Evaluation of a Regional Behavioural Support Program

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Background: Persons living with dementia may often present with responsive behaviours. Behavioural Supports Ontario (BSO) is a provincial initiative to enhance supports and services for persons living with responsive behaviours in acute care, long-term care and community care settings. Long-term care (LTC) settings use one of three BSO models, including two mobile models and one embedded model, depending on the regional health authority. A survey by Grouchy et al (2017) found the embedded model to be the most preferred in terms of service provision and impact on quality of care. The Waterloo Wellington region of Ontario uses the embedded model; however, it is unclear whether this is adequately meeting the needs of LTC residents and staff, and therefore an evaluation of program outcomes was conducted.

Methods: Guided by principles of Utilization-Focused Evaluation (Patton, 2008) and Appreciative Inquiry (Cooperrider & Whitney, 2001), an evaluation of the BSO program was conducted in consultation with BSO members from the regional health authority, family caregivers, and other LTC staff members. The evaluation utilized qualitative (individual and focus group interviews) and quantitative (survey) methods. Areas of focus included service delivery elements related to: 1) collaboration and coordination of healthcare providers; 2) importance of program outcomes; and 3) self-perceived performance of program outcomes.

Results: Qualitative interviews revealed themes related to current challenges in the LTC setting, and future directions that are important to consider for the success of the BSO program in the Waterloo Wellington region. A series of program outcomes were also identified throughout these interviews, and rated based on level of importance and performance in a quantitative survey. Generally, program outcomes were rated consistently across importance and performance by participants; however, some discrepancies could be observed.

Discussion: Aside from the work done by Grouchy et al (2017) and by Gutmanis et al (2015), there are little data available on the impact of the BSO program. This evaluation helps to fill this gap by looking at successful indicators of the program and determining which components of the embedded BSO model are most important as well as the self-reported ratings of level of performance of each of these outcomes in the LTC homes. These findings may be helpful for regions developing similar programs as well as to direct key areas of focus for future program enhancement.

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List of Abbreviations

AI   Appreciative Inquiry

BSO   Behavioural Supports Ontario

GPA   Gentle Persuasive Approach

LHIN   Local Health Integration Network

LTC   Long-Term Care

PRC   Psychogeriatric Resource Consultant

PSW   Personal Support Worker

RN   Registered Nurse

RPN   Registered Practical Nurse

WW   Waterloo Wellington

Chapter 1: Introduction and Overview

As shown in the 'Rising Tide' report in 2010, dementia is becoming more prevalent in

Canada (Dudgeon, 2010). With advanced stages of dementia, often come responsive behaviours.

The behaviours that are exhibited by persons with dementia or other mental health and

neurological conditions are often in response to something important in their personal, social or

physical environment (Alzheimer Society of Ontario, 2014). All behaviours have meaning and

are usually a form of communication to address an unmet need (Alzheimer Society of Ontario,

2014). There are a wide range of responsive behaviours including grabbing or hitting others,

repetitive mannerisms, pacing or wandering, cursing, screaming, or sexually expressive

behaviours (Waterloo Wellington BSO, 2018a). Healthcare providers may attempt to manage

these behaviours through the use of antipsychotic medications or physical restraints (Van

Leeuwen et al., 2018).

In 2010, the Ontario Ministry of Health and Long-Term Care provided $40 million of

funding to develop the support and services available for persons living with responsive

behaviours (Ontario Behavioural Support System Project Team, 2010). Behavioural Supports

Ontario (BSO) was created to enhance the capacity and system coordination across the

continuum of care. There are three core elements of BSO's integrated service delivery including:

i) mobile interdisciplinary behavioural support outreach teams; ii) case management and

transitional supports, dementia day programs and respite care; and iii) specialized short- and

long-stay residential care (Behavioural Supports Ontario, 2018a).

Behavioural Supports Ontario is coordinated independently within each of the Local

Health Integration Networks (LHINs – regional health authorities) within Ontario. In the

Waterloo Wellington LHIN, the BSO program is led by St. Joseph's Health Centre, Guelph,

which coordinates both long-term care home (LTC) and community models (Waterloo Wellington BSO, 2018b). For the purpose of this research, attention will be focused on BSO in long-term care. There are 36 long-term care homes in the WW LHIN. The WW LHIN employs an embedded model in which the multidisciplinary BSO team is hired and operates within each long-term care home (Waterloo Wellington BSO, 2018b). This multidisciplinary team may include nursing, personal support workers (PSW), recreation, and social work (Waterloo Wellington BSO, 2018b).

The focus of this research was to explore how BSO coordinates and collaborates within LTC homes to provide optimal services in long-term care in the Waterloo Wellington LHIN. This research also sought to determine and evaluate the intended outcomes of the Waterloo Wellington BSO program.

This thesis includes a literature review, followed by the study rationale and objectives, the methods utilized in this research, qualitative findings and quantitative results, and a discussion section, which also identifies study strengths and limitations. To begin, the literature surrounding the topic of BSO in long-term care will be reviewed.

Chapter 2: Literature Review

This literature review will provide an overview of the impact of dementia in the context of the Canadian healthcare system, specifically in the long-term care setting. The dementia care quality indicators of antipsychotic and physical restraint use will be addressed, as these indicators are important to the intended outcomes of the BSO program. Background information related to the Local Health Integration Networks, and the Waterloo Wellington region will be provided. Finally, the BSO program and the person-centered care approaches promoted through this initiative will be discussed.

2.1 The Impact of Dementia

By the year 2038 it is estimated that nearly three percent of the Canadian population will have dementia, which translates to approximately 1,125,184 people (Dudgeon, 2010). Dementia is the most significant cause of disability among Canadians aged 65 and older, and is highly costly to the Canadian healthcare system (Dudgeon, 2010). Dementia can be defined as a progressive deterioration of mental processes caused by brain disease or injury in which symptoms may include memory disorders, personality changes, and impaired reasoning (Alzheimer Society Canada, 2018). Dementia is an umbrella term for the set of symptoms that are caused by a variety of disorders that affect the brain (Alzheimer Society Canada, 2018). There are several disorders with similar symptoms that may cause dementia, such as Alzheimer's disease, vascular dementia, Lewy Body disease, and Parkinson's disease (Alzheimer Society Canada, 2018).

Persons living with dementia may often present with responsive behaviours. These symptoms may be exhibited in up to 90% of persons with dementia, regardless of the disease

stage (Foebel et al., 2016). Examples of responsive behaviours may include restlessness or agitation, wandering, screaming, repetitive sentences or questioning, and sexual behaviour (Alzheimer Society Ontario, 2017). The responsive behaviours exhibited by these individuals can be influenced by biological factors such as neurobiological processes, however, they are often caused by unmet needs that cannot be adequately communicated or by a lack of contextual understanding (Gutmanis, Snyder, Harvey, Hillier & Le Clair, 2015; Ontario Behavioural Support System Project Team, 2010). Responsive behaviours may resolve with time and appropriate intervention; however, they can be dangerous to the individual and others if not properly addressed. Responsive behaviours may cause distress to the resident, which in turn has implications for quality of life, mental illness and medical treatments (Beck et al., 2002). The challenges that arise from these behaviours can lead to caregiver burnout and institutionalization for individuals with responsive behaviours (Gutmanis et al., 2015; Ontario Behavioural Support System Project Team, 2010).

2.2 Dementia in Long-Term Care

Frequently, persons with dementia reside in long-term care homes due to the level of support they may require with completing activities of daily living. Long-term care homes provide 24-hour nursing care and supervision in a secured setting (Concerned Friends, 2017). Older adults with psychiatric disorders are more likely to live in institutional settings such as long-term care homes, with dementia and associated behavioural symptoms being leading reasons for admission to these settings (Seitz, Purandare & Conn, 2010). In Ontario, Alzheimer's disease and related dementias are the most common diagnoses within these institutions (McAiney et al., 2006). According to 2011 Statistics Canada data, 7.1% of all older adults aged 65 and over were living in special care facilities such as long-term care homes at this time

(Milan, Bohnert, Vasseur & Pagé, 2014). Nihtilä et al (2007) found that dementia, Parkinson's disease, stroke and mental health problems were more strongly associated with the risk of institutionalization than with the risk of death without institutionalization.

The nursing staff in LTC are often not well equipped to manage individuals with mental health concerns in long-term care homes (Dupuis et al., 2016; McAiney et al., 2006). Providing appropriate care for these individuals may be challenging due to lack of education and training to identify opportunities to implement safe interventions (Dupuis et al., 2016; McAiney et al., 2006). In addition to lack of education and training influencing the safe care practices of older adults with dementia, staff turnover, burnout, absenteeism, and injuries are also resulting implications (Clifford & Doody, 2018; McAiney et al., 2006).

2.3 Antipsychotic and Restraint Use

The high prevalence of dementia and mental health disorders in long-term care is often accompanied by high rates of prescriptions of psychotropic medications (Seitz, Purandare & Conn, 2010). Results from previous studies show that psychotropic drugs are used in approximately 52 to 80% of long-term care home residents with dementia (Willemse et al., 2016). Psychotropic medications may include medication classes such as anxiolytics, antidepressants, antipsychotics, and mood stabilizers (O'Connor et al., 2017). Antipsychotics are frequently used to manage responsive behaviours in adults aged 65 and older with dementia (Van Leeuwen et al., 2018). Healthcare providers may administer antipsychotics to persons with dementia in an attempt to mitigate aggressive or combative behaviours, agitation, restlessness, sleep disturbances, sundowning, wandering, etc. (Saleh et al., 2017). Unfortunately, there are many potential adverse effects with the use of antipsychotics, especially for the older adult population (Van Leeuwen et al., 2018). Adverse effects may include sedation, extrapyramidal

symptoms, and a heightened risk for cerebrovascular events, and mortality (Van Leeuwen et al., 2018). Additionally, antipsychotics can be linked with increased risk of falls due to their sedative effects (Brodaty et al., 2018; Saleh et al., 2017). Due to risks associated with these types of medications, many of the commonly prescribed psychotropic medications are categorized as potentially inappropriate for older adults (Hefner et al., 2015). Despite the risks, and the encouragement from best practice guidelines to use other non-pharmacological measures as first line treatments for managing responsive behaviours, antipsychotics are still frequently used, especially in long-term care settings (Foebel et al., 2016).

Another measure used to manage responsive behaviours in persons with dementia are physical restraints, which are commonly used across many countries when caring for older adults (Ralph & Meyer, 2014). Physical restraints can be defined as any measure that limits an individual's freedom of movement (Cadore et al., 2013). Examples of restraints include lap or waist belts, or restraints attached to a bed, as well as bed rails or locked tables that attach to chairs (Cadore et al., 2013). Similarly to antipsychotics, physical restraints have adverse effects that impact social, physical, and psychological outcomes (Cadore et al., 2013). Physical restraint use is associated with increased risk of cognitive and functional decline (Foebel et al., 2016). There is strong evidence to show that physical restraints are not effective in managing responsive behaviours, reducing falls, or fall-related injuries (Willemse et al., 2016). In a 2009 study, Feng at al. demonstrated that of the five countries included in this analysis (Canada, United States, Hong Kong, Switzerland and Finland), Canada had the highest percentage of physical restraint use in long-term care settings.

Despite available information related to the negative effects of psychotropic medications and physical restraints, these measures are still used to manage responsive behaviours. There is

conflicting evidence as to why these measures are still used. A 2008 study found that increased time pressures experienced by healthcare staff were related to increased psychotropic drug use (Pekkarinen et al., 2008). Similarly, Pekkarinen (2006) found that increased job demand was correlated with increased restraint use. Reasons for restraint use commonly indicated by healthcare workers also included ensuring safety of both staff and residents, facilitating treatment, and compensating for understaffing (Lam et al., 2017).

One of the focuses of improved quality in dementia care in long-term care settings is reducing the use of antipsychotics and restraint use (CIHI, 2018). The *Long-Term Care Homes Act* of Ontario requires homes to reduce the use of both chemical and physical restraints (Government of Ontario, 2007). The BSO program focuses on quality indicators, such as reduced restraint use, when providing education and services across long-term care homes. A Hong Kong study found that nursing staff had inadequate knowledge regarding restraint use, and only 19% believed that there were good alternatives to restraint use (Lam et al., 2017). Evidently, there is a need for further staff education and policy implementation to attempt to reduce chemical and physical restraint use for older adults with dementia in long-term care in order to improve and/or maintain resident outcomes (Feng et al., 2009).

2.4 The Local Health Integration Networks

The province of Ontario is currently divided into 14 regional health authorities known as Local Health Integration Networks (LHINs) (Local Health Integration Network, 2014). A map of the LHINs in Ontario can be viewed in **Figure 1**. The responsibility of each LHIN is to coordinate and fund local health care in order to improve accessibility and patient experience across many sectors including hospital care, primary care, home and community care, long-term care, and mental health and addictions (Local Health Integration Network, 2014).

For the purpose of this study, attention will be focused on the Waterloo Wellington LHIN which was established in June 2005 (Local Health Integration Network, 2014). The WW LHIN covers approximately 4800 square kilometers and is comprised of areas including Kitchener, Waterloo, Wellington, Guelph, Cambridge, and parts of Grey County. Ninety percent of the Waterloo Wellington LHIN covers rural areas; however, 90% of the WW LHIN population resides in urban areas (LHIN, 2014). A map of the WW LHIN is shown in **Figure 2**.

2.5 Behavioural Supports Ontario and Waterloo Wellington

In 2015, Gutmanis, Snyder, Harvey, Hillier & Le Clair identified challenges in available services to meet the needs of older adults with dementia. Challenges for dementia care included: "lack of recognition and under-diagnosis of cognitive impairment; lack of health-professional knowledge about dementia and presenting symptoms; and inadequate knowledge of screening, assessment and care strategies." Due to the inconsistencies in the healthcare system being able to support these individuals, in 2009 the Alzheimer Knowledge Exchange brought key system stakeholders together to develop a strategy for improving care for individuals living with responsive behaviours (Gutmanis et al., 2015). The need for a behavioural support system with an integrated-systems approach was identified as a priority. The following year, in 2010 the development of the Behavioural Supports Ontario program began (Gutmanis et al., 2015).

Behavioural Supports Ontario (BSO) is a provincial initiative to enhance supports and services for persons living with responsive behaviours in acute care, long-term care and community care settings. BSO programs operate within a provincial framework but implementation varies depending on regional resources and needs (Gutmanis et al., 2015). BSO was designed to leverage and collaborate with existing resources such as specialized geriatric services, geriatric mental health outreach teams, community support services, geriatric

emergency management nurses, day programs, primary care-based memory clinics and services offered by the Alzheimer Society (Gutmanis et al., 2015). The BSO program operates under three pillars: 1) system coordination and management; 2) integrated service delivery: intersectoral and interdisciplinary and; 3) knowledgeable care team and capacity building (Behavioural Supports Ontario, 2018b; Gutmanis et al., 2015). Further, there are seven principles that align with the three pillars including: 1) behaviour is communication; 2) person-centred care- respect; 3) diversity; 4) collaborative care; 5) safety; 6) system coordination and integration; and 7) accountability and sustainability (Behavioural Supports Ontario, 2018b; Gutmanis et al., 2015).

When persons living with dementia are no longer able to live at home due to their condition, they frequently move into long-term care homes. In the 2016-2017 fiscal year, 68% of referrals for BSO originated from long-term care homes; the remaining 32% of referrals were directed from the community (Behavioural Supports Ontario, 2017a). Therefore, based on numbers of referrals, it is important to focus on the operations of the services offered by BSO in long-term care in order to adequately support persons living with dementia, their caregivers, and healthcare providers. There were multiple phases in developing BSO, including program design, a testing and development phase, and finally the provincial implementation phase (Gutmanis et al., 2015). By February of 2012, all 14 LHINs had implemented the BSO framework (Behavioural Supports Ontario, 2018a).

In 2017, Grouchy, Cooper and Wong published a study evaluating the three distinct BSO models that were operating within long-term care homes: the embedded in-home model, and two variations of mobile models. The mobile models either have teams that serve multiple long-term care homes within a sub-LHIN region, or a team that serves all homes within the LHIN. The

embedded in-home model has a team that operates within each of the long-term care homes and will be further discussed in the next section.

Grouchy and colleagues attempted to identify which of the models was the most successful in terms of elements related to service provision and quality of care. A survey was conducted to identify differences in the provision of care, and resident outcomes across the different models. This survey incorporated a 5-point Likert scale to measure agreement/disagreement, as well as yes or no responses. Each of the 440 long-term care homes belonging to the Ontario Long-Term Care Association were invited to participate. A 59% response rate was achieved (259 homes). Participants were asked to identify which type of BSO funding model was used within their home. A focus of this survey was examining two quality indicators related to safe and effective care: antipsychotic use and restraint use. InterRAI data was also incorporated into this evaluation, mainly observing data from the Aggressive Behaviours Scale to observe differences in levels of aggressive behaviours across the BSO models. The Grouchy et al. (2017 studied identified three LHINs using the embedded in-home model, and five LHINs using one of the variations of the mobile models; however, which mobile model was being used could not be differentiated, so these data were pooled (Grouchy, Cooper, & Wong, 2017). The embedded in-home model was found to be the most successful of the three models in terms of achieving lower levels of responsive behaviours, aggressive behaviours, and restraint use (Grouchy, Cooper & Wong, 2017).

2.5.1 BSO in Waterloo Wellington

The Waterloo Wellington BSO program employs the embedded in-home model in their long-term care homes (Grouchy, Cooper & Wong, 2017). The embedded model includes staff or teams that are located within the long-term care home. The team includes a variety of disciplines

comprising Personal Support Workers (PSWs), Registered Practical Nurses (RPNs), Registered Nurses (RNs), and Recreational Therapists that receive funding to support the delivery of care for individuals with responsive behaviours within the long-term care home (Behavioural Supports Ontario, 2017b). Each of the 36 long-term care homes in Waterloo Wellington have embedded BSO staff (Behavioural Supports Ontario, 2017b). These selected staff members that are already dedicated workers of the long-term care home, may be referred to as "BSO Champions" in that they pursue leadership roles within the home to help coordinate care and teach effective strategies for managing residents experiencing responsive behaviours (Behavioural Supports Ontario, 2017b). Waterloo Wellington BSO embedded teams received 3,047 referrals for support in LTC in the 2016-2017 time period (K. Viau, personal communication, November 30, 2018). From 2015 to 2018 there was an average of 58 residents per LTC home on the WW BSO caseload (K. Viau, personal communication, November 30, 2018). In addition to supporting residents, BSO teams in long-term care also supported 1,410 family care partners in the 2017-2018 time period, which represented a 10% increase from the 2016-2017 time period (K. Viau, personal communication, November 30, 2018).

2.5.2 The Psychogeriatric Resource Consultant

An additional role important to the success of the BSO program in the long-term care setting is the Psychogeriatric Resource Consultant (PRC). The role of the PRC in LTC is to provide education and support the staff of long-term care homes in managing residents experiencing responsive behaviours (brainXchange, n.d.). There are currently five PRCs that work in the Waterloo Wellington LHIN. PRCs are also responsible for facilitating long-term care staff in the creation of treatment and care plans for the residents experiencing responsive behaviours (brainXchange, n.d.). PRCs may come from a variety of different disciplines such as

nursing or social work and share their knowledge and experience with best practice measures for caring for individuals with dementia and mental illness (brainXchange, n.d.).

There are three main functions of the PRC: 1) consultation; 2) capacity development and network building; and 3) education (brainXchange, n.d.). PRCs are able to consult with LTC staff to help foster a client-centered approach for providing best-practice care at a client-specific level. PRCs may also be involved with transitional care, increasing capacity for incorporation of evidence-based tools such as P.I.E.C.E.S. or the RAI-MDS, as well as knowledge translation (brainXchange, n.d.). The RAI-MDS, the Resident Assessment Instrument – Minimum Data Set, is a tool used to aid in care planning and to monitor the health status of residents living in long-term care (Hutchinson et al., 2010). P.I.E.C.E.S. will be defined further in the following section. Additionally, PRCs facilitate vital connections to outside agencies and resources to help meet the needs of older adults. They are able to help leverage existing services and build capacity across the healthcare system through knowledge transfer at local, regional, provincial and national levels, as well as to advance integration of new legislation (brainXchange, n.d.). Lastly, PRCs help to support education and skill development to care for individuals with responsive behaviours. The education provided also includes support with evidence-based tools such as P.I.E.C.E.S. and the Gentle Persuasive Approach (GPA) (brainXchange, n.d.; Stolee et al., 2009). These educational tools provided and employed by BSO to inform best practice person-centered care will be further discussed in the next section.

2.6 Person-Centered Approaches to Care

2.6.1 P.I.E.C.E.S.

"Putting the P.I.E.C.E.S. Together" is a learning initiative that is focused around addressing the mental health needs of individuals with dementia in order to provide person-

centered care (McAiney et al., 2006). P.I.E.C.E.S. incorporates various aspects of the person that the healthcare provider must consider to understand where the responsive behaviour exhibited by the older adult originates (Stolee et al., 2009). Providers must understand the person's **P**hysical, and **I**ntellectual, and **E**motional health. Next, the providers must support the older adult exhibiting responsive behaviours by maximizing his or her **C**apabilities, social and physical **E**nvironment, and his or her **S**ocial self. All of these components combined may allow the healthcare provider to provide competent care to the person experiencing these responsive behaviours (Hamilton, Harris, Le Clair & Collins, 2010; Stolee et al., 2009). There are several goals of the P.I.E.C.E.S. program that include broadening assessment and intervention knowledge, knowledge translation for improved care, leveraging LTC resources, and unifying the goals and approach to care of older adults with responsive behaviours (McAiney et al., 2006). The P.I.E.C.E.S. model encourages healthcare providers to look further into the responsive behaviours and ask themselves what may have changed in the older adult that may be causing or contributing to the behaviour, for example a urinary tract infection (Hamilton et al., 2010). The next question to explore is what the risks of the behaviour and possible causes may be, for example delirium or overstimulation (Hamilton et al., 2010). Lastly, it is important to identify the next actions to take to create a plan of care (Hamilton et al., 2010). The P.I.E.C.E.S. model fosters interdisciplinary collaboration to ensure best possible care practices for older adults exhibiting responsive behaviours (Hamilton et al., 2010).

2.6.2 Gentle Persuasive Approach

The Gentle Persuasive Approach (GPA) is an educational program designed to assist the interdisciplinary healthcare team in caring for older adults with dementia and responsive behaviours (Advanced Gerontological Education [AGE], 2017). The training was originally

designed to be implemented in long-term care settings but has expanded to acute care settings (Pizzacalla et al., 2015). GPA is an interdisciplinary training program that includes RNs, RPNs, PSWs, Environmental Services, Recreational Therapists, etc, which helps to facilitate teamwork amongst the staff (Pizzacalla et al., 2015). There are four modules included in this training program that focus on personhood, the basic dynamics and function of the brain and its associated behaviours with the progression of dementia, the interpersonal environment, as well as gentle physical techniques for self-protection (AGE, 2017; Pizzacalla et al., 2015). The first module, an Introduction to Personhood, attempts to teach a person-centered approach to understanding older adults at an individual level. The second module focuses on disease progression in terms of the brain structure and function, and additionally how dementia can be linked with responsive behaviours. This module teaches learners about the seven 'As' of dementia; amnesia, aphasia, agnosia, apraxia, altered perceptions, apathy, anosognosia, and attention deficit, and the implications of these factors for caring for the individual with dementia (AGE, 2017). The third module builds on both the first and second modules and encourages providers to utilize communication strategies to verbally de-escalate and safely manage responsive behaviours (AGE, 2017). The fourth and final module teaches gentle and respectful physical interventions that safely and effectively manage responsive behaviours that cannot be successfully mitigated by verbal de-escalation techniques (AGE, 2017). Gillies, Coker, Montemuro & Pizzacalla (2015) have reported that the use of GPA leads to decreased crisis situations, decreased use of restraints and one-to-one observations, as well as fewer safety incidents due to agitated older adults.

P.I.E.C.E.S. and GPA can be used in collaboration with each other to provide person-centered, safe approaches to care and to help effectively manage responsive behaviours without the use of restraints.

With all of these considerations including person-centered care training, BSO functions within long-term care homes to support residents with responsive behaviours, including individuals with dementia.

Figure 1. A Map of the Local Health Integration Networks in Ontario.
Legend:
1. Erie St. Clair
2. South West
3. Waterloo Wellington
4. Hamilton Niagara Haldimand Brant
5. Central West
6. Mississauga Halton
7. Toronto Central
8. Central
9. Central East
10. South East
11. Champlain
12. North Simcoe Muskoka
13. North East
14. North West
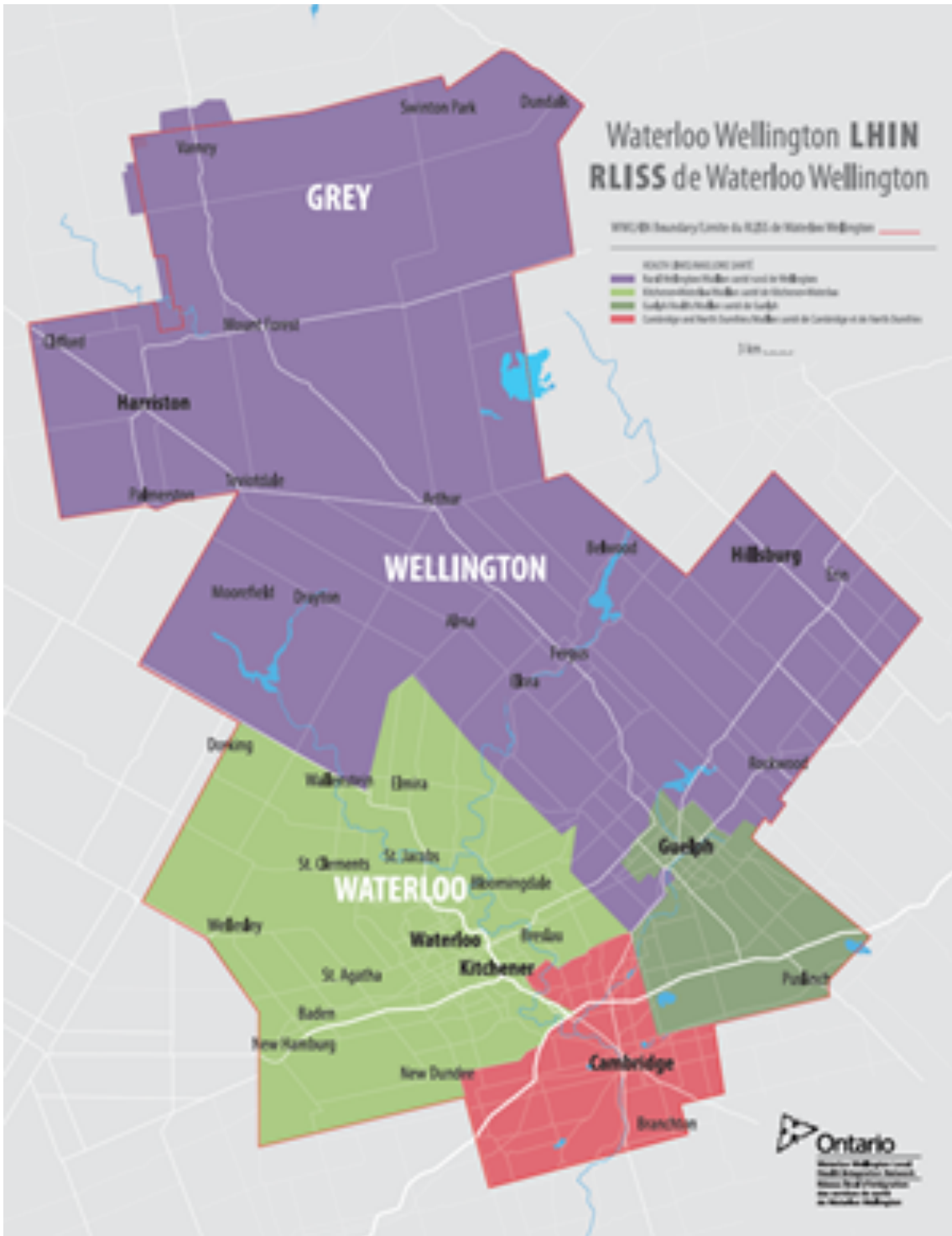
Figure 2. A Map of the Waterloo Wellington Local Health Integration Network

Chapter 3: Study Rationale

As demonstrated in the literature review, dementia is a growing issue in Canada as the population ages (Public Health Agency of Canada, 2017). Dementia is one of the most common causes of cognitive impairment in older adults and contributes to higher mortality rates, increased morbidity, and increased healthcare costs (Naylor et al, 2008). Additionally, older adults and their caregivers become vulnerable in situations where healthcare systems are unable to meet their needs (Naylor et al, 2008). Approximately one-third of older adults aged 80 years or younger diagnosed with dementia, live in long-term care homes. In older adults aged 80 and over, this proportion increases to 42% (CIHI, 2018). Although physical and chemical restraint use has been on the decline, there are still concerns of potentially inappropriate use in the long-term care setting to manage the responsive behaviours that may accompany a diagnosis of dementia (CIHI, 2018).

