foundational need to affirm and to be confirmed in one's own reality" (Frankfurt, 2000, p. 103). This <u>must</u> be exacerbated when one no longer has their own voice and is either entirely lost in cognitive confusion or completely at the mercy of a surrogate's voice – who affirms their reality? The important role of the clinician in supporting patient autonomy should therefore not be overlooked, since they can all too easily be the cause of its destruction when they are dismissive or use negatively judgmental speech, denying those with cognitive impairments their voice (Entwistle *et al.*, 2010). A person in such a state surely cannot have a good quality of life and must be suffering.

In addition to affirming a person's reality, untrue stories do present meaning and value. Patients' narratives may convey both generalized truths and dissatisfaction with care. Whether a communication makes logical sense or not may be beside the point when there is a palpable emotion which can be understood, such as anger, frustration, or sadness — all of which point to non-thriving. Patients with Korsakoff's syndrome are known to tell stories that are moving, insightful, and revealing despite being mistaken or invented (van den Hoof & Goossensen, 2015). Regardless of whether they contained a factual truth or a lived truth, these patient communications provide insights into how they perceived their care – not always communicated to be "good care" (van den Hooff & Goossensen, 2015, p. 383). Wullink *et al.* (2009) found value in allowing patients with intellectual disability to fully articulate their accounts since patient narratives unearthed hidden truths, whether stories were factually true or not. When someone tells a story, it matters to them in that moment for a reason. Dooley *et al.* (2015) recommend professionals spend more time listening to patients (without focusing on facts) to help patients feel valued and to reduce their frustration. Narratives of adults with cognitive impairment may hold something extremely valuable – perhaps not in fact, but rather in the deeper truths behind the story or emotion hidden in sentiment conveyed by it. As such, incorporating personal narratives into care is of utmost importance.

CARE ETHICS

To become more like each other (Elliot, 1992) and to see and help people at their level, the moral theory of care ethics enables delving deeply into the moral significance of relationships and dependencies. In the context of care, care ethics has relevance concerning the communications of cognitively impaired patients where they are the receivers of care in that relationship.

> "Defining care in terms of patient experiences boils down to the following definition of good care: 'care experienced as good care by the patient'."
> (van den Hooff & Goossensen, 2015, p. 383)

Ethics of care is very much grounded in context, concentrated on interpersonal relationships and care as a basic human capacity - it not only recognizes but also responds to the needs of others (Sander-Staudt, 2020; Manning, 2009). Care is the action given to those who need it, who cannot help themselves (Held, 2006), and adults with cognitive impairment whose voices may go unheard in LTCHs definitely fall into this category. Care ethics are concerned with social caring relationships and practices between persons (Held, 2006), and meeting people at their level with face-to-face care.

Individual communications should therefore be valued as part of the commitment to ensure flourishing in life (Sander-Staudt, 2020). This should inevitably force a reliance on the patient with cognitive impairments and their communication as the source of their own "general justified true knowledge" (van den Hooff and Goossensen, 2015, pp. 379, 385). Communication from persons with AD is a vital component to person centered care (Savundranayagram *et al*., 2016) yet a review of 23 dementia studies assessing communication between patients, companions, and healthcare professionals found that these patients are not only hardly being listened to but also that HCPs often omit to verify that patients understand what is communicated to them (Dooley *et al.* 2015). Similarly, one study found that HCPs and patients with intellectual disabilities have different perceptions about the quality of their communications (Wullink *et al*., 2009). Whereas HCPs felt their skills were sufficient to meet patient needs, the patients were unhappy and felt that communications should be improved by HCPs speaking directly to them, taking them seriously, allowing enough time to listen carefully to them, and asking permission before speaking to a surrogate (Wullink *et al.*, 2009). Patient communications can shed light on the quality and quantity of care they receive by using knowledge from their own unhindered and unedited narrative. When a person's communications are repeatedly not valued, there is the potential for harm due to untimely care (van den Hooff & Gossensen, 2014). Qualitative research evaluating the practice of care is taking a more patient-centered approach to valuing patient communication by recognizing the patient's own voice (van den Hooff and Goossensen, 2015). When studies used patient communication to investigate care, patients revealed that their needs were not fully met, which resulted in both physical and mental distress and suffering (Wullink *et al*., 2009; van den Hooff and Goossensen, 2015). Such harms could be ameliorated by valuing their communications.

When communications are de-valued, people fail to flourish; they may be in additional pain and suffering due to physical or psychological neglect. The lack of attentiveness to communications exacerbates harm when care workers are "not attuned to the other's position as the other expresses it, both on a daily and on a long-term basis" (van den Hooff & Goossensen, 2015, p. 378). This highlights a key ethical concern surrounding de-valuing patient communications: if we are not listening at their level, we may not know the basic needs of patients, which, if left unaddressed, will lead to further loss of flourishing and harm. Van den Hooff and Goossensen (2015) describe care ethics as focusing on interdependencies in the context of relations, actions, virtues, and emotions. Within healthcare relations, they find that care ethics pays particular attention to the "physicality, vulnerability and tragedy" of the patient (van den Hooff &

Goossensen, 2015, p. 378), and point out that genuine listening to these vulnerable patients is crucial for healthcare to be effective.

Care ethics requires that basic needs be met, pain and suffering be avoided and alleviated, and the cared for and giver of care have a reciprocal relationship and "meet the other morally" (Sander-Staudt, 2020, p. 4). When a person listens to someone else, they engage in this reciprocal relationship by "*deciding to open oneself up to the other's way of seeing the world*" (Brody and Clark, 2014, p. S8, emphasis added). In this way care ethics and narrative ethics become intertwined and narrative ethics become relevant to revealing what good care can be, particularly in the context of adults with memory problems (van den Hooff & Goossensen, 2015).

2.4 STIGMA & AUTONOMY

> *"*Our society has silenced the voices of grandparents. We pushed them out of the way. We didn't give them the chance to share their experiences, to tell their stories, and to speak about their lives. We put them aside, and so we have lost the treasure of their wisdom." (Pope Francis, 2018, p.11)

Truth is at the very heart of the bioethical principles of autonomy, beneficence, and justice (Scharf *et al.*, 2021). Part of maintaining trust involves the embodiment of professional behaviours like listening to, acknowledging, and empathizing with patients so they feel heard and valued. If communications are known to be dismissed because they are considered non-valid, delusional, or nonsensical ramblings, it raises concerns that the loss of voiced autonomy may be resulting in decreased or damaging care, causing older adults with dementia further harm, suffering, and poorer health outcomes.

STIGMA - NEGATIVE ASSUMPTIONS EXACERBATE PROBLEMS AND WORSEN CARE

> "Older adults … are constantly exposed to deeply entrenched stereotypes that deny their competence to manage their own lives well; some have a hard time believing there is no truth to these biases. When agents experience diminished self-trust, they are less likely to challenge the pervasive biases that structure the options made available to them or to question the system … that encourages them to comply with dominant stereotypes." (Sherwin & Winsby, 2010, p.185)

Older adults with dementia may be at an even higher risk of remaining unheard due to the nature of their disease – and the stigma surrounding it. Stigma creates a lack of dignity and respect that is as unacceptable as any other prejudice (Harrigan, 2010). Regarding a person as 'diminished' due to a decline in cognitive function can result in their being treated as though they were no longer human (Fazio *et al.,* 2018). Stigmatized groups are more likely to be disadvantaged, including with regards to the quality of health care (Sherwin & Winsby, 2010). For at least half a century, Western culture has highly valued reason, cognition, and financial productivity and has frequently associated old age with powerlessness, the result of disease, disability, or uselessness – thereby placing a particular lens on aging in our society (Harrigan, 2010). The assumption that whether someone can live a good life (or not) is directly tied to their ability both to understand good versus bad and to critically reflect on life choices takes a dangerous route by classifying people with cognitive impairments as incapable of having a good life (Burchardt, 2004).

Older adults are often victims of ageism, a particular form of oppression (Sherwin & Winsby, 2010, p. 186). Ageism is the discrimination and stereotyping of people - whether consciously or unconsciously - solely on the grounds of age, resulting in assumptions that the older adults are weak, frail, and incapable (CMPA, 2016; Harrigan, 2010). It has been noted that the worst effect of brain disease is not the functional impairments it causes, but rather, the threat it poses to self and personhood – which itself is dependent on other people (Fazio *et al.,* 2018). Over the last century the increased acceptance of the institutionalization of our older adults has created a stigma that they are burdensome and a major social problem – instead of seeing them "as people who can provide a sense of wholeness and wisdom" (Sherwin & Winsby, 2010, p. 187; Gale, 1989). Stigma and disempowerment can also occur through labeling, infantilism, and objectification – where words do carry weight in driving perceptions and altering approaches to care (Fazio *et al.,* 2018). Such negative attitudes towards older adults denies them opportunities granted to others, severely limits services available to them, and results in their segregation from society (Harrigan, 2010).

Old age and illness themselves can impair autonomy (Entwistle *et al*., 2010) but the additional disrespect of dismissing communications due to dysfunctional cultural beliefs or negative social attitudes arising from the stigma of cognitive impairments furthers this harm by creating serious obstacles to good care and negatively impacting their quality of life (Bahar & Bigdeli, 2020). The stigma of being a dementia patient in a LTCH leaves residents particularly vulnerable since they are subject to stereotypical assumptions about their limited competency (Sherwin & Winsby, 2010). Nurses are of the impression that residents with dementia, even those having fewer limitations, are less capable of expressing and understanding communication acts (Le Dorze *et al.,* 2000). A phenomenological study in Iran found that older adults with dementia experienced a significantly reduced quality of life at the hands of their caregivers due to negative social attitudes surrounding the stigma of dementia (Bahar & Bigdeli, 2020). Since Alzheimer's dementia patients are found to "digress and ramble" (Orange *et al.*, 1994, p. 1163), this stigma towards their communications may be linked to active infringing on their right to have a voice, resulting in barriers to their involvement in decision-making such as those observed among the vulnerable aging, where it has been noted that physicians rush patients or interrupt after as few as 23 seconds (Williams *et al*., 2007). It is unjustifiably paternalistic and a misuse of power when HCPs automatically assume people are not capable of understanding nor of providing relevant input. Such actions break communications and relationships, causing difficulties and suffering for all parties. When a person's communications are repeatedly not valued, there is the potential for harm due to their perceived loss of autonomy (van den Hooff & Gossensen, 2014).

AUTONOMY

> "If we take a broader view of the nature of autonomy, we are more likely to reflect the possibility of expanding opportunities for choice and improving the types of options available." (Sherwin & Winsby, 2010, p.188)

Since older adults with dementia, regardless of the severity of their impairment, are known to seek out and establish ways to compensate for their difficulties and to maintain their autonomy (Dooley *et al.*, 2015; Ward *et al.*, 2008), when their attempts to assert themselves through self-expression and communication are dismissed or ignored by staff, they are excluded from providing a perspective regarding the support they receive (Ward *et al*., 2008).

In the context of disabled persons being cared for in centres such as those providing day care (Maglajlic *et al.*, 2000), it has been reported that despite best intentions little is done to allow autonomous choices, such as to give them the "ability to choose when or how to eat, bathe or dress, or indeed to choose to skip all that" (Burchardt, 2004, p. 748). This stigma results in marginalization, discrimination, and social exclusion (Bahar & Bigdeli, 2020; Ward *et al.*, 2008) – all of which inevitably result in a loss of personhood and a loss of sense of self. Communication from the patient's perspective enables them to make their own autonomous decisions – whereas procedural oppression of their voices by those on whom they depend for care leads to silence (Entwistle *et al*., 2010). Older adults with dementia whose voices have been repeatedly silenced and who have been oppressed may no longer have self-trust, which is essential to exercise autonomy (Sherwin & Winsby, 2010). Such a loss of voice and of autonomy "demands …the acknowledgement and restoration of ourselves" (Frankfurt, 2000, p. 103). It has been noted that Beauchamp and Childress' definition of autonomy, in which decisions are identified as autonomous when they are made "intentionally with *substantial understanding* and freedom from controlling influences" is problematic since autonomous decisions do not seem to include those made by individuals with cognitive disabilities who may have little understanding (Entwistle *et al*., 2010, p. 741, emphasis added).

This problem with autonomy can be viewed through a relational or a traditional lens (Sherwin & Winsby, 2010). The traditional lens of autonomy holds that patients must be sufficiently competent to make well-founded decisions that reflect their own values to have their autonomous decision making respected (Sherwin & Winsby, 2010). The options available to them hinge on each person's unique social, political, economic, and cultural circumstances (Sherwin & Winsby, 2010). Institutional requirements of LTCHs make it difficult to fully address the broad spectrum of individual circumstances, particularly considering the predominant social biases of those caring for them (Sherwin & Winsby, 2010). Unfortunately, traditional autonomy focuses heavily on evaluating the competency of the patient, instead of unearthing the range and nature of the options any given person must choose from (Sherwin & Winsby, 2010). Since residents living with dementia have reduced competency, traditional autonomy would require those with legal authority to decide on the patient's behalf. It is not right that when a person enters a LTCH they must surrender not only legal authority on health issues but also all their rights of privacy and personal control – even over ordinary daily matters such as meals, social interactions, and bathing (Sherwin & Winsby, 2010). Relational autonomy in contrast weaves itself amidst the embodied social location and experience of patients, as is relevant to an assessment of autonomy (Sherwin & Winsby, 2010). It is particularly concerned with questions of social justice, considering the impact of patterns of inequality and prejudice on the options and opportunities available to each person. Indeed, supported decision-making is expected to increase inclusion of persons with dementia in (clinical) research, and aligns itself with justice, beneficence, and autonomy – the latter of which is foundational to informed consent and participation in research (Bierer *et al.* 2021). It has been noted that relational autonomy should be an essential component of PCC since is strengthens and enables a more coherent approach, drawing attention to policies and structures of clinical settings which affect autonomy (Ells *et al.,* 2011). The lens of relational autonomy is important to employ in this case since it is sensitive to the dangers of distorting stereotypes (Sherwin & Winsby, 2010). People are respected as social beings having distinct identities which are developed and maintained within the complexity of social relations.

While LTCHs may be designed to help compensate for lost competencies, such a focus leaves residents vulnerable to mistaken presumptions about their individual levels of competence which in turn leaves little space for attending to remaining levels of autonomy (Sherwin & Winsby, 2010). Where traditional concepts of autonomy favour an ideal of independence, relational autonomy respects dependence and reliance on others as normal and part of every human's day to day life; every person throughout life is interdependent and relies on others in numerous ways, with varying urgency and frequency. The layering of interdependence is normalized and the tendency to devalue those with special needs is resisted; rather it is important to value all persons who are highly dependent, including children and those with serious disabilities (Sherwin & Winsby, 2010).

Older adults with moderate dementia find themselves with limited capacity to make choices in their best interests (Sherwin & Winsby, 2010). While Sherwin and Winsby (2010) do still find that paternalistic treatment is a necessity for overall care when it comes to those having seriously compromised cognitive capacity, I argue that their communications can and should still shape how the interactions happen and thus inform the quality of their care. Most LTCHs are not structured to balance these concerns for those in later stages of dementia, however alternate models of care are beginning to surface which will be able to break the destructive cycle of lost autonomy among older persons. These include models such as Eden Alternative (resident centered; Sherwin & Winsby, 2010), My Home Life (relationship centered; Sherwin & Winsby, 2010) and a model in its early stages in Canada: The Butterfly Model (relationship centered; Vogel, 2018). This new awareness that the resident comes first is gaining popularity across Australia, New Zealand, the United Kingdom, Europe, Japan, China, Canada, South Africa, and the United States (Li & Porock, 2014).

Culture change has at its foundation "person-centered philosophy which advocates for: choice, dignity, respect, self-determination and purposeful living for older adults" (Li & Porock, 2014, p. 1396). PCC is intertwined with culture change and the effort to transition homes from interpersonal care to person-centered (Fazio *et al.,* 2018). Communications and life narrative work via PCC may contribute to changing perceptions and breaking stigma by enabling a person with dementia to have a voice that can be heard, which in turn maintains the person as a "whole person, rather than a demented patient" (Cooney & O'Shea, 2019, p. 2735). Legitimizing their voices may be the key to revealing the person behind the stigmatized disease, upholding their humanity, and giving them back their autonomy, independence, and a better quality of life (Li & Porock, 2014). Once properly understood, impressions and perspectives from older adults with dementia may change carer's opinions regarding what things are important when it comes to care, which may lead to meaningful change.

