

## EXPERIENCES OF CAREGIVERS OF OLDER PERSONS WITH DELIRIUM

EXPERIENCES OF CAREGIVERS OF OLDER PERSONS WITH DELIRIUM  
SUPERIMPOSED ON DEMENTIA IN ACUTE CARE HOSPITALS:  
AN INTERPRETIVE DESCRIPTION STUDY

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TITLE: Experiences of Caregivers of Older Persons with Delirium Superimposed on  
Dementia in Acute Care Hospitals: An Interpretive Description Study

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## **LAY ABSTRACT**

Delirium is a common and life-threatening condition that involves a sudden change in the persons' thinking and attention. Persons with dementia are at risk for delirium, which can lead to hospitalization or can happen during a hospitalization. Delirium can cause distress in caregivers of persons with dementia. The purpose of this study was to better understand the experience of caregivers caring for an older person with both delirium and dementia in the hospital. Findings showed that: (a) caregivers found the experience overwhelming, (b) caregivers worried about the care the older person received, (c) caregivers' experiences were influenced by the nature of their relationship with the health care team, and (d) caregivers can help the health care team recognize delirium early and care for the older person with delirium. Overall, findings can be used to better support caregivers and build a more collaborative relationship between caregivers and the health care team.

## ABSTRACT

**Background:** Delirium superimposed on dementia (DSD) is a highly prevalent, yet difficult to recognize problem in hospitals. Delirium is a disturbance in cognition often seen in persons aged 65 and older. DSD occurs when a person living with dementia (PLWD) also develops delirium. DSD is a highly distressing experience for caregivers.

**Aims:** This study aims to explore the experiences of caregivers of older persons with DSD in acute care hospitals; their role in the detection and management of DSD; and the type of support they require during this experience. The knowledge generated from this study can be used to identify strategies to assist caregivers during their experience, and to improve the early detection and management of DSD, with the aim to improve health outcomes for both the hospitalized older person with DSD and the caregiver.

**Methods:** Thorne's interpretive description method was used. In-person, semi-structured interviews were conducted with nine caregivers of older persons with DSD who were hospitalized in four medicine units. Interviews were transcribed and thematic analysis was conducted.

**Results:** The following themes related to caregivers' experiences were identified: (a) caregivers found DSD to be an overwhelming experience, (b) caregivers were concerned about the quality of care that the older person received, (c) caregivers' experiences were influenced by the nature of their relationship with the health care team, and (d) caregivers can play an important role in the detection and management of DSD.

**Conclusion:** Findings provide guidance in increasing support and building collaborative relationships between caregivers and the health care team. Recommendations on delivering caregiver-centred care to caregivers of older persons with DSD are outlined.

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## **LIST OF ABBREVIATIONS**

ADRD	Alzheimer’s disease or related disorders
DEL-B	Patient Delirium Burden Instrument
DEL-B-C	Caregiver Delirium Burden Instrument
CAM	Confusion Assessment Method
CASP	Critical Appraisal Skills Programme
CIHI	Canadian Institute for Health Information
COREQ	Consolidated Criteria for Reporting Qualitative Research
DSD	Delirium superimposed on dementia
FAM-CAM	Family Confusion Assessment Method
HELP	Hospital Elder Life Program
HQO	Health Quality Ontario
ID	Interpretive Description
MOCA	Montreal Cognitive Assessment
MMAT	Mixed Methods Appraisal Tool
NICE	National Institute for Healthcare and Excellence
PLWD	Person living with dementia
RNAO	Registered Nurses’ Association of Ontario

## **DECLARATION OF ACADEMIC ACHIEVEMENT**

This master's thesis is a report of original research that I conducted under the supervision of Drs. Jenny Ploeg, Maureen Markle-Reid and Sharon Kaasalainen. I developed the study protocol with feedback from my committee members. I completed the research ethics board submission with the assistance of Dr. Jenny Ploeg. I conducted all interviews and transcribed all data recordings during the data collection and analysis phases. I led the data analysis and writing of the thesis with the assistance of the supervisory committee.



## **CHAPTER ONE: INTRODUCTION**

Delirium superimposed on dementia (DSD) is a highly prevalent, yet difficult to recognize problem in acute care hospitals. DSD occurs when a person living with dementia (PLWD) also develops delirium. Delirium is an acute and severe disturbance in cognition and attention that is most often seen in persons aged 65 and older (Inouye et al., 2014; Oh et al., 2017). Hospitalized older PLWD are at a higher risk for delirium compared to those without dementia (Bail et al., 2013). Previous research has found that when compared to older persons with either dementia or delirium alone, older persons with DSD have a higher probability of adverse outcomes, such as increased risk of accelerated cognitive decline, functional impairment, prolonged length of stay, institutionalization, and mortality (Fick et al., 2013; Fong et al., 2012; Morandi et al., 2014; Torpilliesi et al., 2010). DSD in hospitalized older persons is a highly distressing experience for family caregivers (hereafter referred to as caregivers), who provide some level of care to up to 90% of community-dwelling older PLWD (Kasper et al., 2015; Toye et al., 2014; Whittamore et al., 2014). Caregiver distress is a significant concern, because it can increase caregivers' risk for poor physical and mental health status, which may negatively impact their ability to provide care for the older PLWD in the community (Goren et al., 2016; Health Quality Ontario [HQO], 2016; Joling et al., 2010). However, little is known about the experience of caregivers of hospitalized older persons with DSD or the type of supports that they require to improve their experience.