In Ontario, the Behavioural Supports Ontario program attempts to provide support across the community, acute, and long-term care settings for these individuals and their formal and informal caregivers (Grouchy, Cooper & Wong, 2017). Behavioural Supports Ontario involves a variety of staff that must successfully collaborate and coordinate their services in order to support the initiatives of this program (Grouchy, Cooper & Wong, 2017). There is limited research available on the BSO program, with two of the main resources being the work done by Gutmanis et al. (2015) as well as the evaluation conducted by Grouchy et al. (2017). Although the evaluation conducted by Grouchy et al. (2017) suggests that the embedded in-home model is the strongest model for improving resident health outcomes, there is still some disconnect within this model. After discussion with key stakeholders from BSO that have experience with the embedded in-home BSO model, they suggested that there are still some inefficiencies with using

the in-home model and an opportunity for further development of the current structure. Key stakeholders agreed that there is a need to evaluate if and how well the BSO program's intended outcomes are being met in order to further enhance the BSO program.

3.1 Research Questions and Objectives

The purpose of this research is to identify and evaluate the intended outcomes of the Waterloo Wellington BSO program in the long-term care setting within the WW LHIN. Evaluating the intended outcomes will include determining the importance, as well as organizational performance, related to each of these outcomes. BSO program leaders will be able to use the level of importance and performance data to cross-reference against the performance indictor data that they currently collect. This information will be valuable for restructuring or enhancing the activities that BSO currently undertakes. Additionally, this research will also focus on understanding the key indicators of a successful BSO program in long-term care. This evaluation will be completed using principles of appreciative inquiry and utilization-focused evaluation, through a sequential exploratory mixed-methods design. The following research questions were answered:

1. What does the Waterloo Wellington BSO program look like when it is functioning optimally in the LTC setting?

    a. How can BSO members of the LHIN and LTC staff collaborate to coordinate support for residents living in LTC?

2. What are the intended outcomes of the Waterloo Wellington BSO program?

    a. What is the level of importance of each of the intended outcomes to BSO and LTC staff?

b. How do BSO and LTC staff rate their organizations to be performing in relation

to each of the intended outcomes?

Chapter 4: Methods

4.1 Overview

Guided by the principles of Utilization-Focused Evaluation (Patton, 2008), and

Appreciative Inquiry (Cooperrider & Whitney, 2001), an evaluation of the Waterloo Wellington

Behavioural Supports Ontario program was conducted in consultation with BSO members from

the LHIN, family caregivers of persons living with dementia, and staff members from long-term

care homes across the WW LHIN. An Outcome Documentation Evaluation with a Utilization-

Focused Evaluation approach was chosen to inform this study. A sequential exploratory mixed

method design approach (Creswell & Creswell, 2017) was used to collect both qualitative and

quantitative data to inform this evaluation. See **Figure 3** for an overview of the methods that

were used in this study.
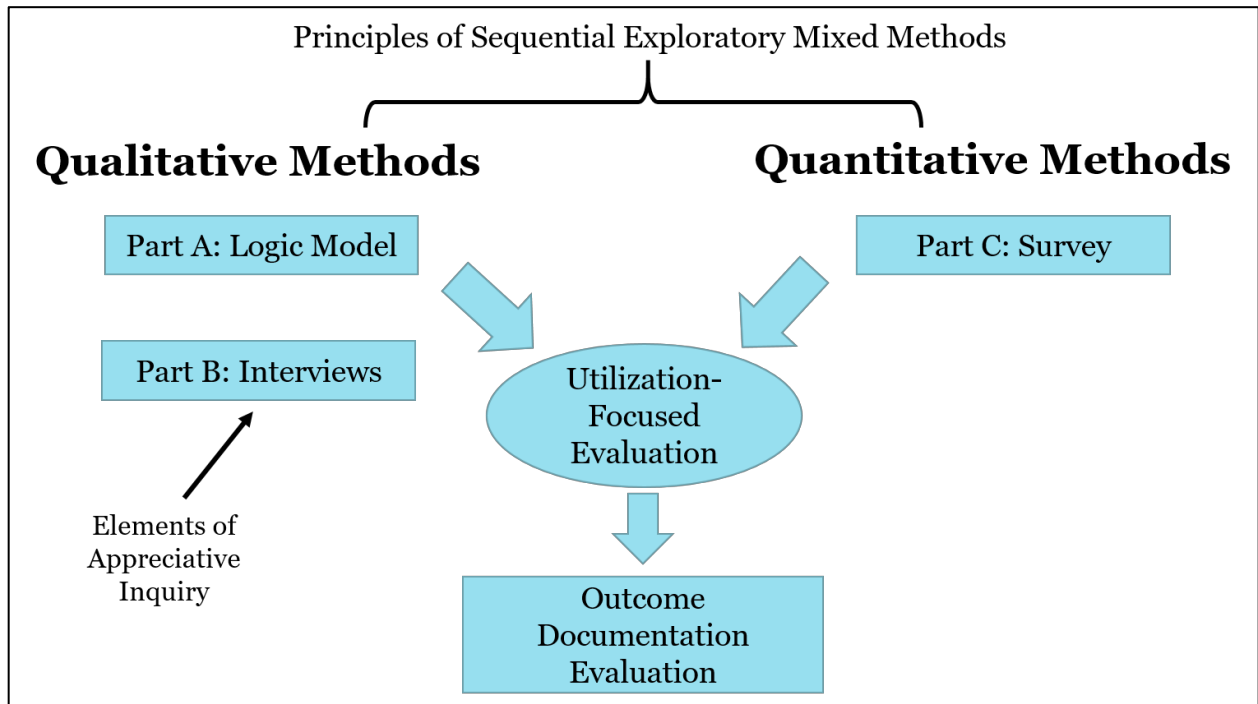
Figure 3. Flow diagram of methods overview

4.2 Outcome Documentation Evaluation

Issel (2014) describes three levels of outcome evaluations. In its most basic form, an outcome evaluation documents the effect of a program in reaching outcomes and impact objectives. The goal of an *outcome documentation evaluation* is to determine to what extent the outcome objectives were achieved (Issel, 2014). The TREW method is followed in which the elements of "in what **T**imeframe, what proportion of the **R**ecipients experience what **E**xtent of **W**hich type of change" are answered (Issel, 2014). In the case of this study, the researcher will aim to determine how well older adults receiving services from BSO in long-term care settings are being supported to manage their responsive behaviours. The timeline discussed will be the inception of the program to the present, in each of the homes, specifically looking at recent experiences since the publication of the results of the Grouchy et al., (2017) evaluation.

In contrast, to determine whether or not the changes or differences observed in a program were truly due to the intervention, an *outcome evaluation* should be conducted. The outcome evaluation is highly rigorous in nature (Issel, 2014) and typically utilizes one of three designs: 1) a randomized controlled trial (RCT), 2) a comparison group, or 3) a pre-post comparison (World Health Organization [WHO], 2000). However, using an RCT design in the case of this study would be impractical due to the healthcare-based setting of BSO in long-term care. RCTs may be well-suited for healthcare issues such as pharmacology trials, however, may be challenging to conduct in other areas of healthcare research (Kessler & Glasgow, 2011). Mixed methods designs are one of the research strategies suggested to provide generalizable findings that can be implemented in real-world settings (Kessler & Glasgow, 2011). As this study seeks to define and clarify program outcomes to determine the elements of a successful program, initial results collected in these preliminary stages could lead towards conducting a more rigorous outcome

evaluation in the future. For example, an RCT could be conducted in the future to evaluate the implementation of an intervention in the long-term care homes, such as an education session to support changes for the BSO program. Homes receiving the intervention could be compared with homes that did not receive the intervention and outcomes could be reassessed based on these results.

4.3 Utilization-Focused Evaluation

Utilization-Focused Evaluation is a method of evaluation that is rooted in the idea that an evaluation is to be designed based on its usefulness *by* and *for* the specific intended primary users (Patton, 2008). There are two fundamental requirements of the utilization-focused evaluation approach (Patton, 2008). First, key stakeholders are to be consulted in order to determine their specific needs and desires for the evaluation to be conducted. Second, the evaluator must use the information provided by the key stakeholders to further inform and guide the evaluation process (Patton, 2008). Two key stakeholders from Behavioural Supports Ontario were identified early in the inception of this project. Throughout this research, these stakeholders were consulted on a frequent basis to ensure this evaluation work could provide useful information that is in line with their identified needs.

4.4 Mixed-Methods Study Design

Principles from the *sequential exploratory mixed methods design* were used to incorporate both qualitative and quantitative data to develop this evaluation. As per the sequential exploratory mixed methods design, qualitative data were first collected and analyzed, followed by quantitative data collection and analysis (Creswell & Creswell, 2017), which can be reviewed in **Figure 4**. The quantitative measures build on the initial qualitative data. One of the

challenges of using this design is determining how to use the information gained in the initial qualitative phase to inform the development of the quantitative measure in the second phase. In this case, interview and focus group data were analyzed to determine additional program goals and outcomes that were then integrated into the survey.

For the purpose of this study, there were three parts (A, B, and C) that fell under two phases of data collection. In Part A, a logic model, a component of early stages of program evaluation was developed in consultation with key stakeholders. In Part B, individual and focus group interviews with healthcare providers, BSO members from the LHIN, and family caregivers occurred. Both Part A and Part B comprise the qualitative phase of this study.

After qualitative data collection and analysis stages were completed, quantitative data were collected and analyzed. In Part C, a survey, informed by the findings from the qualitative component of the study (Part A and B), was distributed to BSO members from the LHIN as well as the long-term care home staff to further inform the evaluation. Utilizing both qualitative and quantitative data permits triangulation for validating data collected and the interpretation during the analysis phase (Cullum, Ciliska, Haynes & Marks, 2008; Koch & Harrington, 1998).

Phase 1	Phase 2	Phase 3	
Qualitative Data Collection and Analysis	Development of the Quantitative Survey	Quantitative Data Collection	Quantitative Analysis and Interpretation of Results
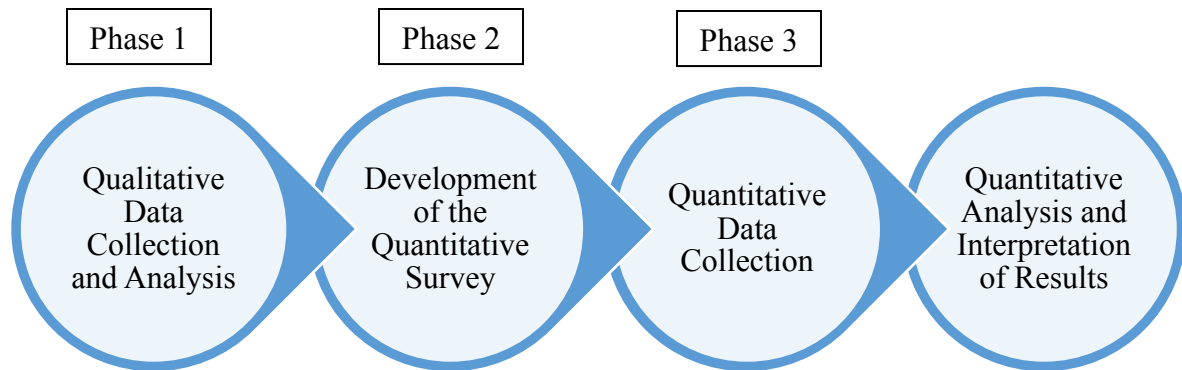
Figure 4. Phases of data collection and analysis as following the sequential exploratory mixed methods design (Creswell & Creswell, 2017)

4.5 Selection, Recruitment, and Ethics

Two key stakeholders from Behavioural Supports Ontario were contacted at the inception of this project to determine interest in having an evaluation conducted on the Waterloo Wellington Behavioural Supports Ontario program. These two key stakeholders provided a vital link in connecting with additional participants for the qualitative and quantitative components of this research. These stakeholders were consulted regularly throughout the evaluation, in line with the utilization-focused evaluation approach.

Purposive sampling was used in this study, to ensure that participants were knowledgeable in the area of research and meet the characteristics of the intended study population (Cullum, Ciliska, Haynes & Marks, 2008; Etikan, Musa & Alkassim, 2016; Patton, 2002). Using a purposive sampling method creates some limitations for the generalizability of this evaluation to other regions across Ontario, as all of the participants recruited for this study are a part of the Waterloo Wellington LHIN. However, data should be generalizable to the long-term care homes across the Waterloo Wellington LHIN that operate under the same embedded

model framework. Ideally, Part B of this study aimed to involve approximately 4-6 dyads of older adults and their caregivers, 5-8 BSO members from the LHIN, and 15-20 long-term care healthcare providers resulting in a total of approximately 24-34 participants. This study was able to include 4 family caregivers, 5 BSO members from the LHIN, and 16 long-term care staff from various homes across Waterloo Wellington, resulting in a total of 25 participants.

Selection from Long-Term Care Homes

The Waterloo Wellington LHIN is divided into four sub-LHIN regions: 1) KW4; 2) Cambridge-North Dumfries; 3) Wellington; and 4) Guelph-Puslinch. To select the long-term care homes to be involved in this study as well as the long-term care staff and family caregivers, the researcher categorized each of the homes based on sub-LHIN region, urban *vs.* rural settings, and the number of long-stay beds (**Table 1**). The number of long-stay beds were divided into three categories (small, medium, and large). Homes with 80 or less long-stay beds were classified as small, 81-130 beds as medium, and 131 or more beds as large. Six categories were established based on these criteria: 1) Urban-Small; 2) Urban-Medium; 3) Urban-Large; 4) Rural-Small; 5) Rural-Medium; and 6) Rural-Large. Six homes were initially selected from each of these categories across the sub-LHIN regions (**Table 2**).

The key stakeholders from BSO assisted with recruitment of participants from the long-term care homes that were initially selected. One of the key stakeholders emailed gatekeepers of the long-term care homes such as the Director of Care or Administrator. These gatekeepers assisted in recruiting healthcare providers as well as residents and their informal caregivers in the long-term care home. LTC staff could include RNs, RPNs, Directors of Care, Recreational Therapists, Physical and Occupational Therapists, and Physicians. LTC staff did not have to be specifically involved in the in-home BSO program but had to provide some level of direct care

for residents with dementia and responsive behaviours. Of the 36 long-term care homes in the Waterloo Wellington LHIN, six homes were initially selected to encompass a variety of settings (i.e. rural and urban) and variety of sizes in each of the sub-LHIN regions. The goal was to have approximately three to five LTC staff per focus group. In line with a snowball sampling approach (Biernacki & Waldorf, 1981; Cullum, Ciliska, Haynes & Marks, 2008), some of the PRCs that participated in interviews also reached out to the long-term care homes they support in Waterloo Wellington for involvement in this study.

Further, the long-term care home gatekeepers such as the Administrator or Director of Care were consulted in order to recruit eligible older adults and caregivers. To be eligible the older adult resident had to live in one of the LTC homes across the WW LHIN, have dementia, with some resulting level of responsive behaviours and have sufficient cognitive capacity to participate in an interview. In turn, family caregivers had to be a primary informal caregiver for an older adult resident with dementia and responsive behaviours living in the WW LHIN. Knowledge of the BSO program was not necessary for these interviews, as questions were focused around aspects of care, rather than the program specifically. The intent was to recruit four to six older adult and caregiver dyads in total, with approximately one dyad from each of the selected long-term care homes.

Selection from BSO members from the LHIN

       The snowball sampling approach was used to recruit BSO members from the WW LHIN. One of the key stakeholders emailed members of BSO from the LHIN, including the five PRCs of the Waterloo Wellington LHIN, on behalf of the researcher. All of the recruitment materials for this study can be reviewed in **Appendices A, B, C, D**.

Ethics

       Ethics clearance for this study was obtained from the University of Waterloo's Office of Research Ethics (ORE #40037).

Table 1: *Long-Term Care Homes in the Waterloo Wellington LHIN divided by sub-LHIN regions, urban vs. rural setting, and number of long-stay beds.*

Long-Term Care Home	Sub-LHIN	Urban/ Rural	# of Long-Stay Beds	City/ Town
KW4 Sub-LHIN				
Chartwell Elmira	KW4	Rural	48	Elmira
Derbecker's Heritage House	KW4	Rural	72	St. Jacob's
A.R. Goudie	KW4	Urban	79	Kitchener
Pinehaven	KW4	Urban	84	Waterloo
Parkwood Mennonite	KW4	Urban	96	Waterloo
Barnswallow Place	KW4	Rural	96	Woolwich
Nithview Home	KW4	Rural	97	New Hamburg
Sunnyside Home	KW4	Urban	110	Kitchener
Trinity Village Care Centre	KW4	Urban	150	Kitchener
Columbia Forest	KW4	Urban	156	Waterloo
Lanark Heights	KW4	Urban	160	Kitchener
Chartwell Westmount	KW4	Urban	160	Kitchener
Winston Park	KW4	Urban	192	Kitchener
University Gates	KW4	Urban	192	Waterloo
Forest Heights	KW4	Urban	240	Kitchener
Cambridge-North Dumfries Sub-LHIN				
Riverbend Place Seniors	Cambridge- North Dumfrie	Urban	53	Cambridge
Cambridge Country Manor	Cambridge- North Dumfrie	Rural	80	Cambridge
Golden Years	Cambridge- North Dumfrie	Urban	80	Cambridge
Fairview Mennonite Home	Cambridge- North Dumfrie	Urban	84	Cambridge
Stirling Heights	Cambridge- North Dumfrie	Rural	110	Cambridge
Saint Luke's Place	Cambridge- North Dumfrie	Urban	114	Cambridge
St. Andrew's Terrace	Cambridge- North Dumfrie	Urban	128	Cambridge
Hilltop Manor	Cambridge- North Dumfrie	Urban	185	Cambridge
Wellington Sub-LHIN				
Twin Oaks of Maryhill	Wellington	Rural	31	Maryhill
Eden House	Wellington	Rural	58	Guelph- Eramosa
Royal Terrace	Wellington	Rural	67	Palmerston
Caressant Care Arthur	Wellington	Rural	80	Arthur
Caressant Care Fergus	Wellington	Rural	87	Fergus
Strathcona (Saugeen Valley)	Wellington	Rural	87	Mount Forest
Caressant Care Harriston	Wellington	Rural	89	Harriston
Wellington Terrace	Wellington	Rural	176	Fergus
Guelph-Puslinch Sub-LHIN				
Morriston Park	Guelph-Puslinch	Rural	28	Puslinch
Elliott Community	Guelph-Puslinch	Urban	85	Guelph
Lapointe-Fisher	Guelph-Puslinch	Urban	92	Guelph
Village of Riverside Glen	Guelph-Puslinch	Urban	192	Guelph
St. Joseph's Health Centre	Guelph-Puslinch	Urban	240	Guelph

Note: Yellow highlighting is to denote rural settings.

Table 2: *Selection categories for the long-term care homes in the Waterloo Wellington LHIN*

Type	# of Homes in WW	KW4	C-N	W	G-P	Total
Urban- Small	3		1			1
Urban- Medium	8	1				1
Urban- Large	10	1				1
Rural- Small	8				1	1
Rural- Medium	6		1			1
Rural- Large	1			1		1
Total Homes in WW:	36			Total Selected:		6

Note: Yellow highlighting is to denote rural settings

4.6 Qualitative Methods

4.6.1 Part A: The Logic Model

A logic model was created with two key system stakeholders from BSO to create a visual representation of various program aspects of BSO operating in LTC including the program goal, the situation, available resources, activities, the intended audience, the outputs and expected outcomes (Public Health Ontario, 2016). The logic model also considers assumptions related to the program, and the external factors or influences that may affect the operations or success of the program (Public Health Ontario, 2016). Definitions of each of the sections of the logic model can be viewed in **Table 3**. Logic models can be very advantageous in program evaluation. The following list highlights a few of the many advantages of creating a program logic model; 1) useful in evaluations to clarify complex relationships within a program; 2) provide a visual source of communication; 3) ensure that important outcomes are not disregarded; and 4) provide a framework for interpreting information (Goldman & Schmalz, 2006).

The logic model is guided by the theory of change and follows the format as shown by Public Health Ontario (2016). Creating a logic model alongside the key stakeholders of BSO helped to clearly delineate the short-, intermediate-, and long-term outcomes of the current activities of the embedded in-home BSO program operating in the long-term care setting. The

logic model provides a foundation for determining if outcomes are being met, in line with an outcome documentation evaluation. The outcomes identified in the logic model of Part A helped to inform the survey questions of Part C. The initial logic model that was created can be found in **Appendix E**.

Table 3. *Definitions of the logic model components.*

Logic Model Component	Description
Program Goal	The overall outcome that the program wishes to achieve.
Situation	The background or context of the program being evaluated.
Resources	The available resources invested into the program
Activities	Program interventions
Audience	Whom the program is targeting. Audience may be divided into primary and secondary audiences. Primary audience is the main audience being targeted, whereas secondary audience are those who may be impacted or influenced by the program indirectly.
Outputs	Products produced through the activities of the program, usually represented as numeric values or percentages
Outcomes	Short-term to long-term expected changes due to a program. Outcomes are associated with direction (e.g., *increased* awareness).
Assumptions	Underlying theories and beliefs about the program and its context, which may influence the development of the program.
External Factors	Factors that influence the program and program success, but are beyond the control of the program planners.

Note: Adapted from Public Health Ontario; Focus On: Logic Model- A planning and evaluation tool (2016).

4.6.2 Part B: Qualitative Interviews & Focus Groups

All interviews followed an Appreciative Inquiry (AI) approach in which questions were deliberately asked in a positive, strengths-based frame to focus on program aspects that are functioning well to leverage a system's capacity to strengthen positive potential (Cooperrider & Whitney, 2001). Appreciative Inquiry seeks to highlight the best aspects of people, their organizations, and their surrounding environments (Cooperrider & Whitney, 2001). This approach deviates from negativity and criticism surrounding an organization or program (Cooperrider & Whitney, 2001). Some of the main focuses of Appreciative Inquiry include achievements, assets, strengths, opportunities, benchmarks, and visions of valued and possible futures (Cooperrider & Whitney, 2001).

Appreciative Inquiry is grounded in five core principles, including the Constructionist Principle, the Principle of Simultaneity, the Poetic Principle, the Anticipatory Principle, and the Positive Principle (Cooperrider & Whitney, 2001). Each of these principles informs the foundational concepts of Appreciative Inquiry's theory-base of change (Cooperrider & Whitney, 2001). The Constructionist Principle is built on the foundation that "human knowledge and organizational destiny are intertwined" (Cooperrider & Whitney, 2001). The Principle of Simultaneity recognizes that inquiry and change occur simultaneously, and that questions asked prepare for what can be discovered (Cooperrider & Whitney, 2001). The Poetic Principle reveals that organizations are sources of studying and learning, similar to an open book (Cooperrider & Whitney, 2001). The Anticipatory Principle demonstrates that having positive images of the future inspires positive actions. Lastly, the Positive Principle is rooted in the idea that positive questions lead to positive change within an organization (Cooperrider & Whitney, 2001).

There are four key stages in AI: 1) Discovery; 2) Dream; 3) Design; and 4) Destiny. These four stages are also referred to as the Appreciative Inquiry "4-D" Cycle and can be reviewed in **Figure 5**. The <u>D</u>iscovery stage involves organizing the system inquiry into the positive change core. The <u>D</u>ream stage then sets a results-oriented image in relation to potential and enhancing the current organization. Next, the <u>D</u>esign stage proposes new or modified strategies for achieving the dream/goal of the organization. Finally, the <u>D</u>estiny stage strengthens and mobilizes the affirmative capability of the organization (Cooperrider & Whitney, 2001). In the centre of this "4-D" cycle is **Affirmative Topic Choice** and is the most important part of Appreciative Inquiry. Selecting the Affirmative Topic Choice is the beginning step of the AI 4-D cycle (Cooperrider & Whitney, 2001). The three to five topics selected represent what the organization wants to discover and learn more about. For the purpose of this study, the Affirmative Topic Choice stage was completed, and the Discovery stage was initiated. The researcher aimed to determine the Affirmative Topic Choices based on ideal operation of the BSO program, and collaboration and coordination between service providers, and began the Discovery phase by exploring the positive experiences of service providers.

There were three different populations of participants interviewed for this study, including; 1) members of BSO from the LHIN; 2) long-term care home staff and; 3) the family caregivers of residents living with dementia in long-term care. Interviewing this diverse population helped to provide a variety of perspectives on how the BSO program is operating within long-term care homes. As part of AI, the researcher sought out to understand what the program looks like when operating at its greatest potential, how healthcare staff coordinate and collaborate to provide care, and the level of support residents and their families are receiving

from this initiative. Additionally, the researcher hoped to identify aspects of the WW BSO program that may be modified or changed to guide and improve future practice.

Semi-structured individual interviews were conducted with BSO members from the LHIN, which included individuals such as psychogeriatric resource consultants, who are a valuable external resource to the in-home BSO program. Semi-structured individual interviews were also conducted with family caregivers of residents living with dementia in long-term care. Family caregivers and older adults had the choice to be interviewed together as a dyad, however, all family caregivers opted to be interviewed individually. Focus group interviews were conducted with the long-term care staff using a semi-structured interview guide. Each of the interview guide documents were first reviewed with the key stakeholders to ensure the questions asked adequately captured their intended outcomes and needs of this evaluation.

The semi-structured interview guides can be reviewed in **Appendices F, G, and H**. The key questions included in the interview guide were intended to provide a foundation for growth and development of topics related to the operations of BSO within the long-term care setting. Focus group interviews provide the same opportunity for development of conversation, with an additional aspect of group interaction. Focus groups lasted approximately 20-30 minutes, and individual interviews were approximately 15-20 minutes in length. The interview questions attempted to reveal the ideal operations of BSO in long-term care homes, and additionally future areas of improvement or goals for the program. Additionally, there were questions asked to address collaboration and coordination efforts between long-term care home and BSO members from the LHIN, and how these efforts may be improved upon. Program outcomes were also be identified throughout the interview and focus group periods, which were subsequently added to the survey completed in Part C.

Individual interviews took place in either an easily accessible, mutually agreed upon location or by way of telephone. Focus groups took place in the long-term care home's conference rooms. Informed consent **(Appendix I, J, and K)** was obtained prior to conducting interviews. In the case that there were situations involving persons with dementia, an assent form was also available **(Appendix L)**. All interviews were audio-recorded with permission from study participants. In the case that the interview took place by telephone, participants were asked to sign, scan and email the consent form back to the researcher prior to the interview. A follow-up feedback letter was also provided to study participants once interviews were conducted **(Appendix M).**
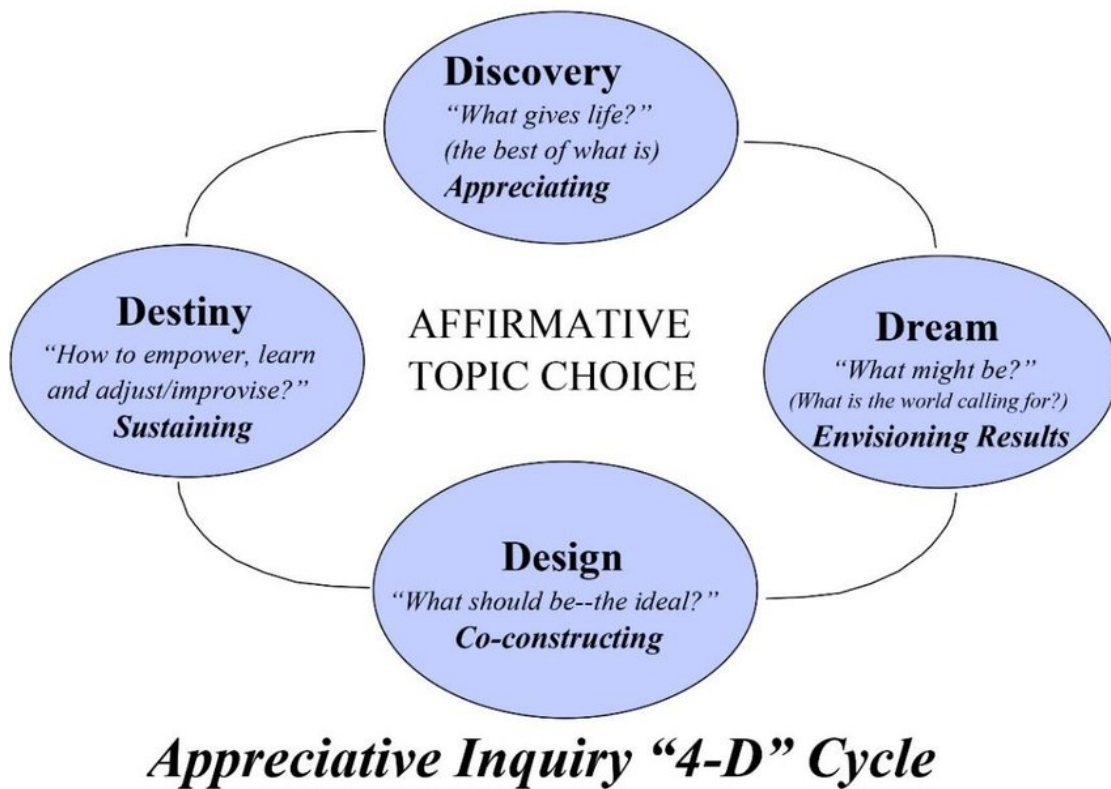
Figure 5. Appreciative Inquiry "4-D" Cycle (Cooperrider & Whitney, 2001)

4.6.3 Enhancing Qualitative Rigor

Although there are some inherent limitations of using a qualitative approach to conduct research, there are methods that can be used to improve the rigor or quality. Bradshaw, Atkinson and Doody (2017) developed a table outlining strategies to attain rigour in qualitative research.

