

Stories of Resident-to-Resident Aggression:
Fears and Experiences in Long-Term Residential Care

by
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Abstract

This thesis explores family caregiver concerns and experiences around resident-to-resident aggression (RRA) in long-term residential care (LTRC). Canadian media reports spanning a ten-year period (2007-2017) about RRA ($n= 64$) were analyzed with a critical discourse lens to examine the representation of family members. Also, family caregivers of residents in LTRC from two British Columbia health regions ($n= 8$) were interviewed about the influence of RRA media reports on perception of safety for themselves and their relatives in LTRC, and their broader caregiving experiences. Family caregivers viewed media reports on RRA as sensational, contributing to the stigma of dementia, and lacking context, but they did not impact the family caregivers' sense of safety. Instead, the lack of access to empowerment structures (i.e. informal power, formal power, information, support, and education) and the ambiguous position of family within the hierarchical power structure of LTRC negatively influenced their caregiving experiences. Findings suggest a need for systemic change to increase family empowerment and role clarity with respect to prevention and management of RRA.

Keywords: Family caregivers; Empowerment; Resident to Resident Aggression; Long-term residential care; Media reports; Systemic change

This thesis is dedicated to the family caregivers
who continue to provide care in long-term care facilities.

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for refusing to be reassigned the role of 'visitors'
and for refusing to stay silent.

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Chapter 1.

Introduction

For the first time in history, one in six Canadians are age 65 and over, exceeding the population of Canadians age 14 and under (Statistics Canada, 2015). Of this population of older adults, 14.9 percent (747,000) live with Alzheimer's disease and other dementias. This figure is projected to increase to 1.4 million by 2031 if nothing changes. In Canada seven percent of older adults (250,000) live in long-term residential care (LTRC) at any given time, and 70 percent of older adults with dementia will die in LTRC (Alzheimer Society, 2010). Of the 5.4 million Canadian family members providing care to older adults in 2012, 14 percent delivered care in LTRC. The consequence of providing care extends beyond time spent in the LTRC facility – of these 743,500 family members, one third reported strain on family relationships (Turcotte & Sawaya, 2015).

A ubiquitous assumption is that the family members who care for older adults in LTRC have fewer responsibilities than those assisting older adults living in private households. Despite the services available to residents in LTRC, however, all their needs may not be met. As well, since the older adults living in LTRC tend to be among the oldest and frailest, they often require more help and care from their relatives (Turcotte & Sawaya, 2015). Family involvement in LTRC impacts the quality of care for the residents, as well as the experiences of other relatives, and staff (Westin, Öhrn, & Danielson, 2009). With rising rates of dementia in LTRC, responsive behaviours (e.g. pushing, striking, throwing items) that cause injury to

other residents and are deemed resident-to-resident aggression (RRA) are also escalating. Encompassing negative physical, sexual, and verbal interactions between residents, this behavior is considered a varied and multifaceted phenomenon (Rosen *et al.*, 2008) consisting of “a complex interaction between the aggressor, the environment, and the injured resident” (Shinoda-Tagawa *et al.*, 2004, p. 2075). In a scan by the Canadian Institute for Health Research of five Nova Scotia nursing homes between 2003 to 2007, nearly half (45%) of the 699 residents in the sample “exhibited one or more behavioural symptoms, which included verbal or physical abuse, social inappropriateness, resistance to care and wandering” (p. 1).

The academic literature on RRA does not mention family members’ perspectives, and the literature on family members’ experiences in LTRC rarely mentions RRA. This represents a significant gap, as family members who spend time in LTRC may often be left alone with residents while staff are on break or providing one-on-one care in a resident’s room when an act of aggression occurs. Family members could be primary witnesses of RRA, and there are currently no guidelines as to how families should report instances of resident-to-resident aggression, or if and how they should intervene. Unlike direct care staff, family members are not unionized and do not have workers’ compensation if they are injured trying to referee an instance of RRA.

McDonald *et al.* (2015a) conducted a secondary analysis of RRA in Canada from data and/or reports from all ten provinces (no data were available from the

territories). The total number of incidents of reported abuse in LTRC facilities was 23,472. Of these 6,455 or 28% were RRA, with physical abuse the prevailing type (McDonald *et al.*, 2015). Castle *et al.* (2015) suggest that RRA may be the “most highly prevalent form of abuse in residential care” (p. 421). It is largely assumed that incidents of RRA are underreported, as the perpetrators and victims often have advanced dementia and thus may not be able to report or the veracity of their reports are questioned (Teresi *et al.*, 2013). Thomson *et al.*, 2011, also stipulate that RRA is underreported as staff lack the training to detect signs of abuse, and physicians spend relatively little time in LTRC facilities. In addition, nursing home staff and administrators may be reluctant to report abuse because they fear adverse publicity, investigations, and fines (Page *et al.*, 2009).

McDonald *et al.* (2015b) suggest that in the absence of research literature, a “driving force raising awareness and propelling action on RRA in Canada has been the recent rise in media reports on this topic that have sensationalized extreme cases, where RRA led to serious injury and in some cases death” (p. 149). Similarly, in her address at Promising Practices in Residential Care the BC Seniors Advocate, Isobel Mackenzie, stated that her office began its RRA research agenda because of the media reports around the phenomenon, and a public report from the BC Coroner’s Office which outlined 16 deaths from RRA in the last two years (2016). This highlights the importance of considering multiple sources, especially when the academic literature is lacking.

At the time of their scoping review, McDonald *et al.* (2015a) noted that there were only 27 peer-reviewed articles on RRA, and only two studies were from Canada, one of which was an unpublished master's thesis. Of these articles, only one focused on family members, and even then, it was not concerned with the experiences of family members, but with their reporting of "non-staff abuse in Michigan nursing homes" (Zhang *et al.*, 2012). Conversely, within the last decade (2007-2017) there have been 64 media reports on incidents of RRA, and over half of these include the perspectives of family members. These media reports were not previously critically examined, despite their major contribution to the level of awareness around RRA, impacting public perception and policy.

In order to begin to address the current gaps in the academic literature, the scope of the present study is limited to family members' experiences and fears of RRA. A critical discourse analysis of media reports of RRA and semi structured in-depth interviews with family members examines the existing narrative around RRA in the media, and whether it influences perceptions of safety for LTRC family caregivers. Finally, what information, support, and education family members require in terms of RRA and their experiences in LTRC is presented. To contextualize these questions, the literature review will provide an overview of the environment of LTRC. Focusing on both the national and provincial background, this will elucidate how the development of the current system of LTRC affects reporting incidents of RRA. Next, the literature around family

involvement in LTRC, the challenges of defining RRA, and the theoretical underpinnings for critical discourse analysis will be explained.

Chapter 2. Literature Review

The following chapter discusses the position of family members within LTRC and LTRC within the framework of Canadian federal policy. It describes how LTRC reflects provincial and territorial differences and lacks a national strategy or standardized range of services. Following this, an overview of the literature on family involvement in LTRC is provided, with a focus on the families of the over 27,000 older adults living in LTRC in British Columbia at any given time (Office of the Seniors Advocate, 2016). From the experience of their relative moving in to the nature of care delivered within LTRC, the section illustrates the ambiguous position of families in LTRC.

Next, the challenges of defining RRA within the sphere of academic research and the LTRC mandatory reporting frameworks are illustrated. This section argues that the lack of a standard definition for RRA impedes both research and reporting, and efforts to recognize and prevent RRA would benefit from being understood through an elder abuse lens at the institutional and system level. Finally, after addressing the gaps in the current state of knowledge outlined in the preceding sections, the rationale for the study is outlined and the guiding research questions are stated.

2.1. Environment of Long-Term Residential Care

2.1.1. National & Provincial Context

In contrast to the attention given to pensions and health care, the needs of older adults within LTRC and their largely female caregivers (family and staff) have seldom seen their concerns occupy national policy agendas. With the exception of Nordic countries, governments in most Organization for Economic Co-operation and Development (OECD) countries have never placed LTRC within the mainstream of the welfare state, instead relegating it to families, provincial or territorial governments, and private or voluntary organizations. The exclusion of LTRC from the 1984 Canada Health Act barred this form of care from the Canadian welfare state.

Long-term care pertains to a continuum of services in Canada, including homecare, retirement homes, assisted living, and long-term residential care facilities, the focus of this study. Long-term residential care facilities (LTRC) are distinguished by the higher care needs of residents and the availability of nursing staff 24/7. LTRC reflects provincial and territorial differences, lacking in a national strategy or standardized range of services. Facilities may be publicly owned and operated, or they may be not-for-profit and charitable. Across Canada, they range in size from four beds to well over 300. On average Canadian facilities are large – 96 beds (Statistics Canada, 2007).

The staff within LTRC are highly stratified with strict boundaries between occupational categories (Armstrong *et al.*, 2009; Blair & Glaister, 2005). Labour is task oriented, with job categories separating the allocation of tasks. Registered nurses (RNs) hold managerial roles, with licensed practical nurses (LPNs) and frontline care workers providing the majority of direct care. LPNs perform the more medically oriented, supervisory and administrative tasks while frontline care workers (e.g. personal support workers, health care aides, residential care aides) handle most physical care work (e.g. bathing, toileting, dressing, feeding). The LTRC sector is highly unionized with about eight in 10 workers belonging to a union (Banerjee *et al.*, 2012).

In British Columbia, over 27,000 older adults live in LTRC at any given time (Office of the Seniors Advocate, 2016). There are currently 292 publicly subsidized facilities in British Columbia, located within five health authority regions: Interior Health, Fraser Health, Vancouver Coastal Health, Vancouver Island Health, and Northern Health. In B.C., 32 per cent of LTRC facilities are owned and operated by the health authorities, while the remaining 68 per cent are run by private operators. Fees for subsidized beds are based on income level, with residents paying up to 80 per cent of their after-tax income (BC Ministry of Health, 2017). British Columbians can expect to pay anywhere from \$932 to a maximum of \$3,022 per month in LTRC. Older adults can also choose a private LTRC facility with no government subsidies at a significantly higher

cost. In a report about LTRC in British Columbia, SunLife Financial estimates private residential care ranges from about \$3,000 up to \$9,000 per month (2016).

Community-based long-term care work is well-documented, but family care work in LTRC facilities historically receives less attention in both research and policy agendas likely because it is believed families “abandon” their older relatives in LTRC and do not participate in care work in this setting. Family members are therefore positioned with little power within the institutional setting, and the institutional setting is positioned with little power within the framework of Canadian federal policy.

2.2. Family Involvement in Long-Term Residential Care

The transition to LTRC is often a quick and disruptive one. In British Columbia, which operates on the ‘First Available Bed’ policy, once a bed becomes available in a facility prospective residents are expected to move in within 48 hours (BC Ministry of Health, 2017). Family caregiving does not end following the admission to LTRC. Despite the continued integral role of family members in LTRC, there is an absence of formal policies to facilitate comprehensive and cooperative interactions among families, residents and staff.

Although family caregiving continues throughout LTRC, the nature of care provided changes. Direct physical tasks are often left to the staff, while family care comprises of indirectly ensuring that adequate care is provided (Buckwalter, Maas & Reid, 1997). This includes communication with staff, monitoring the interactions of staff and other residents, and developing relationships with staff in

order to influence care. This vigilance is not borne of a desire to 'take over' direct care – as Wright (2000) details, family members typically do not want to remain or become involved in practical hands-on care after admission. Instead, families feel that their knowledge about the resident's unique life history, preferences, and requirements could substantially contribute to individualized care for their relative, but that the staff rarely seek this information (Hertzberg & Ekman, 1996).

The lack of formal policies reifies the unstable position of family members in LTRC and, as Baumbusch and Phinney (2014) report, family members are reluctant to express concerns or make suggestions to improve resident care, fearing that the staff may not appreciate 'interference' and that the resident will suffer poorer care as a result. Efforts to involve family members in care should ultimately have a positive impact upon individualized resident care. After all, in the purported 'person centred' LTRC environment, the people staff and families should be centering their efforts around are the residents. As the most vulnerable, residents therefore have the least amount of power in LTRC facilities and will bear the brunt of an inadequate system.

2.3. Resident-to-Resident Aggression and Elder Abuse

Language shapes our thoughts, and so terms must be chosen to carefully convey intended meaning. An understanding of the importance of nomenclature is perhaps why an expert panel of researchers and practitioners deliberated on terms before developing a research agenda on resident-to-resident aggression (McDonald *et al.*, 2015). Some of the terms considered included the words

“violence,” “mistreatment,” “relational aggression,” and finally, “abuse” (McDonald *et al.*, 2015, p.149). Each of these different terms used for the phenomenon of negative and aggressive physical, sexual, or verbal interaction between residents contain their own set of implications about intent, trust, and power. While RRA does not fit the typical definition of elder abuse, as both the aggressor and the attacked can suffer harm, it is elder abuse at the institutional and system level.

This behavior is considered a varied and multifaceted phenomenon (Rosen *et al.*, 2008) consisting of “a complex interaction between the aggressor, the environment, and the injured resident” (Shinoda-Tagawa *et al.*, 2004, p. 2075). Current research on RRA is focused on determining prevalence and incidence (McDonald *et al.*, 2015a; Voyer *et al.*, 2005), triggers and risk factors (Isaksson *et al.*, 2009, Isaksson *et al.*, 2011; Snellgrove *et al.*, 2013), promising interventions (both pharmacological and non-pharmacological) (Dettmore, Kolanowski & Boustani, 2009; Isaksson, Astrom & Graneheim, 2013), and methods of prevention and awareness for staff (Ellis *et al.*, 2014; Banerjee *et al.*, 2012; Teresi, *et al.*, 2012; Payne & Burke, 2005).

The Office of the Seniors Advocate (OSA) found 422 reported incidents of RRA resulting in physical harm for the year 2014/15 (2016) in 304 facilities. Of these publicly funded facilities, 100 are covered by the *Hospital Act* and 204 facilities are covered by the *Community Care and Assisted Living Act*. These acts have separate mandatory reporting frameworks to identify RRA. The mandatory reporting of “serious adverse events,” which includes incidents of RRA, only

came into effect for both acts in 2013. The OSA report identified triggers for RRA that are in line with what is found in the research literature, including:

“communication challenges between residents; residents not respecting each other’s privacy, wandering into rooms or touching/taking another resident’s possessions; the challenges of communal living (competition for a certain chair in the dining room or a particular television channel); racism or intolerance of religious, cultural or sexual orientation differences; loneliness and feelings of abandonment; and anxiety, boredom or chronic discomfort” (2016, p. 2).

LTRC institutions and those who work within them have a duty of providing care to their residents. LTRC institutions are responsible for their residents’ safety and well-being, and are obligated to avoid acts or omissions that can be reasonably foreseen to cause harm to residents (BC, 2009, reg. 96; ON, c.8, 2015).

Whereas abuse of residents by staff obviously breaches this duty of providing care, RRA, which several studies suggest is the most highly prevalent form of abuse in LTRC, constitutes a more insidious transgression (Lachs *et al.*, 2007; Shinoda-Tagawa, Leonard, & Pontikas, 2004). Castle (2012) examined reports from nurse aides ($N=4,451$), of which 97% observed verbal resident-to-resident aggression and 94% observed physical resident-to-resident aggression.

Shinoda-Tagawa *et al.* found that residents living in an Alzheimer unit were three times more likely to suffer an injury from other residents than residents living in a non-specialized care unit (2004). With rates of dementia rising and LTRC

facilities catering to residents with increasingly complex needs, resident-to-resident aggression is a reasonably foreseeable consequence that the LTRC system must address on a policy and facility level.

Moving into a LTRC facility is an act of trust and involves an expectation of care for residents. As stated by the Canadian Network for the Prevention of Elder Abuse, “all abuse is an abuse of power and a violation of trust in a relationship” (2016). The 2011 census found that 7.1% of Canada’s older adults aged 65 and above lived in a LTRC facility; among seniors aged 85 and over, the proportion was 29.6% (Statistics Canada, 2012). Residents in LTRC settings are more likely to be cognitively impaired and have various comorbidities (Schiamberg *et al.*, 2012). Therefore, the residents in LTRC are a population of often frail and dependent seniors who are uniquely vulnerable to abuse and neglect (McDonald *et al.*, 2012).

The Alzheimer’s Society of Ontario describes responsive behaviours as a term preferred by persons with early stage dementia, professionals, and advocates. In their estimation, the term responsive behaviours stresses that “their actions, words and gestures are a response, often intentional, that express something important about their personal, social or physical environment” (2014). The environment in which these responsive behaviours occur is key to understanding the meaning behind them. Furthermore, the responsibility of addressing the unmet needs underlying responsive behaviours, whether these behaviours are

aggressive or not, lies with the LTRC facility tasked with the residents' care (*Alzheimer Society of Ontario*, 2014), and the provincial governments which provide funding.