2.5 ETHICAL CONCERNS - SPEAKING FOR OTHERS & GIVING VOICE TO OTHERS

While professionals, caregivers, and surrogates play an important role in receiving and passing on communications, they should not replace the patient or participant voice. Regarding surrogates, not only is there danger of important subjects not being broached due to sensitivity issues, but the role can also become problematic when patients become barred from conversation, leading to disempowerment and decreased self-worth. However, when any individual *incorrectly* speaks for the cognitively impaired additional problems may surface – thus great care must be taken when assuming such a role.

If healthcare workers and caregivers are primarily relied upon to improve patient communications, they will have limited success. In many cases where there is cognitive impairment, there does need to be some speaking for others, yet speaking for others risks exacerbating loss of voice. This circular method puts onus back on the very people who may consider communications as ramblings to correctly interpret and value them as having real meaning. Indeed, leaving everything to the caregivers has not proven to be the best strategy; in fact, it has led to more harm. For example, patient frustration only increased when professionals tended to revert to their own topic as a mechanism to cope with a dementia patient's confusion, instead of making time to understand them (Dooley *et al.*, 2015). Despite having some knowledge of their condition, patients' lived understanding differs from a physician's factual understanding, such as when patients would claim they were not ill enough to be kept at a residence and wanted to go home, healthcare professionals would simply disregard that knowledge because objectively it is not true, a reaction which resulted in patient confusion, anger, and even aggressive behavior (van den Hooff & Goossensen, 2015). Such a violent reaction ensued because they felt unrecognized, "unheard and treated as a disease" when their personal subjective knowledge about their own health condition was not carefully considered (van den Hooff & Goossensen, 2015, p. 381). Dooley *et al.* highlighted that professionals should give up on trying to achieve factual correctness when conversing with people with dementia and that various methods should be employed to achieve good communication since every patient and practitioner is different (Dooley *et al.*, 2015).

Surrogates play a meaningful role in providing facts; however, acting as both informant and advocate can pose a problem. While listening to the patient is important to uphold their autonomy, it would of course be dangerous to give the patient the only say. Dooley *et al.* believed that one technique - assenting in consent discussions - was sometimes not actually a real agreement but was rather a way of concealing a lack of understanding in order to remain involved in the conversation (2015). Conversely, too heavy a reliance on surrogates can result in communications being overlooked or unheard when incapacity due to cognitive impairment is suspected. One study found that surrogates often did most of the speaking for dementia patients during visits with physicians (except during the initial diagnosis) which resulted in patient disempowerment, withdrawal from social situations, frustration, and diminished self-worth (Dooley *et al.*, 2015). While surrogates do play an important role in the initiation of discussions of dementia-related behaviours and in sharing biomedical information about the patient, they may also omit speaking to certain subjects, to avoid discussing potentially embarrassing topics in front of their relative, sometimes only bring a situation to light once it becomes dire (Dooley *et al.*, 2015). While their closeness to the patient can make them more attuned to needs, that very closeness may pose problems. Family interplay and dynamics make every surrogate situation uniquely challenging, and balance must be sought between the person with dementia, the surrogate, and the HCP when regarding patient communications. Surrogates and their precarious role will be reviewed more thoroughly in Chapter 3.2.

Cognitively impaired adults may be oppressed if their communications have long been de-valued and speaking for them could be an important way to help. Residents whose attempts at communication have been repeatedly silenced through “clinically imposed behavioural norms” (Entwistle *et al.*, 2010, p.742) and who have gradually become accustomed to unjust care, abandonment, and neglect would no longer have any self-awareness to communicate the loss of their voices - they may have internalized their oppression to the point of being unaware of any deprivation (Burchardt, 2004; Nussbaum, 2001). Intervention by someone else may be needed to create change by listening to and sharing their narratives. However, caution must be employed when re-creating another's story, since it can involve the misunderstanding and misappropriation of ideas, which "could actually encourage the kinds of inappropriate paternalism that ethical norms of respect for autonomy are meant to protect against" (Entwistle *et al.*, 2010, p. 744). While it is important to listen to all patient communications and perspectives, being critical to compare and weigh different narratives to be truly ethical in their interpretation, great care must be used to avoid selectively deciding which stories to learn from or value – such as those that are the easiest to interpret, understand, or solve, or are of great importance - or which to ignore or "hold in contempt" (Brody and Clark, 2014, p. S8; Brown *et al.*, 2015). This idea is supported by Saulnier (2020) who points out that "patterns of narrative neglect in medicine are harming not only our capacity to make use of narrative ethics but also our capacity to deliver effective healthcare" (p. 297). Saulnier also points out when narrative power is withheld from vulnerable marginalized groups, the result may be poorer treatments or attention, and that even when stories are told, there is no value to them if healthcare workers are not listening (2020). When we speak for others, we inevitably substitute our own interpretation for theirs (Alcoff, 1991-1992) opening the door to misrepresentation. Inserting our own narrative may not reflect the reality of the other and can be dangerous. We must be extremely careful to determine whether we are imposing *our* opinion of what someone else's narrative should be and what their autonomy should look like – referred to in literature as the substituted judgement standard (Friesen & Gligorov, 2020). For example, Van den Hooff and Goossensen (2015) noted their limitations with respect to a researchers' interpretation of patient communications and that it could have been differently understood by others - but pointed out the value in opening a discussion and raising awareness. Alcoff provides four self-questioning practices to avoid problems. The second and fourth – to consider your location and how it could affect your opinions and to carefully consider the future effect of what is said (Alcoff, 1991-1992) - are extremely important for caregivers and surrogates to consider, given their positions as either medically-minded or intimately close to the individual. Therefore, it is crucial to verify that the desire to help improve communications of others comes from the right place - to help improve *their* lives. Future ramifications of speaking wrongly must be carefully considered.

CHAPTER 3 – ETHICAL CONSIDERATIONS – RESEARCH INVOLVING OLDER ADULTS WITH DEMENTIA

Chapters three expands on the ethics of conducting research with persons with dementia – how to prevent harm and support inclusion, in a general sense. Relevant qualitative approaches for involving older adults with dementia along with the importance of including their voices in research are discussed. The harms and consequences which could occur by not being inclusive of them in the very research meant to help them are discussed. Realistic objectives and outcomes of various types of qualitative research methods with persons with dementia are reviewed considering benefits, limitations, and risks. Components of a research study are carefully discussed, after acknowledging an ethical stance bearing in mind anticipated and foreseeable risks and benefits to satisfy and value respect for human dignity through three main research ethics principles: respect for persons, concern for welfare, and justice.

3.1 REASONING & RELEVANCE FOR EMPIRICAL STUDY

Considering the current devastating state of organizational negligence resulting in elder abuses and long endured neglect in long-term care as it has been brought to light during the COVID-19 pandemic, resident perspective studies seem urgently needed. There is evidence that problems existed in the LTC system prior to the pandemic - they were simply brought to light when additional pressures were placed on the system (Olson & Shingler, 2020; Pugliese, 2020; Grant *et al.*, 2021). Indeed, through the report *Reconciling the care environment and the living environment in long-term care facilities,* it is evident that Quebec's healthcare community has recognized shortcomings in their system and that tensions exist with respect to interpersonal relationships in LTCHs (INESSS, 2020). In addition to structural aspects of long-term care, tensions in interpersonal relationships may very well be linked to residents' communications and how they are valued by staff. It is conceivable that some of the recognized problems of poor care and worsened health outcomes may stem from this. If this is the case, there is some sense of urgency to investigate. Without qualitative study, it remains to be seen whether less value is attributed to residents' communiques, particularly when they are cognitively impaired. Indeed, the 2020 report from the Institut national d'excellence en sante et en services sociaux (INESSS) did point to tensions in interpersonal relationships with a focus on improving their communication strategies, revealing the likelihood of problems at the level of communications, whether they be verbal or non-verbal. Deteriorations at the communications level risks inhibiting older persons from freely exercising their autonomous rights. It is important to recognize that older adults with dementia have the same rights as any person, and as such they have the right to be heard, and a ‘right to voice’ (Swain *et al.*, 1998).

> “Having dementia does not mean a person automatically lacks the capacity to make decisions to participate in research and to contribute his or her knowledge. Excluding the direct voices of people with dementia in the research reinforces stigma and negative stereotyping.” Jim Mann, person with dementia (Mann & Hung, 2019, p. 585)

Relevant qualitative approaches for involving older adults with dementia in research include phenomenological studies (which investigate subjective experiences and interpretations), specific case studies, participant observation studies, and narrative research studies which look at life experiences over time (Scheffelaar *et al.* (2020).

IMPORTANCE OF INCLUDING VOICES OF PERSONS WITH DEMENTIA IN RESEARCH

Involving people with dementia as active participants with voices is of the utmost importance to ensure those having lived experience help reduce the risk of bias and help direct research. The research should serve those with dementia, who in turn can help researchers understand what their priorities are (Mann & Hung, 2019). It been found that having those with lived experience and expertise at the center of research and collaboration is critical in dementia-related research (Flipping Stigma, 2022; Mann & Hung, 2019). Attention should also be paid to be inclusive of people with diverse characteristics to maximize variation of voice and opinion; recent studies have engaged people living with dementia at EVERY stage of dementia, including later phases (Murphy *et al*., 2015; Smith & Phillipson, 2020; Wang *et al.*, 2019).

Furthermore, it is becoming more evident that *only* those with dementia should participate in research centered on their perspectives, due to the effect other peoples’ stigmas have on actively (albeit indirectly) diminishing the freedom and autonomy of participants with dementia. For example, in a study using participatory action research having three advisory groups consisting of people with dementia, the only group which spontaneously and deeply addressed experiences of stigma and discrimination *did not have family members present.* The members of that group concurred that greater freedom of expression arose from the absence of their care partners, whose presence sometimes felt intrusive or gave a sense of losing voice due to their impatience – which stemmed from the lack of a lived experience of dementia (they often felt the need to jump in and help the narrative along). As one member shared: “…when you are just people with dementia together, I think you come out feeling stronger and more confident and able to deal with what's happening to you, rather than having the crutch of your spouse" (O'Connor *et al.*, 2018, p. 50). There is also fear of losing help from caregivers if honest sharing offends them while speaking openly in their presence (O'Connor *et al.*, 2018). In another study, an important and distinctive aspect of their research group was that only people with dementia were included, not care partners (Flipping Stigma, 2022). It has also been noted that combining the data from caregivers with the perspectives of persons with dementia results in a diminished focus on the actual experiences of the person with dementia, which would negate the goal of a participatory study (McKillop & Wilkinson, 2004).

CONSEQUENCES OF EXCLUDING VOICES OF PERSONS WITH DEMENTIA FROM RESEARCH

Considering the serious obstacles to good care and quality of life created by stigma and negative social attitudes surrounding cognitive impairments (Bahar & Bigdeli, 2020), failing to include the voices of older adults with dementia in research would be an additional injustice. Making the mistake of excluding vulnerable people with dementia from important research may even increase their vulnerability, in addition to being unethical and a threat to their dignity (Heggestad *et al.*, 2013). Communications enable people to make their own autonomous decisions. When communications are not recognized by those receiving them as having meaning or value, particularly by those on whom older adults with dementia depend for care, it may lead to complete silencing and to a perceived loss of autonomy on the part of the older person (Burchardt, 2004; Entwistle *et al.*, 2010; van den Hooff & Gossensen, 2014). If they continue to be excluded, treated as incompetent, and treated with diminished respect, we run the risk of those with dementia responding by voluntarily limiting themselves (O'Connor *et al.*, 2018).

BENEFITS OF QUALITATIVE RESEARCH FOR PERSONS WITH DEMENTIA

In addition to ethical value and import, there are some other benefits to conducting a qualitative study involving the voices of persons with dementia. Inclusive qualitative studies are both collaborative and flexible creating a matrix in which complex issues can be explored (Cridland *et al.*, 2016). Qualitative research can clarify an individual's understanding through personal experiences, divulging meaningful and rich data (Scheffelaar *et al.,* 2020). Through self-reporting, deeper truths are learned about lived experiences and realities for older adults with dementia in long-term care institutions. Direct involvement of those with dementia has already proven to be transformative in challenging attitude and driving change (Murphy *et al*., 2015) and co-research has recently begun to improve attitudes and decrease stigma (Mann & Hung, 2019). We cannot understand how a broken bone feels until we have broken one ourselves. Those who are actually living their health state are the ones with not only the "most intimate knowledge of the reductions in function associated with that state" (Salomon *et al.*, 2012, p. 2131) but also the understanding of the ongoing adaptations needed to compensate for functional or behavioural changes. Those without dementia understandably struggle to appreciate how to properly value communications from those with dementia. A good first step therefore should be to strive to first listen to how *they* feel about topics of interest to researchers. As Beard notes (2004), when the research community is receptive to listening to, valuing, and sharing firsthand communications from people living with dementia, we will not only better understand how to improve their care, but we will also give meaning back to their lives. Ward *et al.* (2008) demonstrate how valuable it is to measure the level and quality of communication as a way of evaluating the care of older adults with dementia. They propose to listen more to the perspectives of those with dementia to assess the quality of their care. Involving older participants with dementia in the design of research studies is not only beneficial to the quality of the study, but it also benefits both participants and researchers themselves (Nunn *et al.*, 2021). Participants may not realize the value of their communications, and a benefit of research for these participants may lie in giving them back the value of their voice, and providing value, meaning, and purpose to their participation (Cridland *et al.*, 2016). One participant communicated how the study changed the impression they had of their own voice from being value-less to others, to significantly valuable:

> "I was unsure how people without a science or health background could contribute. I have learned that participants have valid, interesting, and often novel ideas that researchers may not have considered." (Nunn *et al.*, 2021, p. 8)

That research can help improve conditions for others with dementia (Cridland *et al.*, 2016), and can help society better understand how to care for them, may be valued by participants - to know that their "efforts are making a real difference to help improve the lives of people with dementia" (Mann & Hung, 2019, p. 585).

LIMITATIONS & RISKS OF QUALITATIVE RESEARCH FOR PERSONS WITH DEMENTIA

Qualitative studies aiming to give voice to persons with dementia also have certain limitations. Early phenomenological research would have sample sizes ranging from five to 25 people (circa 1989 reported in Creswell, 2007, p. 121); though sample sizes on the smaller end of this range are more typical now. Smaller sample sizes in phenomenological research are needed to maximize the deeper quality of data (Moore & Hollett, 2003) and to yield rich descriptions and better understanding of the participants' experiences (Hung *et al.*, 2017). This research does not strive for generalizability, rather it will aim for some transferability in similar contexts. It has been noted that patterns may not emerge nor repeat themselves with a small sample set within constraints of LTCHs and in some cases, sample size should be increased until saturation (Moore & Hollett, 2003). Despite providing important knowledge, a few rich voices are not translatable to the experiences of others. Through careful preparation, difficulties can be overcome regarding finding willing participants meeting eligibility criteria; however, it may not be possible to obtain a wide range of variation in perspective despite efforts to be broadly inclusive of different stages and interpersonal variability. Though specific findings may not be generalizable, small community studies can drive changes in practice more broadly when their *lessons* are applied at other sites and in other settings (Durocher *et al.*, 2019). Interestingly, a small sample size has been noted as a necessity by Moore & Hollett (2003), who insist that to maximize data quality, smaller and not larger samples sizes are needed. Despite the limitations of a small size, analyzing data from only a few individuals allows for a rich capturing of individual perspectives and impressions from a target population; it enables greater depth of examination and original insights in comparison with a large multi-site study (Durocher *et al.*, 2019). Furthermore, if the goal were to complete such a study during a master's degree, for example, a small sample size would allow for sufficient time to conduct, analyze, and report on the study while meeting the deadlines imposed by departmental timelines.

Another significant limitation to such a participant-based study is that the participants may not actually be able to give their own perspective with respect to the value of their communication. Being members of an oppressed group, persons with dementia may have already internalized some of these social biases, accepting them as normal (Sherwin & Winsby, 2010). They may not believe that their perspective as a person with dementia deserves attention or has any value if they have assumed a reduced sense of self-worth and self-trust (Sherwin & Winsby, 2010). Inviting them to share their experiences may help them to regain both self-worth and trust in their own voice.

ETHICS OF DEMENTIA ADVISORS – VALUE IN STUDY DESIGN AND DATA ANALYSIS

An excellent way to satisfy justice and equity in a study involving with persons with dementia is to include persons with dementia in the design and the analysis of the study. Being involved in the research process as an advisor can be very important to people with dementia – to see that their work can improve lives and elicit real change for others with dementia (Mann & Hung, 2019). In fact, *not* involving the voice of someone with dementia in the research process itself can act to reinforce stigma and negative stereotyping (Mann & Hung, 2019). Both the participants as well as the advisor(s) with dementia should be regarded as both experts and active contributors, regarding them through an "appreciative lens" rather than a "deficit-based lens" which sees people with dementia as impaired and needing protecting (Mann & Hung, 2019, pp. 587, 586).