To ensure credibility, authors suggest establishing rapport at the onset of the interview, as well as demonstrating compassion and empathy during the interview. Utilizing key stakeholders assisted in developing rapport as a mutual connection between the interviewer and participant. Discussing topics such as dementia and care received within the long-term care home was a sensitive topic in which the researcher utilized an empathetic and non-judgmental approach to discussion. Member checking is also a suggested approach to ensure credibility, participants were given the opportunity to review their interview transcript or a summary of the interview for accuracy. For confirmability, Bradshaw and colleagues encourage researchers to take notes during the research process, as well as ensure that findings represent the data that are collected and are not influenced by personal biases. During all interviews, the researcher collected notes on the interview guides to review during the transcription process. The researcher attempted to be reflexive in the approach to research and included direct quotations from participants. Dependability can be achieved by establishing an audit trail throughout the research process to outline the procedures and methods utilized. Lastly, although purposeful sampling may limit generalizability, to ensure transferability, a representation of a diverse group of stakeholders was used and a rich description of results was provided. With all of these strategies in mind, a high level of qualitative rigor can be achieved in this study.

4.7 Quantitative Methods

4.7.1 Part C: Surveys

After qualitative data collection was completed, quantitative data were collected using a survey. Items included on this survey were based in part on the Logic Model (**Appendix E**), as well as drawn from analysis of the qualitative interviews. Participants are able to provide valuable insight into the creation of items for scale development (Streiner, Norman, Cairney, 2015). Members of BSO from the LHIN and LTC staff that participated in interviews and focus groups were asked to complete this survey. Key contacts from the homes, as well as participants that were willing to provide their emails were emailed the SurveyMonkey® link after qualitative analysis was completed **(Appendix N)**. Surveys aimed to categorize which of the outcomes identified through the logic model and interviews were most important to the clinical practice of LTC staff and BSO members from the LHIN. Understanding which outcomes were most important to staff members helped to clarify which program aspects must be focused upon to enhance the success of BSO. Additionally, surveys also asked BSO Members from the LHIN and the LTC Staff to rate their organizations' performance on each of the listed outcomes. Each of the outcomes were rated on a five-point ordinal scale (Streiner, Norman & Cairney, 2015). When evaluating importance of the outcomes, the ordinal variable descriptors: 1) Not Important; 2) Slightly Important; 3) Important; 4) Very Important and; 5) Extremely Important were used. When rating the organizational performance on each of the outcomes, these ordinal variable descriptors included: 1) Poor; 2) Fair; 3) Good; 4) Very Good; and 5) Excellent. Both scales were organized to have more positive adjective descriptors as compared to negative descriptors. The expectation was that respondents would likely show a strong skew towards the positive end of the scale when rating importance and performance (Streiner, Norman & Cairney, 2015).

Allowing for more positive options allows for a finer distinction between answers, and leads to greater discrimination between responses (Streiner, Norman & Cairney, 2015).

As aforementioned, outcomes identified through the program logic model in Part A were used in the survey. In line with the sequential exploratory mixed methods design, information related to program outcomes obtained from qualitative analysis in Part B was also added to this survey in later stages of this work. A sample of the survey can be reviewed in **Appendix O**.

4.8 Data Analysis

Conventional content analysis was used to analyze qualitative data. From the quantitative data, means were calculated in order to make comparisons across levels of importance *vs* levels of performance.

4.8.1 Qualitative

Once data collection was completed, data analysis was conducted. From the audio recordings, interviews were transcribed verbatim into Microsoft Word and uploaded into NVivo 12. Qualitative analysis was informed by a conventional content analysis approach (Hseih & Shannon, 2005) and was completed in NVivo 12 to identify consistent themes across interviews. In this method, the texts were first read repeatedly in order for the researcher to be immersed in the data. Transcribing the interviews also aided the researcher's immersion into the data. Next, a line by line coding approach was used to highlight key ideas and concepts (Hseih & Shannon, 2005). Throughout this process researcher created memos from the initial analysis. Codes were derived from this preliminary analysis and became the initial coding scheme. Codes were then sorted into categories and developed into themes (Hsieh & Shannon, 2005). Using an inductive approach to data analysis allowed for significant themes to emerge from the data instead of

analysing based on preconceived notions or prior assumptions (Hsieh & Shannon, 2005; Thomas, 2006). A PhD-trained health researcher, CT, independently reviewed and coded three transcripts based on the coding structure provided. This review included one transcript from each participant group. CT and KB met to review codes and check for consistency across transcripts to help to enhance qualitative rigor. Agreement was achieved, and the remainder of coding was continued independently by KB. Memos for each participant group were created as a preliminary base of analysis (**Appendix P, Q, and R)**

Additionally, each of the transcripts was independently coded in NVivo12 to identify program outcomes. Once each transcript was reviewed and coded for these outcomes, outcomes were then added to a list to be included for the survey in Part C.

4.8.2 Quantitative

Results from SurveyMonkey® were imported to Excel for analysis. Mean ratings were calculated for "Level of Importance" and "Current Organizational Performance" based on the numeric value of 1-5 that was assigned to each of the descriptive adjectives. The means helped to demonstrate on average, which indicators were most important to services providers involved with the BSO program, as well as in which areas providers feel their organization is thriving or lacking. The means could then be compared across the levels of importance *vs.* levels of performance to identify if the outcomes that are important to providers, are also being performed well across the homes. There may be concern that data cannot be assumed to be interval, however, as Streiner and Norman (2008) discuss, from a pragmatic viewpoint under most circumstances, data from scales can be analyzed as interval data without introducing severe bias. This information may be used to help structure and guide future activities of BSO to better support older adults with responsive behaviours.

4.9 Reflexivity Statement

To reduce the potential for personal biases to affect both qualitative and quantitative data collection and analysis, the researcher attempted to set aside preconceived notions regarding potential outcomes and results. To do this, interviews were transcribed verbatim and an inductive approach to data analysis was used in order to allow themes to emerge naturally from the data rather than fitting them into pre-constructed categories. A reflexive statement to aid in the researcher's position within the research is provided:

"As an RN, working in an acute care setting, I have personal experience with collaborating and coordinating with other healthcare providers, which may inform my opinions or hypotheses of this research. Although the area of care in which I work may have different nuances and practices compared to the long-term care setting, the principle of provider communication and collaboration remains similar. Working on an acute inpatient mental health and addictions unit, I have still had opportunities to provide care to older adults living with dementia and have experienced resulting responsive behaviours.

Hospitals across Ontario follow a least restraint policy, however, the use of mechanical and chemical restraints have very different indications and regulations in the mental health setting as compared to long-term care. With my position as an RN working in the mental health setting, I have experience with the application and administration of both mechanical and chemical restraints, albeit with a very different patient population. This in part may bias my perspective on indicators related to restraint use, however, I will attempt to remain neutral when discussing these topics.

My nursing background has provided me with knowledge of the healthcare landscape across Ontario. During my nursing education I was fortunate enough to be immersed in the

long-term care home setting as a student nurse, which in part sparked my interest to become

involved with dementia research and exposed me to BSO. The Hamilton Haldimand Niagara

Brant LHIN utilizes a mobile model, which differs from the embedded model that I plan to

evaluate in the Waterloo Wellington LHIN.

　　　　Janice Morse (2010) addresses the strengths in being an insider in health research. She

states that having a good understanding of the healthcare environment is an asset in being able

to abide by rules and norms of the healthcare setting. Working with a variety of healthcare

providers, patients and family caregivers through my role as a nurse has helped provide me with

training that I believe will be useful during the qualitative interview stages of this work.

Although I have had some level of exposure to the mobile BSO model, I have yet to experience

the embedded in home-model. I am hopeful that the differences between these models will help to

limit my preconceived opinions of the BSO program. I am aware that my connection to this

research as an RN may impose some inherent level of bias within this research, however, I will

attempt to remain self-aware throughout the process of data collection and analysis and

maintain a neutral standpoint."

Chapter 5: Results

5.1 Qualitative Findings

There were four long-term care homes across the Waterloo Wellington LHIN that participated in long-term care staff interviews. From these homes, a total of sixteen long-term care staff were interviewed in both focus group and individual interview settings. Qualitative interviews were also conducted with five members of the LHIN (including PRCs and BSO Leads), who work with the long-term care homes, as well as with four family caregivers of residents living with dementia and responsive behaviours. No older adult residents participated in this study. An overview of the number of participants as well as their specific role or relation to the resident with dementia can be observed in **Table 4**.

Table 4. Overview of participant position/ role / relationship

Position/ Role/ Relationship	# of Participants	Total # of Participants
Long-Term Care		
Registered Nurse	3	
Registered Practical Nurse	2	
Personal Support Worker	4	
Director of Care	1	
Assistant Director of Care	1	**16 Long-Term Care Staff Total**
Social Worker	2	
Recreation Therapist	1	
Recreation Aide	1	
Dietary Aide	1	
BSO Members of the LHIN		
Psychogeriatric Resource Consultants	4	**5 BSO Members of the LHIN Total**
BSO Administrator	1	
Caregivers		
Wife	1	**4 Caregivers Total**
Daughter	3	
		25 Participants Total

Six homes were initially selected based on the selection criteria. Of the six homes that were initially selected, three homes agreed to participate. Through snowball sampling, a fourth

home participated. The breakdown of the participating homes for the long-term care staff interviews into the selection categories is presented in **Table 5**. Four caregivers participated in interviews on behalf of themselves and their loved one living with dementia and responsive behaviours. As seen in **Table 4**, three daughters and one wife participated. Of the residents associated with these family caregivers, there were three female residents and one male resident. Two of the caregivers included in this study have loved ones living in one of the homes that was involved in staff interviews. The other two caregivers who participated were not associated with the homes interviewed and were recruited through snowball sampling. The breakdown of participating homes for the caregiver interviews into the selection categories can be observed in **Table 6**.

Table 5.   Breakdown of participating LTC homes for LTC staff interviews across the Waterloo Wellington LHIN

Type	# of Homes in WW	KW4	C-N	W	G-P	Total
Urban- Small	3					
Urban- Medium	8					
Urban- Large	10	2				2
Rural- Small	8					
Rural- Medium	6		1			1
Rural- Large	1			1		1
Total Homes in WW:	36			Total Participated:		4

Note: WW: Waterloo Wellington; KW4: Kitchener Waterloo; C-N: Cambridge-North Dumfries; W: Wellington; G-P: Guelph-Puslinch

Table 6. Breakdown of participating LTC homes for caregiver interviews across the Waterloo Wellington LHIN

Type	# of Homes in WW	KW4	C-N	W	G-P	Total
Urban- Small	3					
Urban- Medium	8	1				1
Urban- Large	10	1				1
Rural- Small	8		1			1
Rural- Medium	6					
Rural- Large	1					
Total Homes in WW:	36			Total Participated:		3

Note: WW: Waterloo Wellington; KW4: Kitchener Waterloo; C-N: Cambridge- North Dumfries; W: Wellington; G-P: Guelph-Puslinch

Findings from each of the participants groups are presented separately. An overview of the similarities and differences across each of the participants groups is also included.

5.1.1 Long-Term Care Staff: Interview Findings

The primary aim of the focus group and individual interviews with the long-term care staff was to better understand the current operations of the BSO program, and further to that, what it takes for the BSO program to be successful. Additionally, to answer the sub-question pertaining to the first main research question, questions were posed about collaboration efforts between LTC staff and the external BSO members from the LHIN. Staff were able to identify what aspects of their in-home programs were functioning well, and what types of changes may be needed in order to make the program more successful across the home. Three major themes appeared across these interviews:

1. The Challenges Faced in Long-Term Care Settings

2. The Components of a Successful BSO Program in Long-Term Care

3. Wishes of '*More*' for the Future of the BSO Program

From these three main themes, further subthemes were identified as described in the following sections.

1. *Challenges Faced in Long-Term Care Settings*

Long-term care is not without challenges. Despite the appreciative inquiry format of the interview guide, long-term care staff acknowledged some of the difficulties they face working in this setting and the impact these challenges have on resident care. The increasing complexity of residents; lack of resources, support, and accessibility; and the impact of responsive behaviours on care were cited as some of the main challenges staff face on a day-to-day basis. Although many of the challenges described were general to the long-term care setting, they directly impact the function and operations of the BSO program.

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A. Increasing Complexity of Residents

Long-term care staff frequently discussed the impact of the increasing complexity of

residents within their long-term care homes. One staff member discussed the changes in

presenting illnesses she sees within the home:

> *"I think it's less dementia care now, it's more psychiatric care. I think our training, or mine for sure is focused more on dementia care but we have so many more psychiatric care that we need—" (LTC9)*

This participant also acknowledged the lack of appropriate training in order to be able to

effectively manage these cases and to provide evidence-informed care. Another staff member

from a different home discussed the difficulty of admitting inappropriate cases into their home

and the challenges their BSO team has in effectively engaging and providing care to these

residents:

> *"I would take the opportunity to say we have had some challenges with umm, uhh people with acquired brain injury, especially the younger folks coming into long-term care. I think this team is amazing, but there are still people who are just not umm appropriate for the population we serve here, in terms of being able to meet their care needs. So the younger folks coming in are really needing a day program, like they need, they need to be busy all day. They've come from a group home environment, where they were going to day programs and umm most long-term care homes would not be able to provide the resources that they need for quality of life. So, we can do a lot, we do, do a lot, we're proud of what we do, but there's still things we can't do. It's just pushing it too, too much umm even just given our environment. Like our secured neighbourhood is 30 people, so we can't accept a lot of super high-risk people into that neighbourhood. Thirty independently mobile people, who have you know, brain trauma, we can't have that in terms of risks so long-term care's not the answer for everyone and that's a big gap in our system and I think we all know that." (LTC1)*

In addition to having these individuals placed inappropriately into long-term care; staff admit

that although long-term care may not be the right setting, there is a lack of availability in

resources in other settings to provide care for these individuals:

> *"Yeah sometimes there's people that we can't, we can't cope with in long-term care, but there's nowhere else for them to go that would give them better care." (LTC9)*

The lack of availability of resources to support these individuals outside of long-term care often means that long-term care homes become responsible; however, staff discussed feeling as though they are not adequately able to support these residents within this setting. Additionally, with the addition of these individuals into long-term care homes, staff felt as though it took away from caring for residents with other care needs.

B. *Lack of Resources, Support, and Accessibility*

Many of the staff members commented on the lack of resources available to best support their residents. Issues such as staffing shortages, and high resident-to-staff ratios put strain on the long-term care staff to provide care, and to be attentive to all of the residents' needs. Staff addressed the impact of the staffing shortages in providing care to all of their residents, especially the residents with high intensity behavioural care needs:

> *"Because in most nursing homes you work short-handed, most of the time so. And you just you know, don't have time to deal with you know like the regular people, let alone the responsive ones too." (LTC13)*

With staffing shortages and limited staffing resources, come high resident-to-staff ratios. The number of residents that staff are assigned impacts the amount of time they can spend with each resident:

> *"When I'm one-to-sixty in terms of recreation, I'm kind of limited in how much time I have." (LTC11)*

Staff also commented on the lack of accessibility to resources outside of the home in order to best support their residents living with dementia. For example, once residents are living within long-term care, staff describe challenges in being able to refer them to external services as there are limited options to connect them with these services:

> *"...accessibility for people in long-term care like with mental health or addictions, or dementia, like accessibility in this LHIN is something I've commented on from day one.*

Our resources are limited, uhh and then you know outside resources for education. So Alzheimer's Society we don't get internal, like we can't refer out." (LTC16)

Additionally, in the case that residents may need to be referred to specialized mental health services in hospital, some long-term care staff felt that these residents are not well supported through this resource due to their age, code status (I.e. Do Not Resuscitate (DNR)), and current living conditions:

> *"Yeah. Yeah and then umm, and then this is common, and I think the PRCs can appreciate this, if there is a process in place to Form 1[1] somebody and it's not taken seriously just because they're in long-term care, they're older, they're DNR. Umm I think it really speaks to you know, people's perception of people in long-term care. Umm and so that support is essential if they you know, we do everything internally but it's a process of, and that's our last minute resort to Form 1 and that would be my only comment, and I don't know if anybody else would agree, but that's my hugest concern." (LTC16)*

Moreover, long-term care staff discussed the variability in the quality of transitions from the community to long-term care. Some staff addressed the inconsistencies in information they receive from the community, including families, when transitioning a resident into long-term care:

> *"We do get uhh, sort of a write up on an individual, it depends on their family. Sometimes the family are super supportive, and they can just give us you know, a write out that is incredible and so informative and then sometimes we have people coming in that we know nothing about. You know not everyone is coming from home, some people are coming from community outreach places, you know people who have nobody in their lives, so it's a little bit of a guess where they're coming from." (LTC7)*

Staff also discussed the challenges they face in accessing resources such as the Community Responsive Behaviour Team (CBRT) that operates in Waterloo Wellington. This team includes social workers, recreational therapists, occupational therapists and a registered

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[1] Form 1 is an application for a psychiatric assessment in which a person may be involuntarily held in hospital when deemed a risk of harm to themselves or others.

nurse. The intention of this team is to support individuals in the community with care, service coordination and transitions (St. Joseph's Health Centre Guelph, 2018):

> *"There's a bit of a gap in that, yeah as [LTC2] said, in that transition. We don't hear from them or we don't really know how to access Community Responsive Behaviour. So even when we're touring people in the home, that's sort of a big question mark, no one really knows." (LTC1)*

The lack of coordination between community and the long-term care homes was discussed by staff members as one of the issues and challenges in transitioning residents across settings.

C. Impact of Responsive Behaviours

Staff also noted that care transitions mark a difficult time for residents, and often times there will be increased levels of responsive behaviours:

> *"So that transitional period is a lot more, can be very severe for people. So some people do really well, but generally it's at least 2 or 3 weeks of a major transition in somebody's environment and what they're used to and that is when we see a lot of expressions." (LTC7)*

Increased responsive behaviours often require more resources, including more time spent providing one-to-one care in attempts to support the resident and manage their presenting behaviours. Staff must quickly react to these needs as they have limited time to develop good rapport and relationships with residents:

> *"So because of the situation and the people that are living in the community longer, we don't get to know people early on. Dementia care has changed significantly from the last 20 years, and without you know, so you get them later in the disease where they're not manageable at home for whatever reason. We have to react quickly, and not have the story. We don't have the relationship yet and we need extra people to do that because we're having to learn it quicker in a later stage, in a later period of time." (LTC9)*

Even when staff are able to get to know and understand the residents and their triggers for behaviours, behaviours may change as one staff member commented "*and it's hard because every single person can change from day to day" (LTC14)*. With limited workspace at the care desk for long-term care staff to complete their documentation and necessary paperwork,

responsive behaviours can disrupt the workflow of staff even further, as one staff member stated:

> *"And when you look at our physical set up too, you know, there's not a whole lot of areas for them to go off in. So, we're all congregated around the desk and when someone's escalating (laughs), not a whole lot's getting done." (LTC12)*

Responsive behaviours may also be upsetting to other residents living in the home area, and may be upsetting to the residents themselves:

> *"Yeah and the residents on main floor, if there's one person screaming and yelling, it ticks the whole works off." (LTC13)*

> *"When they're out of control, I can't imagine that feels very good. Then the other residents, they don't get agitated when you know somebody's calm, that helps them, it helps staff, it helps the families, immensely." (LTC12)*

Effectively managing these responsive behaviours, specifically relating to behaviours of agitation and aggression that may cause critical incidents, are challenging for the staff, residents, and families to be able to manage. Ensuring safety of all members of the home can be difficult with resource allocation as well as the physical layout of the home itself:

> *"And when there's something, a big catastrophic event and how do you send somebody, and so they go to hospital for a while, how do you send them back to that same neighbourhood where everybody is terrified of them? Like it's just, how do you get everybody, 'cause it's not just the team then… the resident, the team, the family members, the other residents, how do you… and we have to promise that we're gonna keep everybody safe, like that's our mandate, how do you do that?" (LTC9)*

> *"Yeah, because there's always residents around, so there's always that chance of someone being injured, or someone getting upset and then also getting involved (laughs) and then things just blowing up." (LTC11)*

One of the focuses of the BSO program is to attempt to minimize critical incidents such as resident to resident abuse. Staff discussed the implications of these behaviours and the challenges that present when attempting to care for all residents and find solutions for maintaining safety across the home.

2. *The Components of a Successful BSO Program in Long-Term Care*

Within the theme of components of a successful BSO program, there were four main subthemes that emerged: Having clear program goals, direction, and structure; Interdisciplinary collaboration and open communication; Providing care and interventions that are person-centered; and lastly, the Level of impact of the BSO program in long-term care. The first three subthemes are the direct components of creating a successful in-home BSO program, whereas the last subtheme relates to the impact and the outcomes that can be observed when the program is running at its greatest potential.

A. *Clear Program Goals, Direction and Structure*

In order for the BSO program to operate at its greatest potential, long-term care staff recognized there must be clear program expectations as well as role identification, staff engagement, strong leadership and organizational structure, and an appropriately managed BSO referral process.

i. *The Roles of BSO and the In-Home BSO Team*

One of the main topics of discussion among these participants was the role of in-home BSO teams. The main role that was consistent throughout every interview was the support that the BSO team provides by building capacity across the home. The team does this by first assessing and reviewing the resident and the presenting behaviours, collaborating with the team to determine interventions for care, and then teaching and facilitating these care plans across the care team:

> *"There's so much teaching that goes on daily, and it's just even leading by example. I mean [LTC3], they can ask her to go in to help them problem solve, and she can go in and actually then teach as she's doing umm how to work with that particular resident and they can gather so many ideas from her in just one… time of being there with the resident." (LTC2)*

"They would often, I'm thinking of one specific resident, she's very aggressive physically and verbally. We would walk in and the BSO would often take the lead and talk them through it and show us how they want us to approach the situation and I remember the first time we went in there, they implemented something for the lifts." (LTC14)

The BSO team helps to manage complex cases and provide insight and expertise in managing the responsive behaviours associated with these complex residents. Not only are the in-home BSO team members working to support the residents and to help to manage the responsive behaviours exhibited by residents, but they also work to provide support to the staff as well as the families. The BSO teams take a role in providing education to the staff to improve the behavioural care, as well as coaching the staff to prevent future critical incidents.

ii.   Staff Engagement in the BSO Program

In order for the BSO program to build capacity, the staff of the long-term care home must be aware of the residents on the BSO caseload and understand the interventions that have been put in place to support these residents. Understanding the goals of the program means being engaged with and committed to the program. Additionally, staff must have some level of buy-in to the program in order to attempt to carry out the interventions that have been set in place, as well as be committed to providing best practice care to manage responsive behaviours:

"If they do take time, or understand, or follow the interventions in place it does work." (LTC6)

"And I do see that the [BSO team] are like you know, 'oh I took it upon myself', that autonomy. Autonomy, registered staff, non-registered staff because they're here doing it every day, they want to have to have the commitment. Your staff doesn't have the commitment, you're not helping anybody in the home." (LTC16)

In order for staff to be committed to the BSO program they must be self-aware and accountable for their own goals and limitations. Without self-awareness and accountability, the

BSO team is unable to properly work with other staff or ultimately help the residents on the BSO

caseload:

> *"I think there's been a huge positive impact. Umm I feel that with you know, the ability to take that, the big thing is, and I tell the team, it's self-awareness. We can't succeed until we're self-aware of our own personal goals, and our own personal limitations... I think that we've been very much able to positively impact them with how our process is for referrals, how we communicate to staff, how we work alongside the physicians, it's all a trickle down effect." (LTC16)*

As discussed by LTC16, self-awareness in caring for residents must be consistent across all team

members to positively impact the quality of life of residents.

iii. Strong Leadership and Organizational Structure

As part of the in-home BSO team's responsibility to build capacity throughout the home,

they must take a position of leadership to guide the staff through interventions and care planning.

Further, the BSO teams must feel well supported by their administrators and directors of care to

have a mutual understanding of program expectations and the processes of the program:

> *"Umm, I think I am. Yes I do [feel supported by the administrator and DOC], you know I think sometimes they expect a magic wand, I think they expect a lot more than what I can possibly do sometimes... But I think they're very supportive, maybe high expectations, but I think they're supportive." (LTC16)*

One of the appointed BSO in-home staff members commented on the necessity and

importance of guidance and leadership of the in-home BSO team to share across the staff

members of the home, in order for the program to be successful:

> *"It should be that effective leader to be self-aware and to have that guidance, because when I came in there was no clear leadership, there was no clear path of what to do. You know, they were good, but you know, they need, you need a strong path." (LTC16)*

Once again, LTC16 discussed the importance of self-awareness to adequately provide BSO

services within the home, and to communicate effectively across the care team.

iv. Appropriately Managed BSO Referral Process

Through careful consideration, residents are added to the BSO caseload. The referral process varies across long-term care homes; however, the premise for referrals is the same. When staff are noticing residents with increasing behaviours, they may speak with the BSO team directly, or fill out a referral form. Ideally, comprehensive assessments are completed prior to referral to the BSO team:

> *"We do have a referral form that staff fill out. Umm BSO check that daily to see if there are any outstanding umm and they will go in and assess and they will make sure that all the physical items that may be causing behaviours have been checked off the list and umm if they all have and it's all negative then BSO will umm get on board and work with that resident and the direct staff that are working with that resident." (LTC2)*

> *"Usually if somebody asks me about it before the referral, I will just try and rule out things like pain, infection, some sort of acute scenario, you know, is it a medication change thing, or is it something, you know, approach? So try to rule out all of those things first, before the referral is made." (LTC7)*

Often times, any of the staff members working throughout the home are able to refer to the BSO team; however, some homes acknowledged nursing's role in performing this task:

> *"I don't know that we as recreation would generally put referrals, it's usually nursing that does." (LTC11)*

> *"I've been able to refer to my nurse and have them put it in the notes for BSO to be able to see." (LTC14)*

Nurses were commonly discussed as being the link between the care team, and the in-home BSO staff.

B. Interdisciplinary Collaboration and Open Communication

Within the subtheme of interdisciplinary collaboration and open communication, long-term care staff discussed the importance of strong communication and using an interdisciplinary

approach to care. Staff also discussed their relationship with psychogeriatric resource consultants and their role in facilitating the BSO program in the home.

i.   *Strong Communication Efforts across the Care Team*

As the intention of the BSO program is to provide resident-specific interventions for care to help manage behaviours, these interventions must be communicated across the team in order to be successfully implemented. Throughout all of the long-term care homes, staff recognized the value of open communication across the care team for a well-functioning BSO program:

> *"Because our communication is really good. I think that's when we're functioning at our optimum for sure." (LTC 1)*

> *"So, I think working its best is when we're all communicating, we're all on the same page." (LTC9)*

Each participant was able to identify a variety of ways that information related to resident care are shared across the team. Many staff described conventional methods for information sharing such as the patient specific binders or the Kardex, communication books, shift reports, team huddles and interdisciplinary meetings. Two of the appointed in-home BSO staff members from different homes recognized that traditional methods for information sharing are not always feasible, and you must adapt to peoples' strengths:

> *"So we tried a lot of ways to communicate those interventions. Right now, what we're doing is we have 'Care Tips' in the bathroom. We find that staff go in there and somehow they read the interventions when it's posted there. Now those bathrooms are only used by staff, and you need a key to go in, so it's not like public and families could go into that bathroom. So we share those Care Tips there and we follow up if you've read the Care Tips, this and that. So somehow they are reading the Care Tips when they're in there." (LTC6)*

> *"'Do they have time for the Kardex?' We have to look to people's strengths, let's be realistic, right? It's a very large home, so if it's a quick, everything that's on the Kardex is into the action plan, on top of having personalized resident-specific triggers and a background history to kind of implement in conversation, right? (LTC16)*

Finding a communication method that works for the team for information sharing was discussed as an important part of the success of the BSO program.

ii. Interdisciplinary Team Approach

To successfully care for the residents living with dementia in long-term homes, staff addressed the importance of using an interdisciplinary approach to identify, investigate and manage behaviours:

> *"Umm definitely I feel that we have a superior BSO team. Umm, their ability to work right across all of the disciplines, to umm bring all of us into the problem solving, to allow all of us to umm refer residents, to identify residents, to be involved in the interventions, umm you know it's just a well-oiled machine really." (LTC5)*

Long-term care staff also discussed the importance of being interdisciplinary and avoiding falling into the siloes of the healthcare system:

> *"I just wanted to share, when you hear all of us talk about interdisciplinary too, it's quite important to our home. We're not, we try very hard not to be siloed because we're all kind of on the same team, there for the same reason." (LTC1)*

> *"I think that we're very lucky to have a really good interdisciplinary team and relationship. So social work, chaplain, like we all work quite well together and I think that makes the difference. If you don't just look at the BSO team as being these two." (LTC9)*

Related to interdisciplinary collaboration, staff further discussed the importance in recognizing that all roles of the care team have value in providing comprehensive, person-centered care. Each team member is able to bring a unique perspective to care, and clinical hierarchies should not influence resident care:

> *"With our geriatric psychiatrist coming in, and geriatrician coming in there's such, from a non-clinical perspective, they're such good teachers, and embrace the fact that a PSW has value and has things that are definitely worth offering to that whole picture and story. And it makes you feel valued so that interdisciplinary team, it feels here, is an important part of how to help the residents. So you know, I really value that." (LTC8)*

LTC staff from two different long-term care homes acknowledged the value of various departments such as environmental services, dietary, and laundry services, and their roles in resident care and behaviour management:

> *"So we have a resident that transitioned back from [the hospital] who needs A LOT of activities as part of his toolbox, he needs to stay very busy. So, rec is definitely doing a ton of things, BSO does a ton of things. Our business office is doing activities with him a couple times a week, dietary, laundry, environmental services. Every department he's engaged one-on-one with staff doing various activities." (LTC1)*

> *"Well, and some of us try to learn different languages, like pain, in different languages so we know or food, or different staples, which is nice. Because then you know, if somebody's acting up and you can say 'boli', which means pain in Serbian. If they're Russian, Serbian, Ukrainian, they kind of know. Even our housekeepers are helpful." (LTC14)*

Staff members also discussed their collaboration and coordination efforts with the community and community resource teams to effectively support residents in a comprehensive way:

> *"I think of our [resident] when he first came in, 'member? All the responsive behaviour… and he would leave, he would walk down the highway and then we got the taxicab going for him. How the whole community supported that, we're in a small community, so the whole community supported that." (LTC3)*

Additionally, members discussed their work with the geriatric psychiatrist and geriatrician, in which they are able to review medications and discuss appropriate interventions for care. The coordination with geriatric psychiatry ensures that residents are able to safely live in the home, and lessens the need for transfers to specialized mental health services:

> *"And we have, we've helped a lot of people, especially with geriatric psychiatry that we've been able to retain." (LTC16)*

Staff value the geriatricians and geriatric psychiatrists for their clinical knowledge and expertise, as well as the mentorship that they provide in teaching staff:

> *"We're privileged to have [our geriatrician] who also is a great educator for the teams." (LTC9)*

Incorporating these roles, and working across the healthcare team were discussed as being

valuable to the overall success of the BSO program.