Ramsey-Klawnsnik (2008) urges that “diligent, ongoing supervision is required for both employees and residents having access to vulnerable adults” in order to prevent elder abuse and RRA in LTRC. To not provide the necessary care and supervision is at worst elder abuse through neglect; at best it is systemic abuse at the facility and policy level. The Canadian Department of Justice identifies systemic abuse in institutional settings as being a “great threat” to the safety and well-being of Canadian older adults. Systemic abuse is described as system-wide practices that “produce neglect, substandard care, overcrowding, the violation of dignity – such as over-medicating, limiting freedoms, or issuing incontinence briefs to all residents as a way of managing residents due to a shortage of staff” (Canada Department of Justice, 2015).

When understood as an interaction between frail, cognitively impaired residents, RRA, as an outcome of responsive behaviours, is a suitable term. When one pulls back the focus, however, to include the environment of LTRC in which these aggressive behaviours are a response to, RRA is better understood as systemic elder abuse. Expanding theories and conceptual models of elder abuse for LTRC settings may better inform research, training interventions, and prevention strategies (Castle, 2015). Two conceptual and theoretical models that

are used in elder abuse which could further elucidate the phenomenon of RRA are the risk-and-vulnerability conceptual framework (Baker, 2007) and political economic theories (Perel-Levin, 2008).

The esteemed expert panel of researchers and practitioners that met to deliberate and ultimately recommend a research agenda on RRA decided not to use the term “resident-to-resident abuse”, as it may imply intent on the behalf of the aggressor who might lack capacity and the seriousness of the term could lead to stigmatization that hampers reporting and research (McDonald *et al.*, 2015). While these concerns have merit, future research and social policy must not divorce the phenomenon of RRA from the environment in which it occurs. Provincial and institutional responsibility in RRA are key in understanding the phenomenon, and in addressing it.

2.4. Purpose of Research and Research Questions

There is little research on RRA, and the majority of information family members receive might come solely from first-hand experience and media reports. Indeed, though family members are contributing care in LTRC – by 2038, Canadian families will be contributing over 107 million hours of care each year in this sector – their perspectives are excluded from the research agenda on RRA (Alzheimer Society, 2010). McDonald *et al.*'s 2015 article, *Developing a research agenda on resident-to-resident aggression: Recommendations from a consensus conference*, identified five different research priorities, none of which mentioned

family members. My thesis explores the influence of media reports about RRA on perceptions of safety for family members with relatives who are residents in a LTRC facility in Vancouver's Lower Mainland. This research is qualitative in nature and entails a critical discourse analysis of media reports and semi-structured in-depth interviews with family members. The core questions this study considers are:

(1) What is the current narrative around resident-to-resident aggression in the media?

(2) Do media reports about resident-to-resident aggression influence perceptions of safety for LTRC family caregivers? If so, how?

(3) What information, support, and education do family members want in regards to resident-to-resident aggression?

Chapter 3.

Method

Literature review and critical discourse analysis

This chapter outlines the methods of data collection and analysis, including the search strategy used for the literature review ($N=55$) and the criterion selection of media articles ($N=64$). The theoretical framework of critical discourse analysis that guides the study is explained, using examples of critical discourse analysis on ageism within Canadian media. Following Rozanova's (2010) approach, media reports were obtained from Canada's five major newspapers and the two foremost provincial newspapers from British Columbia, as judged by circulation. Concerns around potential biases in interpretation, as well as the use of reflexivity, strategies to help ensure theoretical validity, and the creation of an interview questionnaire to guide semi-structured, in-depth interviews with family members are discussed. Finally, the evolution of the research from a methodological standpoint is detailed.

Semi-structured in depth interviews and narrative analysis

Family members ($N=8$) were recruited from seven LTRC facilities located in two health authorities in British Columbia's Lower Mainland. Selection criteria, recruitment methods, interview process, measures to ensure rigour and subsequent data analysis are reviewed. Lastly, the socio-demographic characteristics of participants and the LTRC facilities are delineated.

3.1. Review

3.1.1. Data Collection and Analysis

The search strategy used for the literature review is detailed below.

Databases:	Cumulative Index to Nursing and Allied Health Literature (CINAHL); Medline; PsycINFO; AgeLine; SAGE Research Methods; SFU Library; Google Scholar			
Keywords:	Long-term residential care facilities; residential long-term care; long term care; nursing home; nursing facility; hospice	Aggression; Aggressive behaviour; aggressive behavior; responsive behaviour; responsive behavior; violence	Statistics; prevalence; family caregivers; caregivers; informal caregivers	Discourse analysis; critical discourse analysis; semi-structured interviews; qualitative research methods; stories; storytelling; media; news media; newspapers; television

Figure 1: Literature Review Search Strategy

The search yielded 55 viable articles, policy reports, speeches, podcasts, books and book chapters (see References). The articles on RRA were then sorted using NVivo version 11, which is a qualitative data analysis computer software package used to organize and code the articles. A codebook emerged (see Appendix A). NVivo was utilized for ordering, categorizing and grouping of the literature, in order to view gaps and recurrent themes.

3.2. Critical Discourse Analysis of Media Reports

3.2.1. Theoretical framework

All social science hinges on implicit judgments about discourse. These judgments are concealed by more formal procedures of social science methods, wherein “discourse is simultaneously pervasive and invisible” (Potter, 2004, p. 607). Critical discourse analysis examines the way “social power abuse, dominance, and inequality are enacted, reproduced, and resisted by text and talk in the social and political context” (van Dijk, 1996, p. 353). Critical discourse analysis complements the subject of RRA, a phenomenon which is known by many terms, each with their own allusions of power and inequality. Similar to other critical social theories, the possibility of a “value-free” science is rejected and the researcher is tasked with acknowledging their own role in knowledge construction.

Critical social theory, or simply critical theory, stems from the work of a group of German scholars in the 1920s, often referred to as The Frankfurt School (Mogendorff, 2012). These philosophers, sociologists and social thinkers emphasized the “norms, values, and meanings in the constitution of knowledge of society, on the one hand, and the roles of science and scientists in changing the society, on the other” (Mills, Durepos, & Weibe, 2010, p. 261). The goal of The Frankfurt School's Critical Theory is to relate the knowledge achieved through research and commonplace social life with each other. The term *Critical Theory* with capital letters refers to the original ideas, and *critical theory* is used

to describe the more general uses of the term, which has been developed by social theories and philosophies such as feminist thinking, critical realism, and poststructuralism (Mogendorff, 2012).

Poststructuralism, a multi-faceted intellectual movement that emerged in the 1960s, led to the development of critical discourse analysis. Among the key thinkers who helped define poststructuralism are Judith Butler, Jacques Derrida, Umberto Eco, and Michel Foucault. One of Foucault's insights that informs the present study is in regards to the poststructuralist theory of power. Foucault (1980) encouraged the study of the effect of power on a micro-level: the way in which tiny practices and language create effects over long periods of time. While the state, for example, may have the force of an army and heavy artillery, it is the symbols of micro-power, such as the display of the flag and the formalism of uniforms and ceremonies which produce genuine allegiance (Foucault, 1980). Such power is not the product of a structure, but instead unacknowledged and everyday diffusions, such as the linguistic regulation through discourse of the possible and the impossible, the healthy and the diseased, the valuable and the worthless (Johnson, Schein, & Winders, 2013).

Foucault was especially concerned to elaborate this notion of power within institutions, primarily the hospital and prison systems. In a critical discourse analysis of narrative language, the influence of poststructuralism and especially Foucault is foremost. Language is seen not as a sterile mode of meaning transfer

but as dynamic social reality. The term 'discourse' itself refers to an inextricable connection between language and social worlds. Discourse does not lie flat on a newspaper page or hang stale upon the air after a conversation has concluded. All talk, all texts, are social in nature. This is where Fairclough's definition of discourse is relevant: "Discourse analysis can be understood as an attempt to show systemic links between texts, discourse practices, and sociocultural practices" (1995, p. 16-17).

Critical discourse analysis is as theoretically and analytically diverse as the types of dialogue in society – ranging from analysis of news media, teachings in schools, religious rhetoric, etc. While the present thesis will focus on analysis of news media, all discourse analysis has theoretical tenets in common. The present study utilizes Fairclough's three-layer model of critical discourse analysis (1995, 2003), focusing on analysis of the structuring principles that give rise to particular texts and their effects in constructing particular versions of the social world. The first layer, textual analysis, asks: 'What is the text? What does it say? What does it mean and why analyze it further?' The second layer, discursive practice, considers: 'How is the text produced and consumed? What is the context? How do discursive dynamics function through the text to create meaning?' And finally, the third layer, social practice, inquires as to the broader impact of the text/discourse on society and/or the influence of society on the text (Fairclough, 1995).

The first layer, textual analysis, concerns the use of the phrase ‘narrative.’ Often the term ‘narrative’ is viewed as applicable only to fictional media products such as film and television. Equally important is the use of narrative in the construction of non-fiction texts such as news (print and broadcast) and documentary. One aspect of narrative in news media is the control over the flow of information. The information contained in a newspaper story is controlled through such devices as the headline, the opening paragraph, the illustration and the final outcome or conclusion (Benyahia *et al.*, 2014). It is paramount for the present study to possess a thorough understanding not just of the academic literature surrounding RRA, which almost completely excludes the family members’ perspectives, but also of the family member focused narrative created and broadly disseminated by the media. One possible reason that family members feel the need to share their story of RRA in LTRC with journalists is due to frustration at limited access to other avenues of change with the facility itself or provincial policies.

Concerning the second layer, discursive practice, it is worth noting that these media reports are products that rely on sensationalization to be sold – the term “if it bleeds it leads” is used colloquially among members of the media when deciding which story to put on the front page. The family members’ stories may be presented in an inflammatory way, further deepening the mistrust between family members, the staff and management at LTRC facilities, which does not serve the interests of the residents. The majority of family caregivers likely do not have access to academic literature around RRA and so base their care decisions

and feelings of safety and/or fear on stories either heard or read. Critical discourse analysis of news media texts about RRA is an ideal way to identify the functions a particular text is seeking to fulfil, through examining the intended purposes of texts and their appropriateness to the situations which they are encoded.

Habermas (1992) notes that the presentation of personal dilemmas for public consumption adds a layer of authenticity to the rationalist discussion that characterizes the idealized public sphere. Katriel (2012) explains that through

“inserting their voices into the public arena...storytellers display their willingness to either sustain or negotiate the larger significance of their personal stories, suggesting, in so doing, some of the ways in which persons and communities are dynamically constituted through the play of discourse” (p. 290).

Single personal feelings and experiences thus become public issues, capable of influencing the personal feelings of many. Ageist media reports and their influence on public perception of gerontological issues is largely acknowledged, yet there has been no similar academic inquiry in regards to reports on RRA. It is necessary to first understand the information already present from media reports on RRA and its impact on family members' practices and concerns before addressing what information, support, and education is missing.

Analyzing discourse is often a central task for social science. Many articles and presentations in the field of gerontology begin by critiquing sensationalized media reports of population aging (Charise, 2012; Fealy *et al.*, 2011; Rozanova, 2010).

Internationally, critical discourse analysis was used to examine the social construction of older adults with delirium (Schofield, Tolson, & Fleming, 2012), the social participation of older adults (Raymond & Grenier, 2013), age identities (Fealy et al., 2012), and elder care (Weicht, 2013). Closer to home, discursive analysis of Canadian newspapers examined how the media constructs retirement and productive and successful aging (Lagace *et al.*, 2012; Rozanova, 2010; Rudman & Molke, 2009; Fraser *et al.*, 2016).

Rozanova's (2010) study mentioned the use of 'apocalyptic demography' terms such as grey/silver tsunami, used to draw attention to the challenges of population aging. While sensationalized and problematic, this attention is often harnessed by senior-supporting organizations and academic disciplines.

Similarly, while there have only been a couple of academic studies on RRA in Canada in the past few decades, there have been dozens upon dozens of media reports on the phenomena. Half of these media reports feature family members' perspectives, often after the death of a resident at the hands of another resident in a LTRC facility. While family members are conspicuously absent from the scant academic literature about RRA, the opposite is true in media reports.

Like the generational divide the tsunami metaphor tacitly implies, the incomplete stories presented by the media and academic literature separates those who most need to collaborate. Stories traditionally are structured with an "us" vs. "them" narrative, which can serve to engender the environment they describe.

From this understanding of a preference for adversarial narratives within news media it is likely that the narrative around RRA is one of family members decrying neglect by staff and facilities, and that media reports place the onus of prevention of and response to incidents of RRA on staff and facilities, largely ignoring the role of provincial and federal policy.

In regards to Fairclough's third layer of discourse analysis, social practice, the present study will interview family caregivers in LTRC facilities in order to understand the influence of media texts about RRA for family members' feelings of safety. By focusing on the clash between family members and staff, media reports ignore what Ferrah *et al.* (2015) deem: "the responsibility... to continue to grow our knowledge base on the nature of resident-to-resident aggression to prevent harm to an increasing vulnerable population of nursing home residents and ensure a safe working environment for staff... is a responsibility that extends beyond nursing homes to the whole society" (p. 362).

3.2.2. Data Collection and Analyses

The data for the discourse analysis of media reports was obtained using methodology modeled after Rozanova's (2010) approach in the article *Discourse of successful aging in The Globe & Mail: Insights from critical gerontology*. Unlike Rozanova, the current study broadened its search from *The Globe & Mail* to include all of Canada's major newspapers, by circulation: *Toronto Star*, *The Globe & Mail*, *Le Journal de Montréal*, *La Presse*, and *The National Post*. The online archives were searched with the same key words used in the literature

review, minus those pertaining to methodology. The major newspapers of British Columbia, *The Vancouver Sun*, and *The Province*, were also included in the search. Additionally, the three largest broadcast networks, CBC, CTV News, and Global News were included. The search was contained to the past 10 years (2006 – 2016), for manageability and to ensure the most relevant results.

Sampling of the articles was purposive, otherwise known as selective or subjective sampling (Hesse-Biber, *et al.* 2006). More specifically, the style of purposive sampling technique was criterion sampling wherein each search result was judged and assessed as to whether it fulfilled the search requirements, e.g., whether the report discussed RRA, and not solely abuse between staff and residents (Palys, 2008). Once the search turned up no further articles and video transcripts ($n=84$), the remaining articles were screened further to determine significance ($n=64$, see Appendix B). Articles and video transcripts were then analyzed using the method of thematic analysis (Benyahia *et al.*, 2014).

As mentioned, these articles were analyzed following Fairclough's (1995) three-layer model: (1) textual analysis; (2) discursive practice; and (3) social practice. In the textual analysis stage, which sought to answer 'What is the text? What does it say? Who says it?' NVivo was utilized to code the data. Close attention was paid to the flow of information and the function the text seeks to fill. After reading each media report, a reflexive memo (on average 120 words) was written and stored with the report in NVivo, to capture the initial responses and refer to

throughout the research process. NVivo codes in the stage of textual analysis included, 'Headline'; 'Photo' or, 'No Photo', with sub-codes of 'Negative Image' (e.g., bruised and bloody resident); 'Emotional Image' (e.g., family member holding a photo of deceased resident); and 'Neutral Image' (e.g. photo of the outside of residence, stock photo of a young hand holding an aged hand). The final outcome, or conclusion of the article was coded 'call to action', with sub-codes of 'to facility administrators'; 'to government' 'to communities' or 'no call to action'.

In the first stage of textual analysis using NVivo, language pertaining to violence and crime (e.g., abuse, violence, crime, conviction) or dementia-friendly language (responsive behaviour, mention of triggers, mention of environment, relevant life history) were coded. Other aspects coded included whether or not the incident of RRA resulted in death; whether the incident of RRA was one of beating or pushing; the environment of the incident of RRA (private room, at night time or day time, in a common area, etc.); and whether the media report mentioned family members, or actually interviewed a family member or an academic/researcher with a gerontology background, and what these other members were given space to say, and where in the article.