DSD is prevalent among older PLWD. The estimated prevalence of DSD ranges from 40% to 89% in older persons (aged 65 years and older) within North American

acute care hospital units (Fick et al., 2002; Fong et al., 2009; Reynish et al., 2017). Within hospitalized patients specifically with Alzheimer's disease (the most common form of dementia), the incidence of delirium is 25% (Fong et al., 2012). The overall prevalence of delirium is low in the community at 1-2%, yet community-dwelling older PLWD can still develop delirium, leading to an admission to an acute care hospital (Inouye et al., 2014).

Despite the high incidence of delirium in older persons with dementia, this condition is often not recognized by hospital health care teams, which can delay treatment and increase risk of poor outcomes in the older person (Cole et al., 2017; Fong et al., 2009; Fong et al., 2012; Kiely et al., 2009). The symptoms of delirium and dementia often overlap, which makes it difficult for health care teams to recognize DSD without knowledge of the older person's baseline cognitive symptoms (Apold, 2018; Coyle et al., 2017; El Hussein et al., 2015; Wong et al., 2018). Recognition and treatment of delirium is a key component of delirium care and prevention.

Previous research on delirium suggests that caregivers of older persons can assist in delirium detection, because of their familiarity with the older person's cognitive baseline (Coyle et al., 2017; El Hussein & Hirst, 2016; Yevchak, 2013). Furthermore, caregivers can also assist in managing the behaviours associated with both delirium and dementia, such as exit-seeking and resistance to care (Day & Higgins, 2015b; Toye et al., 2014). Resistance to care describes behaviours exhibited by the older person that prevent health care team members from providing them with necessary care (e.g., refusing medical interventions and help with activities of daily living) (Cook et al., 2019; Mahoney et al., 1999). Nonetheless, there is little research (Cook et al., 2019; Mahoney et

al., 1999). Nonetheless, there is little research about caregivers' experiences in detection and management of DSD in hospitalized older persons, or the type of supports that they require to improve their experience and to assist them in detection and management of DSD.

The aim of this study is to explore: the experiences of caregivers of older persons with DSD in acute care hospitals; their role in the detection and management of DSD; and the type of support they require during this experience. Nurses are at the frontline of acute care and often spend the most amount of time with patients and caregivers. Thus, nurses are uniquely placed to support caregivers of older persons with DSD with their experience. The knowledge generated from this study can be used by nurses and nurse educators to identify potential strategies to assist caregivers during their experience, and to improve the early detection and management of DSD. The goal of this knowledge is to ultimately improve health outcomes for both the hospitalized older person with DSD and the caregiver.

### **The Burden of Delirium in Older Persons**

Delirium is a common, life-threatening condition that is distinguished by a sudden change in cognition and attention (Inouye, 2006; Inouye et al., 2014; Marcantonio, 2017). Delirium in older persons can be recognized by its key characteristics, which include acute onset and fluctuating course of symptoms, impaired consciousness, and attentional disturbances (Fong et al., 2009; Inouye et al., 2014; Marcantonio, 2017; Oh et al., 2017). There are three types of delirium: hyperactive, hypoactive, and mixed (Fong et al., 2009; Marcantonio, 2017; Robinson et al., 2011; Yang et al., 2009). Hyperactive delirium can

be distinguished in individuals with the following characteristics: restlessness, agitation, hallucinations, and delusions (Fong et al., 2009; Robinson et al., 2011; Yang et al., 2009). In contrast, the features of hypoactive delirium include lethargy, lack of speech or movement, sedation, and slow responses (Fong et al., 2009; Robinson et al., 2011; Yang et al., 2009). Persons with mixed delirium demonstrate characteristics of both hyperactive and hypoactive types (Fong et al., 2009; Yang et al. 2009).

Delirium is caused by multiple factors and is the result of an interaction between predisposing factors (e.g., baseline vulnerability) and precipitating factors (e.g., events or insults experienced by the individual) (Inouye & Charpentier, 1996; Inouye et al., 2014; Marcantonio, 2017). Predisposing factors of delirium include: baseline cognitive impairment or dementia, age 75 years and older, sensory impairment, multiple comorbidities, and mobility limitations (Inouye & Charpentier, 1996; Inouye et al., 2014). Precipitating factors of delirium include: severe illnesses, infection, surgery, bladder catheters, psychoactive drugs, and electrolyte imbalances (Inouye & Charpentier, 1996; Inouye et al., 2014). Delirium in hospitalized older persons is associated with multiple complications (Inouye et al., 2014; Witlox et al., 2010). A meta-analysis of quantitative studies revealed that delirium was associated with an increased risk of death compared to a control group at an average follow-up of 22.7 months after initial collection of data (Witlox et al., 2010). Delirium was associated with increased risk of institutionalization, dementia, falls, and extended length of hospital stay (Marcantonio, 2017; National Institute for Health and Care Excellence [NICE], 2010; Witlox et al., 2010).