> iii.   *The Role and Function of the Psychogeriatric Resource Consultant in Long-Term
>   Care*

Another topic commonly discussed among the care staff, was their coordination with the

PRCs across the Waterloo Wellington LHIN. Although the embedded model is designed to have

the in-home BSO teams manage the day-to-day tasks, PRCS are able to offer additional support

in managing challenging cases on the BSO caseload:

> *"Yeah, yeah we have a very highly effective – I know I'm biased, but I truly feel, a highly
> effective BSO team, so there's no need for [our PRC] to be involved on the day-to-day.
> But it is nice to know when we're having a specific challenge, we can pick up the phone
> and say this is what's going on and she's always been available to us, which we
> appreciate, I think." (LTC1)*

> *"So yeah, it's like I said, well most of the time we are able to look at our caseload, but if
> we're stuck, we're out of ideas [our PRC] will come in and… you know. Even though we
> just had our monthly meeting already, but you know, she'll come in and give us the extra
> day if we have to." (LTC6)*

PRCs are also able to help with care transitions from community to long-term care and

from hospital back to long-term care. PRCs were described by long-term care staff as having

valuable knowledge and connections with external resources across the LHIN, which helps to

manage complex cases and transitional care:

> *"We worked very closely with our PRC and [the hospital] umm to develop a transition
> plan for when he returned to the home. And she's been sort of that umm objective
> external person with a lot of very good clinical knowledge that has been able to be umm a
> good transition person between two places, I would say that's been positive for us, for
> sure." (LTC1)*

> *"Uhh, you know, if we have a new referral we're just not understanding or we're feeling
> like we're missing some information for their admission, she can typically find it on her
> end, some valuable information." (LTC16)*

"We meet every month just to touch base, discuss anyone in my caseload that we're having a hard time, or we're kind of stuck. So a fresh set of mind, she'll look into it too and we discuss and implement." (LTC6)

Overall the homes value their relationship with their PRC, and appreciate their contributions to the long-term care setting:

"So, the PRCs are very supportive in this region, you know, how we did the BSO in this region is I find it really working." (LTC6)

Having the PRCs as a supplemental resource to the in-home BSO staff was valued by long-term care staff.

C. Care and Interventions are Person-Centered

Long-term care staff acknowledged the importance of person-centered care approaches within their practice to effectively manage behaviours exhibited by residents living within the home. GPA and P.I.E.C.E.S. training were commonly cited across participants as evidence-informed approaches for care. One home discussed their adaptation of a person-centered training module for care that they teach their staff. These training modules recognize the importance of understanding the person and building relationships. Understanding the person, their background and triggers helps staff understand reasons behind the responsive behaviours and realize that behaviours have meaning. Although behaviours may be challenging when providing care, staff emphasized that they should not define the resident:

"No, I'm just smiling thinking about all the wonderful residents that we have (laughs) and like I said we've had some major success stories, we have people who I think in another environment would be considered aggressive, dangerous, you know umm, and would suffer from the stigma around the reaction to their disease. And here you know, we're able to educate the team and make that care plan and show that this is a valued individual with you know, all these things to offer and not just their disease, and certainly not just the negative side effect of their disease." (LTC7)

A number of interventions were discussed throughout interviews with long-term care staff. In order for interventions to help successfully manage behaviour, staff discussed the importance of interventions being person-centered and meaningful. Strategies may be outside of the box, and atypical from regular care interventions:

> *"So, a lot of our residents on [the secure unit], can't cope with going upstairs to the hairdresser because they have to sit and wait. So, we implemented a program where I assist the hair dresser. She comes down we have the old hair dressing books, and we have music playing, and we have punch. Sometimes there's 15 people sitting in there, maybe only 10 are getting their hair done but it came to be just a whole group activity and the hairdresser was totally for it and she helps out, like it works really, really well. And you'll see just the older gentleman going in, they're not getting their hair done, but that's what they used to do at the barbershop or the hairdresser [LTC1: Socialize]. And they'll look through the book and pick out a picture (laughs)." (LTC3)*

Various interventions used to manage responsive behaviours were discussed throughout examples of collaboration efforts and values of the BSO program. Four categories of interventions emerged from the data, including approaches to care, activities, environmental modifications, and medications. It is important to note that these intervention categories are not a theme in and of themselves but help to provide a method of organization for the interventions that were discussed. **Table 7** lists some of the interventions discussed by participants.

Table 7. Types of interventions used in care for residents with responsive behaviours as discussed by LTC staff

Approaches to Care	Activities	Environmental Modifications	Medications
Active listening	Puzzles	Remove residents from stimuli	Should be used as last resort
Language-specific charts and images for translation	Complete flower arrangements	Distraction techniques	
Be timely in meeting requests	Clean eyeglasses	Specific group programming Ex. Hair Salon	
Learn key words in various languages	Music therapy	Implement pool noodles for safe transfer from bed to chair	
Discussion topics Ex. Sports or music	Fold laundry		
Remain calm in situations	Sort file folders		
Avoid arguments	Books and colouring		
Individualized care plans	Go for Walks		

Medications were not heavily discussed as a primary intervention used by staff members to manage responsive behaviours. When speaking about the use of medications, staff members frequently discussed their efforts to use medications as a last resort and also acknowledged that not all behaviours will respond to medications:

> *"Some residents don't respond to those medications. They have those responsive behaviours but it's not changing, it's not improving, so we tend not to go with the medication." (LTC6)*

The discussion regarding interventions and techniques for care among long-term care staff was heavily focused around non-pharmacological interventions, long-term care staff found it to be important to reduce medication use among their residents.

D. Level of Impact of the BSO Program in Long-Term Care

If BSO is operating at its greatest potential within the long-term care home, resident and system-level impacts may be observed. Overall, with proper implementation of the BSO program within a long-term care setting the goal is to see a reduction in responsive behaviours. Many of the participants discussed the impact of BSO on reducing critical incidents throughout the home:

> *"Umm, it'll be a risk-free place for less harming of our residents, resident to resident abuse, resident to staff abuse. Umm… and it'll be much quieter too." (LTC15)*

> *"And also, since BSO has been there, we've had less code yellows, missing residents." (LTC15)*

Additionally, staff discussed the impact of the program on improving quality of life and providing comfort for their residents by meeting their care needs:

> *"At least two of the new people would be in a secured neighbourhood, and medicated, and you know, the team had been able to prevent that by meeting the needs of the resident." (LTC9)*

> *"One of the residents there was beyond help, but we figured it out and BSO helped that, and that person doesn't need BSO now, doesn't need security, doesn't need anything, is on his own now and doing his own thing." (LTC15)*

With BSO model in long-term care, staff feel that they are able to better accommodate residents and manage complex cases with their levels of support:

> *"We wouldn't be able to take the residents that we do without that extra support, that expertise, the support from the BSO community." (LTC7)*

Participants also discussed their value in seeing the impact of the program and the interventions on resident behaviour and quality of life:

> *"When you see a resident go from weepy and scared, terrified, suspicious and then the full circle and they just are happy and engaging now and accepting of care, and loving their environment, that's the biggest umm thing we can take from what we do I think." (LTC2)*

Having the embedded in-home model allows staff to better offer this support in behavioural and dementia-informed care, which staff recognize and for which they are thankful.

3. *Wishes of 'More' for the Future of the BSO Program*

Long-term care staff also had the opportunity to discuss their wishes for the future of the BSO program. Many of the wishes discussed among staff centered on having more resources allocated to the BSO program. Whether it be to add more BSO roles across the home, funding a full-time recreation therapist, having increased monetary resources, increasing opportunities for education, or having the BSO team available more hours throughout the week, these were the most common wishes of staff for the future of the program:

> *"The way it's going now, I think they need more staff on their team, to cover all the shifts." (LTC15)*

> *"More [BSO] roles in the [home]. A bigger team." (LTC7)*

> *"I'd add more team members. I find three 3 staff and [our BSO lead] is not enough. Like [our BSO lead] does an amazing job, I just think she needs more hands. There is a lot of behaviours. I think more staff would probably help alleviate some of the pressure and maybe even bring down some of the behaviours." (LTC14)*

> *"My goal for [our provider] being in BSO for [our LTC home] is 1) to have more embedded staff, and possibly cross-train, I don't know if we could do that. I would love to have another registered staff, one for second and one for third, and I would want another BSO PSW." (LTC16)*

> *"Fund LTC4's rec therapy FTE, I would say that would make sense. I think always the funding is wonderful, like they've moved it forward with the umm whatever homes used to have, and I know some have uhh, a rec therapist instead of umm, uhh, a PSW, which is great, but we need them all." (LTC1)*

One staff member hoped that more resources could be allocated to providing more resident-specific activities:

"I think they need to increase more programs just for BSO residents and activities within the facility. Just to focus on these residents only. I think that's what they need to start doing now. Not just you know, put them with the regular program and we know that they're not going to be comfortable with that." (LTC15)

Additionally, another staff member agreed with the wishes of her colleagues and hoped for more resources to be allocated to the program in order to be able to do multidisciplinary care planning:

"...more resource people so that we can really sit down and do ideally multidisciplinary intervention planning would be lovely... but yeah I think with more time, more resources we would be able to do that more often and have even more holistic effective interventions. Yeah I echo what you said about just more time for planning." (LTC10)

One of the long-term care staff shared her desire for the program to be able to offer more opportunities for education, in order to support her in her care practices:

"I would love to learn more. I personally love learning about behaviours, understanding the behaviours. If there's more education for me, I think it would be better, but I mean funding for that is really hard... Like I would love if I could go to like a seminar and learn all about it. I've already told [our BSO Lead] if there's something and I can opt and even pay half I would, because it's something that would help me in my every day." (LTC14)

Aside from in-home resource allocation, to address one of the challenges faced in long-term care settings, one staff member discussed her wish of having more community support to create smoother transitions for residents into long-term care:

"I think more community, uhh, when we're transitioning someone from home to here. There's a lack of that, and a lack of information, sometimes we are surprised by behaviours that we receive... Yeah, so I would love to see more working with residents, well not residents but people with dementia in their homes. There's, I think there's a lack of support there." (LTC2)

One of the appointed in-home BSO staff members also shared her wish for staff to be more engaged with the program, in order to effectively manage responsive behaviours:

"Well I guess, it's like I said, the buy-in of staff, you know? If they accept it, and they tried it willingly and 100% to try the interventions, or even them to read the resident more and not rushing because of the time they have and that, that would be my utmost

wish. That way we are able to prevent, or read more the responsive behaviour to put the interventions appropriate for that behaviour, right?"

One unique wish mentioned by one of the appointed in-home BSO staff members was to have their home's operating provider adapt a position for a regional manager for behavioural support:

> *"And for [our provider], the teams are you know, it's a highly scrutinized program. I've seen it since day one, umm and I have made mention that [our provider] would do very well with a regional manager for behavioural support in regards to regulation and staffing. That is my goal." (LTC16)*

Ultimately, through the addition of more resources the wish of many of the staff is to be able to better support their residents with responsive behaviours with the embedded in-home BSO program.

5.1.2 BSO Members from the LHIN: Interview Findings

During interviews with the BSO members from the LHIN, which included four

psychogeriatric resource consultants and a BSO administrator; participants were able to identify

many important concepts relating to the BSO program within long-term care. Main themes that

emerged during these interviews include:

1. The Evolution of the BSO Program

2. Defining the PRC role in Long-Term Care

3. Challenges Within the Long-Term Care Setting and the BSO Program

4. Indicators for Success of the BSO Program

5. Wishes of '*More*' for the Future of the BSO Program

1. *The Evolution of the BSO Program*

Psychogeriatric resource consultants shared their perspective on the functions of the BSO

program within the long-term care setting. Participants in this group commented on the changes

that have occurred since the inception of the program in 2012. Although members discussed

some positive changes that have occurred throughout this time period, many of the participants

fear that there have also been many negative changes to the program that have occurred. One of

the positive examples of change that was described was the creation of the BSO long-term care

toolkit that helps define the roles and purpose of the BSO program within the long-term care

setting in order to create a successful program:

> *So, the long-term care toolkit, we developed with a bunch of the long-term care homes at*
> *year three. So year one we kind of said 'what the heck is BSO?' We didn't know, and*
> *everybody kind of, there was 35 homes at the time and we just figured it out. Year two, we*
> *started to get a better idea of what the role of BSO is in the home, what leadership needs*
> *to do, what the other staff need to do. And in year three we figured out in order to have a*
> *successful BSO team in the home, these are the six things that are critical..." (BSO1)*

The toolkit for long-term care homes in the Waterloo Wellington LHIN lists eight

"Performance Flags" that should be utilized by long-term care homes to enhance the quality of

the BSO program. These performance flags include:

1. Is the infrastructure in place to support the BSO initiative?
2. Are the BSO Core Competencies included in the BSO program?
3. Is the available BSO funding being fully utilized?
4. Is there flow within the BSO caseload?
5. Is the Quality Improvement Work Plan moving forward?
6. Are the BSO teams being fully utilized to build knowledge and capacity within the LTCH?
7. Are the care recommendations from the BSO Team being implemented?
8. Is the LTCH involved in planning and facilitation transition from community or hospital to LTC?

As BSO members from the LHIN described some of the changes that have occurred over

time, they fear that the program is beginning to struggle:

> *"We were very, very good. Waterloo Wellington, a very great reputation, and it was a great program, but it's struggling now." (BSO1)*

> *"So you know, where at one point we saw that the majority of the homes were doing really well, it's kind of flipped around where the majority of them are struggling." (BSO2)*

> *"...as far as the overarching BSO program I think it's beginning to drift and I think that's a real risk we're running into." (BSO3)*

One factor that was discussed across all participants within this group, was the lack of

data collection and analysis of the program's quantitative quality indicators. These indicators

help the program leads to better understand how the program is operating across each of the

homes, and what areas may be improved upon:

> *"So sometimes, so here's an example, often at the end of fiscal year, or close to the end of fiscal year, at the end of March we would have some statistics about how much BSO money was used in each home... In terms of the stats, we haven't had a lot of stats. We used to have statistics quarterly, in terms of behaviours that have been affected by BSO and then 3 months later when they're discharged from the BSO program has their behaviour improved? And we used to have those statistics, right? And that was a very*

good marker or determination of how well is BSO working in the homes. We haven't had those stats in two years." (BSO4)

The lack of collection of these quality indicators also influences the PRCs' ability to function to

support the long-term care staff and the in-home BSO programs:

> *"We have some sense with our BSO teams, and we also have some sense that BSO is failing in a lot of homes. We have big concerns about that actually, but without having some of that hard data, the more I guess quantitative data, right? We can't really have some evidence to say this isn't working or BSO isn't working well in homes. So our role has become very limited in what we can do in terms of supporting staff when we don't have sometimes that hard data."* (BSO4)

One participant commented on the plan to bring back the collection of quality indicators

across the home, and evaluate the data that has not yet been analyzed:

> *"I have about two years of data that the, like there used to be a role where they would analyze that. So, we were just talking about collecting that again and completing that two year gap, with the information that we have."* (BSO5)

Participants also fear that there is an increasing gap between themselves, BSO

administration, and the leadership within the long-term care homes to clearly define program

goals and help direct the embedded in-home teams. PRCs also noted that there has been a shift

away from being more involved in visiting with the homes and reviewing how the programs are

functioning:

> *"Hmm, I kind of used to see us as being kind of in between BSO administration and long-term care BSO, right? So we kind of filled that area sort of in that middle line, and we had a unique opportunity to see fairly intimately what was going on in the long-term care home… That has disappeared in the last two years, right?… And I think it's that interplay with the 3 levels so BSO administration, PRCs, and then BSO staff in cooperation with our leadership."* (BSO4)

> *"That was just a natural thing that we as PRCs were involved in, in helping to monitor how the program was running. So that allowed us to have engagement more with the administration and leadership of each of the homes. We would do road trip visits to each of the homes alongside the BSO lead just to review with admin, how they think their BSO program is functioning, kind of oversee a little bit, are they using their funds adequately? Yeah, I think that was an excellent way to be able to collaborate."* (BSO3)

Due to this gap and lack of clearly defined program goals and expectations, participants also commented on the effects this change has on the ability for homes to build capacity and be effective within the homes:

> *"Yeah, I guess our concern, and I have a number of homes where this is evident. I think we've gone backwards. I think that there's less capacity building." (BSO4)*

> *"So umm, their hands are somewhat tied, they have to do what they're being told to do and I think that it's creating a lot of strain on the BSO program and the longer that it goes on like that, the harder and harder it will be to try to repair it and make these homes succeed." (BSO2)*

For the reasons discussed above, the BSO members from the LHIN worry that the in-home BSO program operating in Waterloo Wellington may no longer be successful.

2. *Defining the PRC Role in Long-Term Care*

When discussing the collaboration efforts between long-term care staff and the BSO members from the LHIN, participants discussed and defined their roles in the home as a PRC. PRCs noted that they are not working with the residents specifically but are there to support the long-term care staff: *"And that's exactly our role, it's to support the staff."* One of the important factors discussed was the PRCs' role in consulting and facilitating plans of care, versus making recommendations for care and guiding the in-home BSO team's practice:

> *"So, we don't do an assessment and make recommendations, staff should do this. Probably over the last 15 years I've done that, and it doesn't work, so we don't do that at all because it's gotta be their ideas." (BSO1)*

> *"We're usually on the same page, and I think that's partially because we're not there to give our opinions, we're there to work through the facts with them and try to strategize with them and we're using the information and the knowledge they have to guide our practice." (BSO2)*

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More specifically, participants discussed their role in helping the long-term care homes with challenging and complex cases, as well as helping acquire important information to support care transitions:

> *"And sometimes, it's umm, you know what we see is very complex residents with many, multi-co-morbidities, right? So you have a dementia, a delirium, you might have a mental illness, so lots of issues coming together, so often we're helping the BSO teams to better understand those residents and how can we help them do that." (BSO4)*

> *"Okay, so in that case again, it would be around a very complicated case, umm a very case-based specific where there's learning and pieces of education might be needed based on the presentation of the behaviour. And that the PRC take sort of a lead role in umm, sort of bringing that information together, bringing care partners together to sort of address that." (BSO5)*

> *"I worked with the long-term care home, to try to get some additional information about her history because she had come from out of region so you don't have as much information." (BSO2)*

One PRC compared her role to that of a system navigator, in providing long-term care staff a resource in order to be able to direct care, and provide information and solutions to promote care of residents:

> *"Umm, I think I would just share that umm PRCs are meant to be people that kind of help to be the way-finders or the you know, helping go through the systems." (BSO3)*

A major PRC role discussed among participants was their part in assisting the long-term care staff to enhance their behaviour management practices and build capacity across the home:

> *"So, it's kind of underpinning and assisting the staff to be better at their role." (BSO4)*

> *"When we do consultation it's always based on our role is to build the staff's capacity." (BSO1)*

These components all come together in the PRC role to help coordinate care within the in-home BSO programs operating in long-term care.

3. Challenges within the Long-Term Care Setting and the BSO Program

BSO members from the LHIN also discussed some of the challenges faced in the long-term care setting, which in turn have implications on the BSO program. Some of the main challenges participants addressed were the increasing complexity of residents that are admitted to long-term care, the high rates of dementia among residents, as well as the high resident-to-staff ratios, and high rates of staff turnover in this setting:

> *"So, residents are no longer easy in long-term care, and you probably saw this yourself when you were working in long-term care. Umm almost everybody that comes into long-term care now is late-stage dementia with significant behaviours, and the interplay of all of the residents together, it's complex, it's very complex." (BSO4)*

> *"I think is very important, that is, you know, 80-90% of persons in long-term care have a dementia or a mental health issue and the majority of those will have a responsive behaviour during their stay." (BSO2)*

> *"And staff are expected to manage 10 people, 1 PSW; 1 RPN maybe for 20, 30 people, and then 1 RN, which is responsible for the whole home or half the home, right?" (BSO4)*

> *"I guess the other problem is that over the course of every year, we have somewhere around 30% of staff changes in terms of BSO staff, administrators, Directors of Care because [long-term care] is a revolving door, right?" (BSO4)*

Furthermore, aside from the regular challenges of being a care provider in a long-term care setting, PRCs acknowledged the added difficulty in being an appointed in-home BSO staff member:

> *"BSO staff, it's a tough, tough job, like it's a really… we have some BSO teams have been doing it since '11, 2011-12. We've got some BSO teams that are consistent and have been the same since then which is phenomenal so seven years. But of the 36 teams, that's only maybe three or four of them and the rest have changed because either they've gone as opportunities arise or they're not the right person in the job because it's a hard job, right?"*

4. Indicators for Success of the BSO Program

BSO members from the LHIN were able to describe a number of indicators of a successful BSO program. Foremost, in order for the homes to be successful, they must use their

in-home BSO team to build capacity across the home. To do this, the embedded teams must be

supported to use their hours and allotted funding appropriately. Other indicators of success

included Interdisciplinary collaboration and relationship building; Self-awareness in behavioural

care; Providing person-centered care; and Creating effective care transitions.

A. Building Capacity across the Home

The main indicator for success that the BSO members from the LHIN discussed, was the

in-home BSO team's ability to build capacity across the long-term care home. With only a few

staff members of the long-term care home appointed as the in-home BSO team, participants

stressed that the BSO team must be able to teach and facilitate skills in behaviour management to

the rest of the care team. A major component of building capacity across the home, is proper use

of the allocated BSO hours and funding.

i.   Using Allocated BSO Hours and Funding

Each of the long-term care homes receive funding from the ministry to support their in-

home BSO programs. BSO members from the LHIN discussed the importance of fully utilizing

the funding that is provided:

> *"And so when they're working well, the components of that, is that the funding that the
> long-term care home receives from the LHIN for BSO is fully utilized. So, they use all
> their money. They don't send half of it back to the ministry and it's surprising how much
> of it is not used." (BSO1)*

> *"So when it's working at its greatest potential, homes are using their funding as
> allocated." (BSO3)*

The BSO members from the LHIN also recognized that one of the implications of short

staffing across the long-term care home is that BSO staff are being pulled onto the floor to

provide personal care for residents. Using the BSO team to compensate for short staffing means

that homes are not fulfilling their allocated BSO hours:

> *"So that's the number one thing because they're so short-staffed, staff are pulled, they're not getting their BSO hours, when they're not getting their scheduled allocated BSO hours, and they're not replaced, and they're not used the next week or the next month, then they're just sent back to the ministry. And we have a number of homes that don't use their full BSO hours, which makes it a bad thing." (BSO1)*

> *"One of the challenges is, you know, all the long-term care homes are really struggling with staffing. So pulling somebody from the BSO line, to fill another position in the home to meet the day-to-day needs. And it's really hard, because we would like to see BSO or behavioural health of residents is seen as just as important as you know, filling the bath shift. We don't think the BSO program should be set aside for that necessarily, and so it's hard for the BSO program to advance their work or get anywhere when they're being given so many different hats to wear, they're being pulled off their shift for this or that." (BSO2)*

> *"So being pulled from the floor when they're short with staff to provide the direct care, takes away from the time they're able to do their P.I.E.C.E.S. assessments and follow up with staff, and mentoring of staff and providing of education." (BSO3)*

Additionally, participants stressed that hours must be used appropriately. PRCs also

shared concern that some of the BSO teams across the LHIN are not able to use their allotted

hours appropriately, meaning that the teams are being held responsible for other tasks, loosely

related to dementia and responsive behaviours:

> *"So we have a lot of homes in our LHIN where the leadership gets the money and they might even use the BSO hours but they say to the BSO, and they direct the BSO teams, 'Well we want you to do one-on-one with this person for the next'. I had one BSO PSW call me this week and say they're being directed to spend their days taking the resident outside for the day. That's not an appropriate use of BSO hours, that's babysitting, that's one-to-one." (BSO1)*

> *"Like, we've got one BSO team being charged to manage all the wandering devices in the home. So your job is to manage all the wandering devices, make sure the batteries are charged, make sure they're on the right… how does that build capacity in the home to manage behaviours?" (BSO1)*

> *"'Okay you're BSO, so that kind of has to do with wandering, so maybe we're gonna get you to be responsible for the WanderGuard program" as an example… Or 'we're gonna send the BSO PSW to help assist people in the dining room with eating and we're gonna*

say it's BSO because they're helping the residents with dementia.' But if they're not actually problem solving, or trying to move forward the program in anyway its really just being used to help offset their staffing." (BSO2)

One of the uses for BSO hours has been to provide one-to-one direct care and observations for residents exhibiting high intensity responsive behaviours:

"And we say that always happens, for sure but it's short-term, very limited, and it's kind of like a crisis situation, where you need some one-to-one for that moment in time." (BSO1)

The BSO program is not designed to support this practice, and in the case that one-to-one care is needed, this should be only a temporary practice.

ii.   Utilizing the 'LTC Toolkit' to Guide BSO Practice

BSO members from the LHIN also shared a major element of success being the homes adapting the toolkit that was designed to guide the in-home BSO programs:

"I think that when it's at its greatest potential, the program is really meeting a lot of the objects that are identified in the toolkit that I referred to earlier." (BSO2)

"I think that's one of the, one of first things that we had originally put in the toolkit when that was developed after about the first year of BSO. We came to realize fairly quickly the 6 or 7 things that were very key to making successful BSO." (BSO4)

Participants discussed how this toolkit was designed to be followed in order for homes to leverage their programs. The toolkit is comprised of eight performance flags that should be met for BSO programs to be successful.

iii.   Sharing Knowledge and Expertise across the Home

As the in-home BSO teams have leading knowledge and expertise in behavioural care, these individuals are expected to share their knowledge across the long-term care staff. The teams help to investigate behaviours, develop strategies and approaches for care, and then share and teach these strategies across the care team:

"So again, we have some BSO teams that function beautifully, perfectly, they figure out the behaviour, they figure out what, why it's happening, what to do about it… So their goal is to teach the staff." (BSO1)

"What the BSO program is meant to be, it's to have the team be able to mentor, to show, to teach and then have the staff be able to reciprocate and take over the care and that would show the advancements." (BSO3)

"BSO team members are having the ability to help build up the capacity of the staff through education." (BSO3)

This transfer of knowledge across the care team inherently shows the team's ability to build capacity across the home. The team's responsibility is to be leaders of behavioural care, and leverage the staff's ability to undertake these interventions and further the competencies of behavioural support throughout the home:

"So in essence, capacity building which has a lot of spin off effects too, so their managing more complex behaviours, they have a better understanding of the interplay between mental illness and dementia, they're recognizing things like delirium, psychosis, all of those things better, identification of problems early and then putting strategies in place. So that's the goal." (BSO4)

One again, participants stressed that the BSO team is not in the home to provide direct care, but to work with the staff to develop a plan of care, and share this care plan across the home:

"They're really not, if the program is operating to its greatest potential, they're just helping facilitate that behaviour support within the home, they're not doing it. So the capacity is among the staff." (BSO1)

"I think that if all the homes' staff members feel that they have support within the home, through that BSO program and also have the capacity, for those homes that have built that capacity, to have that skillset, and the knowledge, and the experience to be able to help their residents." (BSO1)

"When it's working at its greatest, that would mean that the actual members on the BSO team would not be the ones providing the direct care…" (BSO3)

Capacity building was discussed among PRCs as one of the main indicators of success of the in-home BSO program.