The second layer, discursive practice, asks 'how is the text produced/consumed? What is the context? NVivo was used to code whether the newspaper was issued daily or weekly and whether it published accounts of RRA that happened locally

(within province); nationally, or internationally. Particularly in this stage, concerns around researcher bias arise. A second stage of reflexive memos around the necessary inability to interact with the news articles as an outsider were written throughout the analysis process to further question the researcher position. Interpretation bias often occurs when the researcher interacts with ambiguous data (Kaptchuk, 2003). The media articles were on average 600-800 words, and so, left little room for ambiguity. Extra attention was paid to the texts that challenged confirmation bias and were unexpected. Ultimately, the recognition of an interpretative process and the need for reflexivity and the unambiguous nature of brief media reports acted as a self regulating mechanism (Kaptchuk, 2003).

Through analyzing the text and discursive practices with NVivo, findings emerged around the perspectives being privileged and the views being restrained, potentially elucidating wider power relations in society. This relates to the third layer, social practice, which seeks to answer 'what is the broader impact of text/discourse on society, and/or the influence of society on text?' Such symbolic power – the power to name and define a group or issue – is often linked to economic and social privilege, and enables dominant group assumptions to impact on the lives of minority groups. Within the media reports, these groups form as those who can ask questions, and who can respond. The questions asked and answered were tracked through grids.

Notably, while half of all media reports analyzed speculated on the thoughts and feelings of family members, only half featured family members speaking for themselves, and only two media reports presented residents' perspectives. In order to test the validity of the conclusions from the three-layer critical discourse analysis – whether it accurately represents the experiences and concerns of family members in LTRC in regards to RRA – outside of the sphere of the media these conceptual arguments were then examined through informing the creation of a questionnaire that guided semi-structured in-depth interviews with family caregivers (see Appendix C). Of the 64 media articles, the single source with the most reports on RRA (20) was *The Toronto Star*, a daily newspaper which was also the news source with the least representation of family members or researchers/academics with gerontological knowledge. The online *CBC News* and *The Globe and Mail* news sources followed *The Toronto Star* in the frequency of reporting RRA, each with fourteen. The sources of the 64 media reports on RRA from 2007 – 2017 are summarized in the table below.

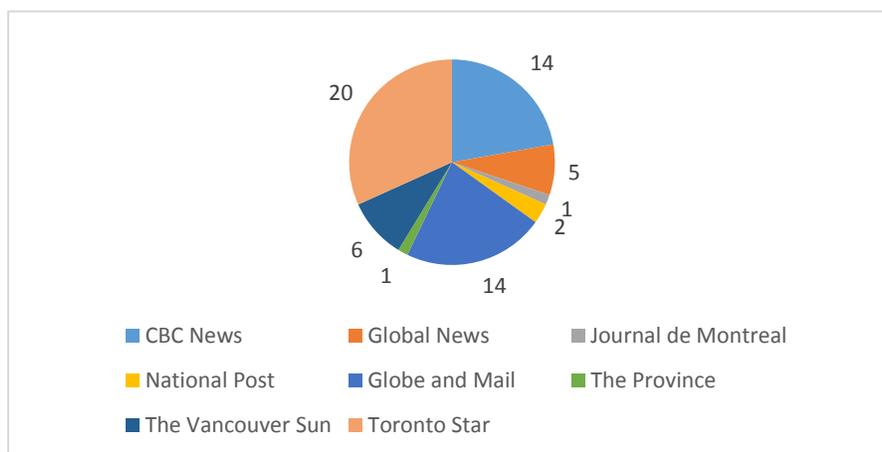


Figure 2: Source of media reports on RRA

3.3. Semi-Structured In-Depth Interviews

3.3.1. Selection Criteria and Recruitment

The selection criteria for interview participants was a.) to be the unpaid family caregiver of a resident in a LTRC facility and b.) have concerns or thoughts around RRA in LTRC. The first criteria were met by screening those who offered to take part in the study the second criteria were largely met by the self-selection process of those interested in participating. Purposive sampling addressed quantity and type of involvement in care work, relationship to resident (e.g. spouse, child, etc.), and length of time relative has been in LTRC. The present study's title, "Stories of resident-to-resident Aggression: Fears and Experiences in long-term Residential care" was partly chosen due to its accessibility to a large audience. Invitations to participate in studies which request "dialogue" or "narratives" can be alienating and misunderstood. "Stories" is an easily comprehensible word choice for a broader audience that may not necessarily have an academic background.

The first stage of recruitment entailed visiting SFU 55+ Continuing Studies classrooms at Harbour Centre Campus. With the permission of the department and the professor, I briefly described the study at the start of class and handed out "invitation to participate" letters (See Appendix D). Additionally, The Alzheimer's Society disseminated the study posters at their caregiving support groups and in their resource centers across the Lower Mainland. With the

permission of the administration, posters were also displayed for two weeks at seniors' centers and community centers in Greater Vancouver (see Appendix E).

3.3.2. Interview Process

After receiving ethics clearance from Simon Fraser University's Research Ethics Board and informed consent was obtained, participants were interviewed one-on-one in a setting of their choosing; either their home, or some quiet area, such as a private room in a community centre or public library. As a token of thanks, each participant received a \$10 gift card to the business of their choice. The interviews were digitally recorded and then transcribed verbatim, and the transcripts were cleaned to remove any identifying information before being used for data analysis. While two participants' first languages were not English (Farsi and Mandarin), all participants spoke English fluently and all interviews took place in English.

3.3.3. Data Analyses

The transcripts were analyzed thematically in NVivo version 11. Utilizing an inductive grounded theory approach to coding, the qualitative coding had three stages: open coding, wherein the data was coded line by line into emerging themes; axial coding, wherein the original codes were further sorted and combined into major categories and defining subcategories; and finally, restrictive coding, wherein relationships among codes and categories were identified. Past qualitative research indicates that meta themes are typically achieved with 10-12 interviews per group (Morse, 2000). The study therefore

sought 10-12 interviews, however, saturation was achieved at eight participants. As Palys (2008) notes, research participants are not created equal: “One well-placed, articulate informant will often advance the research better than any randomly chosen sample of 50 – and researchers need to take this into account” (p. 697).

Despite disparate backgrounds and caregiving relationships, participants shared many of the same experiences and impressions, and the core research questions were met with the same responses. The findings from the interviews were compared with the findings from the critical discourse analysis of the media reports, to tease out conflicting or aligning concepts, as guided by the study’s research questions. The final stage of the study involves sharing emerging findings with research participants and the academic community. In addition to this thesis, I intend to create a two to four-page plain language policy document to disseminate, and vignettes around experiences of resident-to-resident aggression to be used for training purposes, and at least one journal article.

3.3.4. Ensuring Rigour

In keeping with the theoretical and methodological perspectives, trustworthiness — characterized by an accurate and credible portrayal of the participants’ voices and realities in the findings — was used to address rigour. Relevance and credibility entailed auditability, member checking, and combining multiple data sources. Auditability refers to the ‘audit-trail’ left by a researcher, which allows others to trace the methods used in the study and will be tracked through a

“reflexive journal” which outlines daily schedules and logistics, reflections on the process, as well as decisions and rationale. This offers insight into the process for others, as well as for the journal author’s future self (Lincoln and Guba, 1985). The credibility of the findings was further assured by triangulation, wherein multiple and diverse sources and methods are applied – the literature review, both academic and grey literature, reviews of LTRC policies, media articles, and family caregiver interviews.

Further trustworthiness was established through negative case analysis, described by Lincoln and Guba (1985) as a “process of revising hypotheses with hindsight” (p. 309). Finally, member checking is of utmost importance to establish credibility. It is a formal and informal process which occurred continuously. Throughout the interview, participants had the opportunity to make corrections, offer additional insights, avoid later misunderstandings, clarify and confirm statements, and as a researcher I practiced summarizing data in a way that the meaning was not lost (Lincoln & Guba, 1985).

3.3.5. Socio-demographic Characteristics of Participants

Consistent with the majority of residents, staff, and family caregivers in LTRC, all eight participants were female. Interviews ranged from 34 minutes to 97 minutes in length, with an average of 63 minutes and a total amount of 8.5 hours of interview data. The participants’ ages ranged from mid-fifties to early-seventies. The nature of their relationship with the residents in LTRC were varied: two wives, three daughters, one daughter-in-law, and two nieces. Seven participants

were retired, while one, the daughter-in-law, worked fulltime. Six primarily spoke English with their relative in LTRC, while one solely spoke Chinese (Mandarin) and one solely spoke Farsi. Pseudonyms for all participants are used in order to protect their identity and to ensure anonymity.

The relatives LTRC participants cared for were older: an age range of 69 – 99, with an average age of 86. Half of the participants were male (2 husbands, 1 father, 1 uncle) and half were female (2 mothers, 1 mother-in-law, 1 aunt). The medical diagnosis/main reason for admission were varied. Four were dementia (3 Alzheimer's, 1 mixed (vascular dementia and Alzheimer's)), two were physical frailty/mobility issues (participants were 98 and 99), one was encephalitis, and one was paranoid schizophrenia. Four residents were involved in multiple incidents of RRA, wherein two were both the aggressor and the attacked at various points, and two were solely the victim of aggression. For the other four, participants mentioned witnessing environments/actions/events that could lead to RRA and the steps they took to ensure their relative's safety.

Participants shared various details about their relatives: "Larry", a husband of a participant, "Linda", has a Master's in Economics and loves to play Yahtzee and eat apples. "Vashti's" mother-in-law was a skilled school teacher for over 30 years in her native Iran, and has a traumatic life history that is essential to understanding her behaviour in the later stages of dementia. "Gail's" father was an accomplished family physician, and she spoke of how important staying in a Jewish facility was to him and her family. "Anna's" mother was an avid reader who lived through The Blitz bombing by the Luftwaffe (German Air Force) over

Britain in 1940 and 1941, during the Second World War. Her brave attitude and leadership skills aided fellow British citizens in finding shelter and food.

Before the start of our interview, “Wanda” showed me a photo of her husband, “Will”, who worked with the elderly in social work, and spent his entire life in giving professions. Wanda wanted me to recognize Will as “a person and not just a number” before we spoke of him. “Julie’s” fiercely independent aunt, who passed away several weeks before our interview, was a consummate homemaker with a pristine house and a perfectionist’s taste for fine food. “Lily’s” mother was a skilled seamstress who learned to sew in her native China and made clothes for Lily and her sister. “Joan’s” uncle “Frank”, from whom Joan* was estranged the majority of her life, is diagnosed with paranoid schizophrenia and lived on the streets of downtown Vancouver before an injury brought him to the attention of the healthcare system, and from there, into LTRC.

3.3.6. Characteristics of Facilities

None of the participants’ relatives in LTRC were waitlisted to move to another facility, though one relative’s family is considering it as the price differential between their current private facility and a public facility would enable them to provide a full-time paid companion to further supplement care. Their length of stay in the current facility ranged from 21 years to three months, with an average length of stay of 4.1 years (an average length of stay of 1.5 years with the 21-year outlier excluded). Three residents moved into their current facility from another LTRC facility and one moved from a mental institution, where the length

of stay ranged from 14 years to 7 months. Participants spoke of experiences in those three public facilities at length, so they are included in the information tables below. One resident moved from assisted living to the long-term care unit within the same facility, one moved from living independently with home care, and two moved into LTRC directly from hospital.

Two participants had relatives in the same LTRC facility in the Fraser Health Authority region, while the other six were all in different LTRC facilities within the Vancouver Coastal Health Authority region. One was in privately owned and operated 'boutique residence', four were in publicly-funded LTRC facilities, and two were in a mixed private/for profit and public facility. Seven of the participants' relatives in LTRC had their own room, while one is in a four-bed room with three other residents. The participant preferred that to an offered two-bedroom in the belief that there would be a greater staff presence for four residents vs. two. Of the information available for the nine public facilities, four had a combined resident and family council, four had separate resident and family councils, one had a resident council only, While most information was not available for the private residence, further characteristics of the nine public LTRC (5 Fraser Health, 4 Vancouver Coastal Health) facilities discussed by interview participants are summarized in the table below, with information from the BC Residential Care Quick Facts Directory (Office of the Seniors Advocate, 2017).

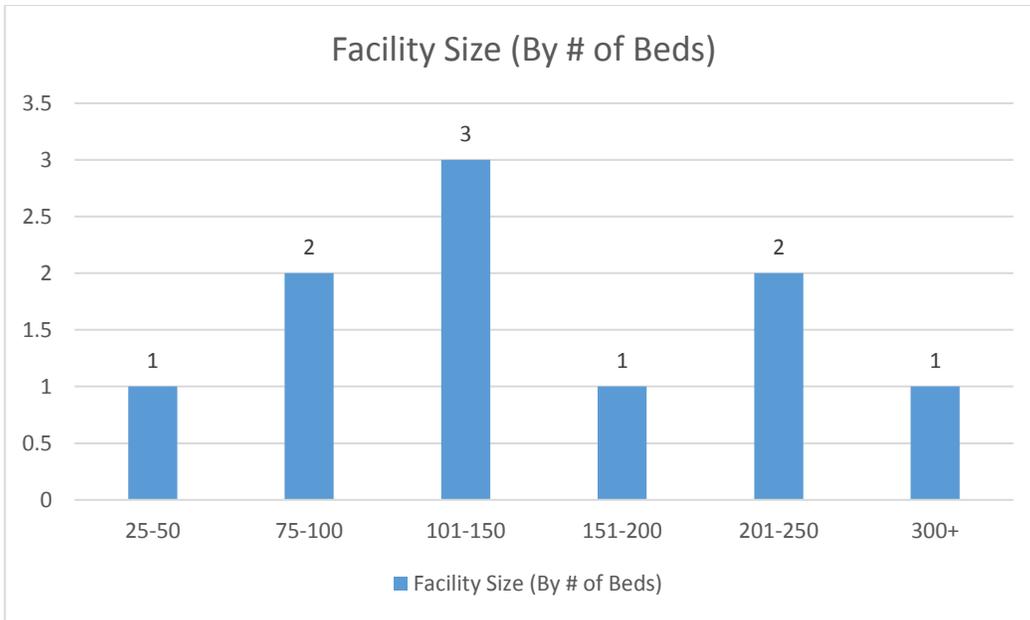


Figure 3: Facility size by number of beds

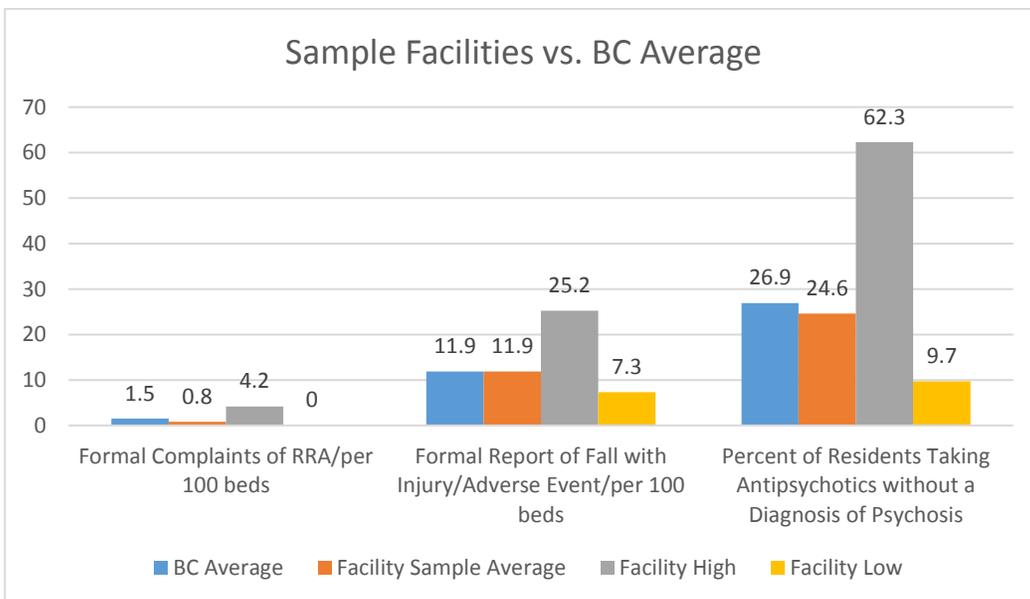


Figure 4: Facilities in study vs. BC average on formal complaints of RRA, formal reports of falls, and percent of residents taking antipsychotics without diagnosis of psychosis

3.4. Evolution of the Research

Negative case analysis, wherein hypotheses are revised with hindsight, is a fundamental component of the evolution of this research (Lincoln & Guba, 1985). As mentioned previously, negative case analysis is a qualitative methodology used to strengthen rigour through revising assertions about the phenomena studied. The term 'hypotheses' in this instance does not have the same meaning as in a quantitative study, wherein a hypothesis is generated at the beginning of a study and then tested using statistical means (Allen, 2017). Rather, the hypotheses developed and revised were generated to make sense of the narratives present (and absent). The academic and grey literature review exposed a lack of consideration of the experiences of family members in LTRC around RRA; this led to the critical discourse analysis of representations of family members in media reports of RRA.