Several researchers are acknowledging the ethical importance of advisors with dementia, or of involving a dementia advisory committee from outside the study setting to inform research projects (Cridland *et al.*, 2016; Mann & Hung, 2019; Oldfield, 2021). Such members could be involved in multiple aspects of the project – from helping develop research questions to data analysis and interpretation (Oldfield, 2021). Involving someone with dementia in the process of study design and data analysis enables valuable insights from lived practical experience to inform the design and the analysis of themes arising from the research data (Phillipson *et al.*, 2016), resulting in a much richer project. For example, with respect to study design, an advisor with dementia can aid in the development of recruitment strategies, in the wording of interview questions (Cridland *et al.*, 2016), and with the specific wording of consent forms (Mann & Hung, 2019).

When only one person with dementia acts as advisor there is a risk that a one-faceted view of living with dementia could lead to bias. Since each person is unique, each person will have their own perspective on living with dementia. If a researcher is unaware of this bias, it could narrow the research scope. A dementia advisory group could be preferable to limit personal biases from the dementia advisor themselves. Furthermore, advisors may be selected from among similarly situated persons within the target environment.

3.2 ETHICAL CONSIDERATIONS OF RESEARCH STUDY COMPONENTS

ETHICAL PRINCIPLES & NORMATIVE GUIDANCES

In their guidelines of human research ethics principles, the Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada encourage researchers to imagine themselves as the participant, valuing respect for human dignity through three main bioethical principles: respect for persons, concern for welfare, and justice (Tri-Council Policy Statement (TCPS 2), 2018). Respect for persons is closely linked with consent (TCPS 2, 2018). Concern for welfare seeks to balance the risks and benefits of research and considers not only the social or economic circumstances of the individual, but also considers how research can be impacted by stigmatization and discrimination which can have serious repercussions for a group (TCPS 2, 2018). Justice is concerned with treating all people with equal respect – fairly and equitably; the balance of power should be equal between the researcher and the participants, groups should not be over- or under-studied due to their vulnerable circumstances, and the benefits and burdens of research participation should be evenly distributed among the population for a study to be equitable (TCPS 2, 2018). Being guided by these ethical standards requires careful assessment of risk, such as considering social repercussions, and privacy and confidentiality risks of research, all of which helps protect participants from unanticipated harm (TCPS 2, 2018).

Although researchers are obliged to justify and to minimize risks that participants are exposed to due to their participation in research, ultimately, it is the prospective participants themselves who must decide whether benefits outweigh risks when they choose to consent to a study (TCPS 2, 2018). However, when it comes to research for people living with dementia, they are most often ‘protected’ as “highly vulnerable victims, who cannot articulate their opinion or have little to offer” (Mann & Hung, 2019, p. 574). Persons with dementia have asserted that they not only have the right to be involved with the research, but they are also the experts when it comes to their own lived experiences (Mann & Hung, 2019). Historically, groups in vulnerable circumstances such as those with mental health issues and diminished capacity for self-determination have been treated unfairly and inequitably in research, including being excluded from participating (TCPS 2, 2018). Furthermore, the stigmatized assumption that such people are so vulnerable that they cannot speak for themselves is unjust (TCPS 2, 2018); each participant’s vulnerability level is different and should be assessed. Justice and equity demand equal assumption of burden and benefit of research; if people with dementia are to be studied, equity demands that they be included to assume some of the risks and the benefits of research. Sherratt *et al.* (2007) voiced the injustice of excluding those with advanced dementia from research focused specifically on their stage solely due to their presumed vulnerability and specified that the viewpoints of these people are needed to inform the research process. Indeed, TCPS 2 specifies that the exclusion of particular groups from research without good cause is not only unjust, but it is also bad science (TCPS 2, 2018). Therefore, we should not uncritically assume the level of capability of persons with dementia to participate in research.

RECRUITMENT – INCLUSION/EXCLUSION

Recruiting this population comes with certain challenges, risks, limitations, and benefits. Obtaining ethics board permissions for recruitment can be more difficult, hinging on each committee's stance regarding research with vulnerable populations. Designing how to recruit involves the assessment of risks and benefits associated not only with the research study itself but also with the methods used to select participants (TCPS 2, 2018).

Common questionnaires used to classify levels of dementia, such as the Cognitive Impairment Test (McKee *et al.*, 2002) or GERRI tool (Tyrell *et al.*, 2006), have been traditionally used as a means to determine inclusion or exclusion. Yet, such questionnaires have been found to result in *overt* judgement on capacity with a risk of leaving a person much more sensitive to self-perceived failures (Murphy *et al.*, 2015). In the opinion of this study's Research Advisor, "MMSE [Mini–Mental State Examination] or MoCA [Montreal Cognitive Assessment] are dependent on the individual, their background and education." Indeed, it has been described with respect to the QoL-AD that increased levels of conscientiousness and awareness mean a person is likely more sensitive to the development of cognitive deficits and therefore it is more "difficult for them to maintain the high standards they set for themselves" which translates to lower scores when it comes to self-assessments of quality of life (Kim & Park, 2017; Woods *et al.*, 2014, p. 2). Furthermore, cognitive impairments may give people with dementia the impression of a better quality of life than may be factually true due to their inability to remember. This would invalidate the use of tests to quantify dementia's effect on wellness - such as the MMSE or the QoL-AD - as screening or inclusion tools (Murphy *et al.*, 2015; Woods *et al.*, 2014). Since dementia can often be diagnosed without them, the use of questionnaires to select for participants is not essential to determine inclusion; medical clinician diagnoses and nurses' judgements and records may be relied on in their stead (O'Shea *et al.*, 2011). That said, the use of site staff aiding in participant selection is a possible selection bias (Tyrrell *et al.*, 2006), which requires careful preparation of site staff for this role to minimize the risk. For example, Charpentier and Soulieres (2013) acknowledged this risk of bias as a necessity to ensure "administration would not misinterpret our presence within their facility and that the participants in our study would not suffer any form of pressure or reprisal" (p.343).

It satisfies justice to be inclusive of participants with diverse characteristics, and it is beneficial to research not only to maximize variation but also to yield a richer, more varied, and deeper understanding of the participants' experiences (Hung *et al.*, 2017). Including participants of differing communication abilities allows for greater diversity and can more comprehensively address research questions that are important for everyone with dementia, including verbal and non-verbal communicators alike. Studies have indicated that persons with early and middle stage dementia can express themselves clearly when it comes to their quality of life or the quality of their care (Tyrell, *et al.*, 2006). While people in late stages or with severe dementia are still communicating in their own ways, properly understanding their communications requires intense periods of observation and studying movement patterns (Ward *et al.*, 2008). Consequently, genuine inclusion of non-verbal communicators with dementia is much more time consuming, requiring extra patience and materials, such as visual aids for participants. Potentially unconventional approaches as well as more careful observations are required during both conversations and data analysis pertaining to these participants (Oldfield, 2021). For example, the use of images such as those available from Talking Mats Ltd. has proven to be a helpful low-tech communication aid for less verbal AD communicators (Reitz & Dalemans, 2016). In the determination of their target population, researchers (with guidance from advisors) should take their abilities into consideration, recognizing that those in later stages of dementia require researchers to have greater skill and time.

CONSENT

> "Dementia is such a degrading disorder for the sufferer, and is so feared by elderly people that, were they able to consent to research, the elderly would gladly do so in order to prevent others suffering in a similar way" (Gilhooly, 2002 in Sherratt *et al.,* 2007, p. 472)

Respect for persons requires an acknowledgement of the intrinsic value of every person as a human being and generally recognizes an individual's ability to make autonomous decisions, including a process of consent that is free from coercion or undue influence (TCPS 2, 2018). Informed consent is meant to be the principal way of respecting a participant's autonomy and is meant to be ongoing throughout a study; it is not a one-time, static agreement. Consent to both care and research, though nuanced and unique in their respective rights, requires input from the cared-for considering decisions about their care; consent should therefore reflect "a continuum of involvement" between the care giver and the resident (Sherwin & Winsby, 2010, p. 187). Through the consent process, competent participants express informed and voluntary agreement (or refusal) to a presented option (Sherwin & Winsby, 2010).

Where a participant is deemed incapable of exercising autonomy due to cognitive impairment, and hence found to not have capacity to consent to research participation, the individual's authorized third party gives consent on their behalf (TCPS 2, 2018). In such cases where the person has some capacity to appreciate the meaning of research participation, the participant must be given the opportunity to assent or dissent to their participation. Allowing a person who may be in a position of vulnerability to assent satisfies respect for persons by involving the individual in their own decision-making (TCPS 2, 2018). Indeed, it is just and necessary to involve members of that group when research involves those who lack capacity to make their own decisions. This is particularly important since the TCPS 2 (2018) clearly delineates that older persons, including those lacking decision-making capacity, should not be excluded from research without a valid reason (such as applicable legal requirements), nor solely due to age. However, including those lacking decision-making capacity should satisfy the condition that only participants within the identified group may address the research question, that there be no more than minimal risk to them, and that there be the prospect of future benefits to participants or the group to which they belong, in this case, older adults living with dementia in LTC (TCPS 2, 2018).

Competency can be contentious when it comes to older adults with cognitive impairments, particularly where the research definition of capacity is not the same as the legal definition (TCPS 2, 2018). While a person may no longer be deemed competent to make informed medical consenting decisions, this should not preclude them from other types of consenting. Competence in decision-making is not absolute – a person's decision-making capacity is complex, requiring assessment over time, and there must be an understanding that a person may be more competent in some areas than others (Murphy *et al.*, 2015). Process consent is suggested as a more appropriate method for approaching persons with demenia, and involves familiarization with the person, seeking consent from them, gaining initial consent, and checking consent during an interview process (Murphy *et al.*, 2015). By following this process, the person's needs, readiness, or reluctance to be involved in research are more clearly understood (Murphy *et al.*, 2015). Bierer *et al.* (2021) on the other hand, voice concern that the pendulum of concern for vulnerability may have swung too far to the protective side, at least in the United States. They highlight the lack of any reference within guidances and regulations allowing for a 'supporter' to aid the vulnerable with impaired decisional capacity in promoting their autonomy; rather, sole attention is given to the legal representative who may trump any decision made by those eager to participate in research (Bierer *et al*., 2021). In their article "Ethical issues in social research involving people with dementia", Sherratt *et al.* point out the difficulties researchers encounter when trying to involve dementia participants, who are traditionally seen as lacking capacity, and they used potential benefits to promote inclusion since in social care research benefits "often relate to issues of empowerment, satisfaction and altruism" (2007, p. 470).

Confirming that proxies are willing to share decision-making during consenting has been suggested as a criterion for selecting participants (Oldfield, 2021) and could be further considered as an inclusion criterion – though it may be difficult to ensure follow-through on the part of the proxy. In their review of the DARES study, Murphy *et al.* noted that proxy consent was used to maximize inclusion – to enable those with severe dementia to participate- and was only used after building rapport and judging a participant incapable of giving informed consent (2015). They used specific criterion to determine this: simple trigger questions touching on current place of residence, the resident themselves, and general orientation. The necessity of proxy consent was determined by failure to respond or to understand (Murphy et al., 2015). Through patience and timing, the DARES study achieved a very low need for proxy consent (7% of 309 participants).

In the context of research, a competent participant must be able to understand the impact of risks and benefits on their wellbeing, comprehend research conditions such as their time commitments, and evaluate whether a study is in their best interest (TCPS 2, 2018). While incapacity regarding decision making may limit which research individuals with dementia can ethically participate in, this protection must be carefully considered when recruiting for research that prospectively benefits those belonging to the group of research focus (TCPS 2, 2018). Accordingly, it has been argued that persons with dementia must be involved in issues of importance to them, and must have the right to be heard and to have their own voice (Sherratt *et al*., 2007; Swain *et al*., 1998). Unfortunately, consenting in long-term care homes has not been well studied (Sherwin & Winsby, 2010). For this reason, it is important to carefully approach consenting and the use of proxies for those who can assent in studies.

CAPACITY TO CONSENT

Capacity to consent among older adults with dementia should be assumed unless there are clear indications of incapacity to consent. Steps for assessing capacity for consenting have been clarified for people with dementia, thus it should not be assumed that they are incapable of making decisions affecting their well-being, including decisions pertaining to participation in research (Sherratt *et al.*, 2007). While it may seem difficult to obtain proper informed consent from people with cognitive impairments (Dong *et al.*, 2014), studies have shown that it is possible (Tyrrell *et al.*, 2006). It is vitally important that people who can benefit from research are not excluded from participating due to concerns over consenting. According to the Alzheimer Society of Canada's charter of rights for people with dementia (Mann, 2020), people with dementia have the right to be involved in decisions affecting them, and "to give our own consent and make our own decisions, as long as we are able" (p. 66).

In the case of a person with dementia who has difficulty in providing written consent but clearly gives signs of wanting to be included in a study, that person should be given the opportunity to indicate consent though verbal or non-verbal means, which would be documented. To this end, consent processes should be adjusted for individuals having lessened verbal capacity using a "more radical approach" to create something more inclusive to their specific needs (Sherratt *et al.*, 2007, p. 469). For example, Table 1, Non-verbal Communication and Responses, provides guidance for researchers that may enable obtaining clear consent from participants who can communicate clearly but non-verbally. The specific questions and responses can be used to record nonverbal body language to acknowledge the person with dementia's desire to participate or not. (See Table 1.)

Table 1. Non-verbal Communication and Responses.*

Nonverbal indications	**Body language used**	**Examples of verbal language of researcher to acknowledge residents' nonverbal communications about participation in the research**
To consent; answer affirmatively	Nodding with head	"Thank you for nodding to show you are saying yes."
	Pointing to prompt YES	"Thank you for pointing to YES to show you are saying yes."
	Smiling with eye contact	"Thank you for smiling to show me that you are happy to participate/continue."
To choose not to participate; to discontinue participation	Frowning/looking away	"OK, I can see that you are frowning/looking away, so I can see that we will not continue." (or need to stop for now)
	Pointing to prompt NO/STOP	"Thank you for pointing to NO/STOP to show you are saying no and that you wish to stop this conversation."
	Shaking head left and right	"OK thank you, I can see you are shaking your head to show me that you are saying no." Or, depending on context: - ... that you want me to stop. - ... that you do not understand. - ... that you want to stop this "conversation".

*Inspired from discussions with Research Advisor.

Similarly, surrogate appropriateness must be clear to avoid issues of paternalism and power imbalances. While people's ability to express their own autonomy, free from the coercion of others and aligned with their own values and beliefs, can be compromised when family takes over (Scharf *et al.*, 2021), ideally surrogate decision makers would be engaged to support the person with dementia in participating. That said, a significant risk of paternalism exists when a surrogate for someone deemed to have less competence believes they have better insight than the participant (Sherwin & Winsby, 2010). Engaging people with dementia to provide their own consent rather than designing a study to enable family or staff to mediate or serve as proxies is a position now widely held, particularly supported by the fact that *people with dementia and their proxies do not share the same views on the matter* (O'Shea *et al.*, 2011, emphasis added).

CONSENTING PROCESS - TIME & PLACE, WORDING & APPEARANCES, FORMING FAMILIARITY

After identifying eligible participants according to a study's inclusion and exclusion criteria (possibly with the aid of site staff), the researcher should personally meet with potential participants to invite them to participate in the research study. This should be a private, one-on-one conversation to ensure the decision to participate is made as freely as possible, without any intimidation or manipulation (McKillop & Wilkinson, 2004). The location should be where they are most comfortable and where they feel happiest (McKillop & Wilkinson, 2004; Murphy *et al.*, 2015; Woods *et al.* 2014) since unfamiliar or noisy environments are stressful and can lead to feelings of insecurity and loss of concentration (Cridland *et al*., 2016; Hung *et al*., 2017; Mann & Hung, 2019). In a long-term care setting, their room can be recommended as a comfortable and happy place, taking privacy into consideration. During the consent visit, the researcher should ideally spend some time with the prospective participant so they may get to know each other. Sufficient time and patience during recruitment and consent conversations help not only to avoid any upset (Murphy *et al.*, 2015), but also helps to build rapport and familiarity. Initiating relationships with participants in advance of a study is recommended (McKillop & Wilkinson, 2004) since it helps make future encounters less intimidating. Residents should be invited to choose on their own whether to take part in the research or not (Tyrrell *et al.*, 2006). Written consent should ideally be obtained from the resident. Where applicable, the consent form should seek permission for audio or audio-video recordings and should also clearly inform participants of confidentiality protections in place, and of their right to withdraw from the study at any point before or during the study. It is also good practice to allow participants to retract things they have said provided it is before the data has been analyzed (Hung *et al*., 2017). For example, if someone wants to take something back at the end of an interview meeting, that data should either be erased or excluded from transcription and data analysis.