> *iv.*   *Ensuring Staff Awareness and Understanding of the BSO Program*

For this capacity building to occur, all staff members across the long-term care home, should have a good understanding of what the program does, and how the program is expected to function:

> *"So if you were to speak to another member of the long-term care team, they would know what the BSO program was and they would understand what that program was, I think that's a really huge component of it as well, is having that respect within the home." (BSO1)*

Staff members should also recognize that when residents are exhibiting responsive behaviours this is not a cue to have the BSO team support one-to-one care or to provide direct care to the residents:

> *"When I see that homes have more one-to-one staff, that's not capacity building that's a trigger for staff to say 'oh Mary's behavioural, we can't manage, you have to get a one-to-one staff.'" (BSO4)*

> *"They are being asked to provide direct care so much to the fact that they are, kind of, it's a lingo that we use, being kind of the '9-1-1' within the home to come and fix this problem." (BSO3)*

One participant mentioned that some of these challenges related to inappropriate use of the BSO team is due to the embedded model, as compared to the mobile model where the BSO team consults on an external basis:

> *"If you have a consultant coming in, you're not going to say to the consultant 'oh well can you go feed Kayla right now?' (Laughs). So I mean, as much as the consultant model is challenging in that they don't know the person or the home, at least they're not going to be pulled away from their work and booby-trapped into this other work either, so that's one of the benefits of that model." (BSO2)*

v.   Strong Leadership within the Home

In order for staff to be aware and understand the intended operations of the BSO program, the home's leadership, including their administrators and directors of care must be aware of and support the intended program goals. Without strong support from leadership, the in-home BSO teams will not be able to function as intended and the program will no longer have the opportunity to be successful in helping the residents:

> *"That's the challenge, right? We're trying to have embedded teams to change the practice of their peers, and in order to do that you need strong leadership support to understand that that's their role, and to support them and to get the other staff to listen to them, right?" (BSO1)*

> *"If it's the case that the leadership, so like the directors of care, the administrators, don't understand the program and they're directing BSO in a direction that isn't really what the intention of the program was. Then the program is not going to be able to support its clientele as effectively." (BSO2)*

> *"I see more and more within some of my homes, that the discrepancy becomes between the leadership of the home and the actual BSO teams…" (BSO3)*

> *"That once we met with leadership, things did change, because leadership is actually responsible for the BSO teams. They're the ones that can effect any change, and without strong leadership involvement, BSO will fall flat anyway." (BSO4)*

Additionally, the members of the in-home BSO team must be committed to supporting residents with behaviours in order to take a leadership role across the home, and support both staff and residents:

> *"And it's like every other home, of course there are staff that aren't as on-board as others but they really championed the people that are." (BSO1)*

Having strong leadership to guide BSO efforts in the home was discussed as an important aspect of the success of the BSO program.

B. Interdisciplinary Collaboration and Relationship Building

For the BSO program to be successful, the BSO members from the LHIN discussed the importance of having strong interdisciplinary collaboration and relationship building across the home's leadership, in-home BSO team, and staff:

> *"And so again, the same thing, [the BSO teams] have to have a good trusting relationship with their leadership and with their peers so that the peers listen to them." (BSO1)*

For the program to operate successfully, the long-term care staff must work across disciplines to provide a comprehensive approach to behavioural care:

> *"And in doing that they're involving the PSWs, the rec staff, the housekeepers, all of the support team no matter what their role is in long-term care. So when it's operating optimally there would be a lot of staff participating..." (BSO4)*

The recreation department provides an important complement to that of the BSO program in their ability to provide resident-specific activities and engagement opportunities for the residents. The BSO team must work closely with the recreation department, to develop and implement care plans for residents:

> *"And just to add to that, this particular home also has a really, the BSO program has a really strong relationship with the recreation department for the activities and I think that's really important too. That they're collaborating together to meet some of the needs of the residents that go beyond just being fed and watered. And the fact that this recreation program, you know if BSO needs any supplies, or you know, the staff identified that this person could really benefit from a notebook, a puzzle, a stuffed animal, the recreation department will mobilize and make sure they have what they need." (BSO2)*

Additionally, in order for PRCs to be successful in supporting the BSO program in their role, they must also develop strong relationships and good rapport with the long-term care homes:

> *"As PRCs we have to, as part of our role, we have to have outstanding relationships with all the homes or they don't want us in." (BSO1)*

"So, I think that the cooperation was made possible because of the relationship I have with the long-term care home, having that trusted relationship, and the home knowing they can come to me and will make something work no matter what." (BSO3)

"I think that the whole role of being a PRC is that you need to be able to build up relationships between all key partners, whether that be the administration, leadership staff within long-term care homes." (BSO4)

The rapport that is built between the PRCs and long-term care staff was discussed as one of the ways PRCs are able to effectively support the homes and enhance BSO services for residents.

C. Self-Awareness in Behavioural Care

Another component crucial for the success of the BSO program is the ability of all the staff to be self-aware, motivated, and dedicated to providing behavioural care across the home. As discussed earlier, the team must have a good understanding of the role of the embedded BSO team in order to function as intended:

"The home's BSO team was very ineffective. So, I think it was partly a human resource issue, the person that they actually selected as being the BSO lead didn't have a good understanding of her job, wasn't motivated, didn't have a good relationship with the other team members, and BSO was falling badly." (BSO4)

BSO members from the LHIN discussed the importance of the dedication of all staff members to provide quality behavioural care in order to support residents and respond appropriately to the behaviours they may be exhibiting:

"So really looking at it from an unmet need perspective and trying to be, trying to really apply a solution-focused approach to create the best care plan and best environment for a person to function at their fullest, despite their diagnosis of behaviour." (BSO5)

With self-awareness and strong commitment of the staff to the principles of the BSO program, staff are able to go beyond the scope of the program and support their residents even further. Behavioural support was discussed as being not only the responsibility of the BSO team, but of each and every staff member working in the long-term care home:

"So, I think that's another reason why it's been so successful, because the contribution to the behaviour supports program and the behavioural wellbeing of the residents has gone beyond just the BSO program." (BSO2)

"Behaviour support is everyone's responsibility, not just the BSO team's responsibility. Everyone has to take ownership and contribute." (BSO2)

Furthermore, acknowledging personal biases at the onset of care, allows staff to provide competent care to all residents, no matter the behaviour exhibited:

"So really trying to put that lens on it, but some people are very much triggered by that behaviour and think it's intentional and then there's like a lack of wanting to be engaging in supporting around a care plan around that. So just what I mean about being aware of their values and biases is how that may limit their understanding of the brain and the diagnosis." (BSO5)

Open-mindedness and self-awareness were discussed as being crucial in order to support all residents.

D. Providing Person-Centered Care

A major component in the success of the BSO program that was discussed was being able to build relationships with the residents on the BSO caseload. Building good rapport comes from getting to know individuals. Utilizing the P.I.E.C.E.S. framework can assist staff members in developing these relationships and better understanding the residents. In turn, getting to know the person ultimately assists the team in being able to develop a person-centered care plan, and implement strategies that are effective in reducing behaviours:

"So, that's a way they can best support the residents is getting to know them and understand them." (BSO3)

"So, looking at the full picture of a person from head-to-toe, using sort of that P.I.E.C.E.S. framework." (BSO5)

"So, the more BSO has an opportunity to get to know the resident, get to know the family, and then understand the information that they're getting, applying it to maybe what they're seeing in terms of their behaviour." (BSO1)

One PRC shared an example of a time she experienced a home utilizing a person-centered care approach to understand a resident, what was important to that resident, and how to implement a plan of care to best support this resident:

> *"She was in her early 60's, a long-standing history of schizophrenia and this is a lady who hadn't had any friends or family… The home accommodated some of her other wishes like being able to go outside and have a cigarette safely, uhh very important to her, make sure that she has her Pepsi every day." (BSO2)*

To provide person-centered care the BSO team and long-term care staff should be conducting comprehensive assessments to understand what is driving behaviour. These comprehensive assessments and care plans should be done in collaboration with the resident, their families, as well as the general care team:

> *"So, they have to do a good assessment, a behavioural assessment, they have to talk to staff, they have to talk to family, they have to really do a good comprehensive behavioural assessment and then they problem solve". (BSO1)*

> *"Yeah, I think that also bringing in the care partners too. Like I think that if one of the P.I.E.C.E.S. about BSO is to really look at who else could be involved to support this person that we may need some expertise around, or dialogue around, or ideas around, even if it's recreation therapy ideas, right?" (BSO5)*

In addition to collaborating with families, staff, and residents to develop a care plan, the long-term care staff should ensure that the language that they are using within the care plan is compassionate and evidence-based in order to best support the residents:

> *"…the language to describe the behaviour is one that is done in a sort of compassionate… and umm best practice-based umm explanations of describing the behaviour and the strategies in care planning related to the behaviour." (BSO5)*

Being compassionate and evidence-based in care approaches helps lead to more comprehensive and sensitive care for the residents.

E. Creating Effective Care Transitions

As the PRCs discussed, much of their role in supporting the long-term care homes comes from aiding in care transitions. One participant discussed an indicator of success being effective care transitions with strong communication and information sharing.

> *"I think when it's also at its fullest, the transitions are smooth and there's information sharing that's happening at its fullest in the best interest of the client and their family." (BSO5)*

When homes are operating at their greatest potential staff should attempt to acquire information through multiple sources to support care transitions and begin the process of providing person-centered care for new residents:

> *"I think that the system has to look at is there information in a different system that we may not have access to, right? So for example home and community care is a main thorough referral process, but is there anything in that documentation that might indicate that they ever went to a day program or, right? And then being able to go out and ask for that information from other sources in addition to what they've received." (BSO5)*

Extracting information from multiple sources may help lead to a better understanding of the person as a whole and will also help to provide more person-centered care.

5. *Wishes of 'More' for the Future of the BSO Program*

Participants were invited to discuss their wishes for the future of the BSO program. Often times wishes included wanting more time and resources to be implemented within the program. Many of the wishes discussed by the BSO members from the LHIN surrounded wanting to develop greater consistency of the BSO programs across the homes in the Waterloo Wellington LHIN:

> *"So, to make it better for the future of BSO we need to do more with creating a consistent program across the 36 long-term care homes, and support to the programs." (BSO1)*

> *"All teams within all long-term care homes would be umm not necessarily working the same… but umm I think going back to that unity of knowing what the expectations are*

and everyone following it and kind of knowing who to go to get the answers that they need." (BSO53)

The participants believe that this improvement to consistency can be achieved through developing a greater connection between BSO administration and leadership, the PRCs and the long-term care homes. Fostering a better connection will allow all parties to be clear on the roles and expectations of the BSO team in order for the program to be successful:

> *"...[PRCs] have been a little more removed from BSO leadership. Not in the homes, but BSO program leadership in Waterloo Wellington, so we've not had any ability to influence or to suggest. So there's a real gap between BSO leadership and what's actually going on in the homes, they don't know." (BSO1)*

> *"I think that if I had one wish for the BSO team, I think it would be good if all the BSO teams had leadership that understood and were supportive of the program and umm oversaw it in a way that was intended. I think that would be my best wish, and whether that would be through the home's own realization, or that would be through BSO leadership following-up with the homes, and making sure they are being accountable. I'm not really sure what the answer is, but I think that would be my one wish because if they're not well supported and they're not functioning well, it's hard for them to have a successful BSO program." (BSO2)*

> *"Yes, umm a very, very integrated, BSO lead that had a keen awareness and understanding of long-term care home needs and BSO functioning, importance of managing the toolkit and implementing the toolkit in long-term care. A BSO lead that had strong relationships and ties with each of the long-term care homes. I guess, better infiltration of the PRCs between the BSO lead and the long-term care homes." (BSO4)*

Another wish related to capacity building, is the homes' ability to accommodate the increasingly complex population that is occurring in long-term care settings, through greater information sharing and more effective care transitions:

> *"One wish… umm, I think part of it would be that their expertise is really umm a knowledge within each long-term care home and the transitions that we're having for you know, well transitions are smooth because the information is being shared back and forth and that the complexity of the population that we're able to sort of manage umm, which is not just put on them." (BSO5)*

One staff wished too, that there might be more money that could be dedicated to the BSO

program in order to establish greater resources for interventions, and implement more staffing

positions across the homes:

> *"I think that it's like any program too, more bodies and more money, umm for not only having the BSO support or staff in long-term care, but even just having money to buy any activities that a resident may need or want, I think that would be amazing. But money is always limited." (BSO2)*

The addition of more resources was cited as one of the ways to enhance the existing BSO

program within long-term care.

5.1.3 Caregiver: Interview Findings

Caregivers were able to share their experiences of their loved ones receiving care in long-term care settings. Questions for this participant group were less focused on understanding the function of BSO and more focused on general care experiences in long-term care. Caregivers also were able to describe behaviours exhibited by their loved ones, and some of the interventions staff had implemented in order to support the older adult resident. Through discussion about care practices, and wishes for the future of care for their loved ones with dementia, there were three major themes identified:

1. Attributes of Care Important to Family Caregivers

2. Difficulties and Challenges Faced in Long-Term Care Settings

3. Wishes of '*More*' for Care and the Future of the BSO Program

1. *Attributes of care important to family caregivers*

Each of the family caregivers spoke about various attributes of care that were important to them as a caregiver. Within this theme caregivers identified being included in the circle of care and being supported by the care team; finding strategies and interventions that support the care of their loved one and; maintaining their loved one's independence.

A. *Being Involved in the Circle of Care and Supported by the Care Team*

Caregivers were asked to describe their most positive experiences with receiving care for their loved ones, who was involved in the experience, and what made the experience so positive. Through many of the examples provided by the caregivers, one attribute that was consistent was the value of having the long-term care staff include them in care planning and decision making regarding the care and interventions implemented for their loved ones:

> *"They're really helpful in trying to pick my brain, if you will, to come up with strategies to help make it easier on Mum." (CG 1)*

> *"I want to be a participant in her care, and I don't want to be just putting up roadblocks." (CG1)*

> *"And they're pretty good at keeping me up to date on anything that happens or if there's anything I need to be aware of." (CG4)*

Similarly, caregivers discussed their value in feeling supported by the care team in decision-making. One caregiver spoke specifically about feeling supported in the decision to trial her mother on an antidepressant:

> *"I do. Like we had talked about that, and I feel that they would listen you know, if I had concerns, for sure... So I had this you know, these hesitations about restarting an antidepressant at this long-term care, but I have agreed. And we had a long talk about it just a few days ago, so yeah I don't feel like anybody's being pushed into it..." (CG3)*

One caregiver also discussed their value in being a direct part of the care of their loved one, and making herself an available member of the care team:

> *"He was so worried about me this morning, because he thinks something's wrong. But you know, so I reassured him, she reassured him. I told them to call me, anytime, 24-7, they can call me. They let me talk to him, and then he'll be calm and he'll be good. It's okay for them to call me anytime, on my cell phone, on my home phone, it's fine with me." (CG2)*

Within this subtheme of being included as part of the care team, caregivers also shared examples of times they felt supported by the long-term care staff, and the impact that this support has on providing quality care for their loved ones in the home:

> *"Yeah, I think my husband has received good care you know, and the staff is very, very supportive and caring. They are really a bunch of caring staff here." (CG2)*

Additionally, the support provided by staff not only impacts the residents, but also the families:

"And as she was getting you know, deeper into the dementia… It was even worse you know, trying to get her interested in socializing, but at this long-term care home it seems like those sorts of concerns and worries are out of mind now because they are doing as much as they can for her in that way." (CG3)

Caregivers described feeling a sense of relief knowing that their loved ones are being taken care of and engaged by the staff.

B. Finding Strategies and Interventions that Support the Care of the Residents

Caregivers discussed some of the responsive behaviours that have come with the progression of dementia in their loved ones. Behaviours such as wandering, anxiety, agitation and some aggression, withdrawing from participating in activities of daily living, hallucinations, and interrupted sleep patterns were identified throughout interviews. Due to these behaviours and expressions of dementia and cognitive decline, caregivers also identified some of the strategies that the care team had put in place to support their loved one. Finding interventions that help limit responsive behaviours were important to the caregivers, as one caregiver shared her goal for her mother's care to be a reduction in her agitation:

"Well for her not to be striking out at the care workers… that would be a really good goal." (CG1)

Caregivers shared some of the interventions that were used in the care of their loved ones in order to reduce behaviours and keep them engaged. Four different categories of interventions emerged, including: Approaches to Care; Activities; Environmental Modifications and; Medications. It is important to recognize that the categories of interventions are not a theme in and of itself but provide a way to organize the interventions discussed by caregivers. **Table 8** outlines the interventions utilized for the care of the residents, sorted into the four aforementioned categories.

Table 8:	Types of interventions used in care for residents with responsive behaviours as discussed by caregivers.

Approaches to Care	Activities	Environmental Modifications	Medications
Engage resident as a participant in care	Music therapy	Close door to bedroom for privacy	Antipsychotics
Engage resident in conversation	Social activities	Transition to private room	Antidepressants
Provide reassurance and redirection	Involvement working in the dining room	Extra staffing for security	
Support with Translation	Recreational Programs		
Language-specific cue cards and prompts			
Gentle touch *(Gentle Persuasive Approach)*			

Regardless of the type of activity, caregivers were mostly concerned with the engagement aspect of activities provided by the long-term care staff. Caregivers want to ensure that their loved ones are engaged and involved with various activities throughout the home, as an important aspect of care:

> *"Okay well, my mother just went into long-term care in February and we were very impressed with the activity coordinator who came when we first came in and talked about getting my mother involved, because she hadn't been involved really in anything for quite a few years. And they had really sort of designed a plan and made sure that they would come in and try to get her and say... to accept going to activities. And they just seemed very into wanting to involve her in any way they could, which I found was great." (CG3)*

Additionally, one caregiver shared her hopes that staff would continue to attempt to encourage her mother's participation despite her withdrawal from activities:

> *"At the very, at the beginning as well I think even the couple of individuals that come in and do activities with them, they were encouraging her to come out and do them and I know in the last little while she hasn't... But at the same time I would hope that they still continue to kind of make an effort because you know, that's the only way you're gonna get it. It's a long day when you're sitting by yourself in a room, just looking at the walls, or watching TV all day." (CG4)*

One of the commonly cited interventions for behaviour was medication. Caregivers shared various opinions on the use of medications. One caregiver shared her negative experiences with the use of psychotropic medications for her mother's behaviour and the lack of efficacy and negative effects the medication had:

"Trazadone, which didn't really have any effect whatsoever on her behaviours." (CG1)

"Umm… they did try her on the Trazadone maybe a little quicker than I would have liked, because I'm not a big fan of drugs for seniors and seeing her in the hospital before she got into long-term care and having her strung out on Haldol wasn't exactly one of my favourite memories." (CG1)

Conversely, another participant discussed her positive experience with medications and the positive effect it had on some of her husband's behaviours and presentation:

"Oh yes, I was okay [with having medications prescribed], because the one that they found was really helping him, and it helped him for a while and I was really happy. Because this all started in 2016 and the medication they prescribed, the psychiatrist prescribed was helping him so much, to me he was liking coming back to himself a little and I could trust him a bit." (CG2)

"And I was fine with the medication yeah, because it was giving me a little bit of comfort knowing that okay, he will sleep tonight, or something like that." (CG2)

Ultimately, caregivers want to find and use interventions for care that support the quality of life for their loved ones, and have positive effects on their behaviours.

C. Maintaining Residents' Independence

One final attribute of care that was important to family caregivers was the aspect of maintaining their loved one's independence. With the transition into long-term care, caregivers recognized it was difficult for their loved ones to lose the independence they once had. When asked what was going well in the care of one caregiver's mother, she addressed the fact that when her mother is up in her wheelchair and freely moving around on her own, this is when care

is going well. Another caregiver spoke about prior discussions with the care team in involving

her mother with setting up the dining room for meals, as her mother once ran her own kitchen.

> *"So one day she's making her own bed, washing her dishes to not having any of that so there was talks at the beginning of maybe having her like come out and help set the dining room and stuff like that…" (CG4)*

Although these two examples are seemingly different, maintaining independence was cited as an

important aspect of care.

2. *Difficulties and Challenges Faced in Long-Term Care Settings*

Caregivers discussed a number of difficulties and challenges faced in long-term care

settings. One of the most commonly acknowledged challenges was time constraints of staff, and

the implication of these time constraints on care:

> *"Well I think that maybe long-term care homes need to look at their staffing ratio. I think long-term care is getting to be, from what I've seen and experienced, you know it's heavier care and it's, or it's behaviours and I think that the staff have to have the extra people on hand to be able to manage everything. These seniors are people too and they deserve extra time." (CG1)*

> *"Yeah, and I get it. Like I'm sure it's not been, like I have to tell you, it's been pretty depressing. Like she's probably, as I look around one of the few people that is still mobile and can do that. So, you know, yeah, I'm sure they're busy with having to take care of everybody never mind remembering to, 'oh let's see if she's available or wants to help here', right?" (CG4)*

With dementia becoming more prevalent in the long-term care setting, participants

acknowledged the challenge of dementia itself and the impacts the symptoms of dementia have

on the residents, staff, and family members:

> *"I mean, I'm really struggling because it's hard to see your mother who used to be a certain you know, person, and all of a sudden now she's got dementia and she is… somebody new, somebody unrecognizable…" (CG1)*

Other challenges addressed included language barriers affecting care and communication,

uncertainty of what will happen in the future if care plans change, and recognizing that not all

staff are as effective at managing behaviours:

> *"There are certain people that are just better with dealing with certain situations. Not everybody's as good. So, I see it that even through the rotation there at the home, you know, there are nurses that can get my mum to do anything, because they just have that experience and they know how to approach situations. And then there's others that are kinda you know, just don't get it. And they're not approaching it the same way." (CG4)*

Through discussion with caregivers, various challenges faced in long-term care were described through their perspective.

3. *Wishes of 'More' for Care and the Future of the BSO Program*

To address some of the challenges faced in long-term care, participants discussed some of their hopes for care. Caregivers were also able to describe some of their wishes for the future of the BSO program after having a discussion of what the in-home BSO program entails. Caregivers would like their loved ones to continue to have ongoing support, and hope that there could be more staff, specifically staff training in managing responsive behaviours available:

> *"I think probably it would be nice if they could do more champions as you say, rather than just having maybe you know, one or two of the staff members that are trained in dealing with behaviours." (CG1)*

> *"So at times, you know when my mum is experiencing more of her like outbreaks and stuff, sometimes they just have somebody trained to be able to deal with it or you know they were waiting for somebody to come in. Or you know, on the weekend you know 'oh [the BSO] team isn't there' or something. So I would say, it would be nice to kind of have that expertise more often and available." (CG4)*

Caregivers also discussed desire for more one-on-one engagement opportunities for their loved one. In the context of the discussion with the caregivers, they described their ideal one-to-one time being more in terms of engagement and companionship, rather than to manage responsive behaviours:

> *"Umm… I would, well I feel like more one-on-one, where a person or staff was sort of assigned, or given some time where they are actually one-on-one, chatting, just being friendly sort of thing. And that may be happening there, but it's hard to know. So like a*

friend, like I almost wish there would be someone coming in regularly uhh… to be with her." (CG3)

Ultimately, caregivers want to ensure their loved ones are receiving the best care possible to ensure high levels of quality of life. Good examples of care as discussed by family caregivers come from including both the resident and family in care, finding and implementing interventions to manage behaviours, and ensuring their loved ones maintain their independence as much as possible.

5.1.4 Comparing Themes across Participant Groups

There were common themes found across the three participant groups involved in this study. The main two themes that were consistent across all three participant groups were *Challenges Faced in the Long-Term Care Setting*, as well as *Wishes of 'More' for the Future of BSO*. Many of the challenges described within this theme were also consistent across all groups. For example, the challenges with high resident-to-nurse ratios and the increasing complexity of residents and prevalence of dementia. Wishes for '*more*' in the BSO program also developed as a theme in all participant groups, with the all of the groups identifying one wish being the addition of more in-home BSO roles to the long-term care homes. Many themes were consistent across the long-term care staff and BSO members from the LHIN interviews as can be seen in **Figure 6**. Additionally, the caregiver and long-term care home staff interviews also contained overlapping themes (**Figure 6**). There were no directly overlapping themes between only caregiver and BSO member interviews.

Conversely, there were some discrepancies across the participant groups. Whereas the long-term care staff discussed the successes they were able to achieve with the BSO program, the

BSO members from the LHIN discussed their concerns with the seeming decline of the BSO

program.

LTC STAFF

Clear program goals, direction and structure

Appropriately managed BSO referral process

Strong communication efforts across the care team

Components of successful BSO program

Interdisciplinary collaboration

Staff engagement and awareness

Person-centered care

Strong leadership

PRC Role

Intervention Types:

Approaches to care
Activities
Environmental
Modifications
Medications

Challenges in LTC

Wishes of *'More'* for the future of BSO

Attributes of care important to family caregivers:
- *Being involved in the circle of care, supported by the care team*

Maintaining resident' independence

Evolution of the BSO program
Building capacity across the home:
- Using allocated hours/ funding
- Using the LTC Toolkit
Knowledge sharing across the home

Self-awareness in behavioural care

Creating effective care transitions
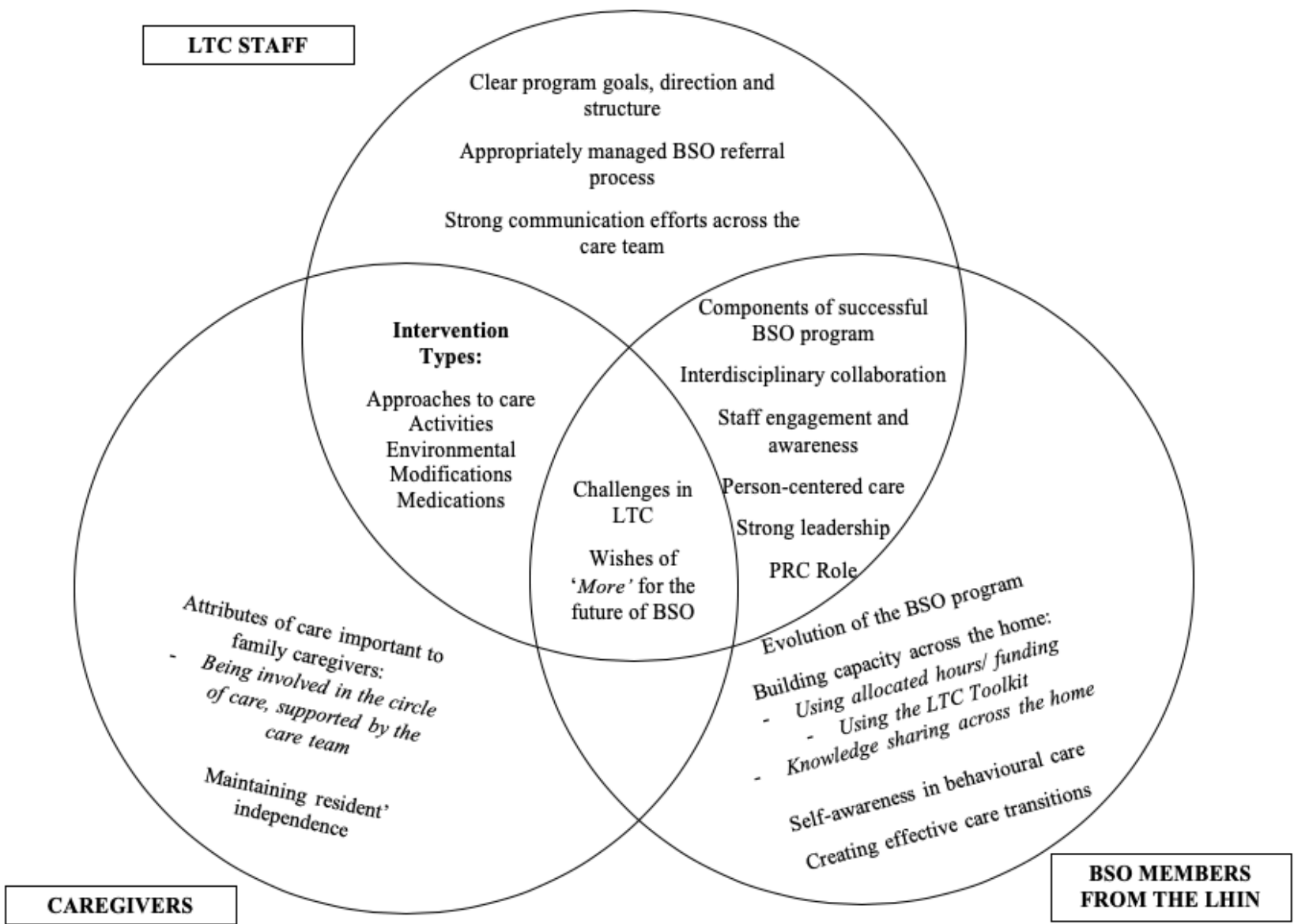
CAREGIVERS

BSO MEMBERS FROM THE LHIN

Figure 6. A comparison of themes and subthemes across participant group

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5.2 Quantitative Results

Twenty-one participants received the invitation to participate in a survey related to BSO program outcomes. These participants included both long-term care staff and the BSO members from the LHIN that participated in the qualitative interview phase. Twenty-two outcomes in total were identified by both key stakeholders at the onset of the project and throughout the qualitative interviews, which can be reviewed in **Table 9** and **Table 10**. Ten respondents completed the survey, for a 48% response rate. The survey took an average of five minutes for respondents to complete. In this time, staff were asked to rate program outcomes on a scale of one to five related to both importance to practice and their organization's level of importance.