The media reports analyzed often used language of violence and crime to describe incidents of RRA, and so the creation of the interview guide stemming from the critical discourse analysis had its assumptions laid upon cultivation theory. Cultivation theorists argue that fear of crime is cultivated by the media (Gerbner & Gross, 1976). Most people lack direct contact with the criminal justice system and learn about crime through media portrayals (Surette, 1992). Crime stories are sensationalized, focusing on violence and often lacking in real world context (e.g., frequency rates) (Beckett & Sasson, 2004). Consistent empirical findings suggest that fear of crime is dependent on attention paid to crime news, and that the cultivation effects of exposure to media on emotional fear may be

arbitrated by perceptions of victimization risk (Chiricos, Padgett, & Gertz, 2000). For example, American students' levels of emotional fear are likely to be elevated following extensive media coverage of massive on-campus shootings (Kaminski, Koons-Witt, Tompson & Weiss, 2000).

The answers of the family caregivers interviewed, however, did not support cultivation theory. While all had read media reports on RRA and “kept an eye on the newspapers for them”, or even had Google Alerts set up to notify them of a new report of RRA, none felt that exposure to these media reports influenced their sense of safety. Therefore, all of the participants' interview data represented ‘negative cases’: cases that do not support the hypothesis (Allen, 2017). And so, the data was reworked to address the negative cases through collecting, analyzing, and interpreting data until an explanation of the data that is inclusive could be offered. The evolution of this research was iterative, and negative case analysis encouraged questioning pre-existing assumptions about the phenomenon of RRA, broadening understanding and encouraging change where required.

Four of the participants had experiences with RRA, and four had fears of RRA. All of them dismissed the suggested impact of media reports on feelings of safety for themselves and residents in LTRC – and, despite disparate backgrounds and caregiving experiences, all of them dismissed the assumptions of the hypotheses in the same way. Thus, the hypotheses that guided the critical discourse analysis of media reports evolved during the interviewing process. Though the conclusions of this research are distinct from the expectations that guided the

literature reviews and critical discourse analysis, the revision of the guiding research hypotheses results in an interpretation of the data that is comprehensive and supported.

Chapter 4.

Results

In this chapter, the result to the three central research questions are presented. As previously discussed, these three questions are: (1) What is the current narrative around resident-to-resident aggression in the media? (2) Do media reports about resident-to-resident aggression influence perceptions of safety for LTRC family caregivers? If so, how? (3) What information, support, and education do family members want in regards to resident-to-resident aggression? When academic literature, family caregivers, and media reports discuss RRA they tell different stories in different ways.

These three sources of data (academic literature, public media, and family caregiver interviews) examine the who, what, when, and where experience of RRA. Media reports and the family members interviewed discuss the “why” and future fears of RRA. Focusing on the media reports and family caregiver interviews, the following themes have been identified: experiences and fears of RRA; safety, risk, and institutionalized ghosting in LTRC. Stemming solely from the family caregiver interviews, the following theme was expressed as vital and was not discussed in the media reports: Moving from ‘Family vs. Staff’ to ‘Partners in Care’. This theme has the two subthemes: Reporting incidents of RRA and Information, Education and Resources for Family Caregivers. Each of these emergent themes and subthemes will be elaborated upon.

4.1. Experiences and Fears of Resident-to-Resident Aggression

Media Reports on RRA

The media reports overwhelmingly were about incidents of RRA leading to death (95%). While family members spoke of RRA in the fullness of the term encompassing negative and aggressive physical, psychological, or verbal interactions among LTRC residents, media reports focused solely on physical aggression. The Canadian media reported Canadian stories, except for the instance of one story of RRA in the United States that crossed the border. The news item appeared in the *Toronto Star* with the headline, 'Ex Pro Wrestler Verne Gagne Accused in Nursing Home Death.' The attention-grabbing intro to the article read:

“During his glory days as a pro wrestler, Verne Gagne shared the spotlight with other burly men in trunks, guys with names like Killer Kowalski, Mad Dog Vachon, The Crusher and Baron Von Raschke. But all of that seemed well in the past until just weeks ago, when authorities say Gagne, 82 and suffering from Alzheimer's disease, apparently body-slammed a 97-year-old fellow patient at the suburban nursing home where they both lived, causing the man's death.”

The article describes how both men “suffered from the mind-robbing disease of dementia” (2009).

This example is representative of the other 63 articles, which most often feature the following terms in the title: 'violence,' 'danger', 'shock', 'abuse,' 'death', 'murder,' and 'homicide.' The two latter terms are used frequently in titles and

article body, despite the articles later describing how no charges were laid due to the aggressor's dementia and therefore a lack of intent, and that law enforcement and legal courts ruled that no homicide had taken place. The articles begin with a sensational title focused on violence and crime, and then describe the action and outcome of the RRA, still using similar language as in the title. For the cause of incidents of RRA, 67% of articles attributed it to the attacker suffering from dementia, 10% mental illness, and 3% brain injury.

Half of the articles discussed the perspective of family members, though it was often limited to expressing grief and/or outrage. Only 18% of articles featured a family member sharing autobiographical details about the resident(s). The involvement of law enforcement was described in 68% of articles. Half of the articles ended with a call for systemic changes in LTRC, namely more staff (64%) and/or increased staff education (25%). The current narrative around RRA as represented through media reports is a necessary but partial one. Necessary, in that it brought to light a phenomenon which was previously largely unknown by the public. Necessary, in that it conveys the urgency of addressing RRA in LTRC.

Family Members on Perceptions of Media Reports and Fears about RRA

When describing their impressions of media reports on RRA, the participants noted that they told a partial story, and that this was dangerous as it increased the stigma around dementia and did not offer solutions while overly sensationalizing the most tragic incidents of RRA. As Linda stated,

“I personally believe that the media should never be allowed to use an adjective. They can't say, 'A horrible death.' A death, they can say. They can't say, you know, 'A disaster has struck.' No adverbs, no adjectives... just state the facts and only the facts, right? And then that would take a lot of the hysteria out of what's... um, and they're into short, incomplete snippets, right? They're out of context for what they report. And, uh, I think it's partly how they get that story, too. The pacing of the story should be done by the people giving them the story, and the reader needs to recognize that the media is stuck in these, little quick, you know, 'got two seconds to get this story out.' So when you're framing that, you have to make sure you're not framing it in a long contextual thing but in a, you know... but they're too quick to jump to a conclusion as to why it's happened, and too great a desire to colour it as an essayist [...]

Or if the media gives out something, saying, you know, this patient, patient was struck by another patient in the hospital sort of thing, they won't say that – it'll be, 'viciously struck,' or, or, um, 'innocent patient was struck,' but they won't say, the other side of it, you know, 'out of 500 patients, this has happened once in 8 years.’”

While Linda talked of the terminology used, Vashti expanded on the lack of context and concern about solutions:

“...one of the problem I found with the news, even with the CBC news, is that they don't go to the root of the problem. They say, 'Oh, a patient attack another patient.' 'One patient killed another patient', '92-year-old man killed another senior in the care home.' Or they are talking about aggression of the patient toward the caregiver. But they don't go to find the root of this problem. And the media, I believe, when they go to find the problem and report it, there should be some follow-up. [...] Ask the family member, maybe they can help them to find the root of the problem. And then if they open the issue and talk about the root of the problem, and also, um, try to gather the alternative solutions for this situation, maybe we come to a point that the government says, you know, push the government, that, to listen to people. I know, I understand, some governments, they don't listen anyway. [...] It's just a report – something happened. But, why it happened, how we could prevent it, is always missing.”

Participants did not feel that media reports influenced their perceptions of safety in LTRC. Their understanding of the 24-hour news cycle – the lack of long-form, in-depth, critical journalism – allowed them to contrast the shallow stories of the

news media with their deeply contextualized experiences and understanding of LTRC. Instead of fearing for the safety of themselves or the residents they care for, they worried about how the media shapes the perceptions of those who are unfamiliar with the environment of LTRC and contributes to the stigma of dementia, as stated by Vashti:

“When I hear this news that they call these patients, it's not just my mother-in-law, they call them, 'aggressive', it really makes me mad and at same time sad. Because I go back to the point that people don't know the history of these people. They don't know about their lives. They don't know how much they've suffered. They don't know how much input they've had, the positive input into their society.

For example, my mother in law was a teacher. For thirty years, she educated so many children. And one of her students, after thirty-five years, we found him in [City 6] and he came to visit my mother-in-law. And she had so much positive impact on these people. Nobody sees this, what they see of them is an old, grumpy, aggressive person that is really hard to manage, and are causing costs for the society, and that's the impression they give to the society. And that's not good. These are humans, these are people, they've already had their input, they've already given their share to the society, and now this is the responsibility of the society, including their children, family members, everybody, to give back to them. They are not some burden on society. They are a part of society.

And to be honest with you, I am 58 years old. I am going towards that direction and sometimes I think, I try hard all my life to be a good citizen, to pay my share, and it's really sad that if I reach the point that they'll just look at me and say, "Oh, why are you alive? Why they keep these people alive? They have to let them die." I hear these kinds of things, when there is a negative news that they call them aggressive people, they create cost, and when these kinds of definitions or labels, um, are put on these people then emotionally and mentally it's impacted on peoples' minds, that, why do people live so long? Why are they around? You know, and, um, people don't look at them as a human anymore.”

Anna discussed how media reports on RRA blamed the residents:

“Because Mum is a perpetrator, you know, she is the aggressor. And it was always a real worry for me. [...] Although I could understand why my mum was being aggressive; I didn't want her to hurt anybody. Um, you know, I couldn't forgive myself if she did. **[sighs]** So, I would see it in the

media, "So and so", so I guess my, my first thought was, they need, the staff needs to be trained to mediate. You can't blame the resident. And there was usually blame on the resident. Even at worse, if the resident is an aggressive person because of the disease, or drugs, that's the disease. It's, it's like when I was a special ed. teacher and a child kicked me, you know, they tell you, you don't like the behaviour but you love the child. They didn't love any of those residents at [LTRC Facility 7]. So I would worry in the media that these people were bad, you know, that it was going to make them look bad, when it wasn't really them. It was the dementia. And I'm not sure that that's known, or what contributes to aggression.

And I also wish it was better portrayed in the media how loving, adequate care can mitigate that because these in the "Naughty Ward" in [LTRC Facility 6], where Mum was sent because she was so bad, so she's in with the very difficult residents. Um, I see less aggression there than I saw at [LTRC Facility 7] and they don't use drugs. So they're not being controlled by drugs. But the staff training, you know, the staff... and it's a happy place, you know, people are laughing."

Wanda felt that media reports on RRA "missed the boat" as they didn't have clear insight into the environment of LTRC:

"I've read them all and what I find is that they kind of miss the boat. Um, it's almost, you know, if they have four care aids on at one time and a nurse, so two are looking after maybe, I think there's 28 in his unit. So two are looking at that section, and two at this section. So lots of time when everybody is in the main dining room or living area, there's nobody around. So no aids at all. And the nurse is doing charting, or something, behind a closed door. So, um, that's what I found. If there were more people in the area, um, like, one person always had to be in the main area. They could defuse things that happen up. Because I've defused... I've stepped in so much. Because I'm, I've been there quite a bit."

In addition to caring for her aunt in a LTRC facility for three years, Julie drew on her experiences as an interviewer for a Seniors' Advocate study which she used to contrast the stories in the media on RRA:

"Well, media has to sell newspapers. And so what do you hear about? You hear about the most egregious things that happen. And I immediately think of the things that were reported where people were seriously injured or killed by, you know, but I, I'm imagining that's probably a minor example

of what happens in the day-to-day life in a residential care facility. [...] I mean I've seen a lot of, what I've seen in those media reports is a lot of forgiveness by families who've lost members. Which, you know, I think that's also media... media dressing things in a way that kind of creates a redemption message. [...] as far as the media is concerned, I think these discussions around violence, it's more about how are we teaching people how to care, and supporting caregivers. I know there was a big announcement about a bunch of money, but what's going to happen? **[sighs]** You know; I'm talking to people who wait two hours to have someone to help them to go to the bathroom. So I'm not optimistic about, even if it is a few hundred million, I'm not sure it's going to be enough. There's a lot of changes in direction, and maybe even changes in how people can live, you know, live together. I've looked at other countries where there are different ways that people can live. Um, and supporting dementia, not just being locked up and put away in that room.”

Juxtaposing the lack of context participants felt media reports on RRA provided, when participants discussed RRA they endeavoured to situate their stories in the organizational, physical, and social environment of LTRC, and relay an understanding of triggers and the histories of residents.

Family Members on Experiences of RRA

Vashti's mother-in-law, who has dementia, has experienced RRA as both the aggressor and the attacked. Vashti explained the difficulties her mother-in-law faces, as she relives the trauma of losing a son to execution in the 1979 Revolution, and the lack of support she receives as the only Farsi speaker at her current facility.

“And the reason they transferred her because of her condition, and her language barrier, and usually when people don't understand her, then she gets mad and she gets aggressive [...] So, basically, there is nobody to understand her language. And that's the reason her condition is getting worse now. And she, most of the time, when she realizes that people don't understand her she gets very aggressive. [...] Mostly that's the thing that triggers her, yeah. She starts yelling and screaming, and obviously when

she starts yelling and screaming it's impacting other residents and, uh, there was a couple times that we found recently that the other residents attacked her. And um, there was a couple times that she attacked back, and there was a physical altercation between the residents and the staff. And in these cases, it's usually that the staff put her in her room – she has a room for herself - and locked the door. Which is not good for her. [...]

That's one of the problems, that the staff don't know these patients. They see them, they go by book, but emotionally, because they don't know their background, they cannot connect with people, with these people in the home care. That's my experience, maybe I'm wrong, but that's what I see always. So it's really hard to communicate, with her. My brother-in-law was executed. He was 18 years old. And she went through a post-trauma depression at that time. And then we got arrested by the Islamic government. It made the situation worse. And my husband is the eldest son, he left, he just escaped from Iran, fled through the mountains, and I just took the kids. And um, that's, sometimes for example, we'd hear from staff, especially when she was in [LTRC Facility 3], during the night - I don't know if she had dreams or something, nightmare - she would wake up and start running in the hallways, calling my brother-in-laws' name. And um, the other sad part was that they executed my brother-in-law they did not give his body back. Did not give us, even the trace of the grave. So, in the past, she always thought that he's alive. Sometimes, in the street, she was looking for him. And I guess, all these thoughts came back to her. **[cries]** And uh... but then, lack of information from the staff, and not knowing her personality..."

Anna's mother also was both an aggressor and attacked, though her distress came not from a language barrier and past trauma, but rather abusive staff and overmedication.

"This period, **[shows previous photos]** she was very aggressive. So she would do things like throw a coffee cup at somebody. The nurses, they'd use physical force. She wanted to walk, so she'd try and stand and they would take her shoulders and yell "Sit down!" **[Mimes pushing down with hands]**. Well my Mum, said, "Don't!" So, my Mum would say, "Don't you talk to me like that my dear!" you know, British, um, and then she would start to hit them. They would hold them both hands, and so she would kick them. So yeah, she was, she was aggressive to them. She loved to read, I would take books, and so they were everywhere. And the other residents would read them. She went over once and said, "Can I look at your book? I just want to see the..." She wanted to see what the cover, title was. And the other lady said, "Mine!" and my Mum said, "No, it

might be mine." And, "Mine!" and, "Mine!" so they started you know, pulling the book, so then both ladies started fighting. **[Mimes punching]** So they both got written up in the Naughty Book, and the book was taken away – "you can't have those books anymore." So, yeah, Mum was angry, angry. So yeah, she was hitting people. And she probably didn't know the difference between hitting a nurse or hitting another resident. So I know, I didn't want other residents hurt. One resident, uh, a man punched her when my friend was there, and said to the aid, "Oh, [Jim] just really punched her!" [and they said] "Well so what? He's just getting back at her. She punched him yesterday, we're not babysitters you know."