Research conducted about older persons' experiences with delirium in acute care hospitals highlights the symptoms and the associated emotional distress experienced during a delirium episode (Grover et al., 2015; Lingehall et al., 2015; Pollard et al., 2015; Schmitt et al., 2019; Weir & O'Brien, 2019). Patients reported that they experienced disorientation, confusion, perceptual hallucinations, and loss of autonomy (Grover et al., 2015; Lingehall et al., 2015; Pollard et al., 2015; Weir & O'Brien, 2019). Patients also reported feeling emotionally distressed, because the condition disrupted their sense of autonomy and control (Pollard et al., 2015; Schmitt et al., 2019; Stenwall et al., 2008a; Weir & O'Brien, 2019).

### **The Burden of Delirium Superimposed on Dementia in Older Persons**

Delirium frequently co-exists with dementia, as dementia is a risk factor for delirium (Inouye et al., 2014). DSD occurs when a person with dementia also develops delirium. Dementia is a chronic and progressive disease with increasing prevalence in older persons. It is a clinical syndrome that is characterized by increasing difficulty with problem-solving, memory, language, and behaviour that leads to difficulties with activities of daily living (Alzheimer Society of Canada, 2018b; Robinson et al., 2015). The subtypes of dementia include Alzheimer's disease (the most common subtype), vascular dementia, Lewy-body dementia, frontotemporal dementia, Parkinson's dementia, and mixed dementia (Robinson et al., 2015). Dementia is a progressive disease, with symptoms worsening until death (Robinson et al., 2015).

Delirium is linked to more poor outcomes in older PLWD, such as accelerated cognitive decline, increased functional dependence, rehospitalization, institutionalization,

and mortality, compared to PLWD without delirium (Fick et al., 2002; Fong et al., 2012; Morandi et al., 2014). Some older PLWD who have recovered from their delirium can recall the distress they experienced during their delirium episode (Morandi et al., 2015b). These older PLWD recalled experiencing anxiety, fear, anger at the situation, and loss of control; they also recalled experiencing confusion and believing that other people (e.g., health care team) were trying to hurt them (Morandi et al., 2015b).

### **Detection of Delirium Superimposed on Dementia**

Delirium detection is a significant concern in the context of dementia. Dementia has similar symptoms to delirium, which make DSD difficult to recognize (Apold, 2018; Coyle et al., 2017; El Hussein et al., 2015; Wong et al., 2018). Failure to quickly identify delirium can prevent prompt treatment and can lead to persistent delirium. Persons with persistent delirium do not return to their cognitive baseline and are 2.9 times more likely to die than persons with resolved delirium (Cole et al., 2009; Cole & McCusker, 2016; Cole et al., 2017; Kiely et al., 2009). Persistent delirium can result in sustained distress for both older persons with delirium and their caregivers (Yevchak, 2013). In addition, DSD is associated with higher risk of negative outcomes in older persons, which include increased length of stay, accelerated cognitive decline, functional impairment, institutionalization, and mortality (Fick et al., 2013; Fong et al., 2012; Morandi et al. 2014; Torpilliesi et al., 2010).

Despite the high prevalence of both delirium and DSD, and the presence of validated delirium screening tools, delirium in older persons remains underrecognized by hospital nursing staff (Meako et al., 2011; Rice et al., 2011). Frontline nurses can play an

important role in delirium detection as they spend a significant amount of time with patients and have the advantage of being able to observe acute changes in health status earlier than other health care providers. Yet, delirium in older persons is frequently underrecognized by nursing staff in acute care settings. It is estimated that nurses fail to recognize delirium up to 75% of the time (El Hussein et al., 2015; Rice et al., 2011). It can be difficult for nursing staff in acute care hospitals to ascertain changes in cognition, as most do not have knowledge of a person's baseline cognitive status, particularly in older persons with dementia, because symptoms of delirium have often been attributed to underlying dementia or age-related changes (Apold, 2018; Coyle et al., 2017; El Hussein et al., 2015; Wong et al., 2018).

Other factors that can contribute to under-recognition of delirium in acute care hospitals include: lack of knowledge of the signs and symptoms of delirium; the perception that delirium detection may not be a priority over other nursing responsibilities particularly within the time constraints of a fast-paced acute care environment; and the absence of resistance to care behaviours (e.g., yelling, pulling away from staff members during care, hitting) in older persons with hypoactive delirium (i.e., the staff do not detect hypoactive delirium in older persons, because they are not demonstrating conspicuous behaviours that that can be perceived as disrupting staff or others) (Coyle, et al., 2017; El Hussein et al., 2015; El Hussein & Hirst, 2016; Wong et al., 2018).