5.2.1 Level of Importance

The first question respondents were asked to answer in this survey was the level of importance of each of the BSO program outcomes: "*Please rate the LEVEL OF IMPORTANCE of each of the listed BSO outcomes to you and your practice on the scale of 1-5. (i.e. How important are each of these outcomes to you and your work in long-term care?).*" The scale ranged from *Not Important* to *Extremely Important*. The specific labels were: 1) Not Important; 2) Slightly Important; 3) Important; 4) Very Important and; 5) Extremely Important.

Respondents rated most of the program outcomes from *Important* to *Extremely Important*, which corresponded to 3-5 on the 5-point scale. One hundred percent of respondents rated *improved quality of life for residents* and *decreased resident to staff abuse* as Extremely Important. Very few responses were distributed toward the lower end of the scale (i.e. Not Important or Slightly Important). For example, only ten percent of respondents rated one program outcome (*decreased need for placement of residents on secured units)* as Not Important. *Improved ability to maintain and enhance workflow* was also rated by only ten percent of

respondents as Slightly Important. Overall, of the program outcomes identified, most were

distributed towards the Extremely Important end of the scale. **Table 9** shows the summarized

results of Question 1.

Table 9. Results of the ratings of *level of importance* of BSO outcomes

Question 1	Not Important	Slightly Important	Important	Very Important	Extremely Important	Total
1. Decreased responsive behaviours	0	0	1	1	8	10
2. Decreased inappropriate antipsychotic use	0	0	2	3	5	10
3. Decreased use of 1:1 Care	0	0	2	4	4	10
4. Decreased need for placement of residents on secured units	1	0	2	5	2	10
5. Decreased stigma around dementia and responsive behaviours	0	0	2	2	6	10
6. Increased awareness of the BSO program throughout the home and community	0	0	0	3	7	10
7. Increased capacity to accommodate high risk, complex residents	0	0	2	3	5	10
8. Increased capacity for staff education and training (Formal and Informal)	0	0	0	3	7	10
9. Improved ability to maintain and enhance workflow	0	1	0	3	6	10
10. Increased ability to the BSO team as a resource (Not to provide direct care)	0	0	0	4	6	10
11. Increased use of comprehensive assessments to identify, investigate and understand behaviours	0	0	3	1	6	10
12. Increased capacity for relationship building between staff, residents and families	0	0	1	2	7	10
13. Increased capacity for including families in care planning	0	0	1	1	8	10
14. Increased capacity to engage residents with resident-specific activities and interventions	0	0	0	4	6	10
15. Improved quality of life for residents	0	0	0	0	10	10
16. Increased community involvement for care transitions	0	0	2	2	6	10
17. Increased capacity to utilize external resources (To refer to and to gain information from)	0	0	0	4	6	10
18. Decreased transfers/ admissions to hospital	0	0	1	2	7	10
19. Decreased # of residents placed on Form 1 - Psychiatric Assessment	0	0	2	1	7	10
20. Decreased need for specialized mental health hospital admissions	0	0	2	1	7	10
21. Decreased resident to resident abuse	0	0	0	1	9	10
22. Decreased resident to staff abuse	0	0	0	0	10	10

5.2.2 Level of Performance

Similarly to the first question, participants were also asked to rate their organization's level of performance on the identified program outcomes: "*Please rate your LTC's LEVEL OF PERFORMANCE as a result of the BSO program, on each of the listed outcomes on the scale of 1-5. (i.e., How well is your home doing on each of the listed outcomes because of the in-home BSO program?).*" As members of BSO from the LHIN do not directly work for any of the long-term care homes, they were asked to provide a global rating of the homes they oversee. Outcomes were rated again on a scale of 1-5 ranging from *Poor* to *Excellent*. Specific labels were: 1) Poor; 2) Fair; 3) Good; 4) Very Good and; 5) Excellent.

There was greater variance in responses in this question. Most outcomes were rated from *Good* to *Very Good*. Sixty percent of respondents rated their homes as *Excellent* in improving the quality of life of residents. Seventy percent of respondents rated their homes as *Very Good* in being able to decrease responsive behaviours. Seventy percent of respondents rated their homes as *Very Good* in being able to increase capacity to accommodate families into care planning. Ten percent of respondents rated their home as poor in being able to increase capacity to accommodate high risk, complex patients. Important to note, there were four outcomes that only had nine responses including *decreasing inappropriate antipsychotic use; decreasing transfers to hospital, decreasing number of residents placed on a Form 1 for a psychiatric assessment; and decreasing the need for specialized mental health hospital* admissions. **Table 10** shows the summarized results of the level of performance of organizations on BSO program outcomes.

Table 10. Results on the *level of performance* of organizations on BSO program outcomes

Question 2	Poor	Fair	Good	Very Good	Excellent	Total
1. Decreasing responsive behaviours	0	0	1	7	2	10
2. Decreasing inappropriate antipsychotic use	0	0	4	3	2	9
3. Decreasing use of one-to-one care	0	2	2	6	0	10
4. Decreasing the need for placement of residents onto secured units	0	3	4	3	0	10
5. Decreasing stigma around dementia and responsive behaviours	0	1	4	4	1	10
6. Increasing awareness of the BSO program throughout the home and the community	0	0	4	5	1	10
7. Increasing capacity to accommodate high risk, complex patients	1	2	2	5	0	10
8. Increasing capacity for staff education and training (formal and informal)	0	2	4	2	2	10
9. Improving ability to maintain and enhance workflow	0	1	8	1	0	10
10. Increasing ability to use BSO team as a resource (Not to provide direct care)	0	1	4	4	1	10
11. Increasing use of comprehensive assessments to identify, investigate and understand behaviours	0	0	4	5	1	10
12. Increasing capacity for relationship building between staff, residents and families	0	0	4	4	2	10
13. Increasing capacity to accommodate families into care planning	0	0	1	7	2	10
14. Increasing capacity to engage residents with resident-specific activities and interventions	0	0	2	4	4	10
15. Improving the quality of life for residents	0	0	0	4	6	10
16. Increasing community involvement in care transitions	0	5	1	4	0	10
17. Increasing capacity to use external resources (to refer out to and to gain information from)	0	0	3	6	1	10
18. Decreasing transfers to hospital	0	1	5	3	0	9
19. Decreasing # of residents placed on Form 1 - Psychiatric Assessment	0	2	4	3	0	9
20. Decreasing need for specialized mental health hospital admissions	0	2	5	2	0	9
21. Decreasing resident to staff abuse	0	3	4	3	0	10
22. Decreasing resident to resident abuse	0	2	5	3	0	10

5.2.3 Comparing Level of Importance against Level of Performance

To better compare how well long-term care homes are performing on each of the BSO program outcomes, to how important each of the outcomes are to homes across the LHIN, the rating scales from one to five were considered as numeric values. Each of the adjectives used to describe the rating scale were assigned a value of one to five in order to calculate the mean for each outcome. For example, *Excellent* was assigned a value of five. A mean for each of the outcomes was calculated using the formula as shown in **Figure 7**:

$$\frac{\Sigma\,(Responses(Assigned\ value))}{Total\ Responses}$$

$$= \frac{\Sigma\,(Responses\,(Assigned\;value))}{Total\;Responses}$$

$$= \frac{((0*1)+(0*2)+(1*3)+(7*4)+(2*5))}{10}$$

$$= \frac{3+28+10}{10}$$

$$= 4.1$$

Figure 7. Sample Calculation for decreasing responsive behaviours in Question 2, Level of Performance.

From these means, a rough comparison can be made across the program outcomes as seen in **Table 11**. The means calculated for level of importance tended to be higher than the means calculated for performance. Further, these means can be used to rank the program outcomes based on importance and performance as seen in **Table 12**.

Table 11. Summary of the means of program outcomes for both importance and performance

	Program Outcome	Mean
Importance	1. Decreased responsive behaviours	4.7
Performance	1. Decreasing responsive behaviours	4.1
Importance	2. Decreased inappropriate antipsychotic use	4.3
Performance	2. Decreasing inappropriate antipsychotic use	3.8
Importance	3. Decreased use of 1:1 Care	4.2
Performance	3. Decreasing use of 1:1 care	3.4
Importance	4. Decreased need for placement of residents on secured units	3.7
Performance	4. Decreasing the need for placement of residents onto secured units	3
Importance	5. Decreased stigma around dementia and responsive behaviours	4.4
Performance	5. Decreasing stigma around dementia and responsive behaviours	3.5
Importance	6. Increased awareness of the BSO program throughout the home and community	4.7
Performance	6. Increasing awareness of the BSO program throughout the home and the community	3.7
Importance	7. Increased capacity to accommodate high risk, complex residents	4.3
Performance	7. Increasing capacity to accommodate high risk, complex patients	3.1
Importance	8. Increased capacity for staff education and training (Formal and Informal)	4.7
Performance	8. Increasing capacity for staff education and training (formal and informal)	3.4
Importance	9. Improved ability to maintain and enhance workflow	4.4
Performance	9. Improving ability to maintain and enhance workflow	3
Importance	10. Increased ability to the BSO team as a resource (Not to provide direct care)	4.6
Performance	10. Increasing ability to use BSO team as a resource (Not to provide direct care)	3.5
Importance	11. Increased use of comprehensive assessments to identify, investigate and understand behaviours	4.3
Performance	11. Increasing use of comprehensive assessments to identify, investigate and understand behaviours	3.7
Importance	12. Increased capacity for relationship building between staff, residents and families	4.6
Performance	12. Increasing capacity for relationship building between staff, residents and families	3.8
Importance	13. Increased capacity for including families in care planning	4.7
Performance	13. Increasing capacity to accommodate families into care planning	4.1
Importance	14. Increased capacity to engage residents with resident-specific activities and interventions	4.6
Performance	14. Increasing capacity to engage residents with resident-specific activities and interventions	4.2
Importance	15. Improved quality of life for residents	5
Performance	15. Improving the quality of life for residents	4.6
Importance	16. Increased community involvement for care transitions	4.4
Performance	16. Increasing community involvement in care transitions	2.9
Importance	17. Increased capacity to utilize external resources (To refer to and to gain information from)	4.6
Performance	17. Increasing capacity to use external resources (to refer out to and to gain information from)	3.8
Importance	18. Decreased transfers/ admissions to hospital	4.6
Performance	18. Decreasing transfers to hospital	3.2
Importance	19. Decreased # of residents placed on Form 1 - Psychiatric Assessment	4.5
Performance	19. Decreasing # of residents placed on Form 1 - Psychiatric Assessment	3.1
Importance	20. Decreased need for specialized mental health hospital admissions	4.5
Performance	20. Decreasing need for specialized mental health hospital admissions	3
Importance	21. Decreased resident to resident abuse	4.9
Performance	22. Decreasing resident to resident abuse	3.5
Importance	22. Decreased resident to staff abuse	5
Performance	21. Decreasing resident to staff abuse	3

Table 12. Ranking and comparing program outcomes based on mean for level of importance and level of performance

Rank	Importance	Mean	Performance	Mean
1	Improved quality of life for residents	5	Improving the quality of life for residents	4.6
2	Decreased resident to staff abuse	5	Increasing capacity to engage residents with resident-specific activities and interventions	4.2
3	Decreased resident to resident abuse	4.9	Decreasing responsive behaviours	4.1
4	Decreased responsive behaviours	4.7	Increasing capacity to accommodate families into care planning	4.1
5	Increased awareness of the BSO program throughout the home and community	4.7	Increasing capacity for relationship building between staff, residents and families	3.8
6	Increased capacity for staff education and training (Formal and Informal)	4.7	Increasing capacity to use external resources (to refer out to and to gain information from)	3.8
7	Increased capacity for including families in care planning	4.7	Decreasing inappropriate antipsychotic use	3.8
8	Increased ability to the BSO team as a resource (Not to provide direct care)	4.6	Increasing awareness of the BSO program throughout the home and the community	3.7
9	Increased capacity for relationship building between staff, residents and families	4.6	Increasing use of comprehensive assessments to identify, investigate and understand behaviours	3.7
10	Increased capacity to engage residents with resident-specific activities and interventions	4.6	Decreasing stigma around dementia and responsive behaviours	3.5
11	Increased capacity to utilize external resources (To refer to and to gain information from)	4.6	Increasing ability to use BSO team as a resource (Not to provide direct care)	3.5
12	Decreased transfers/ admissions to hospital	4.6	Decreasing resident to resident abuse	3.5
13	Decreased # of residents placed on Form 1 - Psychiatric Assessment	4.5	Decreasing use of 1:1 care	3.4
14	Decreased need for specialized mental health hospital admissions	4.5	Increasing capacity for staff education and training (formal and informal)	3.4
15	Decreased stigma around dementia and responsive behaviours	4.4	Decreasing transfers to hospital	3.2
16	Improved ability to maintain and enhance workflow	4.4	Decreasing # of residents placed on Form 1 - Psychiatric Assessment	3.1
17	Increased community involvement for care transitions	4.4	Increasing capacity to accommodate high risk, complex patients	3.1
18	Decreased inappropriate antipsychotic use	4.3	Decreasing the need for placement of residents onto secured units	3
19	Increased capacity to accommodate high risk, complex residents	4.3	Improving ability to maintain and enhance workflow	3
20	Increased use of comprehensive assessments to identify, investigate and understand behaviours	4.3	Decreasing need for specialized mental health hospital admissions	3
21	Decreased use of 1:1 Care	4.2	Decreasing resident to staff abuse	3
22	Decreased need for placement of residents on secured units	3.7	Increasing community involvement in care transitions	2.9

Notably, *quality of life for residents* ranked number one in terms of both level of

importance and level of performance across the long-term care homes. *Decreasing responsive*

behaviours ranked fourth in terms of level of importance, and third in level of performance. Many of the other program outcomes ranked closely in terms of both level of importance and level of performance; however, *decreased resident to staff abuse* ranked second in terms of importance but only twenty-first in terms of performance. There were no other marked differences between ranks of outcomes of importance and performance, however these differences will be examined further in the discussion section.

Chapter 6: Discussion

6.1 Understanding Qualitative Findings

Throughout the course of qualitative interviews with long-term care staff, BSO members from the LHIN, and caregivers, several themes emerged relating to ideal function of the BSO program in the LTC homes across the Waterloo-Wellington LHIN. One finding that was heavily discussed by the BSO Members from the LHIN, was ensuring that the BSO program can function as intended, in order to build capacity and best support residents living with dementia. Long-term care staff and caregivers discussed important topics relating to capacity building, such as interdisciplinary collaboration and open communication across the care team.

Looking at differences between the long-term care homes included in this study in terms of sub-LHIN region, urban *vs.* rural location, and bed size there did not appear to be differences based on these factors. One factor that may have influenced the success of the program was bed size, as larger homes tended to have more appointed BSO staff.

Despite the differences in experiences of each participant group, there were consistencies across many of the themes. Key themes are further discussed below:

Focusing on Building Capacity across the Home

One of the major advantages to using the embedded in-home model is the ability of the in-home BSO team to share their skills and knowledge across the rest of the care team (Grouchy, Cooper & Wong, 2017). In order to successfully build capacity, one of the key indicators discussed by PRCs was that the homes must first have strong support from their leadership, including the administrators and directors of care. A home's leadership ultimately guides the operations and direction of the BSO program within the home. The support of leadership facilitates a top down effect throughout the home. For the BSO team to be most effective,

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leadership needs to minimize the use of the team to support direct personal care needs of the residents. As discussed in interviews, this does not always happen. With clear program goals and acknowledgement of the intentions of the BSO program, staff awareness of the program can develop. Facilitating this top down effect throughout the home involves a commitment to strong, open communication across the home in order to best understand how to support the staff and guide the needs of the program. Interdisciplinary collaboration is key in capacity building to be able to provide comprehensive care for residents across all aspects of care. With this dedication to capacity building, the BSO teams should be able to function as intended, meaning that more time can be spent developing plans of care during high-risk times such as during care transitions.

A next step homes may take to further capacity building efforts would be to educate family caregivers about the BSO program. Despite the difference in long-term care settings, a consistent finding across all four caregivers was the lack of awareness or knowledge of the Behavioural Supports Ontario program. Caregivers were unaware of the program, the intentions of the program, or their loved one's participation in the program. Caregivers were aware of some of the interventions that had been put in place for their loved ones, however, were not aware of the formal BSO program. Having staff members educate the family on this resource may allow them to be more involved in care and provide greater insight to inform care decisions.

If the BSO teams are not able to fulfil their intended to role to support residents with dementia by consulting, and facilitating the knowledge and use of resident care plans across the rest of the healthcare team, the program will not be successful. As one PRC discussed, the mobile model may offer more support in ensuring that the appointed BSO staff are not used to provide direct care; however, according to survey results, the embedded model may have more overall advantages than the mobile model (Grouchy, Cooper & Wong, 2017).

Providing Comprehensive, Person-Centered Care

Across all interviews, components related to person-centered care were discussed. Family caregivers discussed the value of their being supported and involved in decision making, consistent with the work of Dupuis and colleagues (2012) on authentic partnerships between staff and family members. LTC staff and BSO members from the LHIN spoke about their experiences in understanding the person, and tailoring interventions to best meet their care needs. The inclusion of P.I.E.C.E.S. assessments to provide care for residents on the BSO caseload was frequently discussed. Grouchy, Cooper and Wong (2017) found that the embedded in-home model allows the team to complete more comprehensive assessments in a timely fashion, and better include family caregivers. The BSO team should have extra time in their role to be able to effectively complete these assessments in order to devise care plans for residents. In order for these care plans to be successful, findings from qualitative interviews were consistent with the work of others (Dupuis et al., 2016) that families should be and *want* to be consulted, and that including older adult residents in care provision helps to create a true person-centred approach to care (Dupuis et al., 2012; Dupuis et al., 2016; Stein-Parbury et al., 2012). Creating an environment for care that is person-centred may lead to a more successful BSO program in the home (Gutmanis et al., 2015).

Overcoming Challenges in the Homes

Although interviews followed an appreciative inquiry format for questioning, all participant groups were able to identify that there are many challenges faced in the LTC setting, especially with the added complexity of dementia and its associated behaviours (Woodhead, Northrop & Edelstein, 2016). Addressing and overcoming these challenges could in turn help the BSO program become more successful in the homes. Many of the staff members discussed the

challenges associated with individuals staying in their homes for longer periods of time before coming into LTC. Aging in place has been a concept discussed as the desire of older persons to stay in their homes for as long as possible (Kendig, Gong, Cannon & Browning, 2017). Although appealing, aging in place has implications for LTC staff in their abilities to build relationships and develop care plans for their residents due to less time and advancing stages of dementia on admission to the home. Another main challenge addressed throughout the interviews was the difficulties associated with staff having little time to spend with all residents due to increasing resident-to-staff ratios (Harrington et al., 2016). Many participants were hopeful that more in-home BSO roles and staff members could be added to the home for various reasons, including being able to take more time to spend with residents to provide comprehensive care.

Building on Wishes for the Future

As aforementioned, BSO members from the LHIN discussed the importance of building capacity across the home and utilizing the in-home BSO members to teach and facilitate care plans across the entire home. The in-home BSO team should not be used to supplement direct care needs, but to enhance the ability of the surrounding care team. PRCs did admit, however, that with staffing shortages and increasing resident-to-staff ratios (as noted by others, e.g., Dupuis et al., 2016), addition of more in-home BSO members would be beneficial to the success of the BSO program. As the BSO members from the LHIN explained, staffing shortages and increasing resident-to-staff ratios are common across long-term care. Addition of more roles would allow for more comprehensive care across the home, especially if appointed roles such as a full-time recreational therapist could be included. The extra roles and expertise would allow for more time to be spent one-on-one with residents in order to learn their care needs and triggers and be better able to manage their responsive behaviours.

Caregivers were hopeful that their loved ones could receive more one-on-one engagement opportunities, which conflicts with the intentions of the BSO program to decrease the need for one-to-one care. In this case, however, caregivers' desire for more one-to-one engagement was not necessarily to minimize the responsive behaviours exhibited by their loved ones, but relates to the need for more resources to support manageable staffing ratios, and increased BSO funding and hours in order to provide comprehensive, person-centered care for all residents.

6.2 Assessing Quantitative Results

The intention of the survey completed by long-term care staff and BSO members from the LHIN was to better understand which of the intended BSO program outcomes were important to their care practices, and to see how well the homes were seen as performing on these outcomes. As described by the Grouchy, Cooper and Wong (2017) evaluation, the embedded in-home model showed greater success at achieving program outcomes as compared to the mobile models, when evaluated by survey participants. Overall, respondents in this study rated all identified program outcomes to be very important. Performance of long-term care homes on these identified outcomes was also consistent across most homes. The most noticeable difference between level of importance and level of performance ratings was decreased resident to staff abuse. Although the main goal of Behavioural Supports Ontario is to manage and support individuals living with dementia and reduce impact of responsive behaviours, the program outcome that individuals valued most, and felt they were best able to achieve with the BSO program, was improving quality of life for residents.

Additionally, a discrepancy was found comparing the qualitative findings from interviews with the BSO Members from the LHIN with survey results. Members from this

participant group discussed the importance of reducing the number of one-to-one care provision across the long-term care homes, as this is not a measure for building capacity. In terms of level of importance, *decreased use of one-to-one care* ranked twenty-first out of the twenty-two program outcomes listed, with a mean rating of 4.2. The level of performance of this program outcome was also low with a mean rating of 3.4, ranking thirteenth on the list of twenty-two outcomes.

Although one of the main roles of the BSO team as discussed throughout the interviews and throughout the literature is to provide education to staff members (BSO, 2017b), respondents rated level of performance for *increasing capacity for staff education and training* quite low with a mean rating of 3.4 (Rank: 14/22). For future research, solutions for improving this outcome may be valuable to enhance the function of the BSO program.

An outcome that was rated quite high in terms of both importance (Mean: 4.7; Rank: 5/22) and performance (Mean: 3.7; Rank: 8) was *increased awareness of the BSO program throughout the home and community*. When speaking with long-term care staff across the homes, the BSO program and outcomes were quite familiar to these individuals; however, when speaking with family caregivers, none of the individuals were familiar with the formal program. If staff are rating that there is good community awareness of the program, however, family members are stating that they are unaware of the program, this may indicate a disconnect between staff perception of awareness throughout the home and community.

One of the main program outcomes that was initially discussed with key stakeholders, and is discussed frequently throughout the literature (Seitz, Purandare & Conn, 2010; Willemse et al., 2016; Van Leeuwen et al., 2018; Saleh et al., 2017; Foebel et al., 2016), is *decreasing the inappropriate use of antipsychotics*. Within the qualitative interviews, many of the long-term

care staff discussed their attempts at using non-pharmacological interventions rather than psychotropic medications to manage responsive behaviours. *Decreasing inappropriate antipsychotic use* received a mean rating of 3.8/5 and ranked seventh on the list of outcomes. However, although this outcome is one of the main BSO program outcomes and appears to be performed well in comparison to other outcomes; in terms of level of importance, this program outcome was rated on average 4.3, and only ranked eighteenth compared to other outcomes.

On average, ratings of level of importance and performance were generally consistent. Looking at outcomes with low rated levels of performance may be a next step in guiding the future practice of the BSO program to enhance success.

6.3 Comparing against the Literature

As described by Grouchy, Cooper and Wong (2017), the embedded in-home model that is used in Waterloo Wellington has been shown to be more successful compared to mobile team models in important areas of care including care planning and provision, collaboration and team building, and home-level resident outcomes. They found that over 80% of respondents agreed that the in-home model helped to support point-of-care education efforts, assessments and creation of individualized care measures, and provided a foundation for internal support for homes' behaviour management programs (Grouchy, Cooper & Wong, 2017). Having an in-home model improved staff confidence in promoting safety for residents during their care; additionally, the in-home BSO teams provided accessible and comprehensive assessments and incorporated families and residents during these assessments. Lastly, the in-home model was found to have lower rates of restraint and antipsychotic use as compared to other models employed in other regions.

Anecdotally, PRCs described the in-home BSO model used by Waterloo Wellington as having a great reputation across the other LHINs and described being proud of the program. Unfortunately, there are increasing gaps within the program; as PRCs have described, at least half of the homes are beginning to struggle. Despite the value of the embedded model as described by Grouchy et al., (2017) there seems to be areas that this program can improve upon, specifically related to the efforts put towards building capacity across the home. These efforts are likely to be challenged as resource constraints, and an increasingly complex resident population in LTC, put pressure on BSO teams to serve as a resource for direct care rather than capacity-building.

6.4 Strengths and Limitations

One of the strengths of this thesis was the inclusion of both qualitative and quantitative data to evaluate program outcomes. Qualitative findings and quantitative results could be cross-compared to determine key areas for improvement of the embedded in-home model in long-term care. There has been very limited work conducted in evaluating the BSO program, specifically within a regional setting. Grouchy, Cooper and Wong's study (2017) provides a good foundation for understanding the comparison between BSO models in the long-term care setting. This thesis expands their work further by evaluating the embedded model within the Waterloo Wellington LHIN, which anecdotally has held a strong reputation of success across the province. Another strength of this thesis was the ability to include a multitude of healthcare providers working in long-term care homes, including nursing, personal support workers, and dietary aides. BSO members from the LHIN were also included, in their roles as psychogeriatric resource consultants and program leads. An important perspective also included was family caregivers, who have little experience with the BSO program specifically, but strong values in care of their

loved ones. Additionally, to enhance qualitative rigor, a second reviewer was involved in the qualitative analysis stages of this work.

There are also inherent limitations of this research. Due to time and resource constraints there was a limited number of participants involved, which influences the ability to reach saturation and adequate power. Unfortunately, residents living with dementia in long-term care settings were not involved in the intended older adult–caregiver dyad interviews, due to their level of cognitive decline in their advancing stages of dementia. Therefore, reliance was on family caregivers to share experiences on behalf of the residents living with responsive behaviours, receiving care in an LTC facility in the Waterloo Wellington LHIN. Additionally, only four caregivers participated in interviews in this phase, compared to the original intention to include four to six caregiver-older adult dyads. Themes appeared to be generally consistent across family caregiver interviews though it cannot be assumed saturation was reached.

Four of the thirty-six LTC homes across the Waterloo Wellington LHIN participated in focus group interviews. There may be some differences in practices across the homes that opted not to participate. Additionally, there were no homes that represented the Guelph-Puslinch sub-LHIN region. BSO Members from the LHIN discussed the differences in BSO programs across the region and indicated that there was great variation in the quality and successes of the programs depending on the home. Therefore, there may not be an adequate reflection of the challenges with the embedded in-home model in this research.

In respect to the survey, there was no distinction made between participant groups (BSO members from the LHIN *vs*. LTC staff) for confidentiality purposes. Due to the discrepancies within the BSO program across the homes that PRCs oversee, a global rating for performance

indicators may have been difficult to estimate and could have implications on the completion of surveys by BSO Members from the LHIN.

6.5 Conclusion

This thesis aimed to answer two main questions; 1) What does the Waterloo Wellington BSO program look like when it is functioning optimally in the LTC setting and; 2) What are the intended outcomes of the Waterloo Wellington BSO program? Through the use of both qualitative and quantitative approaches these questions were answered. Participants were able to identify important aspects of success of the BSO program, as well as outcomes during discussion in qualitative interviews. They then could provide ratings of these outcomes in terms of levels of importance and performance in the quantitative survey phase. A total of 22 program outcomes were identified through the creation of the logic model and qualitative interviews. Generally, these program outcomes were rated quite high in terms of importance (Mean: 4.53) but showed greater variance in terms of performance (Mean: 3.52). During qualitative interviews utilizing the appreciative inquiry approach, a number of key indicators were described in order for the BSO program to be successful within LTC. The AI approach was helpful in providing a more positive perspective on the process and function of the BSO program, although challenges related to the BSO program were still discussed among participants. Generally, findings were consistent across BSO Members of the LHIN and LTC staff; however, BSO members from the LHIN specifically focused on the importance of utilizing the allocated resources and funding appropriately, and enhancing the program through capacity building within the home.

Through this work, some initial recommendations were developed. In order to orient all key stakeholders to the intended operations of the BSO program, BSO leadership from the LHIN and PRCs should connect in order to discuss the current stance of the BSO program across the

LHIN. Once a clear understanding of the expectations of the BSO program has been developed among PRCs and BSO administration, these individuals should then meet with the in-home BSO teams as well as the LTC leadership to discuss and identify clear program goals and the intended use of BSO funding and allocated hours. The BSO Long-Term Care Toolkit could also be reviewed with in-home BSO teams and LTC leadership at this stage. The quality indicator data should be collected and analyzed once again to gain a quantitative perspective of the program's success and weakness within the home and to ultimately guide and direct changes to the program. Quantitative data from this research could also be used to guide program direction, focusing attention on indicators that were rated low in terms of level of performance within the long-term care homes.