Many family members who are highly involved in the facility care for residents beyond their own relatives and friends. Wanda interceded in preventing incidents of RRA almost every time she visited her husband, which she did daily, though sometimes she was not able to intervene in time:

"Dangerous situations presented themselves daily. One evening I noticed a very warm but confused woman, especially active. She liked to stroke everyone's arm or hair. 'I love you, you're nice to everyone' she [said to everyone she] encountered. When my husband first came to the unit he was the centre of her attention for the first two days. He said to her, 'This is very awkward, you are much older than me.' The staff told me she thought he was her son. Unfortunately, during this evening when she was walking around stroking everyone she came across a woman who was mobile, who was quite angry and strong. I saw them approach each other and before I could jump up to my feet the woman tried to stroke the other. By raising her hand to stroke her, this provoked the other who gave her a push. Not 100% steady the woman stumbled and fell on her back. The sound was loud and terrifying. The woman began sobbing. The staff then came running, the noise triggered a woman who was constantly agitated to bang on her table very loud, and started her high pitch screaming sounds. Apparently this woman ended up in a wheelchair, you know, the stroker."

Wanda's husband also experienced RRA:

"My husband was always agitated with her, she was in the room, she was strong and mobile. Um, there was, oh yeah. This woman only stayed for 8 months, or 6 months. A very aggressive woman, um, and um, I'll say she was Portuguese so she couldn't understand anybody. So there was a sense of frustration. She was young, I would say in her 70s, strong, but

couldn't understand anybody. She would go around and drop to the floor – they'd try to drag her up, they said it was attention seeking. My experience with her, she was just a scary person because she'd go around and pinch nurses and hit them, um, she'd knock on my husband's door and he'd open the door, because that's who he was, and he'd open the door, and she'd come in his room, and drop down. He'd try to drag her out of the room 'cause he's very possessive, it's his room. He'd drag her and she scratched him, uh, that happened a couple of times, he had scratches all the way up his arm. And um, this was um, this was a year ago. I think she came in November or maybe it was April, I don't know, but she was there about 6 months. Um, and they, she was private and then she moved to [City 6], they found her a subsidized... but apparently she didn't do very well. She was in and out of the hospital, trying to control her, her um, her actions. **[sighs]**

So that was a really scary time, yeah. Because I wasn't, you know, I wasn't there, I just noticed scratches on his arm and I said, and they didn't catch it, you know, I came in and I guess it usually happened in the early evenings, and I said, 'Can you put something on here, like disinfectant or something,' and uh, apparently she was pinching everybody, and their shoulders, I guess the staff. [...] I'm always thinking, please, don't get another one of those – I won't mention her name – because you know, it's so scary. [...] So that's part of my experience. Just hoping, oh, there's a new admission, hopefully it's a quiet one. I always ask, 'Are they mobile?' 'Cause that makes a difference, if they can walk around, they can push people, you know.”

Lastly, Julie described the isolation her aunt, who was mentally capable but physically frail, felt during her three years in LTRC. Julie's aunt experienced psychological RRA, which impacted her feeling of safety:

“She was super unhappy there and it was hard sometimes to be around her because her quality of life was... she really hated it there. And there were, you know, around this topic [of the study] I can certainly tell you a little bit about... there were some things that particularly terrorized her. Um, around, um, there was one particular individual, he had dementia. And his wife was also in the facility. Now I don't know if she had dementia, I don't even know who his wife was. But she was relocated downstairs, and he was left upstairs in the facility. And he used to come into my aunt's room at all hours of the day and really frighten her. And never, as far as I know, he never put a hand on her.

But, psychologically she felt really under attack all the time by this fairly large gentleman coming in and behaving in intimidating manners. Stand over her bed, and stop and stare at her, you know, and she knew he had dementia, but and you know, she asked for them to do something. She asked to be able to lock her door, all of the things that people would do **[dry laugh]**. And of course, I've learned doing my interviews in facilities that you don't lock doors easily. Although my aunt was able to lock her door a few times, because she did have a key, they gave her a key, but only when she was going out to appointments, not when she was actually in the room herself. So, yeah, for her psychologically that was very difficult. [...] And she had, you know, there was another woman who was less... she was more responsive to my aunt's request to leave. But this guy, was the guy, I think because he was big that's what scared her, and because he used to often approach her at night, and wake her up, and things like that, that was hard for her.

You know, it's pretty terrifying, by yourself, not feeling safe at night, in your bed. Not, all that, fairly fragile, not able to leap out and run away or anything, you know? She, mentioned his ethnicity, um, and I don't know if he was speaking his own language. I know often people revert back to their original language. I think in her state of mind she couldn't create a bubble of safety for herself. So anything that was intruding on that was part of it. Not being able to say, 'this is my space and I can hold it,' whether it's from sounds or from someone coming in, those kinds of things. There wasn't much room for, you know, and people wouldn't... she couldn't hang a 'Do Not Disturb' sign on her door. **[chuckle]** Something like that. I've encountered that quite a bit in my interviews, the whole feeling, you know, like I'm in a cell where I don't have much privacy or agency in what I'm doing.”

The other four participants interviewed did not have experiences of RRA, though three expressed concerns: two had their relative moved, one to another unit of the facility away from the residents with dementia, and one to another facility where their relative could have a single room. The third mentioned that her mother shares a room with three residents – so chosen with the belief that a staff member would visit more frequently a room with four occupants than the standard two at that particular facility – and that her mother, who is completely immobile, has scratches and bruises that she's 'keeping an eye on', as they may

come from a Macedonian resident and roommate that the participant has seen become agitated when staff or other residents do not understand her. The four participants who described their experiences with RRA did not fear for their safety.

Instead, the primary concern of all participants were the lack of access to empowerment structures (i.e. informal power, formal power, information, support, and education) and how the ambiguous position of family within the hierarchical power structure of LTRC negatively affected their ability to advocate for their relatives. The only participant who was completely happy with the care her relative received, and had neither fears nor experiences with RRA, was the sole participant in a for-profit facility. She called the facility 'the Cadillac of long term care', and was thrilled her father was able to stay there, due to her sister having the means to afford it. She expressed fear for herself, in her mid-seventies, if she ends up residing in LTRC in the future, acknowledging that she could not afford private care.

Indeed, all of the participants stated that they and their family members hope they never require a stay in LTRC. Lily was keen on learning more about Bill C-14, so she could opt for medically assisted death in the case of her own diagnosis of dementia. Wanda shared that her aunt, mentally fit but physically frail in her late 90s, was rejected from receiving medically assisted dying when she applied, and so instead decided to stop eating until her death in January of

this year. When death is seen as preferable to living in LTRC, it suggests that people would prefer to die with dignity than live without it.

4.2. Safety, Risk, and Institutionalized Ghosting

Media Reports Findings

While half of the 64 media reports analyzed mentioned family members, only 17 had family members describing their experiences and perceptions in their own words. Even fewer, only two articles featured the perspectives of residents from LTRC facilities where there had been incidents of RRA. The remaining 45 media reports spoke of family members and residents, but did not allow them to speak for themselves. In examining the word frequency of articles wherein family members were interviewed for the articles vs. those where family members were not allowed to speak in their own words, the language varies. When family members were not interviewed for articles, the language skewed towards violence and crime. Articles with family members more frequently spoke of 'death' caused by incidents of RRA, articles without family members spoke of 'murder.' In reports without family members' perspective, the word 'dementia' appeared more frequently, while with family members, 'dementia' was not used as a catchall.

Family Member Perspectives

The family members who participated in this study spoke of how concerns around safety and mitigating risk eroded person-centred care in LTRC. Instead of

revolving around the needs of the resident, the culture of LTRC could not adapt to individual differences – language differences, autobiographical details – and instead required the resident to be managed, for the resident to adapt to LTRC. The most frequent description of this was through the use of antipsychotic drugs. Linda explains the spiral inappropriate antipsychotic use created:

“But still, there was a great ignorance on the part of the staff, knowing the side effects of the drugs they were giving people. And when they saw a side effect, their reaction was to give more drug. Rather than recognizing that what they were giving their patient as a drug was causing this side effect of restlessness, or irritability, or lack of cognition. Or, the other thing was, they would put them out so badly that the staff would yell at the patient, thinking, not that they're sleepy or slow, but that they can't hear them. Now a patient is getting yelled at, and when you get yelled at you get hostile, right? And there was a staff member who hit [Larry] at [LTRC Facility 1] and another staff member reported it. And that became a big deal. [...] The doctor told me these drugs were prescribed for 'staff anxiety.'”

Similarly, Anna found that overuse of antipsychotics and staff abuse of residents went hand in hand. After Anna made the connection between the high doses of antipsychotics her mother was on and her new aggressive, agitated state, she began advocating for her mother, but despite her considerable efforts the needs of the institution came before the needs of the resident:

“Um, and then the geriatric psychiatrist took over and switched the medication. Oh, I talked to [Doctor 3] in the meantime, her geriatrician, and [Doctor 3] said, of course, wouldn't agree with Ativan, said it's bad, no, stop, suggested Seroquel as being the preferable antipsychotic, and actually the British study said the same. So I got her doctor to switch to Seroquel and I thought it was good, it was improved, she was getting back to her sunny ways. I mean, my Mum's pretty capable, stubborn, independent woman, not like she suddenly turned into this... thing. But the Seroquel, she was slowly getting better. But I know that the LPN was giving her Ativan. They were giving her Ativan on the night shift. Because at night, there are only 2 or 3 staff and 50 people, and if they get up they give them Ativan to put them to sleep, because they assume it's a

sleeping pill. Her chart said 'as needed.' PNR, as needed. So even though the doctor was prescribing Seroquel, I was trying to find out... I felt that they were giving her Ativan, they won't, they really keep all of this close to their chest. So they were giving her Ativan at night.”

The request to stop administering the antipsychotics was not honoured until the institution was threatened.

“Um, so yeah. [sighs] I guess for me, aggression, I recognize that it's a part of dementia, um, but in talking with the doctors for example, in [Doctor 3], the geriatrician, and the doctors at [LTRC Facility 6], um, they say it's, if they're aggressive today doesn't mean they're going to be aggressive next week. It might be an aggressive stage. So... you know the rationale for giving consistent, ordered, scheduled, drugs is not appropriate. [...] So I went home and I phoned Fraser Health, they were closed. I had this woman that they had given me to deal with, in charge of re-placing people. And I said, you know, 'My mum is dying. She's non-responsive, not eating.' They were also giving her Haldol. And Haldol, in my experience is what they'd give people to... I mean, it kills people. Um, I also knew that in the average person given Haldol in 18 months will die, because it causes heart failure. Well, she's in there for heart failure. Anyway, I told this woman, "She is dying. I have documentation, I have been keeping notes, and if she's not moved I'm going to the media." The next day I went and she was sitting up, looking around. "What's happened?" "Oh, we decided not to give her drugs anymore." Um, oh, I also told Fraser Health if she dies – and I thought she was going to die – if she dies, I will ask for a toxicology report, a blood test, I want to know what's in her blood. Within four days she was out of there. You know what she did, though? She was on... I've got the list of drugs. So many drugs they stopped her cold turkey and she started to feel sick and nauseated. Her stomach hurt, which, okay, because of my background I knew that she was going through withdrawal. I talked to whoever I could and said, "I hope she doesn't die because of the withdrawal, because they just stopped her cold turkey." When we got to [LTRC Facility 6], they asked "Why did they stop her cold turkey? Usually they take a month or two to wean them off." And I knew why – because they wanted her blood clean, they were afraid that I'd ask for the toxicology report.”

Linda describes an incident in which a blind woman is left alone, for hours, calling into an empty room while her assigned care aid is busy with other residents:

“There was a blind woman, and what happened is they'd all come together in the morning, in the common room, to have the paper read to them.

Right? And then that would end, that event would end. And so the chairs were also moved there. And, and I, I think, I got there about 11:00. I think what happened, it ended, and then people slowly moved away, right? And she's blind, she's sitting in the middle of the room, with no one around her, saying, "I'd like to go back to my room now." Blind. Empty, chairs are gone, empty. And I remember, so I went, and I looked for staff. And of course it's just at 11, it's before lunch and they're trying to get people down for lunch in wheelchairs and stuff, and I actually, the nurse, she said, "I know, that's my patient, and I just haven't had time to get to her, um, but I'm going – and thanks for letting me know, she's my patient - " and you know, I felt the nurse was horrified and haggard too, right? And that was, I remember that, that was the first, our dear Mr. Campbell's cuts time, early cut time. Right? But um, yeah, so, in the last number of years, things have eased up a bit but it's still pretty ugly."

All of the family members felt that most of the staff were doing the best with what they could, and struggling within the constraints of an underfunded system. While there were examples of some staff that displayed a lack of judgement, training, or compassion, the majority of situations family members described were instances where neglect came about through serving the needs of the institution instead of the needs of the residents. This created an atmosphere where 'relational care' is merely an idea that is paid lip service to, and not practiced. Anna describes a lack of compassionate care at the first residence her mother stayed in:

"So, oh my Mum by the way, the other thing they did - another way that triggers aggression in my mind, is um, at [LTRC Facility 7] they put them in diapers right away. Mum was totally continent when she left the hospital. They put her diapers and she would need to use the toilet. We heard one gal say, "I need to use the toilet," [and the staff said] "Oh, you've got a pad on, use that." Well eventually they just started pooping and wetting their diapers. Again, if they're medicated they're doing it more. My Mum started just using, going in her diapers. They would sit for hours in smelly, dirty diapers. When Mum went to [LTRC Facility 6], I didn't realize this, she had ulcers on her bottom and it took them ages to heal them up. So she had ulcers. Can you imagine how painful that would be? Sitting in your uric acid, you know, the wet diaper, or poop, on an open wound? And hers was, like a loonie, and deep. They measured the, at [LTRC Facility 6] they actually measured the depth and width of one it was so significant. And they measured how it healed, day by day by day. And

they kept track of it. It healed okay because she was no longer sitting in wet, dirty diapers. I mean, imagine when you're in pain and you're a dementia patient, one of the things that triggers aggression is if they're in pain, so yeah, that kind of thing... it, I think aggression is a function of much deeper causes other than "everybody that gets dementia gets aggressive." And I know that it does happen.

Anna and Vashti described their effort to share their relative's personal histories with the staff at their LTRC facilities, in order to ameliorate personalized care:

[Anna] "Oh, and Mum was, um, she went through the war of course, and bombing, and so they put the mask on her face, she was crying, 'No, the room is, it's not caving in, I have to get out, I don't need the mask,' and they said, 'Oh, she's psychotic, she's seeing things!' When I went in, I said, 'Mum, what is it you're seeing?' She thought she was in a bomb shelter, and you know, you had to wear the oxygen mask in the bomb shelter. So when she started saying that, they were saying, 'She's psychotic,' but to her, having this mask - of course she's drugged up - it wasn't as psychotic as it appeared to them. Um, kind of a very narrow, well, and they don't give them credit for very much. Because she's 97, and she has dementia, and she can't hear so she's not responding. They say, 'Are you tired?' and she says, 'Oh, I don't want any fire, it's warm enough,' because she can't hear, and she's also reliving... so they don't give her credit, either. Or listening..."

[Vashti] "I was so upset I went to the supervisor's room and I sat and I talked about my mother-in-law's life, and I said, 'this lady was that lady, suffered so much, and she reached this point and we expect that she should be treated with dignity and respect.' And she made some notes, she understood, and she was very, she was very emotional when I told her the story, but um, that's it. I cried; she listened to me, she made some notes. And uh, that's it. But then it happens again, because it's out of her hands. And the system is not right for these people. There are lots of things that should be done to correct it. [...] The most important things we as a family member want is that when we communicate with the management of these care centers, they listen to us. Proactively. Not just, 'Oh, okay, I just make a note' and then two days later, when you go there, even the person you talk, with him or her, two days ago, can't remember what you said to them. And, you know, don't pretend in front of me that you are making a note and so something is going to happen. If you don't want to do it, just, honestly, be transparent. Say, 'Hey, with the budget we can't do this, forget about it.' But don't pretend that it is important to you, and then you don't even listen to the point that we are explaining to you."

Julie, on the other hand, regrets not speaking to staff in order to advocate on her aunt's behalf. Her aunt's estranged son was her power of attorney, and while Julie was the primary caregiver, she did not feel that she had the power to be listened to.

"I didn't feel like I had the right to communicate on her behalf. I didn't feel I had the agency. And, but you know, I'm not sure now. Because I wasn't officially, legally her guardian or whatever, I didn't do what I wish... on reflection I would do some things differently I think. Um, it's, it's been a, I've thought a lot about it actually. Especially because of how her last day was. I thought a lot about, the part I might have played. I just didn't really want to keep trying to rouse my cousin, it was annoying to me to deal with him in the first place, and I felt I could do things myself. But I wasn't really acting as an advocate on her behalf the way I might've done if my own parent was in the hospital, needing someone to speak on their behalf."