Once consent is obtained and where applicable, participants should be given the opportunity to choose both the time of day and the location for the future meeting(s) with the researcher. If possible, mornings can be recommended since it is generally a better time of day for people with dementia, as they tend to be more clear-minded and cooperative (McKillop & Wilkinson, 2004). At the end of a consent visit, it is good to remind the participant of the next meeting with the researcher (if any) and ask them to enter it in their calendar or diary (McKillop & Wilkinson, 2004). Alternatively, a great way to regularly remind participants of an upcoming visit could be to leave an appointment card having a picture of the researcher, their name and contact information, and the date of the planned visit which can be posted in a calendar or on their wall. Since consent is ongoing, verbal assent should be sought at every study visit to remind participants of the purpose of the project as well as to remind them of their right to withdraw at any time (Cooney *et al*., 2012; Hung *et al*., 2017).

Consenting also carries challenges, risks, and benefits. While the benefits of consenting broadly are clearly the promotion of maximum inclusion, researchers will always have to conform to the laws and regulations imposed on them by their chosen sites. Despite best efforts to give those with dementia full decisional autonomy, their autonomy may still be restricted due to "background social conditions that perpetuate their oppression" (Sherwin & Winsby, 2010, p. 185). In the case of one study referenced by Sherratt *et al.* (2007), out of a total of 194 care homes invited to participate in a dementia-related study, the managers of 46 homes (23.7%) refused access based on their subjective belief that "'residents would not be interested'" (p. 475). Ironically, though we require the consent of participants to be included in a study, in the case of dementia patients this often has little bearing on their actual participation since the managers of homes may restrict access, or the primary carer can have the final decision-making capability (Tyrrell *et al.,* 2006*).* For example, a LTCH may have a legal requirement to verify with a third party (i.e., mandatory or power of attorney) prior to including a resident in research. Bierer *et al.* rightly point out that "disagreeing with a decision is insufficient grounds for challenging capacity" (2021, p. 33), and highlight that evidence of disproportionate exclusion of those with cognitive disabilities from clinical research may be linked to such decision-making issues. In our current social conditions, when a legal representative disagrees with the resident who wants to participate in a study, respect for patient autonomy does not overcome this structural inequality already in place (Sherwin & Winsby, 2010). This may unfortunately result in a family member controlling whether the potential participant even has a chance to be asked if they would like to provide their informed consent. Such pushback from those with the upper hand can - and perhaps should - be documented in such studies. For example, from the many pieces of literature referenced herein, many reported that all participants provided consent, and only a few studies indicate scenarios where others such as family members prohibited consenting (without reference to exact numbers). This may also be a product of only approaching potential participants after obtaining permission from a legal representative. Only two studies indicated a clear number reflective of that proportion: the first, a quantitative study using a scale to rate recorded conversations where a mere 31% of residents consented to participate (n=60), which the authors surmised was partially due to issues with receiving approval from surrogate decision makers (Williams *et al.*, 2012); and the second a randomized controlled trial which evaluated a reminiscence programme in which 93% (n=287) of potential residents with dementia in public and LTC consented to participate, and 7% (n=22) required proxy consent (Murphy *et al.*, 2015). The latter involved the usage of proxies only where the research nurse deemed the resident incapable of consenting.

3.3 TYPES OF PARTICIPATORY QUALITATIVE RESEARCH FOR OLDER ADULTS WITH DEMENTIA

Several different methodologies have been employed to be inclusive of participant voices of older adults with dementia in research. Each has its own benefits and limitations.

USE OF QUESTIONNAIRES AND RATING TOOLS

Though not typically qualitative in nature, questionnaires have influenced qualitative works. Questionnaire based and rating tools studies have been employed to help care providers to measure and demonstrate the impact of caring attitudes on health outcomes (Cossette & Forbes, 2012), to help measure person-centered care to improve health care through "increasing the person focus in both research and clinical settings" (Williams *et al.*, 2012, p. 385), and to enable self-reporting by the person with dementia. Although tools and questionnaires exist to improve quality of life for people with dementia, they still do not allow for circumstantial depth from the voice of those persons themselves. The tools may be helpful in obtaining clear answers to very direct questions and may have wide transferability. Yet questionnaires that can only be answered with *yes, no, or maybe* are stifling and do not elicit participant voice and perspective. While some teams have developed questionnaire-based tools from qualitative and quantitative studies (such as that developed by Cossette & Forbes, 2012 who used role play and real-life testing of their tool), tools that assess wellness and quality of life may not be helpful if they are grounded only in displays of emotion (McKee *et al.*, 2010). Indeed, one quantitative evaluation of tools led to the finding that cognitive impairment itself could not be related to quality of life since varying levels of self-awareness change a person's impression of their quality of life (Woods *et al.*, 2014). In their "qualitative study with elements of participatory research" (p. 2), Olthof-Nefkens *et al.* (2021) pilot tested questionnaires with dyads of persons with dementia using qualitative methods to develop a questionnaire-based tool to measure how people with dementia experience their communication with caregivers. However, limited response options may be too restrictive to properly collect such experiences, and a questionnaire may fail to capture significant and pertinent lived perspectives and impressions of those with dementia. In this way tools and questionnaires used in the place of qualitative studies risk further marginalizing a group already socially excluded by not allowing them to participate fully and freely in their own assessments (McKee *et al.*, 2002). Observational assessment and emotional rating tools, while potentially revealing of patterns for an individual, do not reveal the series of events that may have affected wellness or triggered an affective state – positive or negative; participants may have more to add than a questionnaire or rating tool allows for. While not useful alone, the domains in these tools can be very useful as launchpads for open questions and to highlight aspects of care to observe. However, questioning needs to take a more qualitative approach.

OBSERVATIONAL & INTERVIEW BASED STUDIES

Interviews have been identified as the method of choice to obtain participant perspectives (Creswell, 2007; Murphy *et al.,* 2015). Observing and listening to participants can be better employed to seek out participant perspectives and ascertain how *they* express their needs for their own wellbeing. Resulting data can be subsequently linked to the contexts in which they behave (McKee *et al.*, 2002). When employing observation while conducting other methods, such as interviews or focus groups, it may be helpful to simultaneously record observations, for example in one similar to Table 2, Non-verbal Communication Observations, which is modified from Le Dorze *et al*., (2000). When possible during recorded observations, noting the time at which observations happen can be very useful to allow for deeper analysis *post hoc* to reveal what else may have accompanied a non-verbal communication, such as the person requiring extra time to process, or re-wording of a question. The use of a Post-Observation Non-verbal Analysis table (see Table 3, modified from Le Dorze *et al.,* 2000) enables documentation of additional observations that may have been missed or unobserved using the recorded observations which can be valuable to clarify and deepen understanding of non-verbal communications. Interview based studies conducted with people with dementia range from unstructured to semi-structured. While multiple methods can be employed, such as both observation and interview, many studies will use only one strategy, such as semi-structured in-depth interviews (Charpentier & Soulieres, 2013; van den Hoof & Goossensen, 2014; Reitz & Dalemans, 2016; Ward *et al*., 2008). Though one paper cited that several studies have shown that focus groups are not well suited to persons with dementia (Cridland *et al.*, 2016), at least one other researcher has made good use of them (Beard, 2004) – perhaps due to the employment of multiple methods (in-depth interviews and focus groups). Unstructured interviews are very adaptable and promote co-construction of knowledge (Oldfield, 2021), but may be difficult when trying to elucidate specific information since the participants are able to direct the conversation to address what matters most to them (Moore & Hollett, 2003). Semi-structured in-depth interviews are more complex than simply asking questions and are well suited to understanding lived experiences (Cridland *et al.*, 2016).

Table 2. Non-verbal Communication Observations.

Means of non-verbal communication used by resident	**Time observed (during conversation)**
'yes' and 'no' indicated by a head movement	
Facial expressions	
Body movements	
Attitudes/behaviours that carry particular meaning	
Pointing	
Gestures or Gesticulations	
A code that needs to be interpreted (Something resident uses/says that always means same thing; must know to understand).	Which one:
Writing or drawing	
Means used by interviewer to transmit a message	**Time observed (note question number)**
Gesturing	
Demonstrating	
Using writing or drawing	

Table 3. Post-Observation Non-verbal Analysis.

Means of non-verbal communication used by resident	**Time occurred at during conversation**
Vocalizations or variations in intonation	
A code that needs to be interpreted (*Something resident uses/says which always means same thing and one must absolutely know to understand).	Which one:

Means used by interviewer to understand the resident	**Time occurred at during conversation**	**Effort needed** (0 no effort –1 some effort –2 much effort)
Asking yes/no questions		
Verifying		
Waiting		
Giving a choice of responses		
Interpreting		
Guessing		
Being very attentive		
Calming the resident		

Means used by interviewer to transmit a message	**Time observed at during conversation (note question number)**
Simplifying/rewording the sentences	
Checking if resident has understood* (be careful not to hurt feelings!)	
Asking resident to repeat	
Reformulating	
Repeating	
Speaking very slowly	
Speaking very loudly	

Preparing an interview guide itself is the most critical part of an interview-based study. The interview guide not only directs and shapes the interview process, but it also has downstream effects (Cridland *et al.*, 2016), directly impacting the quality and comprehensiveness of the data collected. Essential components should include an introductory statement, ice breakers or warm up questions to help develop rapport and ease participants into a flowing conversation, and simple, straightforward, 'single-faceted' interview questions to make for a less intellectually demanding interview (Cridland *et al.*, 2016). While using direct questions is best for people with dementia, it remains important to avoid using leading questions as much as possible (Cridland *et al.*, 2016). Finally, once satisfied with a version of an interview guide, it is recommended to pilot test it with someone with dementia to identify anything that could be misunderstood or lead to confusion (Cridland *et al.*, 2016). If done well, a semi-structured interview based qualitative study can be completed within a reasonable amount of time and yield rich and deep insights.

Even if a study has been carefully prepared, without the involvement of patient advisors there is a significant risk of the researcher bringing in their own bias (which could be unrealized due to existing endemic stigma). While going into a study from a specific subjective perspective lends value in the context of an interview, underlying cultural biases or stigma may still be unrealized and be potentially stifling or hurtful to the stakeholders. For example, even "the social desirability of the interviewee may bias the process" of an interview (Murphy *et al.*, 2015). In this very thesis, I had not appreciated my original use of the term 'elderly' with dementia as objectifying (from my location as a young person) – when informed of this, the word was replaced throughout with 'older adult'. As another example, upon comparing two phenomenological studies that both used interviews and recognized stigma as negatively impacting quality of life and a serious obstacle to good care for people with dementia, one continually referred to their participants as dementia *patients* (Bahar and Bigdeli, 2020) whereas the other referred to their participants as being *elderly adults* or *people with dementia* (Toivonen *et al*., 2018, emphasis added). The avoidance of the impersonal and potentially disempowering word "patient" acted to remove any additional stigma imposed by the application of a word which infers dependency on others for survival. Patient advisors may aid in identifying such sensitive nuances.

CO-RESEARCH & PARTICIPATORY ACTION (PAR) STUDIES

Co-research and Participatory action research (PAR) studies are playing dynamic roles in changing research and the lives of people with dementia and are perhaps the most ideal method since they culminate in real change. Scheffelaar *et al.* (2020) evaluated qualitative instruments used to assess and improve quality of care by involving long-term care residents including those with intellectual disabilities in the research as co-researchers. Co-researchers were able to actively help prepare, use, and evaluate the qualitative instruments (such as the 'Am I Satisfied' instrument or the 'Clients about quality' instrument), and as such played an active role in identifying the two instruments to be best implemented to monitor quality of care relationships from the resident's perspective (Scheffelaar *et al.*, 2020). Nunn *et al.* (2021) found that involving older adult participants, some of whom had dementia (information obtained by Research Advisor from the author), in the design of a research study was beneficial not only to the study design, but also to the participants and researchers themselves; it held the power to change a person's understanding of the value of their own voice.

PAR based studies have been increasing worldwide over last twenty years, across Japan (Nomura *et al*., 2009), Australia (Goeman *et al*., 2016), Canada (Dupuis *et al.* 2021, Dupuis *et al*., 2012a, 2012b; Fortune *et al*., 2015; Hickman *et al*., 2015, 2016; Mann & Hung, 2019; McKeown *et al*., 2015; O'Connor *et al.*, 2018), the UK (Rodgers, 2018), and Belgium (Hendriks *et al*., 2013). They are exciting since they not only benefit both people living with dementia and the design of the research itself (Dupuis *et al.*, 2021) but they also culminate in action, creating change! Within PAR, knowledge is co-created, and research has an actionable goal of personal and social betterment (Dupuis *et al.*, 2021) – as such it carries an actionable social justice agenda, without being research for the sake of research – which can simply conclude and go nowhere. For example, the *Flipping Stigma on its Ear* toolkit at https://www.flippingstigma.com/ is the direct result of a PAR study. People with dementia (including my Research Advisor) shared their lived expertise and worked with academic researchers to create a real and useful tool to help healthcare workers, family members, and people with dementia address stigma and discrimination via a website that is simple and easy to navigate (Flipping Stigma, 2021; O'Connor *et al.*, 2018; Dupuis *et al.*, 2021).

Co-research and PAR studies have many benefits and seem to be the best option for participatory research of older adults with dementia. They demonstrate that people with dementia have invaluable contributions to offer to increase knowledge and to the betterment of practice (Mann & Hung, 2019). Furthermore, persons with dementia who act as co-authors can not only offer the unique perspective of living with dementia, but they can also act as both a participant in interviews and a facilitator of the interviews of others with dementia (Cridland *et al.*, 2016). Having them so intricately involved removes most if not all risk of stigma interfering in study design. Despite many benefits, this method of research has some limitations to consider, including time related ones. Such studies are generally much lengthier; steps involve collecting and analyzing data, reflecting and interpreting it, sharing it, and determining the action that will result from the collaborative work (Dupuis *et al.*, 2021). Throughout the study, researchers must take time to reflect on and to meet and discuss roles with the participant, particularly when they are unsure regarding how much and what kind of involvement may be safe and most meaningful:

> "One challenge for me, (the researcher) was to decide how to maximize the opportunities for (the co-researcher with dementia) to contribute and not to overburden him…He encouraged me to ask him about what he was willing to do…To develop trust, researchers need to stop making assumptions about what the person with dementia can contribute. Researchers may find themselves surprised at how much they can gain just by asking the person with dementia."
> (Mann & Hung, 2019, pp. 583-584)

Though on the whole PAR and co-research studies are likely the best approach to uncover unheard voices while insisting on some form of action, time constraints with respect to data collection and analysis must be considered. Likewise, as with all research study designs, the methods used should be carefully chosen to yield an answer to the research question(s).

3.4 INTERACTIONS WITH PARTICIPANTS WITH DEMENTIA

RISK MANAGEMENT – BEFORE INTERACTIONS WITH PARTICIPANTS

After consent but prior to encounters with participants, it is a good idea to meet with the primary caregiver (for example the head nurse in a LTCH) to manage sensitivity and avoid upset. The intent and focus of the discussion are to help the researcher behave or speak appropriately for that individual, for example using appropriate prompts or cues to guide conversation safely, or to avoid triggers – such as specific actions, words, or questions (Murphy *et al.,* 2015). Also, in any study there may be risks despite the researcher's best efforts, such as unpleasant memories which may surface during conversation and may leave participants in a state of agitation or anxiety (McKillop and Wilkinson, 2004; O'Shea *et al.,* 2011). Any risks should be clearly detailed in consent forms and communicated to participants, family, and site staff, as applicable (O'Shea *et al.,* 2011). There should be planning as to how these situations will be managed, with support from caregivers and transparency with the research team. For example, each institution may have its own structure and support staff in place. At all times, the researcher must maintain the confidentiality of everything spoken between the participant and the researcher.

INTERACTIONS WITH PARTICIPANTS - CHALLENGES & TIPS: THINGS TO DO AND NOT TO DO

Since persons with dementia have been found to be more sensitive to the emotions of others (Ward *et al.*, 2008; Woods *et al.,* 2014), researchers should ensure a positive demeanor – one that is pleasant and patient (Cooney *et al*., 2012; Oldfield, 2021). Similarly, being attentive to any relevant changes to the environment where research takes place (such as other residents yelling, or site staff disagreeing loudly nearby) is paramount since overcrowding and loud noise can lead to apprehension, anxiety, and psychological distress (Cooney *et al*., 2012; Hung *et al*., 2017; McKillop & Wilkinson, 2004). For example, caregiver distress has been found to be associated with a lower quality of life as reported by the person with dementia, pointing to their sensitivity to the emotional climate around them (Woods *et al*., 2014).