References

Advanced Gerontological Education. (2017). *GPA fact sheet.* Retrieved from:

https://ageinc.s3.amazonaws.com/uploads/2017/01/ENG_2017_GPA_FACT-

SHEET_3RD-EDITION.pdf on December 4, 2018

Alzheimer Society Canada. (2018). *What is dementia?* Retrieved from:

http://alzheimer.ca/en/Home/About-dementia/What-is-dementia on November 15, 2018

Alzheimer Society Ontario (2017). *Examples of responsive behaviours.* Retrieved from:

https://alzheimer.ca/en/on/We-can-help/Resources/Shifting-Focus/Examples-of-

responsive-behaviour on November 15, 2018

Behavioural Supports Ontario. (2017a). Beha*vioural Supports Ontario Annual Report 2016-*

2017. Retrieved from:

http://www.behaviouralsupportsontario.ca/Uploads/ContentDocuments/BSO%20Annual%

20Report%202016-17.pdf on October 2, 2018

Behavioural Supports Ontario. (2017b). *14 LHIN models guide- May 2017.* Retrieved from:

http://hnhb.behaviouralsupportsontario.ca/Uploads/ContentDocuments/BSO%20Model%2

0Reference%20Guide_May2017.pdf on November 5, 2018

Behavioural Supports Ontario. (2018a). *Background.* Retrieved from:

http://www.behaviouralsupportsontario.ca/29/Background/ on October 25, 2018

Behavioural Supports Ontario. (2018b). *Provincial framework of care.* Retrieved from:

http://behaviouralsupportsontario.ca/25/Provincial_Framework_of_Care/ on October 25,

2018

Biernacki, P., & Waldorf, D. (1981). Snowball sampling: Problems and techniques of chain

referral sampling. *Sociological methods & research*, *10*(2), 141-163.

Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach

in health care research. *Global qualitative nursing research*, *4*, 2333393617742282.

BrainXchange. (n.d.). *Psychogeriatric resource consultants.* Retrieved from:

http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Psychogeriatric-Resource-

Consultants.aspx on November 12, 2018

Brodaty, H., Aerts, L., Harrison, F., Jessop, T., Cations, M., Chenoweth, L., ... & Sachdev, P. S.

(2018). Antipsychotic deprescription for older adults in long-term care: The HALT study.

Journal of the American Medical Directors Association, *19*(7), 592-600.

Cadore, E. L., Moneo, A. B. B., Mensat, M. M., Muñoz, A. R., Casas-Herrero, A., Rodriguez-

Mañas, L., & Izquierdo, M. (2014). Positive effects of resistance training in frail elderly

patients with dementia after long-term physical restraint. *Age*, *36*(2), 801-811.

Canadian Institute of Health Information [CIHI]. (2018). *Dementia in long-term care.* Retrieved

from: https://www.cihi.ca/en/dementia-in-canada/dementia-across-the-health-

system/dementia-in-long-term-care#ref2 on December 13, 2018

Canadian Institute of Health Information [CIHI]. (2018). *How dementia impacts Canadians.*

Retrieved from: https://www.cihi.ca/en/dementia-in-canada/how-dementia-impacts-

canadians#ref1 on November 13, 2018

Clifford, C., & Doody, O. (2018). Exploring nursing staff views of responsive behaviours of

people with dementia in long-stay facilities. *Journal of psychiatric and mental health

nursing*, *25*(1), 26-36.

Concerned Friends. (2017). *Long-term care guide.* Retrieved from:

http://www.concernedfriends.ca/understanding-long-term-care/long-term-care-guide on

November 29, 2018

Cooperrider, D. L., & Whitney, D. (2001). A positive revolution in change: Appreciative inquiry. *Public administration and public policy*, *87*, 611-630.

Creswell, J. W., & Creswell, J. D. (2017). *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.

Cullum, N., Ciliska, D., Haynes, B., & Marks, S. (Eds.). (2008). *Evidence-based nursing: an introduction*. John Wiley & Sons.

Dudgeon, S. (2010). *Rising tide: the impact of dementia on Canadian society: a study*. Alzheimer Society of Canada.

Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012). Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia*, *11*(4), 427-452.

Dupuis, S., McAiney, C. A., Fortune, D., Ploeg, J., & Witt, L. D. (2016). Theoretical foundations guiding culture change: The work of the Partnerships in Dementia Care Alliance. *Dementia*, *15*(1), 85-105.

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, *5*(1), 1-4.

Feng, Z., Hirdes, J. P., Smith, T. F., Finne-Soveri, H., Chi, I., Du Pasquier, J. N., ... & Mor, V. (2009). Use of physical restraints and antipsychotic medications in nursing homes: a cross-national study. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences*, *24*(10), 1110-1118.

Foebel, A. D., Onder, G., Finne-Soveri, H., Lukas, A., Denkinger, M. D., Carfi, A., ... & Liperoti, R. (2016). Physical restraint and antipsychotic medication use among nursing

home residents with dementia. *Journal of the American Medical Directors Association*, *17*(2), 184-e9.

Gillies, L., Coker, E., Montemuro, M., & Pizzacalla, A. (2015). Sustainability of an innovation to support and respond to persons with behaviors related to dementia and delirium. *Journal of Nursing Administration*, *45*(2), 70-73.

Goldman, K. D., & Schmalz, K. J. (2006). Logic models: the picture worth ten thousand words. *Health Promotion Practice*, *7*(1), 8-12.

Government of Ontario. (2007). Long-Term Care Homes Act, 2007, S.O. 2007, c. 8. Retreived from: https://www.ontario.ca/laws/statute/07l08 on February 13, 2019

Grouchy, M., Cooper, N., & Wong, T. (2017). Implementation of Behavioural Supports Ontario (BSO): An evaluation of three models of care. *Healthcare Quarterly*, *19*(4), 39-73.

Gutmanis, I., Snyder, M., Harvey, D., Hillier, L. M., & LeClair, J. K. (2015). Health care redesign for responsive behaviours—the Behavioural Supports Ontario experience: lessons learned and keys to success. *Canadian Journal of Community Mental Health*, *34*(1), 45-63.

Hamilton, P., Harris, D., Le Clair, K. & Collins, J. *Putting the P.I.E.C.E.S. together*. 6th Ed. Canada

Harrington, C., Schnelle, J. F., McGregor, M., & Simmons, S. F. (2016). Article commentary: The need for higher minimum staffing standards in US nursing homes. *Health services insights*, *9*, HSI-S38994.

Hefner, G., Stieffenhofer, V., Gabriel, S., Palmer, G., Müller, K. M., Röschke, J., & Hiemke, C. (2015). Side effects related to potentially inappropriate medications in elderly psychiatric patients under everyday pharmacotherapy. *European journal of clinical pharmacology*, *71*(2), 165-172.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research*, *15*(9), 1277-1288.

Hutchinson, A. M., Milke, D. L., Maisey, S., Johnson, C., Squires, J. E., Teare, G., & Estabrooks, C. A. (2010). The resident assessment instrument-minimum data set 2.0 quality indicators: a systematic review. *BMC health services research*, *10*(1), 166.

Issel, L. M. (2014). *Health program planning and evaluation*. Jones & Bartlett Learning.

Kendig, H., Gong, C. H., Cannon, L., & Browning, C. (2017). Preferences and predictors of aging in place: Longitudinal evidence from Melbourne, Australia. *Journal of Housing for the Elderly*, 31(3), 259-271.

Kessler, R., & Glasgow, R. E. (2011). A proposal to speed translation of healthcare research into practice: dramatic change is needed. *American journal of preventive medicine*, *40*(6), 637-644.

Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of advanced nursing*, *28*(4), 882-890.

Lam, K., Kwan, J. S., Kwan, C. W., Chong, A. M., Lai, C. K., Lou, V. W., ... & Chi, I. (2017). Factors associated with the trend of physical and chemical restraint use among long-term care facility residents in Hong Kong: data from an 11-year observational study. *Journal of the American Medical Directors Association*, *18*(12), 1043-1048.

Local Health Integration Network. (2014). *Ontario LHINs.* Retrieved from: http://www.lhins.on.ca/ on October 4, 2018

McAiney, C. A., Stolee, P., Hillier, L. M., Harris, D., Hamilton, P., Kessler, L., ... & Le Clair, J. K. (2007). Evaluation of the sustained implementation of a mental health learning initiative in long-term care. *International Psychogeriatrics*, *19*(5), 842-858.

Milan, A., Bohnert, N., LeVasseur, S., & Pagé, F. (2014). Living arrangements of seniors-Families, households and marital status-Structural type of dwelling and collectives, 2011 Census of Population. *Statistics Canada*.

Morse, J. M. (2010). How different is qualitative health research from qualitative research? Do we have a subdiscipline?. *Qualitative Health Research*, *20*(11), 1459-1464.

Naylor, M. D., Hirschman, K. B., Bowles, K. H., Bixby, M. B., Konick-McMahan, J., & Stephens, C. (2007). Care coordination for cognitively impaired older adults and their caregivers. *Home health care services quarterly*, *26*(4), 57-78.

Nihtilä, E. K., Martikainen, P. T., Koskinen, S. V., Reunanen, A. R., Noro, A. M., & Häkkinen, U. T. (2007). Chronic conditions and the risk of long-term institutionalization among older people. *European journal of public health*, *18*(1), 77-84.

O'Connor, D. W., D'Cunha, C., Clifton, T., Huppert, D., Lowy, H., Macfarlane, S., ... & Hoeve, J. T. (2017). Quality indicators of psychotropic prescribing to people with dementia in aged psychiatry inpatient units. *Aging & mental health*, 1-6.

Ontario Behavioural Support System Project. (2010). *Behaviours having meaning.* Retrieved from http://brainxchange.ca/Public/Files/BSO/Behaviours-Have-Meaning-Full-Report.aspx on October 25, 2018

Osborn, R., Moulds, D., Squires, D., Doty, M. M., & Anderson, C. (2014). International survey of older adults finds shortcomings in access, coordination, and patient-centered care. *Health Affairs*, *33*(12), 2247-2255.

Patton, M. Q. (2002). Qualitative interviewing. *Qualitative research and evaluation methods*, *3*, 344-347.

Patton, M. Q. (2008). *Utilization-focused evaluation*. Sage publications.

Pekkarinen, L., Elovainio, M., Sinervo, T., Finne-Soveri, H., & Noro, A. (2006). Nursing

    working conditions in relation to restraint practices in long-term care units. *Medical Care*,

    1114-1120.

Pekkarinen, L., Sinervo, T., Elovainio, M., Noro, A., & Finne-Soveri, H. (2008). Drug use and

    pressure ulcers in long-term care units: do nurse time pressure and unfair management

    increase the prevalence? *Journal of clinical nursing*, *17*(22), 3067-3073.

Pizzacalla, A., Montemuro, M., Coker, E., Martin, L. S., Gillies, L., Robinson, K., ... &

    Gusciora, J. (2015). Gentle Persuasive Approaches. *Orthopaedic Nursing*, *34*(2), 101-107.

Public Health Agency of Canada. (2017). *Dementia in Canada, including Alzheimer's disease.*

    Retrieved from: https://www.canada.ca/en/public-health/services/publications/diseases-

    conditions/dementia-highlights-canadian-chronic-disease-surveillance.html on November

    13, 2018

Seitz, D., Purandare, N., & Conn, D. (2010). Prevalence of psychiatric disorders among older

    adults in long-term care homes: a systematic review. *International Psychogeriatrics*, *22*(7),

    1025-1039.

Stein-Parbury, J., Chenoweth, L., Jeon, Y. H., Brodaty, H., Haas, M., & Norman, R. (2012).

    Implementing person-centered care in residential dementia care. *Clinical*

    gerontologist, *35*(5), 404-424.

St. Joseph's Health Centre Guelph (2018). *Geriatric Outreach Services*. Retrieved from:

    www.sjhcg.ca/our-programs-of-care/geriatric-outreach-services-2/ on July 15, 2019

Stolee, P., McAiney, C. A., Hillier, L. M., Harris, D., Hamilton, P., Kessler, L., ... & Le Clair, J.

    K. (2009). Sustained transfer of knowledge to practice in long-term care: Facilitators and

barriers of a mental health learning initiative. *Gerontology & Geriatrics Education*, *30*(1), 1-20.

Strauss, A., & Corbin, J. (1998). Basics of qualitative research (2nd ed.). Newbury Park, CA: Sage.

Streiner, D. L., & Norman, G. R. (2008). Health measurement scales: a practical guide to the development and use.

Streiner, D. L., Norman, G. R., & Cairney, J. (2015). *Health measurement scales: a practical guide to their development and use*. Oxford University Press, USA.

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American journal of evaluation*, *27*(2), 237-246.

Van Leeuwen, E., Petrovic, M., van Driel, M. L., De Sutter, A. I., Vander Stichele, R., Declercq, T., & Christiaens, T. (2018). Discontinuation of Long-Term Antipsychotic Drug Use for Behavioral and Psychological Symptoms in Older Adults Aged 65 Years and Older With Dementia. *Journal of the American Medical Directors Association*, *19*(11), 1009-1014.

Viau, K. (2018). Waterloo Wellington LHIN Behavioural Supports Ontario (BSO) Activity tracker data highlights: BSO in long-term care (LTC) 2015-2018. Personal Communication. Received on November 30, 2018.

Waterloo Wellington BSO. (2018a). *Who we serve.* Retrieved from: http://ww.behaviouralsupportsontario.ca/188/Who_We_Serve/ on October 25, 2018

Waterloo Wellington BSO. (2018b). *Partners.* Retrieved from: http://ww.behaviouralsupportsontario.ca/153/Partners/ on October 25, 2018

Willemse, B. M., De Jonge, J., Smit, D., Dasselaar, W., Depla, M. F., & Pot, A. M. (2016). Is an unhealthy work environment in nursing home care for people with dementia associated

with the prescription of psychotropic drugs and physical restraints?. *International psychogeriatrics*, *28*(6), 983-994.

Woodhead, E. L., Northrop, L., & Edelstein, B. (2016). Stress, social support, and burnout among long-term care nursing staff. *Journal of Applied Gerontology*, *35*(1), 84-105.

World Health Organization. (2000). *Evaluation of psychoactive substance use disorder treatment- Workbook 7* (No. WHO/MSD/MSB/00.2b). Geneva: World Health Organization.

Study Recruitment Email- Older Adults and Caregivers
Evaluation of a Regional Behavioural Support Program

Dear Participant

My name is Kayla Brooks and I am an MSc student working under the supervision of Paul Stolee in the School of Public Health and Health Systems at the University of Waterloo. I am contacting you to ask that you participate in my study in conducting an evaluation of Behavioural Supports Ontario (BSO) in the Waterloo Wellington LHIN. This email has been sent on behalf of the researchers of this study, myself and my supervisor Dr. Paul Stolee.

Participation in this study asks that individuals partake in an interview in which questions related to experiences utilizing the services offered by BSO in long-term care facilities will be addressed. Interviews may last approximately 30-45 minutes. There will be no remuneration provided for involvement with this study. I would like to assure you that this study has been reviewed and has received ethics clearance through a University of Waterloo Ethics Committee.

The final decision to participate in this study is yours. If you are interested in participating, please contact me at km3brooks@uwaterloo.ca, so we may organize a suitable time and location for this interview.

If you have any further questions, do not hesitate to email me at km3brooks@uwaterloo.ca.

Thank you,

Kayla Brooks

APPENDIX B

Study Recruitment Email- Members of BSO from the LHIN
Evaluation of a Regional Behavioural Support Program

Dear Valued Member of BSO,

My name is Kayla Brooks and I am an MSc student working under the supervision of Paul Stolee in the School of Public Health and Health Systems at the University of Waterloo. I am contacting you to ask that you participate in my study in conducting an evaluation of BSO in the Waterloo Wellington LHIN. This email is being sent on behalf of the researchers of this study, myself and my supervisor Dr. Paul Stolee.

Participation in this study asks that individuals partake in an interview in which questions related to the operation of BSO in long-term care facilities will be addressed. Interviews may last approximately 30-45 minutes. Additionally, a short survey will be administered to participants to determine satisfaction with the current BSO program. There will be no remuneration provided for involvement with this study. Please be aware that your decision to participate (or not participate) will not be shared with your employer, or affect your employment or status at the organization. I would like to assure you that this study has been reviewed and has received ethics clearance through a University of Waterloo Ethics Committee.

The final decision to participate in this study is yours. If you are interested in participating, please contact me at km3brooks@uwaterloo.ca, so we may organize a suitable time and location for this interview.

If you have any further questions, do not hesitate to email me at km3brooks@uwaterloo.ca.

Thank you,

Kayla Brooks

Study Recruitment Email- Long-Term Care Staff
Evaluation of a Regional Behavioural Support Program

Dear Valued Member of [Long-Term Care Facility],

      My name is Kayla Brooks and I am an MSc student working under the supervision of Paul Stolee in the School of Public Health and Health Systems at the University of Waterloo. I am contacting you to ask that you participate in my study in conducting an evaluation of Behavioural Supports Ontario in the Waterloo Wellington LHIN. This email has been sent on behalf of the researchers of this study, myself and my supervisor Dr. Paul Stolee.

      Participation in this study asks that individuals partake in a focus group or individual interview in which questions related to the operation of BSO in long-term care facilities will be addressed. Both focus groups and individual interviews will last approximately 30-60 minutes. Additionally, a short survey will be administered to participants to determine satisfaction with the current BSO program. There will be no remuneration provided for involvement with this study. Please be aware that your decision to participate (or not participate) will not be shared with your employer, or affect your employment and/or status at the organization. I would like to assure you that this study has been reviewed and has received ethics clearance through a University of Waterloo Ethics Committee.

      The final decision to participate in this study is yours. If you are interested in participating, please contact me at km3brooks@uwaterloo.ca, so we may organize a suitable time and location for this interview.

If you have any further questions, do not hesitate to email me at km3brooks@uwaterloo.ca.

Thank you,

Kayla Brooks

APPLIED HEALTH SCIENCES UNIVERSITY OF WATERLOO PARTICIPANTS NEEDED FOR RESEARCH PROJECT:

Evaluation of a Regional Behavioural Support Program

We are looking for BSO members, long-term care home staff, and older adults and their caregivers to take part in a study to conduct an evaluation of the Behavioural Supports Ontario (BSO) Program in the Waterloo Wellington LHIN.

As a participant in this study, you would be asked to: take part in an interview and/or focus group that will be approximately 30-60 minutes in length. Additionally a short survey may be administered to better understand how BSO functions in long-term care home settings.

For more information about this study, or to participate in this study, please contact:

**Kayla Brooks
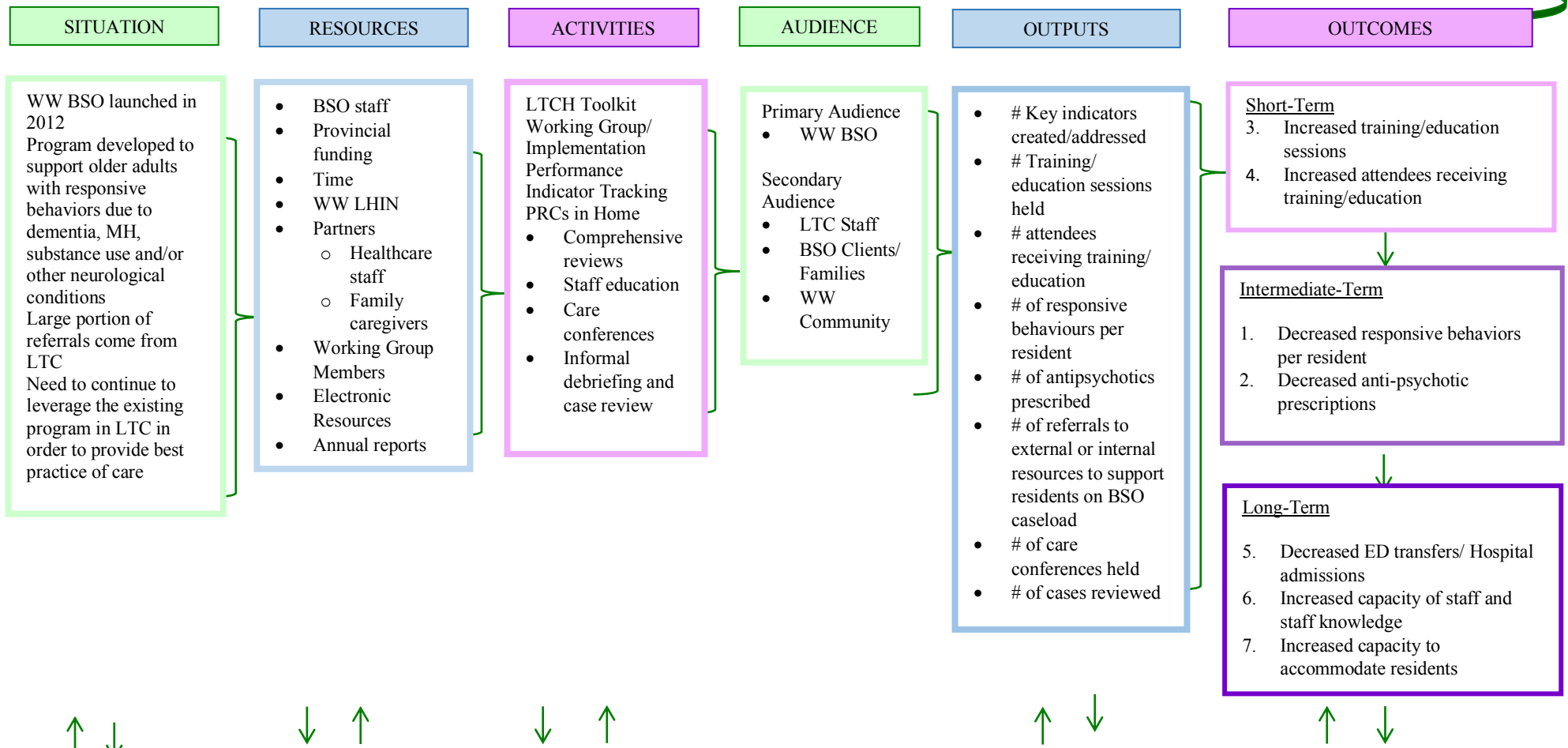School of Public Health and Health Systems
University of Waterloo**

Email: **km3brooks@uwaterloo.ca**

This study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee.

APPENDIX E

WW BSO Logic Model

Program Goal:
To support older adults living with responsive behaviours due to dementia, mental health, substance use and/or other neurological conditions using primarily non-pharmacological approaches through the provision of education, training and other resources for informal and formal caregivers in long-term care homes.

SITUATION	RESOURCES	ACTIVITIES	AUDIENCE	OUTPUTS	OUTCOMES

SITUATION

WW BSO launched in 2012
Program developed to support older adults with responsive behaviors due to dementia, MH, substance use and/or other neurological conditions
Large portion of referrals come from LTC
Need to continue to leverage the existing program in LTC in order to provide best practice of care

RESOURCES

- BSO staff
- Provincial funding
- Time
- WW LHIN
- Partners
  - Healthcare staff
  - Family caregivers
- Working Group Members
- Electronic Resources
- Annual reports

ACTIVITIES

LTCH Toolkit
Working Group/
Implementation
Performance
Indicator Tracking
PRCs in Home
- Comprehensive reviews
- Staff education
- Care conferences
- Informal debriefing and case review

AUDIENCE

Primary Audience
- WW BSO

Secondary Audience
- LTC Staff
- BSO Clients/ Families
- WW Community

OUTPUTS

- # Key indicators created/addressed
- # Training/ education sessions held
- # attendees receiving training/ education
- # of responsive behaviours per resident
- # of antipsychotics prescribed
- # of referrals to external or internal resources to support residents on BSO caseload
- # of care conferences held
- # of cases reviewed

OUTCOMES

Short-Term
3. Increased training/education sessions
4. Increased attendees receiving training/education

Intermediate-Term
1. Decreased responsive behaviors per resident
2. Decreased anti-psychotic prescriptions

Long-Term
5. Decreased ED transfers/ Hospital admissions
6. Increased capacity of staff and staff knowledge
7. Increased capacity to accommodate residents

Assumptions
- Adequate resources to support BSO activities
- Realistic timeline for implementation
- Toolkit is comprehensive enough to support function of LTCH
- BSO members, LTC staff will want positive change and program modifications
- Long-term care homes and the community will support this initiative

External Factors
- Responsive behaviours may not be resolved through non-pharmacological approaches
- Persons with dementia are an at risk/vulnerable population
- Push-back from HCP's to use non-pharmacological interventions
- LTCH without embedded BSO teams (BSO is an external resource in some homes)
- Unexpected changes in funding and resources
- Actual # of staff that will attend training/education sessions
- Push-back from families/other caregivers

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APPENDIX F
Interview Guide: BSO Members from the LHIN
Evaluation of a Regional Behavioural Support Program

CONTEXT QUESTION:
1. Can you please share your name and your role with BSO?
   a. What does your role entail?

Audio-recording will now begin

MAIN QUESTIONS:
2. What does the BSO program look like when it's operating at its greatest potential?

3. What do you value most about BSO?

4. How do you feel that BSO can best support its clientele?

5. Describe a time when you felt a sense of excellent cooperation between the long-term care home staff and BSO?
   a. What made this cooperation possible?

6. How do you approach solving disagreements or discrepancies between yourself and the long-term care home staff?

7. Please, describe 1 wish you have for the future of BSO.

8. How do you feel that BSO has impacted the lives of residents living in long-term care? Please provide an example.

ENDING QUESTIONS:
9. Is there anything else you think I should know, or anything else you would like to share?

10. Are there any additional questions or clarification you may like to ask me?

APPENDIX G
Interview Guide: LTC Staff- Focus Group
Evaluation of a Regional Behavioural Support Program

CONTEXT QUESTION:
1. Can you please share your name and your position at [Name of Long-term Care Facility]

Audio-recording will now begin

MAIN QUESTIONS:
2. Describe what BSO means to you in terms of your work:
   a. Their role/ function in long-term care
   b. Who they support
   c. Main goals/ purpose of BSO

3. Describe your role in referring residents to BSO services.

4. What does the BSO program look like when it is operating at its greatest potential?

5. Describe a time when you felt a sense of excellent cooperation between yourself and BSO.

6. What is one wish you have for the future of BSO?

7. How do you feel your current practice has impacted the lives of residents with responsive behaviours living in long-term care? Please provide an example.

ENDING QUESTIONS:
8. Is there anything else you think I should know, or anything else you would like to share?

9. Are there any additional questions or clarification you may like to ask me?

APPENDIX H
Interview Guide: Older Adults and Caregivers
Evaluation of a Regional Behavioural Support Program

CONTEXT QUESTION:
1. Can you please share your names and relation to the resident?

Audio-recording will now begin

2. Have you heard of the Behavioural Supports Ontario program, if so what do you know about this program?

MAIN QUESTIONS:
3. Please describe your most positive experience with receiving care within the long-term care home.
    a. What did care look like when it was going well?
    b. Who was involved?
    c. What made the experience positive?

4. What can BSO do to ensure you/your loved one feels well-supported?

5. What is one wish you have for the future of BSO?

ENDING QUESTIONS:
6. Is there anything else you think I should know, or anything else you would like to share?

7. Are there any additional questions or clarification you may like to ask me?

Letter of Information
Evaluation of a Regional Behavioural Support Program
Participant Group: Members of Behavioural Supports Ontario
Student Investigator: Kayla Brooks, MSc (c); km3brooks@uwaterloo.ca
Supervisor: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 ext. 35879

A. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to develop an evaluation of the services that Behavioural Supports Ontario (BSO) provides within long-term care homes in the Waterloo-Wellington LHIN. The aim of developing this evaluation is to better understand how BSO should ideally coordinate and collaborate with care providers in long-term care to provide a foundation to guide and improve future practice.

B. WHO CAN PARTICIPATE?

We are looking for members of BSO that service long-term care homes in the Waterloo Wellington LHIN. To have a comprehensive overview of how the program operates at its highest level of efficacy, we are also interested in speaking with long-term care home staff as well as older adults and their caregivers.

C. WHAT WILL I BE ASKED TO DO?

Participants from BSO will be invited to partake in individual interviews that will be approximately 30-45 minutes in length. Interviews will be conducted to help to identify what the BSO program looks like when operating at its greatest potential, and what aspects of the program can be modified or changed to guide and improve future practice. With your permission interviews will be audio-taped to ensure that the information collected is accurate, anonymous quotes may be taken from these interviews. Any and all identifying information will be removed. Participants are not required to answer any questions they may not wish to.

After interviews are conducted, participants will be asked to complete a short survey regarding some of the anticipated goals and outcomes of the BSO program. This survey will be available to participants electronically by email after the interview period. Interview data may be used to inform questions on the survey.

Please be aware that participation in this study is voluntary.

D. WHERE WILL THE STUDY TAKE PLACE AND WHEN?

The study will take place in a mutually agreed upon location, or by telephone. The study will take approximately one year to complete in its entirety, however, participants are only asked to take part in one interview (30-45 minutes), and will be asked to complete a short survey through SurveyMonkey, an online survey tool. The survey should only take approximately 5-10 minutes to complete, and a link will be emailed to individuals after participating in the interview portion of this study.

E. CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

Participants may with draw from the study at any time, up until the point of publication. If you wish to withdraw from the study, you may notify the researcher during the interview or by way of email: km3brooks@uwaterloo.ca.