Institutional ghosting is a term coined by Davis and Pope (2010) to denote the way that "the lack of policy that supports training for communication effectiveness for caregivers of persons with Alzheimer's disease constitutes a de facto, hidden policy of neglect" (p. 2). Davis and Pope assert that people's identities remain, even in the midst of advancing Alzheimer's disease, but that the current policies and practices in LTRC treat the disease instead of the person. Participants described how the residents they cared for were institutionally ghosted, rendered invisible by their diagnosis. Often this was in the name of 'safety'. Residents numbed by inappropriate antipsychotics are safer for other residents and more easily managed by staff. Anna's mother, who entered the residence walking with a walker, was denied physical therapy and consigned to a wheelchair.

When Anna advocated for her mother, explaining that she had been an amateur athlete who swam the English Channel and that physical fitness was still

important to her sense of self, it made no difference in her mother's care. When Vashti taped a poster in her mother-in-law's room, with phonetically spelled out words in Farsi, to enable communication with her mother around such simple requests as food and water, it worked with some staff, but then was ignored by others. When Julie's aunt was on the resident council, she decried the fact that nothing was ever achieved, and that the wishes she discussed were not the same as what staff recorded in the minutes. At the hour of her death, Julie's aunt was denied without explanation the type of painkiller she had requested when given a choice between the two by the physician. Instead, she received a suppository four hours after she requested pain relief; twenty minutes before she died.

Lily was amazed by the purple dot program in her mother's facility:

“So I guess that's quite common, across the, across the uh, um, full care residence, care centers. I'm just assuming, because in our care centre, wow, you know, you walk down the ward and almost all of them have purple dots! I guess one, you know, like, I guess even if they acted out once or twice, they would be labeled. Even if they have subsided, even if their aggression or aggressive behaviour has subsided. The dot remains!”

In a facility which provides instrumental, task-oriented care instead of intersubjective, person-oriented care, the purple dot remains while the individual fades. When those with advanced dementia cannot speak for themselves, family members' being seen as full partners in care is necessary for relational, patient-centered care to exist. Linda describes how exhausting it is to advocate for patient-centered care in a system that does not support it:

“First of all, you're tired yourself because you're dealing with all these issues, and um, yeah you want to think that everything is safe and caring.

I had, yeah. I can see families being very... it's so out of control. And there's so many things that are stupid that happen there that you can't stand. That you have to, you know? And you have to fight for everything. You have to actually be very proactive. And you're least able to do it because you're dealing with a sick family member. So when you're least able to do this, you have to do it more. And you're surprised; the big surprise is that this is not a caring society. It's not a caring, proactive caring organization. It becomes very, wanting the routine, the simplicity of a routine in a non-routine situation.”

The examples of resident-to-resident aggression experienced by family members showed how current models of LTRC fail at accommodating difference and recognizing the individual behind the diagnosis.

4.3. Moving from ‘Family vs. Staff’ to ‘Partners in Care’

Family Member Perspectives

Gail, who is pleased with her father’s care, spoke of the stress of when he was in the hospital and they were contending with the ‘first available bed policy.’ She was worried that he would be placed in a Gentile facility, which would have been alienating for her Jewish father.

“When we were in the hospital, and dealing with where dad was going to go next [...] I said, because I had been told to take this tact, I said, ‘Well my dad must have kosher food.’ Because I was told was that was one way you could get into [LTRC Facility 5]. But what they said to me was, um, ‘that doesn’t matter, we will bring in kosher food for him.’ So that didn’t seem to be any guarantee of getting in there. And they said, ‘Just jump up and down and say, ‘he must in that facility.’” Well, that didn’t seem to matter, no matter how much jumping up and down I was doing. Plus, I went to see them there, uh, and I know the intake social worker there. And she said, you know, Gail, we don’t have a bed right now. She said, I would tell you the truth. So, if there’s no room there’s no room, and he was going to need to go somewhere. Uch! And then when they told us, I can’t remember if it was [Faraway City 4] or [Distant Area 3], and I thought, oh God, that’ll be the real end of him. Plus, just knowing how hard it will be for all of us to visit.”

Anna has several neighbours who are caring for relatives with early stage dementia at home, and spoke of how she was unable to convince these neighbours to seek information or support at the local Alzheimer's Society meetings Anna attends:

"I don't think people realize how hard the journey is going to be ahead of them, and they just, I don't think they have any idea what they're going to be facing. They say, 'Oh well, I'd like to get into [LTRC Facility 8], it's just up here, I think I'll go visit [LTRC Facility 8], because that would be handy for my brother, if he's in [LTRC Facility 8].' And I'm saying, 'If you can pay privately, yeah you can pick. But if you're subsidized by Fraser Health you don't get to pick.' And they don't even understand that. They don't realize how powerless they're going to be, and they don't realize how difficult it's going to be. And a lot of families are trying to not face it."

Most family caregivers spoke of the transition to LTRC as challenging. For all of the interview participants, their relatives were hospitalized, and then waited at the hospital for placement in a LTRC home. Linda described how this transitional period from hospital to LTRC facility sets up an 'us vs. them' dynamic with families and staff:

"...there are a hundred things I can't even remember that I had to fight for. Because there are so many - and every family member has to. And so it creates a "we" and "them." And, uh, you come in hostile because something's happened to your loved one, and you've also had some really bad disappointments all along the way before they get there. Either with the paramedics or the hospital, you know, the just the, the establishment. And it's un-proactive, it's very non-proactive, so it's frustrating. And the family member is a victim here, trying to get help. And you have a belief there's help everywhere. Someone is going to be proactive to help you. You see someone fall down, you pick them up, right? But they go, "Oh, well, he didn't fall in the right way." Or, "Does he, does he have his ID?" or, "Oh, well, we can't treat anyone like that." There's all this 'no' in the system which creates a barrier to begin with, between the family member and administration. And the administration thinks the family member is the enemy as well."

Anna expressed her frustration as being patronized as a 'Harriet Housewife' by the geriatric psychiatrist when she questioned the amount of antipsychotics her mother was on. Wanda described the four months in hospital when her husband was waiting for placement as "sheer hell." When asked what could have made the situation better, Wanda said that the best thing would have been if the healthcare workers stopped seeing her as someone to be handled, and instead as someone to work with and be open and honest with:

"Um, they need to have something saying, 'Okay,' they need to be honest, right from the start. 'Okay, we don't have enough beds, and you're going to have a long waiting period. We'll do our darndest for you.' That's all you need instead of me trying to phone them, 'Is he on the waiting list?' and 'No, no, they have women in med beds, your husband is a man so we have less beds.' And that's because, I don't know, doesn't seem to matter there, but that's the way they turned me off, saying that. So they need to talk about the journey.

Alzheimer's Society needs to say, 'We can't help you with resources, only maybe some education. We can't access the health system, so you're going to have a long wait.' Just to be honest and talk about this. You go there, and think they're going to solve anything, no. I guess I was dumb, and I worked in health, so. You need to just be honest and tell, 'This is a journey. You're possibly going to wait for four months, we'll do the best. You're going to have to take dirty laundry home every day, because the nurses are not care aids like that, they can help a little bit. [...]

Communication is so important, 'I'm sorry,' 'Yeah, I'm sorry you don't have enough money to give my husband the care he really deserves, okay, so what can we do? Let's work together, instead of trying to hide.' Really that's the whole basic thing, I would say. Be honest and say, 'The system is broken, we don't have enough money for seniors, but this is how you can help and give suggestions.'

For Joan, she knew little about her estranged uncle, who had formerly been homeless in the Downtown Eastside, and even less about paranoid schizophrenia. She discussed how her caregiving journey could have been positively impacted by being invited to the table with formal care providers:

"I think **[sighs]** it may have been useful for the mental health team to have me in some meetings with them. Because I really didn't know [Frank]. And, didn't know his situation very well. Um, and, uh, yeah, certainly didn't know about paranoid schizophrenia. I mean, you know the words, you kind of

can imply what that probably means, but some of these behaviours that he exhibits, um, might be indicative, like, I just think it would have been better if they had invited me. Because they were coming around, and um, still are, but I think less frequently because he doesn't like them, and um, I just think maybe we could've pulled things together a bit more, and then maybe my sister would still go with me, I don't know. I don't know. You know, you just guess, right? [...] I hear, I mean, about these things, [care conferences] I think that I couldn't go to one... I mean, they kind of have them on their terms, right? And so if you can't go to one they just carry on without you. So I remember I couldn't go to one and then I inquired at the desk about another one, they said something about it would be another year, and then, really time has just gone by.”

At the most immediate level – the day to day experiences of family caregivers advocating for their relative in LTRC – all participants described situations where their opinions were not sought nor considered when offered.

4.3.1. Reporting incidents of Resident-to-Resident Aggression

Family Member Perspectives

There are currently no guidelines around how a family member should report an incident of RRA, and to whom. As shown by Figure 3, the facilities in the present study are actually somewhat below the BC average of reported incidents of RRA if one were to go by the information presented by the BC Residential Care Quick Facts Directory (Office of the Seniors Advocate, 2017). As participants described, however, incidents of RRA are much more common-place. Perhaps one consequence of the media reports on RRA is the sense that the only acts of RRA worth reporting are the ones that lead to serious injury or death. Anna, who was desperate to move her mother away from the mistreatment at the first facility she was placed in, wrote a letter which she disseminated to the health authority, the provincial government, and the Office of the Seniors Advocate.

“I had been working since January to get her transferred and they wouldn't. I wrote to Isobel MacKenzie, I wrote to Fraser Health, I was phoning, I had a whole list of people I was constantly calling [...] but they're very dismissive. Fraser Health, um, dismissive. I mean, you're powerless. You're absolutely powerless. So I went to Isobel MacKenzie, the Seniors' Advocate, I thought, "Good. She's on my side," um, not really. Um, big organization, what's one little person? It's not a Seniors' Advocate, I guess it's sort of, in general trying to improve seniors' care. And when I phoned Fraser Health... so no, the letters didn't do too much.

And I'll tell you, so I got moved because I threatened to go to the media. And they knew I'd gotten all this stuff, that I'd written, whether I'd document it or not, would've looked good on the news. But what I did do, I went to the third level of complaint at Fraser Health directly and talked to [Person 2], and I think she happens to be one person that really is in it for seniors. And so she has now gone to [LTRC Facility 7] and they're being investigated. And I heard that they are no longer going to be allowed to take dementia patients. I sent my letters all over and didn't get anywhere. When you get that list at Fraser Health, and also MLAs in Victoria... MLAs weren't too interested. So I guess, I guess you just have to keep trying. But it took... [LTRC Facility 7] is just being investigated now, and this letter was September 2016. And I started, I started January 2016. So it's been a good 18 months from the time she went in there to get anywhere.”

Other participants expressed frustration with reporting conditions or incidents with the management at the LTRC facility. Vashti, whose mother-in-law went to the hospital several times following an incident of RRA, presented a logical argument with her husband about how hiring another care aide (preferably one who spoke Farsi) would cost less and help to prevent incidents of RRA, versus the system having to pay thousands of dollars for ambulances and hospital stays. Linda, having cared for her husband in a facility for over 20 years, recognized the futility of speaking to management about monetary issues.

“For me, I think it's our entrepreneurial healthcare government system – a system that should never be entrepreneurial – hence the problem I have with the doctor who wanted to beef up his billings, right? And, unnecessary referrals, unnecessary treatments that will cause more harm than good. So the clash is at the level that's beyond where the patients

live. I think it's the duty of care of the province. And the facility is an arm of the province that has been starved. But you know, they get to run three or five years, running something into the ground, and they get to go home, pennies in their pocket when it's done bankrupting people. So that's my whole thing. It's the way the government disperses the money. I guess, is what I think is the key cause of this. From educating, providing, yeah, it's a big monster. But I really like to blame Peter when it's Peter.”

These quotes are representative of the experiences other participants discussed around their sense of possessing ‘low credibility’ as family members within the hierarchy of LTRC, and the lack of importance given to LTRC by the provincial government. In order to empower family members, further information, education, and resources are required.

4.3.2. Information, Education, and Resources for Family Caregivers

Family Member Perspectives

When asked what information, education, or resources for family caregivers that the participants wish they had, above all they wanted to be respected as a partner in the care of their relative. From this respect would stem the inclusion in care decisions. Beyond this, Vashti wished for more opportunities to network and connect with other family caregivers, and to have support in the form of emotional and financial counselling. Anna wished she had been better educated around the misuse of antipsychotics and its side effects so she could have interceded in her mother’s care sooner. Wanda suggested the creation of navigators, to help family caregivers on their journey through the healthcare system by quickly pointing to appropriate resources and triaging the deluge of information.

None of the participants, at any of the LTRC facilities their relatives had stayed at, had received any guidance around what to do in the event of an incident of RRA. All participants felt that this information was warranted, especially as they often experienced being the sole caregiver in common areas with many residents, while staff members were administering private care in individual rooms, or on breaks. These common areas do not have call buttons, and, participants either had to shout for a staff member, or intercede themselves, or both. Wanda shared that while she's been told to consult a staff member for simple things, such as moving wheelchairs or giving food to residents, when she's interceded in an altercation she has always been thanked by staff members afterwards. Wanda described the moral distress of the situation: being unsure how to intervene, but knowing that if she did not harm would befall one or several residents.

The family members who participated in the present study were highly involved in caring for their relative while in a LTRC facility. Family caregivers viewed media reports on RRA as sensational, contributing to the stigma of dementia, and lacking context, but they did not impact the family caregivers' sense of safety. Instead, the lack of access to empowerment structures (i.e. informal power, formal power, information, support, and education) and the ambiguous position of family within the hierarchical power structure of LTRC negatively influenced their caregiving experiences.

Chapter 5. Discussion

5.1. Practical Implications

The following chapter will interpret and describe the significance of the findings in light of what is already known about RRA in LTRC, guided by the the themes discussed in the previous chapter. The research questions that initially guided this study 'missed the boat' as much as participants felt the media reports describing RRA did, the hypotheses evolved throughout the course of the research. Family members did not worry about their safety or their relative's safety in LTRC because of media reports depicting the most extreme incidents of RRA. Findings suggest a need for systemic change to improve resident care and strengthen the position of families within LTRC, which will in turn shed light upon incidents of RRA. The practical implications and action-oriented recommendations stemming from the findings will be discussed in turn.

Experiences and Fears of Resident-to-Resident Aggression

Transforming the role of LTRC to meet the needs of an aging population is daunting; changes need to occur at the individual resident level with the assessment and delivery of day-to-day care, with the training of staff, with the organizational culture of the nursing home, and with the regulatory context in which homes operate. While media reports also call for change to improve resident care, the focus is on education for staff and increased staffing levels to meet the heightened care needs of residents. Family members exist within these

media reports to react to RRA, but not as part of the solution to address RRA or in need of education and support in their own right. Media reports reify the culture of biomedical erasure in which the incidents of RRA occur: the reduction of older persons with dementia to their disease. When the interview participants spoke of the incidents of RRA they had witnessed, interceded in, or their relatives had experienced, they described them in rich, contextual terms.

Research identifies several triggers for RRA, which were echoed through the participants' experiences including: communication challenges between residents; residents wandering into rooms or touching/taking another resident's possessions; the challenges of communal living; and anxiety, boredom or chronic discomfort (Benbow, 2016; Snellgrove et al., 2013; Trompetter, Scholte, & Westerhof, 2011; Teresi, 2002; Zhang, 2012). The Seniors' Advocate (2016) report on RRA in LTRC identified that almost half (48%) of facilities had individual wander guard bracelets for residents who were known to wander. Similar technology, or the use of locking systems for private rooms, would have helped Julie's aunt, who felt constant psychological distress at being unable to avoid unwanted trespass into her room.

In responding to incidents of RRA, family members identified a need for guidelines around if, and how, they should intercede. If they are to alert staff, there should be call buttons installed in common areas. If the staff are not able to arrive in time, and the family member faces a choice of either interceding or

allowing potential harm to befall residents, there needs to be support for them. If they intervene, there should be institutional policies in place for them to debrief and report the incident. In preventing incidents of RRA, family members stressed a need for LTRC to structure care with an understanding of and sensitivity to the life history of residents, in order to identify potentially distressing situations. The Seniors' Advocate (2016) report on RRA calls for increased staffing to meet the needs of a more complex LTRC population, increased education and training for staff, standardized reporting for staff, and facility design/behavioural management such as anti-wandering interventions. None of these recommendations mention family members, who would benefit from increased education and training and the ability to access standardized reporting.