Early identification is vital to initiate intervention and to prevent persistent delirium because most cases of delirium can be reversed by treating the underlying cause (Cole et al., 2009; Cole & McCusker, 2016; Cole et al., 2017; Kiely et al., 2009;

Registered Nurses' Association of Ontario [RNAO], 2016). Caregivers who possess intimate knowledge of the older PLWD can play an essential role in supporting the early identification and management of DSD for hospitalized older persons with DSD.

Furthermore, as delirium is linked with longer hospital stays, caregivers' involvement can lead to earlier detection and treatment of delirium, which can facilitate the older PLWD's discharge home (Marcantonio, 2017; NICE, 2010; Witlox et al., 2010). However, little is known about caregivers' experiences and role in the detection of delirium in older persons with DSD. Given the poor outcomes and distress associated with delirium, early identification is vital to initiate treatment and management (RNAO, 2016). To bridge this gap, some nurses have consulted caregivers to determine the older person's cognitive baseline, illustrating the contribution caregivers could make in improving delirium detection during hospitalization (Coyle et al., 2017; El Hussein & Hirst, 2016).

### **Caregivers of Older Persons with DSD**

Delirium in older persons during acute care hospitalization can cause high levels of distress in caregivers, which can result in negative impacts on their physical and mental health (Beardon et al., 2018; Carbone & Gugliucci, 2015; Dassel & Carr, 2016; Goren et al, 2016; Joling et al., 2010; Kiecolt-Glaser et al., 1991). The distress experienced by caregivers, particularly those caring for PLWD can be concerning, because they provide care to up to 90% of the care of PLWD in the community (Kasper et al., 2015). As such, maintaining the health of these caregivers is critical. Canadian caregivers are estimated to provide an average of 26 hours of support per week to the older PLWD, more than caregivers of older people without dementia who provide an



average of 16 hours per week (Canadian Institute for Health Information [CIHI], n. d.b).

It has been estimated that in 2018, Canadian caregivers provided 358 million hours of informal care, compared to 230 million hours provided in community care and 60 million hours in long-term care (Alzheimer Society of Canada, 2010). These data demonstrate the significant contributions made by caregivers to the care of PLWD, thus illustrating the importance of preserving their health. Due to the functional impairment and behavioral symptoms associated with dementia, caregiving for an older PLWD is linked to higher physical and emotional burden on caregivers, compared to caregivers of older persons with other chronic conditions (Brodaty et al., 2014; Pinquart & Sörensen, 2003; Seidel & Thyrian, 2019).

Without the support of caregivers in the community, older PLWD may require hospitalization and can have a hastened long-term care admission, preventing them from being discharged home (HQO, 2016). This fact highlights the need to support caregivers of PLWD during acute care hospitalization with DSD (Alzheimer Society of Canada, 2018a; HQO, 2016; Kasper et al., 2015). Yet, there is little research about the experiences of caregivers of older persons with DSD in Canadian acute care hospitals and the type of support they require, if any.

### **Reducing Caregiver Distress and Increasing Caregiver Roles in Delirium Detection and Management**

Previous literature on delirium and DSD provide suggestions on reducing caregivers' distress during the hospitalization. Caregivers may feel shocked and anxious at observing the abrupt changes in personality and behaviour in the older person with

delirium (Day & Higgins 2015a; Day & Higgins, 2015b; Stenwall et al., 2008b; Toye et al., 2013; Schmitt et al., 2019; Whittamore et al., 2014; Yevchak, 2013). Findings from these studies suggest that increased communication from the staff about the older person's plan of care can help alleviate the distress and improve caregiver satisfaction (Day & Higgins 2015a; Day & Higgins, 2015b; Stenwall et al., 2008b; Toye et al., 2013; Schmitt et al., 2019; Whittamore et al., 2014; Yevchak, 2013).

Additionally, previous studies also suggest that increasing caregivers' participation in the older person's care can decrease caregiver distress and guilt, with some caregivers expressing that they would like to learn more about delirium and how they could manage it (Clissett et al. 2013; Day & Higgins 2015a; Day & Higgins, 2015b; Schmitt et al., 2019). The provision of evidence-based education to caregivers not only alleviates distress and anxiety, it also utilizes caregivers' knowledge for the detection and management of delirium (Carbone & Gugliucci, 2015). A previous study showed that caregivers are eager to learn more about delirium (Bull et al., 2016). Furthermore, when educated about delirium, caregivers' knowledge about the condition can improve and they can take the correct action when observing a change in the older person's health status (e.g., informing health care team) (Bull et al., 2017; Bull et al., 2016; Keyser et al., 2012). Lastly, a meta-analysis of five randomized controlled trials suggests that caregiver involvement in the care of older persons with delirium can reduce length of the hospital stay (McKenzie & Joy, 2019).