Interactions with participants need to be carefully approached. Participants should be referred to only with respectful and appreciative terms such as "expert", and never deficit-based such as 'patient' or "dementia-sufferers" (Cridland *et al.*, 2016, p. 1776). On the day(s) of participant interactions, along with taking the time for a preamble and chit-chat to "set the scene" (Murphy *et al.*, 2015, p. 816), researchers should re-introduce themselves and re-describe the project and the main objective (Cooney *et al*., 2012). When it comes to interview studies, participants may feel they need to decide who is safe to disclose to (O'Connor *et al.*, 2018). For this reason, re-assuring confidentiality from start to finish is paramount – they need to know that their care will not be affected if they open up and freely reveal their subjective truths about their experiences with dementia (O'Connor *et al.*, 2018). After reassuring confidentiality, the researcher must assess temperament, and be open to pausing (in the case of changing mood or tiredness) or deferring (where the resident seems less lucid) research visits to a later date (Cooney *et al*., 2012; Murphy *et al.*, 2015). The researcher should pay close attention to resident body language throughout study visits to assess for disengagement on the part of the resident (McKillop & Wilksinson, 2004; Murphy *et al.*, 2015; Oldfield, 2021) as well as their ongoing willingness to participate. Body language can include both verbal and nonverbal signs of anxiety, such as restlessness and agitation. If there are multiple visits, remind participants of upcoming meetings (Oldfield, 2021). At the end of visits where participants disclosed personal information, assure them of confidentiality, and taking the time to thank them properly and sincerely for their participation (Murphy *et al.*, 2015; McKillop and Wilkinson, 2004). Make sure they are calm and feel positive about their experience and are not left feeling uneasy or wanting to communicate more (Murphy *et al.*, 2015; McKillop and Wilkinson, 2004). Field notes should be noted immediately following an interview, but not during so as not to interfere (Durocher *et al.*, 2019).

It is important that researchers consider the risks they may pose to those they seek to recruit to their research (or research team). There are certain risks that should be identified and carefully managed while interacting with people with dementia. Since LTCH residents are already objects of institutional power (Oldfield, 2021), they may be intimidated by researchers, perceiving them to also have power over them. Researchers should be mindful that residents may fear repercussions of abandonment or loss of care, which may lead to restraint or silence on their part, e.g., by withholding views or not insisting that their own wishes be followed, where they otherwise would. Such fear of repercussions can leave them susceptible to abuse or exploitation, including that which occurs in the service of academic pursuits (Sherwin & Winsby, 2010). Relevant questions for researchers to reflect upon to help address the risks researchers may pose to participants with dementia have been extracted from the Flipping Stigma (2022) website (created out of the PAR study by Dupuis *et al*. (2021)) and are provided in Table 4: Self-Questioning for Researchers Working with People with Dementia.

Table 4. Self-Questioning for Researchers Working with People with Dementia.

QUESTIONS FOR RESEARCHERS TO CONSIDER
How are my assumptions as a researcher challenged?
As a researcher, are there ways that I have inadvertently made people with dementia feel like I see them as incapable?
In trying to involve people with dementia in research, have I instead contributed to "tokenizing" people with dementia?
Have I ever assumed that someone with dementia is not capable of taking part in and contributing to research just because I know they have a diagnosis?
What ways can I make sure to always communicate respect and dignity when I am conducting research with someone with dementia?

Research ethics principles of Justice, Respect for Persons, and Concern for Welfare guide study design and procedures, including appropriate adaptations or protections in response to a person's vulnerability circumstances, and natural aging process (TCPS 2, 2018). Appropriateness must also be relative to stages of dementia. Similarly, it is important to be sensitive to the potential stigma associated with the label of dementia or Alzheimer's and to ensure information in consent forms or in questions asked is appropriately simplified to the participants' stage of dementia (Sherratt *et al.*, 2007). For example, instead of referring to an interview, potential participants may be less intimidated when verbally invited to have *a conversation*. To further minimize any intimidation, it is important for researchers to dress in everyday clothes, and to be "among" participants, at their level, and not "perched behind a desk" or frantically filling in forms while a participant is speaking, which is intimidating (McKillop & Wilkinson, 2004, p. 120). Participants can also be told that their involvement will help the researcher towards a goal, such as a master's or doctoral research project or a specific learning goal, since knowing they are helping someone can be very meaningful (Mann & Hung, 2019). It is possible that people with dementia either may not remember that they have dementia, may not self-identify as having dementia, or may not have been told their diagnosis due to the associated stigma. Since using the term “dementia” can trigger distress (McKillop & Wilkinson, 2004; Oldfield, 2021; Pesonen *et al.*, 2011), it is recommended that the label should neither be used directly with (prospective) participants verbally nor on recruitment materials or written consent. Instead, alternatives can be used, such as the term “memory problems” or a term that the (prospective) participant uses themselves, keeping in mind that every person will be different in the way they describe themselves (Oldfield, 2021).

Including older adults with dementia in research is critical to be inclusive of their voices, providing them with the right to be heard. It further ensures that those with lived experience can help direct research and reduce risks of researcher bias. Involving older adults with dementia in research requires considerable planning, thought, and ethical considerations. Benefits and limitations must be thoughtfully deliberated throughout every step of a study (this chapter focused on the steps from eligibility criteria to the method through which their voice is involved). Thoughtful risk management enables safer and more successful interactions and helps establish check points for researchers to take pause and consider the risk they themselves may pose before commencing a research project. Only once these steps have been taken can the research project finally take form and be ready for ethics approvals. The following final chapter provides a detailed template for such a study, carefully structured to be inclusive of older adults with dementia in long-term care to give legitimacy to their voice.

CHAPTER 4 – THE PROPOSED STUDY

This final chapter provides a detailed template protocol that is carefully structured to be inclusive of older adults with dementia in long-term care to give legitimacy to their voice. It was an aim to incorporate into this thesis a small qualitative study for which a protocol was submitted, reviewed, and approved by both the CIUSSS Ouest-de-l'Ile REB and the McGill IRB. However, COVID restrictions in place after all necessary ethics approvals had been obtained prevented access to the two approved research sites. Thus, this chapter presents an exemplar study based upon the one prepared, which may be conducted within the time restraints of a master's degree. The Background and Prior Knowledge components were extracted from the protocol and were expanded in earlier chapters of this thesis.

If a researcher wished to initiate a study based on the protocol that follows, their literature search should be updated. Furthermore, the compilation of prior knowledge which grounds and informs the study would need to be re-assessed and inserted to complete the presented protocol.

4.1 RESEARCH RATONALE & OBJECTIVES

A small qualitative resident-perspective study for persons with dementia living in LTCHs will help to uncover the subjective truths these older persons with dementia hold about the value their communications have with others. Contributing to filling this knowledge gap, the study will reveal their communication experiences and can motivate similar methods for their inclusion in phenomenological research on matters important to their wellbeing. Hopefully, such information will shed light on how to better care for them. The proposed research study is a phenomenological qualitative study using observation and semi-structured interviews. The goal is to investigate impressions and perspectives of older adults with dementia in LTCHs in Quebec about how their communications are received by those caring for them, and how they feel that impacts their wellbeing. Going deeper, prompts allow for exploring what they may have done to overcome misunderstandings and miscommunications, which could provide valuable information.

PROTOCOL NAME: GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents with dementia in long-term care about the value of their own communications.

OBJECTIVE

The overall objective of this study is to learn from people with dementia living in LTCH (preferably at least two sites located in Montreal, Quebec) what value they feel their own communications carry with site personnel who give them daily care, and what impact they feel that has on their wellbeing.

RESEARCH QUESTION

Among older adults with dementia in long-term care in Quebec, what are the residents' own perspectives and impressions of both how their own communications are valued by site personnel caring for them and how they feel that impacts their wellbeing?

4.2 QUALITATIVE RESEARCH DESIGN & METHODOLOGY

STUDY DESIGN

Since the experiences of communication problems for people with dementia has been found to be more problematic in LTCHs versus home care (Ward *et al.*, 2008; Tyrrell *et al.*, 2006), LTCH sites - commonly referred to as CHSLDs in Quebec - are the ideal choice for a study. LTCHs have been at the forefront for having issues relating to older adult patient care, therefore these are a good first target for a phenomenological, small-scale, qualitative perspective study to investigate concerns for potential loss of voice and to give legitimacy to their communications.

The first step in appreciating how to properly value communications from those with dementia should be to strive to first listen to how *they* feel their wellbeing is impacted by whether their communications are received by their care givers or not. The study design centers on a semi-structured individual interview, incorporating some observation.

QUALITATIVE METHODOLOGY

A hermeneutic phenomenology approach is the chosen method to answer the research question, since it can uncover perceptions and experiences that may otherwise be overlooked due to underlying cultural values and social practices. A hermeneutic research approach has its emphasis on subjective interpretations of meanings of social phenomena and thinking, and is particularly relevant for studying people who are inseparable from their particular culture (Toivonen *et al.*, 2018) as older adults in LTC are when placed into the specific culture of a LTCH for care until death. As such, it is an appropriate method for this study which seeks to uncover the essence of residents' perspectives and impressions of the value of their own communications.

Several perspectives and beliefs characterize the hermeneutic research approach for this study. A critical theory perspective, sometimes referred to as the transformative paradigm (Kivunja &

Kuyini, 2017), will be utilized since all the philosophical assumptions of this interpretive framework best fit the subject material. Ontological beliefs (nature of reality) include that reality is based on power and identity struggles (Creswell, 2007), and in this case, there may be oppression arising from stigma surrounding dementia, mental abilities, LTC and age. Epistemological beliefs (how reality is known) of critical theory outline that reality is known through the study of social structures, freedom and oppression, and power and control (Creswell, 2007). A key part of the epistemological beliefs of critical theory is that reality can be changed through research which uncovers agency that is hidden by social practices and leads to liberation (Kivunja & Kuyini, 2017). This is an important point to address since it may be one of the few potential benefits of the research that is of interest to research participants – the hope that this research will contribute to efforts to improve communications between residents with dementia and personnel in LTCHs, and specifically at the very location where prospective participants reside. Axiological Beliefs address the role of values in the research, and critical theory recognizes a diversity of values existing within a community (Creswell, 2007). Indeed, diverse values are involved in LTCHs, most notably: government/social values that guide oversight and resourcing, institutional values, professional values of health care professionals, and personal values of residents and personnel. Similarly, Canadian culture itself will impose its own values regarding how we value our older persons. The methodological beliefs, that is the approach to inquiry, starts with assumptions of power and identity struggles, documents them, and imagines calls for action and change in the conclusion of the study (Creswell, 2007), where practices are found to diverge from stated values that ought to guide those practices.

Data collection will involve multiple individuals who experienced the phenomenon with a focus on understanding the essence of the lived experience. All communications and perspectives will be listened to and analyzed carefully to avoid simply taking note of the ones that are the easiest to interpret, understand, or solve, or are of great importance to the researcher (Brown *et al.*, 2015). Additional observations will be collected where possible to mitigate this risk, such as employing methods like those used by Le Dorze *et al.* in their Montreal Evaluation of Communication Questionnaire for use in Long-term Care (MECQ-LTC; 2000). Two similar tables have been created as an aid (see Tables 2 and 3 in Chapter 3: Tables for Recording Observations & Analysis) to capture frequency and means of communication used by residents and by the interviewer during semi-structured interviews. Such data will enable a rich representation of the communication of the person with dementia in LTCHs (Le Dorze *et al.,* 2000).

Review of reflexive journaling and the interview transcripts with the supervising researcher, project advisor, and as necessary the research team, will take place during analysis to avoid mistakes and mitigate risks the researcher poses to participants (e.g., due to stigma bias). The data sources of participants' communications and/or the meaning behind them must be properly and carefully understood, not taken to always be factual truths in and of themselves, though this should be considered (Entwistle *et al.*, 2010). From anything said within the context of interviews or observations, the researcher(s) will strive for a careful and methodical interpretation of what it means. Since bracketing personal experiences can be a challenge encountered in data collection, reflexive journaling to be aware of personal biases will be used to help view data from transcripts not as "'wrong or right, or 'accurate or inaccurate', but as products of their contexts" (Smithson, 2000, p. 112). Reflexive journal entries will be employed throughout data collection, including before and after each interview, to note researcher biases and to consciously minimize their influence so that the researcher remains truly open to whatever the participants may reveal (Smithson, 2000).

4.3 STUDY POPULATION

Older persons (aged 65 and older, the commencement of old age status in Canada; CIHI, 2021) living in long-term care who have been reliably identified as having middle-stage dementia are to be included. Since the goal of the proposed study is to assess communications, and since people with dementia frequently communicate non-verbally (Oldfield, 2021), being inclusive of non-verbal communicators is important for the study. However, observing and properly understanding the communications of older adults in late stages or with severe dementia is both beyond the scope and the timeline of such a project and is well beyond the capabilities of the student researcher. It is for this reason that recruitment is limited to those who can provide their own consent to participate in research.

Those with additional health impairments affecting communication due to decreased cognition are excluded from the study (Murphy *et al.*, 2015).

This study design does not make use of common questionnaires to select for its participants due to the risk of their *overt* judgement on capacity leaving potential participants with a sense of failure (Murphy *et al.*, 2015). Instead, dementia is ascertained with the help of head nurses' judgements and site records (O'Shea *et al.*, 2011).

ELIGIBILITY CRITERIA

Below are the eligibility criteria for the small-scale perspective study including older adults with dementia in long-term care.

Inclusion Criteria

1. Residents of LTCHs already diagnosed with dementia aged 65+ (Le Dorze *et al.*, 2000)
2. Residents assessed to be in *middle-stage* dementia
    a. Assessed by site personnel (Head Nurse)
3. Capable of comprehensibly communicating verbally and non-verbally
    a. Assessed by site personnel (Head Nurse)
4. Capable of consenting to this research project (written or verbal)

Exclusion Criteria

1. Residents who only use non-verbal communications <u>and</u> whose non-verbal communications are unclear
2. Residents with aphasia (inability to communicate clearly)
3. Residents who, despite being able to consent, have a mandate or curator whose permission is required and who does not agree with their participation in the study (where applicable)
4. Residents who do not communicate in English
5. Residents who have health conditions (in addition to dementia) that affect cognition

4.4 SAMPLE SIZE DETERMINATION

To contribute to triangulation and validity of data for this small-scale project, three participants at each of two LTCH sites, for a total of six participants, will be recruited. Public (CHSLD) sites are chosen instead of private homes to decrease variability between the two. (*N.B.* there may still be variations such as differences in intake criteria with respect to the level of care residents require).

4.5 RECRUITMENT & CONSENT

For a complete overview of all the site interactions and visits from recruitment to post-analysis please refer to Appendix 1: Schedule of Events.

Recruitment

Administrative procedures surrounding recruitment involve working closely with each site to determine steps required before potential participants are approached. The recruitment phase will take place over one to two weeks, commencing with recruitment posters (see Appendix 2: Recruitment Poster) being put up in the chosen locations for each CHSLD. Each poster has contact information for the research team. Paper copies are also provided to site personnel for interested participants.

After identifying potential participants, the head nurse will provide them with a Participant Release Consent Form (Appendix 3) through which potential participants will give their permission for site staff to release their personal information to the research team. The Participant Release Consent Form also acts to ensure that the recruiting nurse carefully verifies that all eligibility criteria are met.

Prospective participants themselves and/or their head nurse or family members can direct any study related questions back to the researcher (via phone or email). Answers can be addressed immediately or can be addressed in person on consent day.

Consent

Consent forms invite participants to choose the time of day for the meetings, although mornings will be suggested since they may be more clear-minded and cooperative at that time of day (McKillop & Wilkinson, 2004). The location for the conversation should be where they are most comfortable and where they feel happiest (their room will be recommended, considering privacy) (Murphy *et al.*, 2015; Woods *et al.* 2014; McKillop & Wilkinson, 2004). During the consent visit, the researcher will spend some time with the participant so they may get to know each other to help the interview be less intimidating. The participant will be left with an appointment card with a picture of the researcher and their contact information.

The main consent form (refer to Appendix 4: Participant Informed Consent Form) for participants is based on a specific site's approved template but is modified to use a larger font (14), simplified language, and fewer sections to facilitate easier reading and comprehension for older adults with dementia. Care is taken to use sensitive wording for participant facing materials. The title of the consent form does not make overt use of any sensitive label. While the project's title for the ethics reviewer is:

"GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents **with dementia** in long-term care about the value of their own communications", the patient facing materials have the project title:

"GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents **with memory problems** in long-term care about the value of their own communications".