Safety, Risk, and Institutionalized Ghosting

Family members mentioned concern around media reports on RRA contributing to the stigma around dementia. Goffman (1963) refers to stigma as 'spoiled identity' while Link and Phelan (2001) describe it as persons being negatively labelled which results in a loss of status, power, and an increase of discrimination and stereotyping. Language is a vital tool in addressing the stigma around dementia. Media reports frame persons with dementia as deviants or victims, sources of suffering or sufferers. The Alzheimer's Society of Canada has had a document delineating a person-centered approach to communication since 2012, but this has not been adapted by the media. The person-centered philosophy

views people with dementia first and foremost as individuals with unique attributes, personal values and history. Media reports that include family members' perspectives in their own words adhere more closely to guidelines around person-centred language use.

Participants described how the communication breakdown when attempting to advocate for residents with staff who provide instrumental, task-oriented care and for whom dementia is viewed as a hopeless, totalizing disease, resulting in a lack of trust in any intent or content of communication from the resident. Family members who emphasize the person are seen as being out of touch, unable to accept their relatives' progressive disease. The pathologizing of residents on the part of staff and the resulting view of family members as not possessing information relevant to care produces instrumental caregiving, which McLean describes as "dangerous... any program of dementia care built on instrumental goals risks fostering a mentality of sanctioned abuse through dehumanizing and immoral practices" (2007, p. 207).

Similarly, the language used in media reports contributes to institutionalized ghosting, reifying the very tenets of an ageist society in which the neglect and underfunding of LTRC occurred, despite decrying it. The phenomenon of ghosting pertains to "a term used to describe a malfunction in video reception, occurs when a replica of something is super-imposed, slightly off-centre, on the real thing. Disconcerted, the viewer tries to adjust. The 'visible' hinges on what

we humans zoom in on and render ‘visible’” (Davis & Pope, 2010, p. 2). Within LTRC facilities, through attuning to the residents’ wishes, particularly with help from the resident’s family, the dementia will no longer be seen as a set of unexplained behaviours that obscures the person behind the disease.

Elaborating on the policies in the US that lead to institutionalized ghosting, Davis and Pope (2010) discuss how ‘policy is often determined by public perception’ (2010, p. 6). In an analysis of articles about dementia published by Time Magazine in the 1980s, 1990s, and 2000s there was a shift in the language used to discuss Alzheimer’s disease: in the 1980s it was viewed as ‘relentless, devastating, heartbreaking.’ Approaching the 2000s the language changed – persons with dementia are beginning to ask for a voice in the public narrative around their disease, and the practices and policies that address it. The shift of media focus to the person with dementia’s perspective and voice is vital.

As Swaffer (2014) notes about the lack of uptake on person-centered language guidelines advocated by international Alzheimer’s Societies:

“Print and other media virtually insist on continuing to use outdated and disempowering negative language, preferring to refer to people with dementia as demented and suffering, as these sad-sack stories are more likely to promote viewers or readers to engage. [...] Unfortunately, governments like to use this disempowering and offensive language, and the Alzheimer’s Associations and societies do little to prevent it, most

likely because the likelihood of governments or philanthropists providing it or increasing research funding, for people who appear to be living well, would be challenging (p. 13).”

These studies, and the accounts of family members within the present study, remind us that dementia is not just a medical issue but a social one, and as such requires more than a medical model of care and support. Indeed, Kitwood used the term “malignant social psychology” to describe how persons with dementia are first compromised and then judged negatively when they react to negative positioning with hostility, learned helplessness, or depression (1997).

Though the media, in this study and others, has been found to present stereotypes about aging and health conditions, it can also be harnessed to educate its readership with a more contextualized discourse on aging and the heterogeneity of an aging population, persons with dementia, and their families through adhering to person-centred language and engaging multiple stakeholders, most notably persons with dementia and their families. Within the LTRC facility, the dynamic nature of dementia progression and the unsuitability of an extended course of medication or a ‘purple dot’ to address BPSD should be reviewed and questioned more frequently than once a year at a care conference. As the participants identified, true person-centred care is proactive, anticipating and adapting to change, while reactive care serves the interests of maintaining the routine of the institution.

Moving from 'Family vs. Staff' to 'Partners in Care'

Participants expressed a desire to leverage their understanding and experience in order to improve care for residents in LTRC. This desire can only be realized if family members are seen as partners in care. In order for true relational care to happen there needs to be a recognition of the fact that all members of the team – family, residents and staff – have knowledge to bring to bear. Participants spoke of being advocates for their family members, and how that advocating was successful or not depending upon whether the facility valued them as someone with knowledge to advocate on behalf of the resident. Formal power to safeguard true relational care would be granted to family members if there were policies supporting their involvement in LTRC. Empowering families would lead to improved, personalized care for residents. The current policies around LTRC serve the facilities and not the residents or their families.

Despite their known presence in LTRC, there are only two policies that loosely address families in British Columbia: (1) health authorities are required to 'encourage and support' Family Councils. Unlike Ontario, however, Family Councils are not required. (2) Family members are to be 'invited' to their resident's annual care review, or care conference (BC Ministry of Health, 2012, 2017). Again, as participants described, there is no requirement to accommodate family members to ensure they are actually able to be present. Ensuring that the annual care conferences were scheduled to accommodate the presence of family

members and residents who want to attend; incorporating the residents' and family members' feedback around the residents' life histories into the care plan; establishing family councils so that family members have formal networks for peer support and education.

Reporting procedures for family members around RRA need to be developed and implemented to further elucidate as to the true prevalence and nature of the phenomenon. In 2013, B.C., residential care facilities governed by the Community Care and Assisted Living Act began specific reporting of RRA and Hospital Act facilities were required to report "serious adverse events," which include incidents of physical resident to resident aggression. There are variances across these two definitions of a 'reportable incident', which the Office of the Seniors Advocate found created difficulties when they compared facilities across different sites (2016).

The disparities in reporting for facilities extends beyond what they define as a reportable incident to the fact that there are three different ways incidents can be reported: 1) for facilities under the Community Care and Assisted Living Act, incidents are reported to the Medical Health Officer within the Health Authority; 2) for Hospital Act sites, facilities are required to report incidents to the Minister of Health, and the processes are not consistent across the Health Authorities; 3) Sites that are owned and operated by the Health Authority, regardless of which act they fall under, may also report voluntarily to the B.C. Patient Safety and Learning System (PSLS) (Office of the Seniors Advocate, 2016).

The PSLS is a voluntary, web-based patient safety event management tool used by care providers within the B.C. Health Authorities for reporting and educational purposes. Privately-owned residential care facilities do not have access to the PSLS. The definition of what constitutes a reportable incident of RRA is broader under the PSLS, ranging from outcomes of 'minor harm' to 'severe harm' and even death. The CCALA and the Hospital Act, conversely, do not consider RRA leading to minor physical harm a reportable incident (Office of the Seniors Advocate, 2016). Every LTRC facility likely has highly involved family caregivers, who, like the participants in this study, visit multiple times a week and possess a deep, contextual knowledge of the residents and their dynamics. To improve the care in this burgeoning sector there needs to be a standardized way for family members to report their concerns for resident safety, and any incidents of RRA.

5.2. Study Limitations

While this study further contributes to our knowledge of family member perspectives on RRA, several limitations can be identified. All interview participants in this study were women. While this is an accurate reflection of the gendered environment of LTRC wherein the majority of residents, staff, and primary family caregivers are women, the study would have been richer had it also included the caregiving experiences of men. Furthermore, including the perspectives of residents and staff would have been ideal to arrive at a more fulsome understanding. Additionally, had the interview included more participants who were newer to LTRC and do not have the same depth of experience to

contrast with media reports, the influence of media reports on feelings of safety could have been different.

Beyond their experience with the LTRC environment, half of the participants were recruited from the Simon Fraser University 55+ Continuing Studies program, while the other half were recruited via posters at community centres and through the Alzheimer's Society support groups. This demonstrates that the participants are connected to the community and may have more privilege in regards to education and recreation than other family caregivers. The self-selection to volunteer as either a research participant or an interviewee for a media story is preceded by the certainty that your story is worth sharing. Self-selection bias is a major problem in research in sociology, psychology, economics and many other social sciences. Other methods of inquiry, such as critical ethnography within a LTRC facility, may further tease out the complex power relations therein and include the perspectives of persons with dementia who reside within LTRC.

5.3. Reflexive Perspective

This research evolved over the course of two years and the researcher who wrote the proposal in 2016 is not the same as the researcher who wrote this thesis. Beyond being two years older, the health crisis of a loved one and the ensuing experience of being a primary caregiver irrevocably altered my perspective on family caregiving. No longer an outsider looking in, but instead, an insider/outsider. Throughout the negative case analysis, maintaining a reflexive perspective and questioning the researcher role as my thesis evolved was key in

braiding the different strands presented within the research. The results of a study directly stem from the methodology; put differently, the way in which we answer questions guides the answers we receive. This research entailed an iterative process of acknowledging the experiences of the participants as deviating from the assumptions that guided the creation of the research questions and further analyzing the data and the researcher role.

In terms of my thesis, the interviews were intimate and personal. One participant invited me into her home. For the other participants, the interview was at a time and in a private room of a public place of their choosing. Occasionally this meant I travelled out of Vancouver for two hours by public transit to arrive at the community centre or library most convenient for them. Through the consent process and my humble demeanor, I strived to acknowledge that the participants were experts in their own experiences. I endeavoured to underline that though I was asking the questions, my voice was not the one of authority nor was it my role to legitimate their voices as family caregivers. In other words, I endeavoured to not present myself as a younger, twenty-something, privileged White researcher acting as the 'knower' and locating the participants as the 'known'.

Despite my efforts, however, participants may have not felt comfortable admitting that media reports caused them fear or concern about RRA. A research methodology that allowed for anonymity, such as a survey, or a longer research process that enabled the building of rapport could have elicited different answers. On the other hand, perhaps the research process enabled them to view their caregiving experiences with distance, inviting them to consider them from my

perspective and divorcing the responses from the emotional lived experience. Or, perhaps, the cultivation theory of media consumption shaping fears of situations did not hold true as the participants were highly involved caregivers who contrasted the shallow media stories with their deeply contextual experiences.

While my own experiences as a family caregiver granted me insight, the danger then became filling in the blanks with my familiarity. Through reflexive memos I tracked any instances where I may have mapped my own understandings onto the interpretation of the participants' stories. I noted when I used certain terms that the participants began to use those terms in their following answers, e.g., referring to LTRC as a 'reactive' system instead of 'proactive.' When hearing of the particular difficulties caring for their relatives who do not speak English and the weight of historical trauma, the difference between my experiences and those of the participants was more pronounced.

Even considering my privilege as a White woman completing her Master's within my memos felt like 'confessions of whiteness' simply constituting a 'form of pleasurable relief' (Applebaum, 2010, p. 19). As if such confessions absolve me from any complicity in perpetuating a system that enables my privilege.

Acknowledging one's privilege and social location does not enable one to shed them at will. As a person with privilege it is important to "study and talk about how your privilege acts both as a shield and as blinkers for you... we need to remember that each of us... is going to say something dumb or insensitive. Our best bet is to acknowledge our mistakes openly and learn from them" (Kendall, 2006, p. 150).

A question returned to many times in my memos was, 'what is my role and how can I meet my obligations to participants and their communities?' This question, along with others, brought into sharp relief the critical nature of the relationship between participants and the negotiation of all aspects of research and its outcomes. Beyond my academic contributions, I felt the need to work on a policy brief to disseminate research findings among a larger audience. In particular, as a student, a feedback loop of question and answer, writing reports and quickly receiving grades becomes normative.

Conversely, while the research process in terms of a thesis is guided by our committee, ultimately the effort is our own. The road to complete this thesis was longer and more solitary than other types of research I had previously undertaken. The revision of hypotheses through negative case analysis entailed becoming comfortable with unexpected answers; to avoid the intellectually arrogant trap of thinking that we know what we are doing. Rather than eliciting the expected responses, the questions posed in my research study were a springboard used by participants to voice their concerns and aspects of their experiences most salient to them.

5.4. Recommendations

5.4.1. For Future Research

In the context of increasingly constrained residential care systems, these findings raise particular concerns which require further study: the possible misuse of antipsychotics leading to increased aggressive behaviours and the ramifications

of family members supplementing formal care without access to formal power. A potential trigger for RRA not addressed previously in the academic literature that family members identified was the improper use of antipsychotic medications. In the BC Office of the Seniors Advocate Residential Care Facilities Quick Facts Directory (2017) an average of 27% of residents are taking antipsychotics without a matching psychiatric diagnosis. The Office of the Seniors Advocate RRA Report (2016) cited the Canadian Foundation for Health Improvement which found in a controlled study at 56 Canadian LTRC facilities that decreasing the use of antipsychotics led to less incidents of aggressive behaviour.

In LTRC antipsychotic medications are used to manage agitation and aggression, but antipsychotics have limited efficacy, result in poorer quality of life, and are associated with a high risk of adverse effects, including mortality (Schneider *et al.*, 2005; Schneider *et al.*, 2006; Gill *et al.*, 2007). Clinical guidelines now recommend nonpharmacological interventions as the initial course of action for managing behavioural and psychosocial symptoms of dementia (BPSD) including agitation and aggression (Rabins *et al.*, 2007; Salzman *et al.*, 2008; Mitka, 2012). Evidence of effective nonpharmacological approaches would bolster efforts to reduce the use of inappropriate antipsychotics in LTRC. Systemic reviews evaluating the effect of inappropriate antipsychotics for the management of BPSD have small statistically significant effects in reducing aggression but the significant risks (up to and including death) greatly outweigh the benefits (Ballard *et al.*, 2006; Schneider *et al.*, 2006).

By contrast, nonpharmacological approaches have no reports of adverse effects (Jutkowitz *et al.*, 2016). When examining the rationales providers and family members cited for the use of antipsychotic medications in LTRC residents with dementia a wide variety was found, suggesting that LTRC teams and family members poorly understand the use of antipsychotics (Bonner *et al.*, 2015). The accounts of family members around the use of inappropriate antipsychotics in LTRC indicate that the prescribing culture, and not individual evaluations of residents' care needs, are what ultimately leads to unsuitable and dangerous misuse of antipsychotics. For these reasons, research into the overuse of antipsychotics and its link with RRA is highly warranted.

The study findings suggest that media reports on RRA do not affect feelings of safety in LTRC for highly involved family members themselves or for their relatives that they care for. Instead, these family members expressed concern that media reports on RRA increase the stigma surrounding dementia. This finding, however, cannot be generalized due to the limited sample size. Future critical discourse analysis could consider the stigmatization of dementia, and further studies on whether or not media reports on RRA negatively affect the general public's understanding of dementia. Large-scale stigma reduction approaches with demonstrated outcomes are lacking. Given world-wide aging trends and increasing rates of dementia this is an important area for future research. Beyond public perception, stigma affects a person's willingness to seek diagnosis, to seek support once diagnosed, and a lack of willingness to

participate in research (Burgener & Berger, 2008; Garand *et al.*, 2009; Milne, 2010). Swaffer (2014), as a researcher with early onset dementia, advocates for the inclusion of people with dementia in the discourses about them. Borrowing from the disability literature, Swaffer (2014) calls against discourses that are ‘about people with dementia, without them’ (p. 13).

Discursive constructions of age identity occur in association with other identities, including gender and race, and certain identities are foregrounded, resulting in the privileging of one identity over another (Fealy *et al.*, 2012). Future critical discourse analysis studies of media reports on the experiences of persons with dementia would be strengthened if they included an intersectional lens to further understand how these identities overlap and transect. The inclusion of family members and persons with dementia in reports on RRA would reframe them from victims and witnesses to key stakeholders in relation to the problem.

5.4.2. For Government

On February 20th, 2018, the newly elected New Democratic Party announced the British Columbia Budget – priorities for the next several years. Among the budget report was an announcement of “a \$548 million investment over three years [that] will mean better residential care for seniors and more qualified support staff in assisted living facilities. This will help ensure that our seniors, parents and grandparents are treated with dignity and respect” (BC Ministry of Finance, pg. 6). The literature reviewed and the accounts of the family caregivers in this study underline that meeting the needs of an aging population is not just a medical

issue but a social one, and as such requires we move beyond a medical model of care and support to safeguard true relational care through policies. 'Better residential care for seniors' would result from policies supporting family member involvement in LTRC.

Ensure that annual care conferences require accommodating the presence of family members and residents who want to attend; ensure that residents' and family members' feedback around the residents' life histories are fundamental to the care plan; ensure that family councils are not just 'encouraged' but are secured through policy, as in Ontario, so family members have formal networks for peer support and education. Support the development of standardized, provincial reporting procedures for staff and family members to elucidate the true prevalence and nature of RRA.