Previous literature suggests that caregivers' role in delirium detection and management can be improved with appropriate education and support from staff

(Carbone & Gugliucci, 2015). Furthermore, studies have suggested that when trained, families, with their knowledge of the individuals' cognitive baseline, can assist health care team members with detecting delirium in older persons (Bull et al., 2017; Flanagan & Spencer, 2016; Inouye et al., 2012; Steis et al., 2012). For example, a variation of the Confusion Assessment Method, called the Family Confusion Assessment Method (FAM-CAM), is a tool designed to be administered by clinicians with a family member to obtain their assessment of the client's mental status (Inouye et al., 2012). Caregivers can also be trained to use the FAM-CAM and help detect postoperative delirium (Bull et al., 2017). In relation to management of delirium, caregivers can be educated to use their knowledge of the older person to provide an intervention (e.g., report observations of the older person's behaviour to a health care provider) and assist the health care team (Carbone & Gugliucci, 2015). Furthermore, as delirium may persist past a hospital stay or may reoccur at home, caregivers are in an ideal position to recognize delirium onset and contact the health care provider (Carbone & Gugliucci, 2015). While caregivers can be trained to participate in the detection and management of delirium, consistent communication, education and a relationship of trust with the health care team is key (Rosenbloom & Fick, 2014).

### **Employing a Relationship-Centred Approach to Care with Caregivers**

Health care providers who take a relationship-centred approach to care with caregivers may lessen caregiver distress arising from the DSD experience and increase their role in DSD detection and management in acute care hospitals (Nolan et al., 2006; Nolan et al., 2004). Relationship-centred care is an approach that aims to shift the focus

of care from solely on the person receiving care (e.g., older person with DSD) to also supporting the relationships and needs of both health care providers and family caregivers (Brown Wilson et al., 2009; Nolan et al., 2006, Nolan et al., 2004; Tresolini & Pew-Fetzer Task Force, 1994; Watson, 2019). This approach recognizes the contributions of both health care providers and caregivers, and describes how both groups can work in partnership with older persons to ensure they receive the best possible care (Brown Wilson et al., 2009; Nolan et al., 2006; Tresolini & Pew-Fetzer Task Force, 1994).

The premise of the relationship-centred care approach is that good care is also relationship-centred. Relationship-centred care can only occur when patients, caregivers and health care providers experience six senses, described as the Senses Framework: sense of security, sense of belonging, sense of continuity, sense of purpose, sense of achievement, and a sense of significance (Nolan et al., 2006, Watson, 2019). While work on the relationship-centred care approach has originated in long-term care, the Senses Framework has been applied in acute care to encourage caregivers of older persons with multiple chronic conditions to play an active role in shaping care (Nolan et al., 2006). Examples of how the six senses could be applied to caregivers in acute care include the following: (a) Security – providing regular, clear information, (b) Belonging – being encouraged to participate in care as appropriate, (c) Continuity – partnership programs that encourage caregiver involvement in the older person’s care, (d) Purpose – deciding on mutually agreed goals for care, (e) Achievement – involvement in evaluation of care, and (f) Significance – investing resources to create a comfortable environment (Nolan et al. 2006). The relationship-centred care approach is relevant and applicable to the

experiences of caregivers of DSD, and may have potential utility to increase their role in DSD detection and management. As such, the relationship-centred care approach was used to develop interview questions for the current study and was considered in data analysis.

### **Problem Statement**

DSD is highly prevalent in older persons in acute care hospitals. The prevalence of DSD in hospitalized older persons ranges from 40% to 89% (Fick et al., 2002; Reynish et al., 2017). Previous research has found that DSD can lead to adverse outcomes, including functional impairment, accelerated cognitive decline, prolonged length of stay, institutionalization, and mortality (Fick et al. 2013; Fong et al., 2012; Morandi et al. 2014; Torpilliesi et al. 2010)

DSD in hospitalized older persons is a highly distressing experience for caregivers (Beardon et al., 2018; Toye et al., 2014; Whittamore et al., 2014). Caregiver distress stemming from DSD and during acute care hospitalizations is a concern, because it can increase the caregivers' risk for poor health outcomes and can have a negative effect on their ability to continue providing care for the older PLWD in the community (Goren et al., 1991; HQO, 2016; Joling et al., 2010; Lwi et al., 2017). This is important because caregivers provide 80% to 90% of the care at home to older persons (Alzheimer Society of Canada, 2010; CIHI, n.d.a; CIHI, n.d.b; Kasper et al., 2015).

Despite the high incidence of delirium in older persons with dementia, it is frequently underrecognized by health care team members in acute care settings, which can delay treatment, increase risk of cognitive decline in older PLWD, and lead to the

older PLWD being discharged with delirium (Cole et al., 2017; Fong et al., 2012; Fong et al., 2009; Kiely et al., 2009). Recognition and treatment of delirium is a key component of delirium care and prevention. Nurses spend the most time with patients at the bedside and are uniquely placed to detect delirium early, a role which has been recognized in the literature (Apold, 2018; Coyle et al., 2017; El Hussein et al., 2015; Schnitker et al., 2020; Wong et al., 2018). However, lack of awareness of the older person's cognitive baseline, insufficient knowledge about delirium, and the absence of overt symptoms of delirium (e.g., yelling, resistance to care) contribute to the under recognition of delirium seen in previous studies (Apold, 2017; Coyle et al., 2017; El Hussein et al., 2015; El Hussein & Hirst, 2016; RNAO, 2016; Wong et al., 2018).