F. RISKS AND BENEFITS

There are no identified or anticipated risks for this study. There are no anticipated direct benefits for this study, participants will not be remunerated for their involvement.

G. CONFIDENTIALITY AND DATA SECURITY

To ensure confidentiality, no identifying information will be attached to study participants' responses. Any identifying information will be removed from the interview transcripts and surveys during the data entry period, and stored in a separate file. Individual's names will not be included in published materials, instead unique identification numbers/pseudonyms will be assigned. Email addresses will be collected during the interview, but will be stored in a file separately from the data. Written records, etc. will be stored in a locked cabinet at the University of Waterloo. All electronic files will be stored on a protected server, and each will be password protected. Only researchers associated with this study will have access to this data. Data may be shared publicly, however, your identity will remain confidential. All data will be stored for a minimum of 7 years.
Please note that as you will be completing part of this study using an online survey provided by SurveyMonkey; with information transmitted over the internet, privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g. government agencies, hackers). SuveryMonkey temporarily collects your computer IP address to avoid duplicate responses in the dataset but will not collect information that could identify you personally.
Please also be aware that employers will not be informed of your decision to participate (or not to participate) in this study, and this will not affect your employment and/or status with the organization.

H. QUESTIONS

If at any time you have questions regarding the proposed research, please do not hesitate to contact the **Supervisor: Paul Stolee**, School of Public Health and Health Systems, University of Waterloo, Waterloo, ON, 519-888-4567 ext. 35879; stolee@uwaterloo.ca or **Student Investigator: Kayla Brooks**, MSc (c), School of Public Health and Health Systems, University of Waterloo, Waterloo, ON, km3brooks@uwaterloo.ca
This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

I. CONSENT FORM

By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

TITLE OF THE STUDY: Evaluation of a Regional Behavioural Support Program
I have read the information presented in the information letter about a study conducted by Kayla Brooks, under the supervision of Dr. Paul Stolee, School of Public Health and Health Systems, University of Waterloo. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca. For all other questions contact Kayla Brooks at km3brooks@uwaterloo.ca.

   I am aware the interview will be audio recorded to ensure accurate transcription and analysis.

   I give permission for the use of anonymous quotations in any thesis or publication that comes from this research.

I agree of my own free will to participate in the study.

Participant's name: _____

Participant's signature: _____ Date:_____

Researcher's/Witness' signature_____ Date:_____

APPENDIX J
Letter of Information
Evaluation of a Regional Behavioural Support Program
Participant Group: Long-term Care Staff
Student Investigator: Kayla Brooks, MSc (c); km3brooks@uwaterloo.ca
Supervisor: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 ext. 35879

A. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to develop an evaluation of the services that Behavioural Supports Ontario (BSO) provides within long-term care homes in the Waterloo-Wellington LHIN.   The aim of developing this evaluation is to better understand how BSO should ideally coordinate and collaborate with care providers in long-term care to provide a foundation to guide and improve future practice.

B. WHO CAN PARTICIPATE?

We are looking for healthcare providers that work in long-term care in collaboration with the Waterloo Wellington LHIN BSO program. To have a comprehensive overview of how the program operates at its highest level of efficacy, we are also interested in speaking with members of BSO as well as older adults and their caregivers.

C. WHAT WILL I BE ASKED TO DO?

LTC staff will be asked to participate in a focus group, or interview to better understand how staff are able to coordinate with members of BSO to provide comprehensive care to residents exhibiting responsive behaviours. The focus group or interview will be approximately 30-45 minutes in length. Before the focus group is initiated, you will be asked to confirm that you agree to participate. With your permission all interviews will be audio-recorded to ensure that the information collected is accurate. Anonymous quotes may be derived from these interviews. Any and all identifying information will be removed. Participants are not required to answer any questions they may not wish to.
In the event that a staff member may not be able to be involved with the focus group, but still wishes to participate, an individual interview can be conducted. Individual interviews will be approximately 30-45 minutes in length. Theses interviews will also be audio-taped (with permission) and anonymous quotes may be taken. Any and all identifying information will be removed. Participants are not required to answer any questions they may not wish to.
After focus group interviews are conducted, participants will be asked to complete a short survey regarding some of the anticipated goals and outcomes of the BSO program. This survey will be available to participants electronically by email after the interview period. Interview data may be used to inform questions on the survey.
Please be aware that participation in this study is voluntary.

D. WHERE WILL THE STUDY TAKE PLACE AND WHEN?

The study will take place in a mutually agreed upon location, or by telephone. The study will take approximately one year to complete in its entirety, however, participants are only required to take part in one interview or focus group, and will be asked to complete a short survey through SurveyMonkey, an online survey tool. The survey should only take approximately 5-10 minutes to complete, and a link will be emailed to individuals after participating in the interview portion of this study.

E. CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

Participants may with draw from the study at any time, up until the point of publication. If you wish to withdraw from the study, you may notify the researcher during the interview or by way of email: km3brooks@uwaterloo.ca.

F. RISKS AND BENEFITS

There are no identified or anticipated risks for this study. There are no anticipated direct benefits for this study, participants will not be remunerated for their involvement.

G. CONFIDENTIALITY AND DATA SECURITY

To ensure confidentiality, no identifying information will be attached to study participants' responses. Any identifying information will be removed from the interview transcripts and surveys during the data entry period, and stored in a separate file. Individuals' names will not be included in published materials, instead identification numbers/pseudonyms will be assigned. Email addresses will be collected during the focus group/interview period, but will be stored in a file separately from the data. Written records, etc. will be stored in a locked cabinet at the University of Waterloo. All electronic files will be stored on a protected server, and each will be password protected. Only researchers associated with this study will have access to this data. Data may be shared publicly, however, your identity will remain confidential. All data will be stored for a minimum of 7 years.
Due to the nature of focus group interview, the research team and other participants in the focus group will know what you have said. We ask that you keep in confidence information that identifies or could potentially identify a participant and/or his/her comments.
Please note that as you will be completing part of this study using an online survey provided by SurveyMonkey; with information transmitted over the internet, privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g. government agencies, hackers). SuveryMonkey temporarily collects your computer IP address to avoid duplicate responses in the dataset but will not collect information that could identify you personally.
Please also be aware that employers will not be informed of your decision to participate (or not to participate) in this study, and this will not affect your employment and/or status with the organization.

H. QUESTIONS

If at any time you have questions regarding the proposed research, please do not hesitate to contact the **Supervisor: Paul Stolee**, School of Public Health and Health Systems, University of Waterloo, Waterloo, ON, 519-888-4567 ext. 35879; stolee@uwaterloo.ca or **Student Investigator: Kayla Brooks**, MSc (c), School of Public Health and Health Systems, University of Waterloo, Waterloo, ON, km3brooks@uwaterloo.ca

I. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

CONSENT FORM

By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

TITLE OF THE STUDY: Evaluation of a Regional Behavioural Support Program
I have read the information presented in the information letter about a study conducted by Kayla Brooks, under the supervision of Dr. Paul Stolee, School of Public Health and Health Systems, University of Waterloo. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca. For all other questions contact Kayla Brooks at km3brooks@uwaterloo.ca.

   I am aware the focus group or interview will be audio recorded to ensure accurate transcription and analysis.

    I give permission for the use of anonymous quotations in any thesis or publication that comes from this research.

I agree of my own free will to participate in the study.

Participant's name: _____

Participant's signature: _____ Date:_____

Researcher's/Witness' signature_____ Date:_____

Letter of Information
Evaluation of a Regional Behavioural Support Program
Participant Group: Family Caregivers
Student Investigator: Kayla Brooks, MSc (c); km3brooks@uwaterloo.ca
Supervisor: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 ext. 35879

A. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to develop an evaluation of the services that Behavioural Supports Ontario (BSO) provides within long-term care homes in the Waterloo-Wellington LHIN.   The aim of developing this evaluation is to better understand how BSO should ideally coordinate and collaborate with care providers in long-term care to provide a foundation to guide and improve future practice in supporting older adults with dementia.

B. WHO CAN PARTICIPATE?

We are looking for older adults and their caregivers that receive services from BSO. Additionally, members of BSO and the long-term care home staff will be consulted to gain a better understanding of the processes of BSO at a care provider level.

C. WHAT WILL I BE ASKED TO DO?

Older adults accompanied by caregiver(s) will both be invited to partake in interviews that will be approximately 30-45 minutes in length. Interviews will be conducted to help to identify positive experiences you have had when utilizing BSO's services, and what aspects of the program can be modified or changed to guide and improve future practice. During this interview time, both older adults and caregivers will have the opportunity to share their experiences with the services offered by BSO. With your permission, interviews will be audio-taped and anonymous quotes may be taken from these interviews. Any and all identifying information will be removed. Participants are not required to answer any questions they may not wish to.
Please be aware that your participation in this study is voluntary.

D. WHERE WILL THE STUDY TAKE PLACE AND WHEN?

The study will take place in a mutually agreed upon location, or by telephone. The study will take approximately one year to complete in its entirety, however, participants are only asked to take part in one interview.

E. CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

Participants may withdraw from the study at any time, up until the point of publication. If you wish to withdraw from the study, you may notify the researcher during the interview or by way of email: km3brooks@uwaterloo.ca.

F. RISKS AND BENEFITS

There are no identified or anticipated risks for this study. There are no anticipated direct benefits for this study, participants will not be remunerated for their involvement.

G. CONFIDENTIALITY AND DATA SECURITY

To ensure confidentiality, no identifying information will be attached to study participants' responses. Any identifying information will be removed from the interview transcripts and surveys during the data entry period, and stored in a separate file. Individual's names will not be included in published materials, instead identification numbers/pseudonyms will be assigned. Written records, etc. will be stored in a locked cabinet at the University of Waterloo. Only researchers associated with this study will have access to this data. All electronic files will be stored on a protected server, and each will be password protected. Data may be shared publicly, however, your identity will remain confidential. All data will be stored for a minimum of 7 years.
Please be aware that although long-term care home staff may be aware of your participation in this study as they have provided recommendation for your involvement; ultimately your choice to participate (or not participate) will not affect your care or services provided by BSO or the long-term care home.

H. QUESTIONS

If at any time you have questions regarding the proposed research, please do not hesitate to contact the **Supervisor: Paul Stolee**, School of Public Health and Health Systems, University of Waterloo, Waterloo, ON, 519-888-4567 ext. 35879; stolee@uwaterloo.ca or **Student Investigator: Kayla Brooks**, MSc (c), School of Public Health and Health Systems, University of Waterloo, Waterloo, ON,km3brooks@uwaterloo.ca
This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

I. CONSENT FORM

By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

TITLE OF THE STUDY: Evaluation of a Regional Behavioural Support Program
I have read the information presented in the information letter about a study conducted by Kayla Brooks, under the supervision of Dr. Paul Stolee, School of Public Health and Health Systems, University of Waterloo. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca. For all other questions contact Kayla Brooks at km3brooks@uwaterloo.ca.

   I am aware the interview will be audio recorded to ensure accurate transcription and analysis.

   I give permission for the use of anonymous quotations in any thesis or publication that comes from this research.

I agree of my own free will to participate in the study.

Participant's name: _____

Participant's signature: _____ Date:_____

Researcher's/Witness' signature_____ Date:_____

Verbal Assent Script Overview of Letter of Information
Evaluation of a Regional Behavioural Support Program
Participant Group: Older Adults with Dementia (and Family Caregivers)
Student Investigator: Kayla Brooks, MSc (c); km3brooks@uwaterloo.ca
Supervisor: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 ext. 35879

A. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to understand how the Behavioural Supports Ontario (BSO) program is functioning in long-term care homes to support older adults with dementia.

B. WHO CAN PARTICIPATE?

Residents of the long-term care home along with your family or friends are invited to talk about some of the services you've received from BSO and the long-term care home staff.

C. WHAT WILL I BE ASKED TO DO?

Both you (the resident) and your caregiver (family or friend) will be asked to be a part of a 30-45 minute interview to talk about your care experiences. With your permission, interviews will be audio-taped and anonymous quotes may be taken from these interviews. Any and all identifying information will be removed. You do not have to answer any question you do not wish to answer.
Please be aware your participation in this study is voluntary.

D. WHERE WILL THE STUDY TAKE PLACE AND WHEN?

The study will take place in a mutually agreed upon location, or by telephone. The study will take approximately one year to complete in its entirety, however, you are only asked to take part in one interview.

E. CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

You may choose to withdraw from the study at any time, up until the point of publication. If you wish to withdraw from the study, please notify me, the researcher during the interview or by email: km3brooks@uwaterloo.ca.

F. RISKS AND BENEFITS

There are no identified or anticipated risks for this study. There are no direct benefits to doing this study, but we hope that this research will lead to positive changes in the care received in long-term care homes.

G. CONFIDENTIALITY AND DATA SECURITY

To ensure your information remains confidential, there will not be any identifying information attached to your responses. Your name and any other identifying information will be stored away in a separate locked file when I input the information into the

computer. Only researchers involved in this study will have access to the information. The information we collect may be shared publicly, but your identity will remain confidential. All information will be stored for a minimum of 7 years.

Although the staff of the long-term care home may be aware of you and your caregiver participating in this study, your choice to participate (or not to participate) will not affect your care or services provided by BSO or the long-term care home.

H. QUESTIONS

If you have any questions about the study, please do not hesitate to ask. The contact information is below:

Supervisor: Paul Stolee, PhD
School of Public Health and Health Systems,
University of Waterloo
Waterloo, ON
519-888-4567 ext. 35879
stolee@uwaterloo.ca

Student Investigator: Kayla Brooks, MSc (c)
School of Public Health and Health Systems
University of Waterloo
Waterloo, ON
km3brooks@uwaterloo.ca

This study has been reviewed and received ethics clearance through Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Assent Form
Evaluation of a Regional Behavioural Support Program
By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read and listened to the information presented in the information letter about a study conducted by Kayla Brooks, under the supervision of Dr. Paul Stolee, School of Public Health and Health Systems, University of Waterloo. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca. For all other questions contact Kayla Brooks at km3brooks@uwaterloo.ca.

  Do you understand the interview will be audio recorded to ensure accurate transcription and analysis?

  Do you give permission for the use of anonymous quotations in any thesis or publication that comes from this research?

  Do you agree to participate in the study?

_____   _____
Name of Participant with Dementia (Print)   Date

_____
Name of Caregiver/ Legally Authorized Representative (Print)

_____
        _____
Signature of Caregiver/ Legally Authorized Representative (Print)   Date

_____
Name of Person Obtaining Assent (Print)

_____
        _____
Signature of Person Obtaining Assent   Date

Date:

Hello Participant,

I would like to thank you for your participation in this study entitled *Evaluation of a Regional Behavioural Support Program*. As a reminder, the purpose of this study is to identify what the Behavioural Supports Ontario program looks like when operating at its greatest potential, and what aspects of the program can be modified or changed to guide and improve future practice of care for older adults exhibiting responsive behaviours in long-term care facilities.

The data collected during interviews will contribute to the development of an evaluation of the Behavioural Supports Ontario program within long-term care facilities operating within the Waterloo Wellington LHIN. This evaluation may then be used to guide and improve future practice of BSO.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 40037). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions please contact Kayla Brooks; km3brooks@uwaterloo.ca Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide your email address, and when the study is completed, anticipated by August 2019. I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email as noted below.

Kayla Brooks
University of Waterloo
School of Public Health and Health Systems
Email: km3brooks@uwaterloo.ca

Dr. Paul Stolee (Faculty supervisor)
University of Waterloo
School of Public Health and Health Systems
Email: stolee@uwaterloo.ca
Phone: 519-888-4567 x35879

Email for Invitation for Survey Participation- Members of BSO and LTC Staff
Evaluation of a Regional Behavioural Support Program

Hello (Name of Participant),

I hope you are doing well! Thank you again for choosing to participate in an interview to discuss the current operations of BSO within the long-term care homes of Waterloo Wellington. As discussed during the interview period, I am writing to you to complete a short survey through the link that I have provided in this email. The purpose of the survey is to rate which of the program outcomes that have been identified are most important to you, and additionally to rate your long-term care home's performance on each of these outcomes. The survey should only take approximately 5-10 minutes to complete. The deadline for completing of this survey is Friday June 21, 2019.

Your answers will be collected anonymously, and will not be linked to your email or name. Please note that as you will be completing part of this study using an online survey provided by SurveyMonkey; with information transmitted over the internet, privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g. government agencies, hackers). SurveyMonkey temporarily collects your computer IP address to avoid duplicate responses in the dataset but will not collect information that could identify you personally.

Survey Link: https://www.surveymonkey.com/r/LL9QWY2

Just another reminder that this survey should only take about 5-10 minutes to complete (there are 2 questions to complete), and is due back by Friday June 21, 2019. Please do not hesitate to email me with any questions you may have about this survey or study.

Thank you,

Kayla Brooks

Outcome Survey
Evaluation of a Regional Behavioural Support Program

1. Please rate the **LEVEL OF IMPORTANCE** of each of the listed BSO outcomes to you and your practice on the scale of 1-5. (I.e. How important are each of these outcomes to you and your work in long-term care?)

	1. Not Important	2. Slightly Important	3. Important	4. Very Important	5. Extremely Important
1. Decreased responsive behaviours	○	○	○	○	○
2. Decreased inappropriate antipsychotic use	○	○	○	○	○
3. Decreased use of one-to-one care	○	○	○	○	○
4. Decreased need for placement of residents on secured units	○	○	○	○	○
5. Decreased stigma around dementia and responsive behaviours	○	○	○	○	○

Figure A. Sample of survey provided to BSO Members of the LHIN and LTC staff (Importance)

2. Please rate your LTC's **LEVEL OF PERFORMANCE** as a result of the BSO program, on each of the listed outcomes on the scale of 1-5. (I.e. How well is your home doing on each of the listed outcomes because of the in-home BSO program?)

Note: For PRCs, please rate the overall performance of the LTCs you oversee.

	1. Poor	2. Fair	3. Good	4. Very Good	5. Excellent
1. Decreasing responsive behaviours	○	○	○	○	○
2. Decreasing inappropriate antipsychotic use	○	○	○	○	○
3. Decreasing use of one-to-one care	○	○	○	○	○
4. Decreasing the need for placement of residents onto secured units	○	○	○	○	○
5. Decreasing stigma around dementia and responsive behaviours	○	○	○	○	○

Figure B. Sample of survey provided to BSO Members of the LHIN and LTC Staff (Performance)

APPENDIX P
Memo – Qualitative Analysis of LTC Staff Interviews
June 17, 2019

While looking through the transcripts and coding each of the interviews for the long-term care staff, I found that there were consistent messages that appeared throughout the data. Consistent topics across interviews included 1) Communication strategies for sharing resident' care plans; 2) interdisciplinary collaboration; 3) the roles of Behavioural Supports Ontario (BSO) and the in-home BSO teams; 4) person-centered approaches to care; 5) strategies and interventions for managing responsive behaviours; 6) challenges faced in the long-term care setting;7) and the impact of the in-home BSO team.

The most frequently discussed topic across the long-term care staff interviews was strategies for communicating plans of care across the various staff working in the home. Care plan binders, Kardex, communication books, signs, and team meetings were some of the listed strategies for communicating care plans. Communication was also addressed when staff were asked to describe what the BSO program looks like when operating at its greatest potential as well as discussions around interdisciplinary collaboration. Many participants discussed the importance of communication across the care team for the success of the program and resident care. Interdisciplinary collaboration efforts also focused heavily on being able to communicate across the various disciplines in order to provide comprehensive care to residents.

In relation to interdisciplinary collaboration, LTC staff discussed the numerous members and disciplines associated in the long-term care setting, as well as the importance in information sharing across these disciplines. Many participants also discussed the importance of removing clinical hierarchies from their practice and focusing on collaboration to avoid the siloes that are frequent across the healthcare system. In a few of the interviews, participants discussed their

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collaboration with geriatric psychiatrists and geriatricians, as well as their role in the BSO program.

Staff were able to identify a number of functions of the BSO program as well as roles of the in-home BSO team. A commonly cited role was the BSO team's role in creating interventions for behaviour management and teaching and facilitating these plans to the care team. The Psychogeriatric Resource Consultants also brought up this role when discussing the intended function of the in-home BSO teams. BSO teams are intended to build capacity across the home by having designated staff members with additional knowledge and expertise in dementia care and responsive behaviours in order to guide the care team's practice. The BSO program was developed to support staff, residents and families in behaviour management and resource provision. An important step in supporting staff, residents and families, is building relationships and using person-centered approaches for care.

Within the category of person-centered approaches to care, staff discussed the importance of Gentle Persuasive Approach and P.I.E.C.E.S. to inform care practices. These practices stem from being able to understand the person, their background and environment to provide best-practice care. Being person-centered in your approach to care does not stop at the level of the resident, it also means including family care partners to create care plans and interventions. One staff member insightfully stated:

"No, I'm just smiling thinking about all the wonderful residents that we have (laughs) and

like I said we've had some major success stories, we have people who I think in another

environment would be considered aggressive, dangerous, you know umm, and would suffer

from the stigma around the reaction to their disease. And here you know, we're able to

educate the team and make that care plan and show that this is a valued individual with

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you know, all these things to offer and not just their disease, and certainly not just the

negative side effect of their disease.”

Breaking the stigma surrounding dementia and the behaviours or expressions that may occur

because of this illness is important for homes, and successful dementia-informed care practices.

Another topic that was discussed throughout the long-term care staff interviews were

some of the interventions the BSO team has used in order to manage responsive behaviours

across the home. Staff stressed the importance in being creative in your approach to creating

interventions, as well as making the interventions as resident-specific as possible in order to be

successful. Common interventions that were discussed included music, puzzles and activities,

removing the resident from stimuli or triggers, conversation, and in high-risk cases, medications.

The approach to implementing these interventions needs to be calm and staff must actively listen

and observe to meet the needs. One staff member acknowledged that behaviours have meaning,

and often are in response to an unmet need. Staff must work diligently to try to understand these

behaviours and implement strategies based on the resident.

Working in a long-term care setting does not come without challenges. A few of the

interviews mentioned staffing shortages as a problem faced in long-term care. Without adequate

staffing, BSO team members may not be able to fulfil their true role in the home as an educator

and facilitator of care, but then become direct care providers. PRCs discussed this issue in some

of the failing BSO teams across the Waterloo Wellington LHIN. The BSO team must be used in

addition to the care team in order to successfully manage behaviours and continue to build

capacity across the home.

If the BSO program is allowed to run as intended, there can be great success.

Components of a successful BSO program according to the long-term care staff interviewed

included staff buy-in, and good communication across the care team. Strong leadership and support from the directors of care and administrators is also an important aspect of the BSO program, as well as strong leadership and direction from the in-home BSO team for the other care staff. Staff members must also be self-aware and acknowledge personal biases in order to provide competent dementia-informed care. Important outcomes of the BSO program such as reduced responsive behaviours and critical incidents demonstrate that a BSO team is functioning optimally in the home from the perspective of the LTC staff.

There were various disciplines and perspectives reflected throughout the LTC staff interviews including registered nurses, registered practical nurses, personal support workers, director of care, assistant director of care, social worker, recreation therapist, recreational aide, and a dietary aide. Many of the staff members interviewed were a part of the in-home BSO teams. Despite the fact that not all participants were designated BSO "Champions", the staff interviewed had a good understanding of the intended purpose and role of the BSO program. I think however, as these homes chose to participate in the evaluation, they may have stronger functioning BSO programs than those that elected not to participate. It would be interesting to have the opportunity to connect with homes that did not initially participate to discuss the operations of their in-home BSO program. The PRCs described the differences in the BSO programs in long-term care homes across the Waterloo Wellington LHIN, stating that there are essentially 36 BSO programs, not one single overarching program.

APPENDIX Q
Memo – Qualitative Analysis of Interviews of BSO Members from the LHIN
June 6, 2019

As I have been coding my interviews conducted with the Psychogeriatric Resource

Consultants (PRCs) and the Behavioural Supports Ontario (BSO) lead, I have found that there

are very consistent messages and key themes. It appears that the BSO program in long-term care

in the Waterloo Wellington LHIN has changed quite significantly over the last two years.

One of the key messages has been that strong leadership from both the administration

within the long-term care homes (the DOCs and administrators) as well as leadership from the

BSO lead is paramount for the success of the BSO program. Within this theme, role clarity of the

in-home BSO team, identification of the main purposes of the BSO program, as well as the

intended goals should be consistent across the homes. In talking with the PRCs I have learned

that this is not the case, as there many variations across the program, and therefore the success of

the individual programs are quite variable.

The in-home BSO team should be used to build capacity across the long-term care home

staff. This in essence means that the dedicated BSO champions should use their enhanced

knowledge and skills regarding behavioural support to educate their peers and facilitate care

planning (strategy and intervention development) to enhance the care of residents with

responsive behaviours. For the program to be successful, it is important that the BSO team is not

used to provide direct care, but rather facilitate and support the care practices of the other staff.

With the successful implementation of the BSO program, i.e., following the

recommendations of the long-term care BSO toolkit, BSO has great ability to have positive

impacts on both the lives of residents as well as system outcomes. Outcomes that have been

identified include ability to accommodate more complex cases, reduced number of critical

incidents, reduced emergency department visits, reduced hospital admissions, decreased utilization of external resources, and increased purpose and meaning in the lives of residents being cared for.

Currently there are many gaps within the Waterloo Wellington BSO program, which seems to be in part due to changes in leadership structure. Additionally, with high rates of staff turnover, including LTC leadership roles, the orientation process, and development of the BSO program throughout the home has struggled. PRCs are finding that the BSO program has begun to trend negatively.

With all of these findings considered, there are a few clear recommendations. First, BSO leadership and PRCs should connect in order to discuss the current stance of the BSO program within the home. Secondly, PRCs and the BSO lead should connect with the in-home BSO teams as well as LTC leadership to discuss and identify clear program goals and the intended use of BSO funding and allocated hours. Thirdly, quality indicator data should be collected and analyzed to gain a quantitative understanding of program success and weaknesses, and direct program changes.

APPENDIX R
Memo – Qualitative Analysis of Caregiver Interviews
June 17, 2019

Unfortunately, residents were not involved in these intended dyad interviews due to advanced stages of dementia. As part of the inclusion criteria, residents were to be living with dementia in a long-term care home within the Waterloo Wellington LHIN. To truly understand the operations of the BSO program, residents with responsive behaviours and advanced stages of dementia were included in these interviews, with a family care partner sharing experiences on their behalf.

I was able to interview 3 daughters and one wife as part of this participant group. Despite these individuals having loved ones in 3 different homes, many of their experiences and hopes for care were the same. Consistent across all four caregivers, was lack of awareness or knowledge of the Behavioural Supports Ontario program. Although discussed throughout the home among staff, the formal name and program intentions do not seem to be shared with families.

All of the caregivers spoke about attributes of care that are important to them as family care partners. A consistent attribute that was shared across all four interviews was being included in care as a family care partner. Other key attributes included being well supported by the staff, and ensuring that their loved one is well taken care of. Two individuals also discussed their value of having their mothers maintain their independence while living in long-term care. Ultimately, it seems as though the family caregivers would like to ensure their loved one is being adequately cared for.

Despite the fact that the residents had various types of responsive behaviours, many of the caregivers discussed similar wishes for the future of the program including more staffing and more training related to dementia and responsive behaviour management. Many caregivers also discussed a desire for more one-on-one engagement opportunities for their loved one, which however, conflicts with the intended use of the BSO program as one-to-one care should be decreased. Conversely, this does relate to the need for more resources to support more manageable staffing ratios, and increased BSO funding and hours in order to provide comprehensive, person-centered care for all residents. Three of the caregivers also discussed the importance of engagement in activities that are resident-specific in order for them to be successful, which would mean additional human and monetary resources.

Overall the messages across the caregivers were similar. Caregivers value person-centered care that includes both them and their loved ones in decision making. They value respect from the care team, and strategies and interventions that promote a better quality of life for their loved one. Despite the small sample size for this participant group, these preliminary themes can be derived from this data. For the future it would be interesting to include residents with early stages of dementia that are more involved in their plan of care, and who can speak to their experiences with care as well as their future wishes for the Behavioural Supports Ontario program.

Permission to use Appreciative Inquiry "4-D" Cycle Image

Diana Whitney <diana@positivechange.org>
Wed 07-17, 4:56 AM

Kayla
Thank you for asking. Yes you may use our image, with appropriate citations.
Good luck with your thesis.
Warm regards,
Diana

Diana Whitney, PhD
Founder, Corporation for Positive Change
Co-Founder, Taos Institute
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Author: Appreciative Leadership and
The Power of Appreciative Inquiry

Kayla Marie Brooks
Mon 07-15, 12:52 PM
david.cooperrider@case.edu; diana@positivechange.org
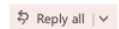
Good Afternoon,

I am writing to you in hopes that I may be granted permission to use the "Appreciative Inquiry "4-D" Cycle" Image from your 2001 paper, *A Positive Revolution in Change*, for my Master's Thesis. Please let me know if this is a possibility as I would love to be able to depict the AI process with this image.

Thank you for your consideration,
Kayla Brooks RN, MSc (c)
School of Public Health and Health Systems
University of Waterloo
Waterloo, Canada
km3brooks@uwaterloo.ca