5.4.3. For LTRC Facility Administrators

With the planned increase in funding to the residential care sector, facility administrators should offer increased education and training for family caregivers as well as staff; the education and training should include standardized reporting of RRA for staff and family caregivers; and implement facility design/behavioural management such as wander guard bracelets and call buttons in common areas. The dynamic nature of dementia progression should be emphasized and the questioning by family members and staff (e.g., of the suitability of an extended course of medication or a 'purple dot' to address BPSD) welcomed.

5.4.4. For Media

The media is a major source of health information for the public, shapes public perceptions, and can direct the discussion around issues. Members of the media should provide further context to their stories by consulting with family caregivers, residents, facility administrators, and experts in gerontology. When not able to consult with these stakeholders, members of the media should be explicit about the views they are privileging. Members of the media should utilize the Alzheimer's Society of Canada document detailing a person-centred approach to communication, to guide person-centred language use when discussing persons with dementia. These guidelines can inform journalists on how to report RRA news in a sensitive and accurate manner. As well, Canadian journalists need to increase and improve the coverage of RRA, to dispel false understandings of RRA and dementia and to support necessary public health efforts and systemic change in LTRC.

5.5. Conclusion

This research began with a literature review in three parts: (1) the environment of LTRC; (2) Family involvement in LTRC; and (3) RRA. The review of academic and grey literature revealed a discrepancy wherein the literature on RRA does not mention family members' own experiences, and the literature on family members' experiences in LTRC does not mention RRA. As Canada does not currently have a national dementia strategy or national oversight for LTRC, the system of LTRC therefore reflects provincial and territorial differences. The lack

of standardized services and historical underfunding in this sector results in haphazard care for the 27,000 older adults living in LTRC at any given time in BC (Office of the Seniors Advocate, 2016). Many family members remain active in providing care to their relatives following admission to a LTRC facility. However, in the hierarchal, stratified atmosphere of LTRC family members are positioned with little power to advocate on behalf of residents.

The majority of academic literature on RRA has been published within the last ten years; as an emerging concern, much is still unknown. Past research on RRA delineates the prevalence, triggers, risk factors, promising interventions, and methods of increasing prevention and awareness through staff education.

Researchers, such as McDonald *et al.* (2015), recognize the recent surge of media reports on RRA within Canada that “sensationalize extreme cases, where RRA led to serious injury and in some cases death” as a catalyst for action and raising awareness (p. 149).

Within Canada alone, the amount of media reports on RRA within the last ten years ($N=64$) is over double the amount of English-language journal manuscripts ($N=27$) available internationally. And while none of the academic literature on RRA at the time of this thesis mentioned the role of family within LTRC, over half of media reports on incidents of RRA include the perspectives of family members. In order to address the current gaps in the academic literature, the scope of the present study was limited to family members’ experiences and fears of RRA. A critical discourse analysis of media reports of RRA and semi structured in-depth interviews with family members ($N=8$) examined the existing

narrative around RRA in the media, and whether it influenced perceptions of safety for LTRC family caregivers.

The first guiding research questions was created following the literature review, and the second and third guiding research questions were created following the critical discourse analysis of media reports on RRA:

- (1) What is the current narrative around RRA in the media?
- (2) Do media reports about RRA influence perceptions of safety for LTRC family caregivers? If so, how?
- (3) What information, support, and education do family members want in regards to RRA?

The first guiding research question was answered using Fairclough's three-layer model of critical discourse analysis (1995, 2003). This analysis revealed that the narrative of family members within media reports was one of reaction, and when calls for future action were made – most frequently for more staffing or staff education – the role of family members and how they can be supported within LTRC, and in turn support residents, was not considered. Additionally, media reports that did not speak with a resident, family member or gerontology expert directly, would use language associated with violence and crime, whereas media reports that did engage with these stakeholders used dementia-friendly language. A semi-structured interview guide was developed to examine the final two guiding research questions.

Eight family member caregivers currently providing care to a relative in LTRC, all female, were interviewed. The transcripts were analyzed thematically in NVivo version 11, using an inductive grounded theory approach to coding. Despite disparate backgrounds and caregiving relationships, participants shared many of the same experiences and impressions, and the core research questions were met with equivalent responses. Family members felt that the language used and messages conveyed in news media reports on RRA represented and reified the power imbalances, dominance, and inequality already existing in LTRC. Unequivocally, family members resisted the idea that media reports on RRA, which they all had read and expressed an interest in, influenced their feelings of safety within LTRC.

This unexpected response was further analyzed and the initial assumptions that guided the creation of the questionnaire examined through reflexive memos. Three themes emerged: (1) Family member perceptions on media reports and fears and experiences about RRA, wherein four family members had experiences with RRA and four had concerns; (2) Safety, risk, and institutionalized ghosting, wherein the current policies and practices in LTRC that treat the disease instead of the person were described, as well as instances of systemic abuse; and (3) Moving from 'Family Vs. Staff' to 'Partners in Care', which had the sub-themes highlighting the lack of avenues for family members to report incidents of RRA and the necessary information, education, and resources required by family caregivers. While the data was rich, this study was limited by not including the caregiving experiences of men, or the perspectives of family

members who are not as highly involved in care. As well, other methodologies such as critical ethnography would be valuable in facilitating the inclusion of the experiences of residents and staff.

Many family caregivers who spend a significant amount of time with their loved ones who are residents in a LTRC facility are the resident's proxy decision makers, with power of attorney and a duty to adhere to the resident's wishes. Their views, and their representation of residents' desires, are vital to include when determining proper policies, practices and technologies to aid prevention of and response to RRA in LTRC. Addressing the current ambiguous position of family members in LTRC top-down through the creation of equitable policies that translate into collaborative practice between staff and family members, would improve the care for residents. This is not to suggest that family members should be expected to provide care for residents, but rather to recognize the roles they currently hold and how the system fails to support them and their relatives in LTRC.

Incidents of RRA, when originating from residents with cognitive deficits in an environment not tailored to meet their needs, are not crimes with intent. Nor are they accidents: an unfortunate occurrence that could not have been prevented. They are preventable. In the current system of LTRC the injuries and deaths from RRA do not originate in one major and single unpredictable event, but instead stem from a steady form of common violence which normalizes them. The daily news covers the problem one clip at a time, framing the issue of RRA as episodic and unconnected, and ignoring the potential for resounding change. Comparing

Canada's incidents of RRA to other countries shows that injury and death within LTRC are not accidents, are not unavoidable, but rather are system failures. The shocking stories of RRA leading to death presented by the media are canaries in the coal mine of LTRC. While it is important to probe the representations of RRA within the media and the role of family members within LTRC, even more important is to act.

The way forward to address RRA, and the inequities in LTRC, is not just about what causes incidents of aggression, but also what causes safety. Involving family members in addressing RRA and recognizing family members as deserving of education and support within their own right is imperative. The potential of technologies such as wander guard bracelets and call buttons in common areas should be harnessed to address RRA. Policies that support and clarify the role of family within LTRC, and policies that standardize and mandate the reporting of incidents of RRA are required. And finally, care should be structured with an understanding of and sensitivity to the life history of residents. Critical to enhancing safety for present and future residents in LTRC is the philosophy that only an unethical system would allow the culmination of triggers, environment, and a lack of attention to result in harming a vulnerable person.

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Appendix A. NVivo Codebook

- 1.0 Influencing Change
 - 1.1 Systemic Change
 - 1.2 Staff Education
 - 1.3 Educating Families
 - 1.4 Improved Sharing of Power
 - 1.5 Medical Care
 - 1.6 Accountability
 - 1.7 Space, Physical Layout
 - 1.8 Activities
 - 1.9 Communication
 - 1.10 Prevention & Awareness
 - 1.10.1.1 Risk Assessment
 - 1.10.1.2 Surveillance
- 2.0 Defining Responsive Behaviours
 - 2.1 Challenges
 - 2.2 Cost
 - 2.3 Dementia
 - 2.4 Brain Injury
 - 2.5 Triggers
 - 2.6 Abuse
 - 2.6.1 Sexual Abuse
 - 2.7 Intent
 - 2.8 Outcomes & Actions
 - 2.8.1 Action
 - 2.8.1.1 Beating
 - 2.8.1.2 Pushing
 - 2.8.2 Outcome
 - 2.8.2.1 Death
 - 2.8.2.2 Hospitalization
 - 2.9 Disclosure
 - 2.10 Fear
 - 2.11 Importance
 - 2.11.1.1 Stats
 - 2.12 Mental Illness
 - 2.13 Prevalence
 - 2.14 Resident to Staff Aggression
- 3.0 Environment
 - 3.1 For Profit vs. Not for Profit
 - 3.2 LTC in Canada
 - 3.2.1 Policy
 - 3.3 Organizational Environment
 - 3.3.1 Lack of Staff
 - 3.4 Physical Environment
 - 3.5 Social Environment
 - 3.6 Structural Violence
 - 3.7 Country Comparison
- 4.0 Ageism & Value of Persons with Dementia
 - 4.1 Institutionalized Ghosting

- 4.2 Stigma
- 5.0 Intervention
 - 5.1 Interceding in Incident
 - 5.2 Involvement of Law Enforcement & Legal Systems
 - 5.2.1 Lawsuit
 - 5.3 Non-Pharmacological Interventions
 - 5.4 Pharmacological Interventions
 - 5.4.1 Antipsychotics
- 6.0 Bon Mots
- 7.0 Media
 - 7.1 Language
 - 7.1.1 Violence
 - 7.1.2 Crime
 - 7.2 Source
 - 7.2.1 CBC News
 - 7.2.2 Global News
 - 7.2.3 Journal de Montreal
 - 7.2.4 National Post
 - 7.2.5 The Globe and Mail
 - 7.2.6 The Province
 - 7.2.7 The Vancouver Sun
 - 7.2.8 Toronto Star
 - 7.3 Staff Perspectives
 - 7.4 Titles
- 8.0 Family Caregiver Experience
 - 8.1 Autobiographical Information
 - 8.2 Mentions Volunteers but not Family
 - 8.3 Power
 - 8.4 Reporting
 - 8.5 Interview Questions
 - 8.5.1 Initial Questions
 - 8.5.1.1 Relationship to Relative
 - 8.5.1.2 Relative Age
 - 8.5.1.3 Relative Main Medical Diagnosis
 - 8.5.1.4 Relative's Length of Stay at Facility
 - 8.5.1.5 Relative's Previous Residence
 - 8.5.1.6 Relative Waitlisted
 - 8.5.1.7 Frequency of Visits & Activities
 - 8.5.1.8 Other Visitors (Family or Friends)
 - 8.5.2 SAFER Questions
 - 8.5.2.1 Involvement in Caregiving
 - 8.5.2.2 Impressions of Media Reports
 - 8.5.2.3 Media Reports Affecting Caregiving
 - 8.5.2.4 Media Reports & Vigilance
 - 8.5.2.5 Experiences Witnessing or Interceding in RRA
 - 8.5.2.6 Relative's Experiences with RRA
 - 8.5.2.7 Discussing Fears or Experiences with other FM
 - 8.5.2.8 Discussing Fears or Experiences with Staff
 - 8.5.2.9 Media Reports Useful in Promoting Awareness or No
 - 8.5.2.10 Media Reports and Feelings of Safety at Facility
 - 8.5.2.11 Information, Education or Resources for FM

9.0 Research

9.1 Future Research

9.2 Measures

9.3 Methodology

9.4 Models

9.4.1 NDB Model

Appendix B. Media Reports References

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Appendix C. Interview Questions

Sociodemographic Questions:

- 1.) What is your relationship to your relative who lives in the facility? (Spouse, child, grandchild, friend, etc.)
- 2.) How old is your relative?
- 3.) What's your relative's main medical diagnosis/reason for admission?
- 4.) How long has your relative been a resident of the current facility?
- 5.) Before moving into this facility, where did your relative live?
- 6.) Is your relative currently waitlisted to move to another facility?
- 7.) How frequently do you visit your relative, and what type of activities do you do while you're there?
- 8.) In addition to yourself, do other family members care for your relative?

Interview Questions:

- 1.) Tell me about how you became involved in caring for your relative living at [facility]?
Probe: Did you care for them before they moved into the facility?
- 2.) What is your impression of media reports about resident-to-resident aggression in long-term care facilities?
Probe: Do you read/watch them frequently?
- 3.) Do these media reports about resident-to-resident aggression affect your involvement in caring for your relative living at [facility]? If yes, how?
- 4.) Do these media reports about resident-to-resident aggression make you feel the need to be more vigilant about your relative's wellbeing and care at [facility]?
Probe: If yes, how have you become more vigilant?
- 5.) Have media reports about resident-to-resident aggression affected your relationship with staff at [facility]? If so, how?
- 6.) Have you had any experiences witnessing or interceding in an incident of resident-to-resident aggression?
- 7.) Has your relative been in an incident of resident-to-resident aggression? If yes, please tell me about it.

- 8.) If you have fears and/or experiences around resident-to-resident aggression, have you discussed them with other members in your family, and/or family members of other residents at [facility]?
- 9.) Do you feel like you can discuss your fears and/or experiences about resident-to-resident aggression with the staff at [facility]?
- 10.) Do you think that the media reports on resident-to-resident aggression are useful in promoting awareness about the phenomenon?
- 11.) Have media reports about resident-to-resident aggression influenced your feelings of safety in [facility]? If so, how?
- 12.) What information, education, or resources do you wish you had in regards to resident-to-resident aggression in long term care facilities?
- 13.) Is there anything you would like to talk about before we end the interview? Any question I should have asked, but didn't?

Appendix D. Invitation to Participate



DEPARTMENT OF GERONTOLOGY

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Letter of Information *SAFER Study:*

Stories of resident-to-resident Aggression Fears and Experiences in long-term Residential care Master's Thesis in Gerontology

Invitation

You are being invited to participate in a research study about how media reports around resident-to-resident aggression influence family caregivers with a loved one in long term residential care (LTRC) and what information, support, and education family members want in regards to resident-to-resident aggression. Your participation in this study will help us better understand the experiences and concerns of family member caregivers in regards to resident-to-resident aggression in LTRC, and will inform policy and practice in this area.

This study is being conducted by a M.A. Candidate in the department of Gerontology at Simon Fraser University.

Background

With rising rates of dementia in LTRC, responsive behaviours that can lead to resident-to-resident aggression are escalating. There is little research on resident-to-resident aggression, and almost none about family members' concerns, experiences, and safety. Family members may receive the majority of information about resident-to-resident aggression from media reports. This study seeks to understand and compare 1) what the research says about resident-to-resident aggression; 2) what media reports say about resident-to-resident aggression; 3) what family caregivers say about resident-to-resident aggression.

Participation

If you choose to participate, you will be interviewed once for approximately 1 hour. You will be interviewed about your involvement with your relative who lives at the study site. You will also be asked about your thoughts on media reports around resident-to-resident aggression and any experiences with resident-to-resident aggression.

If you are interested in learning more about this important research study, please contact the study's Principal Investigator:

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Appendix E. Poster

2016s0387

INVITATION TO PARTICIPATE IN A GERONTOLOGY RESEARCH STUDY

SAFER Study:

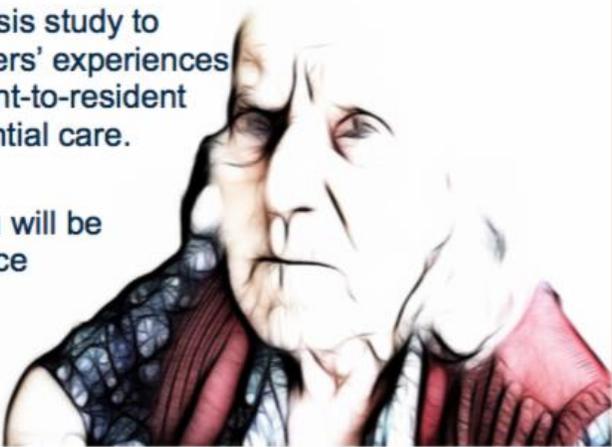
**Stories of resident-to-resident Aggression Fears
and Experiences in long-term Residential care**

Are you a family member or friend of a resident in a long-term residential care facility?

I am conducting a Master's thesis study to learn more about family members' experiences and/or concerns around resident-to-resident aggression in long-term residential care.

If you choose to participate you will be interviewed at a time and a place that is convenient for you.

You will receive a \$10 gift card in appreciation for your time.



For more information, please contact the principal investigator:

Denise Beaton, M.A. Candidate, SFU Gerontology
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Version 3:
December 6,
2016



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