Caregivers can play an important role in the early detection of DSD due to their familiarity with the older person (Bull et al., 2017; Flanagan & Spencer, 2016; Yevchak, 2013). Nurses are often in close contact with caregivers and as such can help facilitate caregiver participation in DSD detection and management (Schnitker et al., 2020). It is important to support caregivers during their experience of DSD to maintain their health and ability to care for the older PLWD in the community. Engaging caregivers in the detection and care of DSD can facilitate prompt intervention and assist in the management of behaviours associated with delirium. Moreover, understanding caregivers' experience of DSD can guide health care providers and organizations to improve the care of older persons with DSD and their caregivers (Kuluski et al., 2017; Kuluski et al., 2019).

Researchers have advocated for the involvement of caregivers in detection and management of older persons with delirium as it may improve delirium recognition and lessen caregiver distress (Bull et al., 2017; Bull et al. 2016; Clissett et al. 2013; Day & Higgins 2015a; Day & Higgins, 2015b; McKenzie & Joy, 2019; RNAO, 2016; Schmitt et al., 2019). Yet, there is limited research that explores caregivers' experiences of DSD in hospitalized older persons; their potential role in detection and management of DSD; and barriers and facilitators to their engagement in care.

It is especially important to understand caregivers' experiences of DSD, as these caregivers are experiencing the distress from the intersection of both dementia and delirium. Previous literature has shown that caregivers of older PLWD experience more caregiver burden than nondementia caregivers, which increases their risk for poor physical and mental health outcomes (Beardon et al., 2018; Brodaty et al., 2014; Carbone & Gugliucci, 2015; Pinquart & Sörensen, 2003; Seidel & Thyrian, 2019). Thus, understanding their experience can assist in formulating solutions to support caregivers to decrease their distress, while simultaneously utilizing their knowledge to assist in DSD detection and management. Moreover, previous research suggests that increasing caregiver participation in the care of older persons with delirium can decrease their distress (Clissett et al. 2013; Day & Higgins 2015a; Day & Higgins, 2015b; Schmitt et al., 2019). Hence the purpose of this study was to generate knowledge to help identify potential strategies to improve the experiences of caregivers in the care of hospitalized older persons with DSD and to investigate how they may play a role in improving the detection and management of DSD.

## **CHAPTER TWO: REFLECTIVE SUMMARY**

In this reflective summary, I describe my professional experiences caring for older persons with delirium, dementia, and DSD, thus highlighting my motivations for pursuing the current study. I have been interested in both dementia and delirium throughout my nursing career. I was inspired to become a registered nurse (RN) while volunteering at a long-term care home because I was impressed by how the nursing staff delivered person-centred care to older PLWD. While completing my nursing degree, I volunteered with the Hospital Elder Life Program (HELP) in a general medicine unit at a local teaching hospital. HELP is a multi-component delirium prevention program that aims to reduce the incidence of delirium in hospitalized older persons by targeting risk factors, such as cognitive impairment, dehydration, and sensory limitations (Inouye et al., 2014). As a HELP volunteer, I delivered non-pharmacological interventions to older persons at risk for or with delirium. I also witnessed the distress experienced by older persons experiencing delirium and their family members. These experiences inspired me to learn more about strategies to support caregivers.

My interest in the area of delirium grew when I began working as an RN in general medicine, cardiac, and vascular surgery units in acute care hospitals. While working in general medicine, I cared for older persons who had delirium in addition to their pre-existing dementia. During this experience, I observed how difficult it was to distinguish between the two conditions without knowing the person's baseline cognition, due to the overlapping symptoms between dementia and delirium. Therefore, I found that some nurses, including myself, consulted families to determine whether the older



person's behaviour differed from their baseline behaviour or level of cognition. I continued to make this observation when I started working in cardiac and vascular surgery units, where postoperative delirium was common. Witnessing delirium frequently at work further spurred my interest in the topic. Therefore, I sought to further develop my knowledge on this topic when I started my graduate studies in nursing. In the first year of my graduate education, I completed a clinical placement with HELP at another teaching hospital.

Across my volunteer, work, and clinical placement experiences, it was clear that delirium caused distress among the nursing staff. From the nursing staff's perspective, the person with delirium required a lot of care, redirection, and monitoring in a hectic environment with limited resources. These experiences led to increased workloads and caused distress to nursing staff, many of whom believed that they were unable to provide safe, quality care to their patients. I found that when I cared for a person with delirium, I often spent a substantial amount of time reassuring the person and preventing injury, which decreased the time I spent caring for other patients. Thus, when family members were present, my co-workers and I often asked them to watch the older person with delirium. It was during these moments that I recognized family members' potential to become involved in caring for the older person with delirium.

I witnessed how delirium negatively impacted patients' health. I observed how the hyperactive behaviours in delirium (e.g., pulling IV lines and external pacer wires, repeated events of trying to transfer out of the bed unsafely) could impact patient safety. I also witnessed how the sedation and lethargy induced by delirium and psychoactive drugs

used to manage hyperactive delirium delayed patients' recovery from their illness and surgery. Delirium was also distressing to patients, who experienced hallucinations and cognitive disturbances within an unfamiliar environment.