After consent has been given, participants are left with an appointment card (please refer to Appendix 5: Appointment Reminder Card) containing a picture of the researcher and their contact information, as well as the date of the upcoming meeting to have a conversation with the researcher.

4.6 STUDY INSTRUMENT

The Semi-Structured Interview Guide was created involving several rounds of revisions and testing. Combinations of various study guides and approaches were practiced with family members, the Research Advisor, and a member of the Thesis Committee. More structured questionnaires (*e.g.,* see Olthof-Nefkens *et al.*, 2021, Table 3) proved difficult for obtaining accurate depictions of reality since structured response options could not collect relevant nuances. Conversely, leaving the interview unstructured using a single question to open conversation as per van den Hooff and Goossensen (2015) - where residents freely communicated their experiences in a nursing home - did not facilitate collection of the specific information sought. Therefore, a custom guide was created, using both personal experience from speaking with and listening to older adults in LTCHs and a combination of other approaches from the literature (*e.g.,* modified tables from Le Dorze *et al*., 2000). The guide was put through many renditions and practice interviews before its completion.

Two members of the research team will be present on the day of interviews: the interviewer, and a recorder (for example, the Principal Investigator) to take notes and assist. Each semi-structured interview will consist of three parts: a gentle introduction/ice breaker, the semi-structured interview '*conversation*', and closing statements with thank-yous. These are described briefly below and in the interview guide (refer to Appendix 6: Semi-Structured Interview Guide). Non-verbal communications will be recorded and aided through various methods, such as verbal acknowledgment on the part of the researcher to acknowledge body language (refer to Table 1 in Chapter 3), written notes to record body language (refer to Tables 2 and 3 in Chapter 3), and the use of talking prompts (refer to Appendix 7: Prompt Board and Individual Communication Aids). The anticipated total time for the interview is 30-40 minutes.

Three Part Semi-structured Interview:

PART 1: Gentle Introductions/Icebreaker (2-5 min)

First, the researcher introduces themselves, describes the project and the main objective, re-affirms consent, reassures the participant of confidentiality, and indicates that they are free to stop at any point. Gentle icebreaker questions help to set the mood of the conversation. At the first meeting, a bit of time is spent getting to know each other. The gentle introductions/icebreaker ends by asking permission to audio-video record the ensuing conversation. If additional interview conversations are held (e.g., conversation started and then postponed), the gentle introductions/icebreaker is repeated and will include a high-level recap of the previous conversation.

PART 2: Conversation/Semi-structured interview section (20 – 30 minutes MAX)

The second part of the meeting consists of an approximately 20-minute-long semi-structured interview. This is described to the participants as a meaningful *conversation* to sound more welcoming and less intimidating than an interview. Since it has been described that the overall feeling of being listened to can be affected by whether the resident freely chose to leave home and move into LTC (Tyrell *et al.*, 2006), when possible, a baseline will be established by asking participants whether it was their choice or someone else's decision for them to leave home.

Several optional prompts per question are provided in the guide, to be used if needed to aid in breaking silence, to rephrase to improve understanding, or to facilitate elaboration. It is not intended that all be asked – they simply help to guide and continue to draw out the residents' perspectives. A visual aid will be employed where relevant. Throughout the conversation, attention will be paid to body language for signs of tiring and other expressions.

PART 3: Closing / Thank you (2-5 min)

Each participant will be thanked for their contributions and assurances sought that they are content, i.e., not left wanting to say more, nor feeling any unease (Murphy *et al.*, 2015; McKillop & Wilkinson, 2004).

The conversation will end with a focus on something happening that day in the researcher's routine life, such as "It's my 6-year-old's birthday, so I will go home and bake a birthday cake!"

to remove all focus from the resident and what was discussed. The intention is to remove any risk of leaving them unhappy or in distress.

An envelope, self-addressed to the researcher with blank paper inside, will be left with the participant at the end of each meeting in case the participant wishes to share something further after the researcher has left (McKillop & Wilkinson, 2004). This is to mitigate any potential for anxiety or sleep lost as a result of wishing they had said something following the interview (McKillop & Wilkinson, 2004). However, the Research Advisor for this project noted that anxiety is easily avoided by trying to end the conversation the way it started, thus the employment of some fun personal anecdote - something happy the person with dementia can relate to with the goal of removing focus from the resident. Field notes and observations will be noted immediately following the meeting (Durocher *et al.*, 2019).

4.7 DATA ANALYSIS

RIGOUR

This study will establish validity in several ways, via observation, rich and thick verbatim descriptions of participants' accounts to support findings from interviews, triangulation, development of a coding system through thematic analysis, and peer review debriefing (Described in, *e.g.,* Morse, 2015; Murphy *et al*., 2015).

Triangulation strategies will be used to confirm the data collection and interpretation of data. For example, two researchers (one as interviewer and transcriber, second as note-taker) should be present at each interview, will independently review transcribed interviews and notes, and will reconcile any discrepancies or uncertainties together (as soon as reasonably possible after each interview). Other means of confirmatory triangulation are the individual interview(s) with the participants, the inclusion of two sites (Noble and Smith, 2015), and the person with dementia serving as a Research Advisor who will aid with the analysis of the transcripts.

Credibility establishes the internal validity of the research. Credibility will be addressed in part through collaboration of site personnel to aid in recruitment by identifying a pool of eligible potential participants, introducing the research project to them with a brochure and noting questions about or interests in possible participation for the researcher to follow up with during the consent process. They will not be present during consent or data collection.

Transferability - that is external validity, generalizability, and dependability (reliability) - depend in part on the quality of the data and the quality of analysis. Transferability is somewhat addressed through having two sites but is still limited due to the small size of the project. Dependability speaks to the reproducibility of the study and will be directly impacted by analysis of the data and how well it is done.

ANALYSIS

Thematic analysis (TA) will be used to analyze observational data as well as data obtained from the transcribed audio-video recordings. Certain assumptions about the nature of the data will help determine the type of analysis and the claims to be made with respect to the data set (Braun & Clarke, 2006). A rich thematic description of the entire data set will require accurate reflection on the content of the whole of the data, to the end of obtaining a rich overall description. Inductive TA will be used since themes identified may not necessarily relate to the 'verbatim' questions, rather the themes are linked to the data itself and a more bottom-up approach is applied (Braun & Clarke, 2006). Latent themes will be identified, meaning that underlying ideas, assumptions, and ideologies will be examined during analysis, which will involve interpretative work (Braun & Clarke, 2006). A more essentialist/realist (or experiential TA) epistemology will also be employed since it focuses on the participants standpoint and how the world is experienced and understood from their perspective (Braun & Clarke, 2013), which is in line with the epistemological beliefs of critical theory (Creswell, 2007). The six-step thematic analysis described by Braun & Clarke (2006) will be employed to 1) familiarize and transcribe verbal data, 2) generate initial codes 3) search for themes 4) review and refine themes 5) define and name themes and finally 6) produce the report containing the concise essence in answer the research question. Data analysis strategies will focus on first analyzing transcripts for significant statements, followed by creating meaning units, textural and structural descriptions, and finally ending with a description of the "essence" (Creswell, 2007). Transcripts will be carefully read and re-read, employing margin notes and memos to form initial codes (Braun & Clarke, 2006). Significant statements will first be identified, followed by meaning of statements and themes of meanings, and finally exhaustive description(s) of the phenomenon will be reported.

4.8 ETHICAL CONSIDERATIONS & ACCOMODATIONS

Certain accommodations will be made to uphold dignity, justice, respect for persons, and concern for the welfare of the participant. After consent and prior to the interview, a meeting time will be set with the primary site staff caregiver (head nurse) to provide the researcher conducting the interview with certain information to help inform and shape the conversation. Importantly, certain trigger words or subjects may require sensitivity on the part of the researcher during the interview or there may be known “codes” that require interpretation (e.g., “something the resident uses or says which always means same thing and that must absolutely be known to be understood”, as per Le Dorze *et al.*, 2000, p. 44).

For the semi-structured individual interview(s), the word ‘conversation’ will be used instead of ‘interview’ to set a more welcoming and warm tone. The word ‘dementia’ will be avoided and replaced with ‘memory problems’.

Although a single interview for each participant is anticipated, flexibility allows for pausing the interview and coming back to it either after a break or on a different date, since it is recognized that changing mood or tiredness may require a pause.

Throughout the conversation, consent will be re-affirmed at regular intervals and questions will be carefully worded to be direct but not leading, allowing sufficient time for participants to reflect and respond with short regular breaks as needed (Oldfield, 2021). If they appear to contradict themselves, it will be permitted since people with dementia change their minds (McKillop & Wilkinson, 2004). Factual questions or recalling feelings will be avoided since this requires immediate memory and may be more difficult to answer and could create a risk that the person with dementia may feel excluded or like a failure due to not being able to do, remember, or give a response (Murphy *et al.*, 2015). Instead, events that are more emotionally grounded and hinge on participants’ strengths will be sought since these are likely more easily remembered (Moore & Hollett, 2003; Murphy *et al.*, 2015; Oldfield, 2021).

4.9 DATA MANAGEMENT

The entire interview will be conducted, audio-video recorded, and later transcribed by the (student) researcher. Written notes and observations will be taken by both the (student) researcher and Principal Investigator (Supervisor).

All data from this study, including audio-video recordings, transcripts, and other research documents will be stored in a coded format on a secure server under the responsibility of the Supervisor. Audio-video recordings will be saved until after publication (or graduation) in case of the need for verification, and then securely destroyed. The transcripts and other research documents will be retained in a coded format for 7 years and then securely destroyed.

Participants will be identified only on consent forms and by a code on all other research documents. The key that links a code to each participant will be kept secure and separate from the consent forms and other research documents.

Data including transcripts and observations will be shared with the Research Advisor for analysis. Data may also be shared within a Thesis Committee for their review or (potentially) collaboration with analysis, where applicable.

A final results debrief for participants will be offered, at which time participants will individually receive a brief description to update them on the progress of the research project and the value of their participation towards that goal.

A summary report in a debrief will also be offered to the site manager at each site. No individual data will be communicated to maintain participant confidentiality, and since some participants may have very identifying mannerisms, habits, or vocabulary, no such data will be shared at this meeting.

A report of this study may be submitted to an appropriate peer-reviewed journal. Reports may also be presented to scholarly audiences (academic conference).

4.10 LIMITATIONS

Four main limitations of this research study relate to limited variations of perspective, inclusivity, the potential inability of participants to evade oppression, and the challenges of a short time frame. Through careful preparation, difficulties will be overcome regarding finding willing participants meeting eligibility criteria; however, it may not be possible to obtain a wide range of variation in perspective despite efforts to be broadly inclusive of different stages and interpersonal variability. However, the study can drive changes in practice more broadly by applying lessons learned to other sites and settings (Durocher *et al.*, 2019). While steps are taken to include all residents with limited verbal communications, some may be included due to selection bias of site personnel, or some may need be excluded. For example, older residents with dementia who only use non-verbal communications *and whose non-verbal communications are unclear* - although they can be understood with effort (Ward *et al.*, 2008, pg. 643) – will be excluded from this study since this would take greater skills and background than the scope of a small master's level study. Another significant limitation to such a participant-based study is that as members of an oppressed group, participants with dementia may have already internalized some social biases, accepting them as normal (Sherwin & Winsby, 2010). They may not be able to give their own perspective with respect to the value of their communication if they have assumed a reduced sense of self-worth and self-trust (Sherwin & Winsby, 2010). A short time frame in a study run by a novice researcher can provide its own limitations. Analyzing for themes and determining the true essence of experiences may be challenging to complete within a relatively short period of time.

While small size may erroneously be considered a limitation, it is not a true limitation. A small size allows for a rich capturing of individual perspectives and impressions from a target population and maximizes a deeper quality of data (Moore and Hollett, 2003) to yield rich descriptions and better understanding of participant experiences (Hung *et al.*, 2017). Analyzing data from a few individuals enables greater depth of examination and original insights, in comparison with a large multi-site study (Durocher *et al.*, 2019). A small number of participants also helps to minimize the limitations of a short timeframe for conducting, analyzing, and reporting.

4.11 CONCLUSION

This chapter provided a detailed template protocol structured to give legitimacy to the voices of older adults with dementia in LTC by helping to uncover their subjective truths about the value their communication acts hold. Though the proposed study had received ethics approvals for use in two sites in Montreal, it was not conducted due to COVID-19 restrictions at the proposed study sites. The following chapter will discuss the reasonings behind choices made for this protocol with reference to earlier sections of the thesis.

CHAPTER 5 – DISCUSSION AND CONCLUSION

5.1 DISCUSSION

The proposed study will help to fill the gap in subjective perspective studies involving older adults with dementia. Communication was proposed by Carl Elliot as the key starting point for solving ethical problems, since it alone follows a persons' shifting story as their life unfolds, and their perceptions change. By designing a study with communication at its center, the research ethics of Respect for Persons, Concern for Welfare, and Justice as they affect residents can be best understood.

PCC involves interpersonal relationship taking into account the whole person in their proper context and strives to maintain personhood by collecting and using personal experiences and involving the person themselves as a partner in care. Taking time to know the person during the recruitment and consent processes and using face-to-face interviews that are shaped like and presented as conversations adheres to a PCC framework. It enables people with dementia to express their feelings and enables effective communication, both highlighted as central to appreciating the perspective of the person with dementia (Fazio *et al.*, 2018). Learning truths of participants lived experiences through their own communications whether factually true or not reflects a narrative ethics component in the research plan. It allows a dialogue that seriously considers the perspective, experiences, uniqueness, and sense of self of the other person. Furthermore, care ethics is grounded in context, seeing care as a basic human capacity that responds to the needs of others (Sander-Staudt, 2020; Manning, 2009). By creating time and space to observe and record what residents in LTCHs want to communicate, care ethics is satisfied in the action of listening to those who need to be heard, and who otherwise may not be able to help themselves – whose voices may go unheard. Taking time to form a relationship in advance of the interview and meeting these older people with dementia in their own rooms, face-to-face at their own level upholds care ethics' concern with social caring relationships and practices between persons (Held, 2006).

Stigma and autonomy were carefully considered while building the proposed study. The use of non-stigmatizing language was extremely important. Replacing the word elderly with older person was one such example where cultural stigma was not immediately self-realized. Every older person is seen as valuable – their communications having so much to offer and to teach anyone who will listen. Similarly, the autonomy of each older person is of the utmost importance in this study – which seeks to give back and enable their autonomy as far as (legally) possible. Respecting relational autonomy justifies the decision that this protocol does not include or seek any other impressions or voices (such as care providers) aside from those of the participants with dementia. While traditional autonomy is focused heavily on competency, relational autonomy concerns itself with the embodied social location and experience of patients. This enables full attention on what is communicated by the persons with dementia.

In recognition of the potential urgency needed to address shortcomings in Quebec's healthcare system with respect to LTCHs, an empirical qualitative study was designed to have maximum impact within the short timeframe of a master's degree. Phenomenology was determined as most appropriate since it would investigate subjective experiences occurring right now, whereas other methods used for older adults with dementia may have been more concerned with change over time (*e.g.,* narrative research). Involving persons with dementia as active participants with voices was of the utmost importance to ensure their experience was at the forefront of research – to help reduce bias and to enable the research to serve *them*. The people being interviewed, by giving their perspective and impressions, will be the ones to help the researcher understand what their priorities are, through rich and meaningful self-reporting, aided through carefully selected prompts in the interview guide. A small sample size (n = 6) was selected to maximize variation and transferability while maintaining high data quality and richness. It was also meant to enable study completion within imposed departmental timelines.

The inclusion of an advisor with dementia (Jim Mann) was of the utmost importance to satisfy justice and equity by involving someone from the group of interest in the study design. My research advisor provided a wealth of advice. He was invaluable to help refine my approach and re-word questions for my interview guide. I learned that complex or long sentences are much harder for persons with dementia to understand and can lead to confusion and frustration. He also taught me how best to be mindful of environment and body language in an interview. While having an advisory group would be preferable for the range of perspectives they would provide, time constraints regarding the formation of such a committee limited that option.

An ethical approach of respect for persons and concern for welfare informed the inclusion, recruitment, and consent process. The study design did not make explicit use of questionnaires since they could be harmful to the person with dementia. Inclusion of any participant regardless of their differing communication abilities was of the utmost importance to satisfy justice, and so care was taken to prepare extra materials, such as tables to record non-verbal communications, responses, and observations as well as visual aids for less verbal participants. It was acknowledged that those in later stages of dementia who could not communicate clearly required greater skill and time beyond that of a master's level researcher. Had this group been included, the protocol would have included an assent process for those participants and a proxy to consent on their behalf to be included in research.