Family members were also distressed to see the sudden change in the person's cognition, which involved witnessing the person engage in behaviours inconsistent with their typical personality. One patient's son, for example indicated that his father's experience with hyperactive delirium was "the second-worst day" of his life.

During these observations, I was most curious about the experiences of caregivers of PLWD who are more likely to experience distress compared to caregivers of older persons without dementia (CIHI, n.d.b.). I wondered how the caregiver experienced delirium of a PLWD, whether DSD had an impact on their caregiving experience, and what type of supports they required during the hospitalization. At the same time, I realized that these caregivers were also an important resource for nursing staff to help them detect delirium, because they provide information about the person's baseline cognitive status. Furthermore, caregivers also have the potential to help staff in managing delirium in hospitalized PLWD. These experiences led me to design and conduct the current study.

## CHAPTER THREE: LITERATURE REVIEW

### Search Strategy

A literature search was conducted to address the following question: *What are caregivers' experiences caring for older persons who have delirium superimposed on dementia in acute care hospital inpatient units?* A research librarian was consulted to review the chosen search strategies. The databases Ageline, CINAHL, MEDLINE, and PsycInfo were searched from January 2008 to September 2020 with combinations of the following terms: *delirium, dementia, dementia superimposed on dementia, caregivers* and *family caregivers*. Handsearching was also conducted on the 2014-2020 issues of the following journals: *American Journal of Alzheimer's Disease and Other Dementias, The Gerontologist*, and *International Journal of Older People Nursing*. Citation searches of included articles that focused on DSD were conducted using Google Scholar to identify other articles. The reference lists of studies meeting the inclusion criteria were also reviewed to identify other eligible studies.

The criteria for inclusion in the review were: (a) research article of a primary study with a focus on caregivers' experience caring for an older person with DSD in a hospital inpatient unit (e.g., general medicine, and other inpatient units) within an acute care hospital, and (b) English-language articles. Articles were excluded if: (a) they included persons without delirium, and (b) if delirium was related to alcohol withdrawal, advanced cancer, or end-of-life. Alcohol withdrawal-related delirium was excluded because it requires distinct screening and management strategies (Clinical Institute of Withdrawal Assessment for Alcohol, use of benzodiazepines) (Oh et al., 2017; Schuckit,

2014). Delirium within the palliative care context (e.g., advanced cancer, end-of-life) was also excluded due to the unique aspects of the context, which include knowledge of impending death (Finucane et al., 2017; Hosker & Bennett, 2016). Studies set in the intensive care unit were not included due to the difference in the acuity of illness and environment between the ICU and other inpatient units.

### **Search Results**

The search yielded two articles meeting the inclusion criteria (Fong et al., 2019; Yevchak, 2013). These two articles were based on two distinct studies that were both conducted in hospital inpatient units in the United States of America (Fong et al., 2019; Yevchak, 2013). One of the articles is an unpublished PhD dissertation (Yevchak, 2013). Given the limited number of articles found, I expanded my inclusion criteria to include two articles that were conducted in a rehabilitation inpatient unit within a skilled nursing facility in Northern Italy (Grossi et al., 2020; Morandi et al., 2015a). These two articles were based on the same prospective cohort study that investigated caregivers', older persons' and health care staff's experiences with DSD (Grossi et al., 2020; Morandi et al., 2015a). Each article presented a different set of analyses from the same study (Grossi et al., 2020; Morandi et al., 2015a). Grossi et al. (2020) conducted a quantitative correlational analysis to investigate predictors of distress in caregivers of older persons with DSD. Morandi et al. (2015a), conducted both quantitative descriptive and thematic analyses to evaluate caregivers' and health care staff's experiences of DSD.

Among these four articles, the following designs and analyses were used: quantitative, descriptive correlational study nested within a prospective observational