The goal of this project was to include only those who were capable of consenting to research on their own. Ideally, capacity to consent to research participation was to be assumed to not exclude anyone from participating in research relevant to them. However, in the case of the two sites from which this study intended to recruit, there was an institutional requirement to obtain prior approval by family before a resident could be invited to participate in a specific research project. This necessitated an adjustment in the exclusion criteria, delineating the exclusion of those residents who, despite being able to consent, had a mandate or curator whose permission was required and who did not agree with their participation in the study. In this way, it was unfortunate to observe that their autonomy may still have been restricted as Sherwin and Winsby feared, due to "background social conditions that perpetuate their oppression" (2010, p. 185).

Since the experiences of communication problems for people with dementia were found to be more problematic in LTCHs versus home care (Ward et al., 2008; Tyrrell et al., 2006), and since they have been at the forefront for having issues relating to older adult patient care, LTCH sites were chosen for the study. Middle stage dementia was chosen as the target population for inclusion since it is the longest stage and the one most fraught with communication changes; it is also less studied than early stage.

The chosen method for the small qualitative resident-perspective study for persons with dementia living in LTCHs was a phenomenological qualitative study using observation and semi-structured interviews. Interviews were identified as the preferred method for obtaining participant perspectives since combined with observation they can best ascertain how participants express their needs for their own wellbeing. A semi-structured interview allowed for a narrowing of the focus of the interview, to achieve a specific goal: participants' impressions of the value of their own communications. Although a PAR based study would have been preferable due to its many benefits, the complexity and time constraints of such a study exceeded the expectations and time constraints for a master's thesis project, for which the proposed protocol was developed.

Where possible, PAR studies should be more broadly encouraged and employed since they can combine all the features of interview and observation but with a positive definite result: ACTION! PAR studies can involve persons with dementia as co-authors with unique perspectives of living with dementia, as a participant in interviews, and a facilitator of the interviews of others with dementia. As such, PAR studies can be incredibly meaningful to the participant with dementia, and can teach the researchers to trust, to stop making assumptions, and to be open to all they can gain by simply asking their co-researcher with dementia. Researchers interested in PAR will require ample time (years), and a sizable team (including an appropriate dementia advisory group) to facilitate the many steps involved in data collection, analysis, reflection and interpretation, as well as the dissemination and determination of the action that will result from the collaboration.

Hopefully the research contained in this thesis will help motivate and act as helpful resource for researchers to conduct perspective studies for older persons with dementia in LTCHs to respond to the goal to give legitimacy to their voices and to similar goals. By drawing on such methods involving older adults to incorporate their perspectives and views into a larger body of research, the gap in the research may be filled. Such progress may help shed light on the state of elder abuse – or even help to resolve it. The voices of older persons with dementia from LTCH's are crucial to breaking the cycle of stigma and to affect real change in culture. Providing evidenced-based research could prove to be the best motivation for a change that is so timely.

Over the past two years, the long-standing problems in Quebec's LTC system have been brought to the forefront. There has never been more awareness of mistreatment of our older persons, and there has never been a louder call to action as that given by the Quebec Seniors' Minister: "People have to call out situations when it's going bad, we cannot just close our eyes, close our ears and not take care of these vulnerable people" (Grant *et al.*, 2021, para. 23).

While this is still foremost in our minds, and as resources and funding for research and change for persons with dementia is made available, these strategies are highly relevant and needed. Small pilot studies can lead to more broad studies, which can in turn stimulate and effect change. In an era where patient partners are valued in health care to help understand quality of care, and where co-research and PAR are blossoming, this or similar research projects can also help inspire patient partners with dementia be active participants in care teams and on research teams. Research can therefore motivate involvement of persons with dementia. By being involved in research, that person's understanding of the value of their own voice can be changed – achieving the ultimate goal in giving them back respect, value, and autonomy.

5.2 CONCLUSIONS AND FINAL THOUGHTS

This thesis explored ethical considerations and potential qualitative research methodologies to provide possible solutions to the gap in the research to involve older adults with dementia living in long-term care, towards the goal of giving legitimacy to the voices of older adults with dementia and to value and hear their perspectives and impressions.

To move beyond reliance on legal methods for change, in this thesis I advanced an argument that participatory resident-perspective qualitative studies could provide valuable insights to help drive change in the LTCH environment. The objective was to create a research protocol that could be readily used to give legitimacy to the voices of the older adults by collecting the perspectives and impressions from residents with dementia in long-term care about the value of their communications. The original hope was to employ the protocol within the limits of a (this) master's degree.

Older persons with dementia, many of whom reside in long-term care, have been found to make up a significant proportion of the rapidly expanding older adult population in Quebec and

Canada. Problems in comprehension, word finding, and short-term memory loss arising from dementia may impede effective communication between patients and health care professionals. Considering the awful truth of the devastating state of care in the long-term care environment as revealed by the COVID-19 pandemic, there is urgency and value to be widely inclusive of these perspectives.

A review of the historic focus in dementia research revealed an excess from the perspectives of care providers. More recent studies have provided evidence of communications from older adults with dementia not being valued and have described how research can and should be more inclusive of the participant voice. A review of the literature found that little is known regarding how those with dementia feel about the value of their own communications or their opinions on how their communications are received by others affects their wellbeing.

The main body of the thesis reviewed the ethics of conducting research with persons with dementia – how to prevent harm and support inclusion, in a general sense. Findings from the literature were reviewed, and foundational moral theories (Person-Centered Care, Care Ethics, and Narrative Ethics) were employed as helpful lenses. Stigma and the nature of autonomy for older adults with dementia were identified due to the role they play. The importance of examining risks before developing research protocols was addressed.

The ability to communicate was found to be central to maintaining a sense of dignity and exercising rights. Denying the importance and value of another's voice in this sense obstructs the exercise of their autonomy and is thereby an injustice. Their loss of voice could be linked to poorer treatment and care –perhaps even categorizable as abuse. A clear pattern of problematic de-valuing of patient communiques in long-term care - particularly in Quebec - was evident. Therefore, it was understood that an important first step in addressing this issue is to learn from the residents themselves their perspectives regarding how they feel about the legitimacy of their communications.

Relevant qualitative approaches for involving older adults with dementia in research were reviewed in depth. The importance of including these stakeholders' voices as well as the harms and consequences which could occur by not being inclusive of them in the very research meant to help them were discussed. Benefits, limitations, and risks of various qualitative research methods with persons with dementia revealed what could realistically be achieved through each different type of research study. Furthermore, each component of a research study was carefully discussed, bearing in mind the ethical stance to satisfy and value respect for human dignity through respect for persons, concern for welfare, and justice. Though on the whole PAR and co-research studies were found to be likely the best approach to uncover unheard voices while insisting on some form of action, when time constraints with respect to data collection and analysis were considered, this method did not meet the constraints of a master's level project.

A detailed template protocol for a small hermeneutic phenomenological qualitative resident-perspective research study employing observation and semi-structured interview was proposed to help fill this knowledge gap in research involving older adults with dementia living in long-term care settings. It was structured to give legitimacy to their voices by helping to uncover their subjective truths about the value their communication acts hold with and for others, as well as themselves. The protocol can be adapted and used broadly to enable a better understanding of how to improve care while giving meaning back to the lives of older adults with dementia.

The proposed study relies on a solid ethical framework to address the question "Among the older adults with dementia in long-term care in Quebec, what are the residents' own perspectives and impressions of both how their own communications are valued by site personnel and how they feel that impacts their wellbeing?"

This proposed study would be an important step in addressing the issue of loss of voice of those with dementia in LTCHs and would aid in giving back not only value to residents' communications but also meaning to their lives. By giving legitimacy to voices of older adults with dementia who are living in long-term care right now, insights into their lived realities may prove instrumental to direct and shape action for change.

Our older adults do not have their lives ahead of them – nor do they have the luxury of time to wait for legitimacy to finally be ascribed to their voices. We need to give their voices legitimacy now.

APPENDICES

APPENDIX 1. SCHEDULE OF EVENTS

EVENT:	Recruitment Phase	Consenting Day	Meeting **with site staff** to pre-discuss the residents	Reminder of conversation day	Semi-structured **Interview(s)**	Final results debrief **for participants**	Final results debrief **for site manager**
Length of time	1-2 weeks before consenting day (ongoing)	1 day per site	15-30min max per site	Minutes (days prior to appointment)	~40 min/ participant	~1 hr max	~ 1 hr
Description	- Bring recruitment material to site - Target population: middle stage dementia/Alzheimer's candidates, identified by site staff -Prospective participants/their head nurse/ family members can direct any study related questions to	-If contributing a special event, researcher introduced by recreation manager.[1] -After event, once residents are back in rooms/alone, Head Nurse introduces researcher to potential participants to one-on-one[2] discuss study, answer questions, and invite them to consent. -Researcher allows participant to select date and time on a morning for the conversation (interview). [3]	- In person or zoom team meeting. - 15-30 minutes -Purpose is to learn information that would be helpful for the researcher in the interview[1]	**Primary site caregiver** to remind participants them of their upcoming appointment	-Two team members present: Researcher + recorder (PI) -See Semi-Structured Interview Guide. -Bring Tables for recording observation. -Bring Communication Aids.	-Brief description to update participants on project and the value from their sharing - special event optional	-Sharing of research study results and conclusions, any helpful trainings learned, relevant feedback to site from the **<u>amalgamated</u>** data from both sites[1]. - No individual data will be communicated - No sharing of identifying

	researcher (via phone or email).	-Researcher leaves a reminder card with participant -Researcher to identify the site staff responsible for the care of consented participants[4], and select a date prior to the interview to meet (by email or in person)					mannerisms, habits, or vocabulary,
Other notes	Site recreation team manager can help verbally advertise if there is a special event planned	[1] In the case of multiple floors, this may consist of multiple events [2] One-on-one to keep it confidential & unintimidating which would be the case if consent sought among a group of peers immediately following an event. [3] Make the appointment dates right away and let the care worker know to schedule it in their calendar. [4] Speak to head nurse of that sector.	[1]See pg.1 of Semi-Structured Interview Guide	Tip: use the appointment card left with them with the researcher's picture on it.	-if pt has a less lucid day, researcher will re-schedule using their appointment card - check in on other participants if they would like to meet	[1]In the case of multiple floors, this may consist of multiple events on the same day per site	[1]Data from one site will be merged with the other site to avoid any recognition of participants

APPENDIX 2. RECRUITMENT POSTER

YOUR VOICE!
YOUR IMPRESSION!
YOUR PERSPECTIVE!

Research Project
[towards earning a DEGREE in xxxxxxx, XXXXX UNIVERSITY]

My name is [NAME]. I am a [student] researcher. I invite residents with memory problems to participate in my project.

CONTACT:
[FIRST LAST NAME]

DEPARTMENT:
[INSERT DEPT]

PHONE:
[XXX-XXX-XXXX]

EMAIL:
[EMAIL ADDRESS]

Supervised by [Primary Investigator]
[PI Title]
[PI Faculty]
[INSTITUTION]

STUDY NAME

GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents with memory problems in long-term care about the value of their own communications

I invite you to have a conversation with me about how you feel about communicating your thoughts and feelings to others while living in the residence.

If you are interested, **ask your nurse if you are eligible to participate!**

[INSERT DETAILS ON ANY SPECIAL ACTIVITY ON CONSENTING DAY]. On the same day, I will meet with residents who are interested in participating in this [student] project.

APPENDIX 3. PARTICIPANT RELEASE CONSENT FORM

HEADER:

INSERT LOGO OF PARTICIPATING

INSERT LOGO OF ACADEMIC INSTITUTION

Project Name: *Perspectives and impressions from older adults with dementia in long-term care about the value of their own communications*
REB Study #: [STUDY NUMBER]
PI: Dr. [FIRST LAST NAME] [**Student] Researcher:** [FIRST LAST NAME]

PARTICIPANT RELEASE CONSENT FORM

1. Introduction

The purpose of this release consent form is for potential participants to consent to the release of their personal and clinical information to the research team and for the recruiting nurse to ensure they meet the eligibility criteria.

Information to be provided to the research team will include details related to eligibility and exclusion criteria for the study, including a person's clinical diagnosis and level of dementia.

Eligibility Criteria

1. Residents of LTCHs already diagnosed with dementia aged 65+
2. Residents assessed to be in or around middle-stage dementia
    a. As assessed by site personnel (Head Nurse)
3. Capable of comprehensibly communicating verbally and non-verbally
    a. Assessed by site personnel (Head Nurse)
4. Capable of consent (written or verbal)

Exclusion Criteria

1. Residents who only use non-verbal communications and whose non-verbal communications are unclear
2. Residents with aphasia (inability to communicate clearly)
3. Residents whose mandate or curator does not agree with their participation in the study
4. Residents who do not communicate in English
5. Residents who have health conditions (in addition to dementia) that affect cognition

2. Nature and objectives of the research project

We know that older people with dementia have communication problems, but most of what we know comes from their caregivers.
We want to listen to people with dementia, to learn about their experiences with communication and how communication affects their wellbeing.

The project involves individual conversations with 6 people, aged 65 and older, who have dementia (in and around the middle stage). During each conversation, the Student Researcher will ask questions about how the person with memory problems feels about communicating their thoughts and feelings to others in the residence**.** The Lead Researcher will be present to take notes of what is said. However, the note-taker will not write down any information that could identify anyone.

Each conversation will be audio-video recorded. After the conversation, the student researcher will watch the recording and transcribe what is said. She will not write down any information that could identify anyone (such as people's names, the name of the residence). The researchers will read the written notes, from all the conversations, to learn more about communication experiences of some people with memory problems.

3. Contact information

To contact the [Student] Researcher by email: [EMAIL]
You can also reach the Principal Investigator, Dr. [FIRST LAST NAME], by telephone at: XX-XXX-XXXX or by email at: [EMAIL].

4. Monitoring of the ethical aspects of the research project

The Research Ethics Board of [SITE OR REB NAME] has given ethics approval to this research study and is responsible for monitoring the study.

Declaration of Consent

Title of Research Project : GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents with dementia in long-term care about the value of their own communications

---

Printed Full Name of Potential Participant

Signature of Nurse Assisting with Recruitment

I have asked the potential participant and they have consented to releasing their personal and clinical information (that is relevant to the research) to the research team.

I have contacted the potential participant's mandate or curator and they are agreeable to the potential participant being invited to participate in this research and to providing their own consent for participation in this research.

Furthermore, by signing this document, I agree not to share any information about who participated in the research with others in the organization.

Printed Full Name and Title of Nurse Assisting with Recruitment

---

Signature Date

***N.B.* Every page can have a footer with Page _ of _**

APPENDIX 4. PARTICIPANT INFORMED CONSENT FORM

HEADER:

INSERT LOGO OF PARTICIPATING

INSERT LOGO OF ACADEMIC INSTITUTION

INFORMATION AND CONSENT FORM

Title of the research project:	GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents with memory problems in long-term care about the value of their own communications
Lead Researcher:	[NAME, TITLE, DEPARTMENT, INSTITUTION].
Student Researcher:	[NAME, TITLE, DEPARTMENT, INSTITUTION].
Research Advisor:	[NAME], [RELEVANT EXPERIENCE]; Lives with dementia.
Sponsor or granting agency:	[Unfunded/Funded {Thesis} Research]
Protocol number:	*[insert REB file number]*

1. Introduction

We invite you to participate in a [Master's student's] research project. Please read and think about the information on this form before deciding if you want to participate. If you choose to participate in this project, we will ask you to sign this form. We will give you a copy of this form to keep.

This form may have words you do not understand. Please ask the researcher to explain anything that is not clear. Ask the researcher any questions you have.

2. Nature and objectives of the research project

We know that older people with memory problems have communication problems, but most of what we know comes from their caregivers.
We want to listen to people with memory problems, to learn about their experiences with communication and how communication affects their wellbeing.

The project involves individual conversations with [6 people], aged 65 and older, who have memory problems. During each conversation, the [Student] Researcher will ask questions about how the person with memory problems feels about communicating their thoughts and feelings to others in the residence**.** The Lead Researcher will be present to take notes of what is said. However, the note-taker will not write down any information that could identify anyone.

Each conversation will be audio-video-recorded. After the conversation, the student researcher will watch the recording and write down what is said. [She/He] will not write down any information that could identify anyone (such as people's names, the name of the residence). The researchers will read the written notes, from all the conversations, to learn more about communication experiences of some people with memory problems.

3. Conduct of the research project

3.1 Location, time involved, and number of visits

You will be asked to participate in a conversation with the [Student] Researcher at your own residence.

The [Student] Researcher will meet with people interested in the project to review this information and consent form, discuss the project and answer any questions. If you choose to participate, you will be able to choose the time of day for your meeting if you would like that. The Researcher will leave you with an Appointment Reminder card with her picture. It will also have [her/his] phone number and email so that you or your nurse can reach [her/him] if you ever have any questions or concerns.

Before the conversation, the [Student] Researcher will meet with your primary caregiver to learn of any specific "codes" or actions that you may use in communication and to guide the conversation safely for you. This will be most important for conversations with participants who communicate non-verbally.

Each participant will be invited to have a conversation with the [Student] Researcher in a private and comfortable place (such as your room). The conversation will be 30-40 minutes. However, if you begin a conversation and want to stop and continue another day that is ok. Just tell the researcher. There will be no more than three visits with you.

3.2 Nature of your participation

If you choose to participate, you will be invited to have an in-person conversation with the researcher. We would first spend some time getting to know each other, and then we would chat about some of what's going on here, your life, and what is good and what is not, and how that makes you feel.

You will be free to answer any way you want, and to only share what you want. The conversation will take 30-40 minutes, but at any point we can stop for any reason. We can continue on another day. You will be able to choose the time of day for your meeting(s) if you would like that. The researcher will leave you with a new Appointment Reminder card with her picture.

4. Risks associated with the research project

The research team believes that participating in this research project carries little risk to you. There is a risk that information that you share with researchers will become known to others. To prevent that, the researchers protect your private information in many ways. These include: securely storing all research documents; using a code instead of your name on all documents (other than this Information and Consent Form); not including any personally indentifying information on written notes); and not sharing any specific comments from you with the staff where you live.

5. Benefits associated with the research project

There is no obvious benefit to you for participating in this research.

We hope that this project will help other people to understand what some older people with memory problems, living in a CHSLD, feel about these things.

By providing general feedback to the person in charge of this home, our study may help the people caring for you to provide better care. This may improve communications with older people with memory problems where you live. No information will be shared that can identify you.

6. Voluntary participation and the right to stop participation

It is your choice to participate in this research. You can choose not to participate. You can stop the conversation to take to take a break, stop for the day and continue the conversation another day, or stop completely. Just tell the researcher to stop. You do not have to give a reason to stop.

Consequences for care

If you choose not to participate (or if you choose to stop participating), the quality of the care you receive will not be affected.
If you choose not to participate (or if you choose to stop participating), it will not affect your relationship with the people who care for you.

Consequences of withdrawal – data storage

If you choose to stop participating, we will not collect any more data. You can ask us to erase the audio-video-recording and not use any information we learn from you in the research reports. However, after the information from all the conversations is analysed and reported in the Student Researcher's master's thesis, it will not be possible to remove what we learned from you.

7. Confidentiality

Storage of data/samples – Protection

Everything that you say will be kept just between you and the research team; it will be kept totally confidential from everyone else. Your family and people who work here will not know about anything you say, unless you decide to tell them. We want you to feel free to be completely honest, knowing that you will be in a safe space.

All information collected during this research study (including personal information) will remain confidential to the extent provided by law. You will not be identified by your name. Instead, a code number will be used. Only the Lead Researcher will have the information to link your name with the code number.

Storage of data– Duration

All information and materials from this project will be kept secure at McGill University, under the responsibility of the Lead Researcher, for 7 years after the project ends. After that, it will be destroyed in a secure manner.

Dissemination of overall results

What you share during the conversation will be combined with what other participants share. That may be published or shared at scientific meetings, but it will not include your name or the name of any participant. No one will know who said it.

8. Compensation

You will not receive any money for participating in this research study.

9. Should you suffer any harm

Damages/medical care

Should you suffer harm of any kind following any procedure related to this research study, you will receive all the care and services required by your state of health.

Non-waiver of rights

By agreeing to participate in this research study, you are not waiving any of your rights nor discharging any of the researchers, or the institution or its employees of their civil and professional responsibilities.

10. Contact information

You can ask your nurse to contact the researcher, or you can contact them by email at: [INSERT RESEARCHER EMAIL].

You can also reach the principal investigator, Dr. [FIRST LAST NAME], by telephone at: XXX-XXX-XXXX or by email at: [INSERT PI EMAIL]

11. Complaints

For any questions about your rights as a research participant, or if you have comments or wish to file a complaint, you may contact:

[INSERT CONTACT FOR SITE; NAME; at 1-XXX-XXX-XXXX or by email at [EMAIL].

12. Declaration of interests

The researchers have no personal interest that could conflict with their role as a researcher. It is important to remember that although you will speak about a lot of things concerning your life at the home with the researchers, they are not involved with your care at your home in any way.

13. Monitoring of the ethical aspects of the research project

he Research Ethics Board of [INSERT SITE NAME OR REB NAME] has given ethics approval to this research study and is responsible for monitoring the study.

Declaration of Consent

Title of Research Project : GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents with memory problems in long-term care about the value of their own communications

Do you accept to be audio-video recorded during interviews?
☐ Yes ☐ No

Signature of participant

I read the Information and Consent Form. Both the research study and the Informed Consent Form were explained to me. My questions were answered, and I was given enough time to decide. After thinking about it, I want to participate in this research study that is described above, including the use of all personal data collected.

Name and signature of participant Date

Signature of the person obtaining consent

I have explained the research study and the terms of this Informed Consent Form to the research participant, and I answered all questions asked.

Name and signature of the person obtaining consent Date

***N.B.* Every page should have a footer:**

Version # DD-MMM-YYYYY Page _ of _
[SITE NAME REB ICF TEMPLATE or details as per site requirements]

APPENDIX 5. APPOINTMENT REMINDER

[FIRST LAST NAME]

[Researcher]
[DEPARTMENT, INSTITUTION]
Phone XXX-XXX-XXXX
Email [INSERT EMAIL ADDRESS]

You are meeting on:

We will have a conversation about how you feel about communicating your thoughts and feelings to others while living in the residence.

Study Name: *GIVING LEGITIMACY TO THEIR VOICES! Perspectives and impressions from residents with memory problems in long-term care about the value of their own communications*

APPENDIX 6. SEMI-STRUCTURED INTERVIEW GUIDE

HEADER:

Project: *Perspectives and impressions from older adults with dementia in long-term care about the value of their own communications*

REB Study #: ___________________ Date and time: _____________________

Participant Number: _____________________

Interviewer Name: _____________________

Semi-structured Interview (CONVERSATION) Guide

BEFORE commencing interview (NOTES from caregivers about resident):

Do they understand they have dementia?

Would using the word dementia or Alzheimer's cause a responsive behaviour?

Other trigger words:

Would they remember coming to live here + whether it was their choice?

Known code*?____

_ *Codes require interpretation (eg. Something the resident uses or says which always means same thing and that must absolutely know to be understand (Dorze *et al*., 2000)).

Favorite activity

Disliked activity

Favorite food/drink

Disliked food/drink

OTHER (ie Hard of hearing)

____

____

____

____

____

____

____

PART 1: Gentle Introductions/Icebreaker (5 min)

GENTLE INTRODUCTIONS

To be included/repeated at all visits (up to a maximum of 3)

- Nice to see you again
- Introduction about me (university student, I'm learning about…for my masters) Today's goal: to have a conversation with you, to contribute towards master's degree and maybe a publication
- I want to talk with you about living in the residence. I want to understand more about some of what's going on here, your life, and what is good and what is not.

- Seek consent again; thank for their participation
- Affirm confidentiality, it's a safe space; anything said will not impact their care in any way!
- Remind that we can stop at any point; either resume at a later time or date, or stop completely

ICEBREAKER

Interview 1:

- Hearing your perspectives like yours is so important to me – it's why I decided to do Masters!
- Goal for masters: through my work others understand perspective and feelings of ppl like you
- Let's learn a little bit about each other:
    - share about my family growing up; What about your family?
    - Share about my kids at home; Did you have kids? Grandkids? Tell me about them!

Icebreaker subsequent interviews:

- Always start at Baseline Question 2

PERMISSION TO RECORD

To be included/repeated at all visits (up to a maximum of 3)

- I'm audio-video recording what we say to help remember important things you say
- Will never be shared with family or staff, only with research team
- Do I have permission to **record this** to listen to again later on?

PART 2: Conversation/Semi-structured interview section (20 – 30 minutes MAX)

BASELINE QUESTION 1a) This looks seems like a nice place, how do you like living here?

Possible prompts if they don't elaborate:

i. Do you have a favorite pastime/or activity you like to do? Do you like ______ (caregiver info)
ii. Is there an activity or time of day you don't enjoy? Do you dislike ________ (caregiver info)
iii. Do you have a favorite meal? Do you like __________ (caregiver info)

- *Personal Example: We always thought my dad loved pasta – until my mom died, and I offered him pasta for dinner since I thought he like it so much, and he told me that actually he never really liked pasta! I guess sometimes kids don't know everything about their parents when they think they do!*

iv. Is there a certain food or drink that you really don't enjoy? What about_____(caregiver info)

v. Is there anything that's the best thing in your day that you couldn't live without?
  - Has it ever changed? *see Appendix A: 'To learn if they **share their feelings**'*
  - If NO, do you feel things ever change here in your daily routine?

BASELINE QUESTION 1b) *See caregiver notes: if they don't remember, SKIP THIS!)*

Did you choose this residence to move to? residence?

- *Did your family want you to move here? How did they feel about it? Did you agree with them?*

BASELINE Question 2) So – how are you feeling so far today?
(TO BE ASKED AT EVERY VISIT TO ESTABLISH BASELINE MOOD THAT DAY)

Main Question 1) I'd like to chat about making your own decisions here at the residence. Is there an activity here that you really enjoy? Do you make your own decisions about (participating in) that activity?
USE PROMPT PICTURE BOARD (Supplementary Material 3)
Food/drinks (favorites, preferred time of day to eat, who to eat with), What to wear, Music preferences, TV shows or channels, pastimes (books)/fun activity (bowling)

Possible prompts if they don't elaborate:

i. How do you feel when you get to make your own decisions?
ii. Today this is what I chose to wear. I love your outfit. Did you pick it?
iii. I started my day with a coffee today. Do you like to start your day with coffee?
iv. Do you feel that what you have to say matters to others?
v. Sometimes people here are rushed or may not be patient to wait for a decision. Have you encountered that here? How did that make you feel?
  1. What were you doing when they were (rushed / impatient)?
    a. Were you sleepy? (Did they come back later?)
      i. How did that affect your being able to make a decision?
      ii. How did it make you feel to be asked when sleepy?
    b. Was someone there to support you and help you make the decision?
      i. How did [having no one with you]/[their presence] make you feel?

Main Question 2) Do your carers know how you feel about different activities here (PICTURE BOARD PROMPT). Do they know what activities you enjoy doing (or what you dislike)?

Possible prompts if they don't elaborate:

i. For example, is something you really enjoy that you would like to have more of?
ii. Do your carers know about that?
iii. How do they know (how you feel about different activities)?
iv. Has this ever changed?
  i. How did you feel about that change?
  ii. Did you feel you could tell someone about it? /Did you tell someone?
  (Be sure to use Appendix A here)

Main Question 3) Is there one or a few people who you feel most comfortable sharing your troubles with?

Possible prompts if they don't elaborate:

- Why do you prefer to communicate with them?
- What makes it/them special?
- How do they make you feel when you share with them?
- Why not share with other people?
  - Do the other people lack something?
  - (Only if applicable - Do you feel differently with others when you try to share?)

OPTIONAL ADD ON QUESTION 4) If you are having a bad day/ just not feeling great would you tell anybody?

FINAL QUESTIONS: Was there anything else you would like to share with me today?
Do you have any last questions for me?

Again, everything that was spoken between us will be kept confidential within the research team.

{STOP THE RECORDING}

PART 3: Closing Remarks (2-5 min)

(Pay attention to body language – make sure they are settled Murphy *et al.*, 2015) (2-5 min)

To be included/repeated at all visits (up to a maximum of 3)

- I've stopped recording now
- So happy to listen to everything you've shared
- Thank you so much for giving me your time and for your sharing
- valuable to me to hear in your words your side of things / point of view
- believe it will help others understand more about your perspective, in a completely anonymous way without your name attached to it
- again, no one except the research team will know what you've said

To be included only at the final visit

- I hope to have the interviews finished by…. I really appreciate your help with my master's project! I would you like me to come back and tell how things are going around then, and play some more violin at the same time as a little way of saying thank you
- If there is something else that you remember later and would like to tell me, I will leave you with a stamped self-addressed envelope with a blank piece of paper in it, so that you can reach me.

To be included/repeated at all visits (up to a maximum of 3)

~ Now, I'm off to {*…. insert personal anecdote about something fun in my life to end on a light fun note!}* ~

Appendix A: OPTIONAL CONVERSATION PROMPTS to learn about communication preferences

Possible prompts to help in each question’s situation. They will not necessarily all be used verbatim.

1) Prompts to facilitate elaboration:	
To go deeper:	• Go on? or • Can you tell me a bit more? or • How did that make you feel? or • Do you want to describe that further? Or • Do you do things differently when you feel that way? o feel good: Are you more patient, loving, calm, more social, eat more, laugh more, exercise more • What do you mean by (the word) xxxxxx • What did you do to overcome misunderstandings and miscommunications?

To explain something **upsetting:**	• Can you help me understand why this was so upsetting to you?
	• What made you feel this way?
	• What do you do when something like this happens/when you feel that way?
	    o E.g., when I feel.... I just want to ….
	    o If feel bad: get angry, grumpy, pray, cry, yell, stay alone in room, avoid other people, get quiet, read something, watch TV, listen to music etc.)

To learn if they **share their feelings**:	• Have you told your carers that you feel this way? (Who do you most often tell?) • Do you try to find someone to tell or maybe call someone on the phone when you feel this way? • Did you feel free to express how you felt with other people here?

To learn **how** they share **feelings**:	• How did you let them know?
	    o Did you share how you felt about it with words or actions? or
	    o What did you do or say to communicate this (e.g., smiled?)? or
	• Did you have enough time to communicate everything about how you felt?

To learn impressions on **response of others &** how that made them **feel:**	• How did others respond? / Did anyone notice your actions or behaviour?
	    o How did you feel when they did that?
	• Did you feel like they listened to you and understood?
	    o How did you know they understood you? (Did they try to help you?) or
	    o What made you think they didn’t understand you?
	        ▪ how did that make you feel?
	            • Cared for, understood, valued, like a valuable person?
	    o Do you feel different after communicating with them? Why?
	    o What would it be like if……?

2) Prompts to respond to silence or if they don’t understand:	
	• Is there an image here that can help you (point to prompt boards) • Would you like more time to think on this? • Reword the question – ie. Let me re-word that for you • Would you like me to come back to this later? • Give an example (personal is ideal) • Are you feeling tired, Would you like me to come back another day to continue? o Would you prefer to stop completely?

APPENDIX B: NOTEWORTHY REMINDERS & CAUTIONS to use as often as needed

REMINDER OF/CAUTION FOR	**WHAT TO DO**
Resident shows signs of tiring	Offer to pause or end the interview
Resident struggles with words/verbal communication	Offer blank paper and pens, offer talkingmats.com laminated images DO NOT SUGGEST WORDS if struggling for a word, WAIT. SUGGESTING WORDS IS TOO DISTRACTING (as per Jim Mann)
Researcher responses to resident sharing	• "Very interesting" – perspective • "Very important" – point • "I never knew…thank you…so glad to know how" (Murphy *et al.*, 2015)
Researcher on phrasing questions	• ASK question and then STOP. Elaborate before asking a question – or they won't recall the question. • Don't rely on memory in the questions • Avoid direct questions (Above advise from Research Advisor) • Don't offer hypothetical situations – no longer clear b/c not based on factual life
Hesitancy from resident to share	• Don't worry –family and staff won't hear this • There are no right or wrong answers • Your experiences are all that matter today
Regular check in between Questions	• How are you doing? • Are you still enjoying this conversation? • Do you feel you'd like to continue or prefer to take a little break? • Would you like to stop for today?

APPENDIX C: Post-Interview Narrative Summary: Reflections and Comments (to be written immediately following interview): [leave space for 1 full lined page]

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***N.B.* Every page can have a footer with Page _ of _**

APPENDIX 7. PROMPT BOARD & INDIVIDUAL COMMUNICATION AIDS

PROMPT BOARD:

INDIVIDUAL PROMPT PICTURES: From talkingmats.com*, used with permission.

*Except for the stop hand sign prompt

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