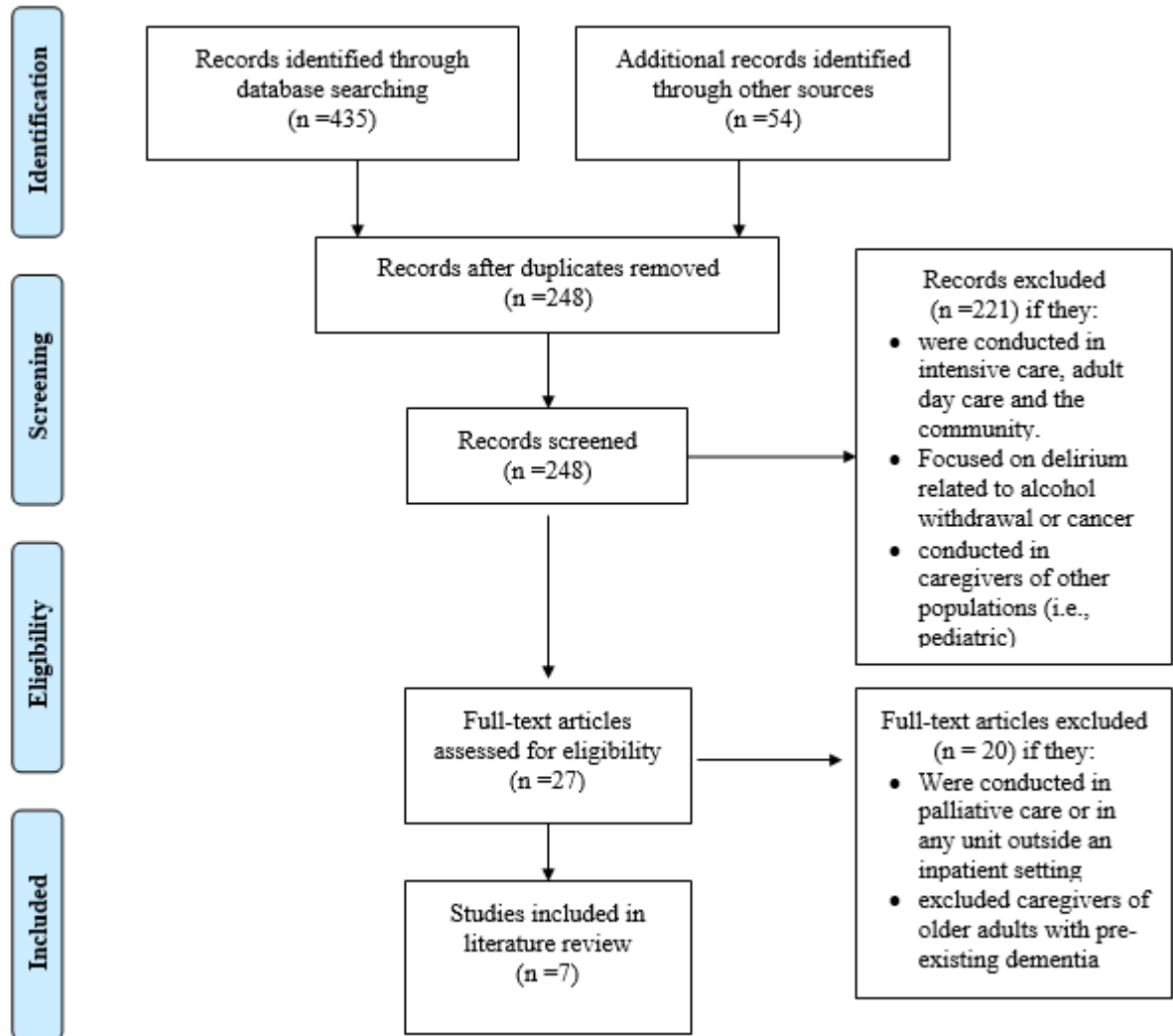
study (Fong et al., 2019); prospective cohort study that used quantitative descriptive, quantitative correlational, and qualitative content analysis methods (Grossi et al., 2020; Morandi et al., 2015a); and an exploratory study that used descriptive and comparative statistics, as well as thematic analysis (Yevchak, 2013). All four articles described the experiences of caregivers of older persons with DSD. One article reported the experiences of delirium of both caregivers of older persons with baseline dementia and without baseline dementia (Fong et al., 2019). The experiences of the two groups (with/without baseline dementia) were reported separately for comparison of delirium burden (Fong et al., 2019). Appendix A contains the data extraction tables detailing the four articles.

Given that the above four articles still represented little research on this topic, I further expanded the inclusion criteria to include three articles where the authors studied the delirium experiences of two sets of caregivers: (a) caregivers of older persons with dementia and (b) caregivers of older persons without pre-existing dementia (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). Unlike Fong et al.'s (2019) study, the authors of these studies did not report the delirium experiences of caregivers of older persons with DSD separately from caregivers of older persons without pre-existing dementia. These three additional studies were conducted in Australia (Day & Higgins, 2015b; Toye et al., 2014) and the United States of America (Schmitt et al., 2019). Among these articles, the following designs were used: qualitative phenomenological (Day & Higgins, 2015b); qualitative interpretive description (Schmitt et al., 2019), and descriptive mixed methods utilizing both descriptive statistics and qualitative content analysis (Toye et al., 2014). Appendix A also contains the extraction tables for these three articles.

The following section will summarize the methodological critique of the seven included articles (Day & Higgins, 2015b; Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013). This section will be followed by a description of the study findings. Findings from articles that distinctly reported the experiences of caregivers of older persons with DSD will be discussed first (Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Yevchak, 2013), followed by findings from articles that did not report the experiences of caregivers of older persons with DSD separately from caregivers of older persons without pre-existing dementia (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). Findings from the literature are described in relation to the literature search question: *What are caregivers' experiences caring for older persons who have delirium superimposed on dementia in acute care hospital inpatient units?* Figure 1 shows the results of the literature review using a diagram based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework (Moher et al., 2009).

**Figure 1**

*PRISMA Framework Depicting Literature Search*



### **Methodological Critique of the Literature**

Each article was critiqued according to Critical Appraisal Skills Programme (CASP) (2018a; 2018b) quality appraisal criteria for cohort and qualitative studies. The mixed methods appraisal tool (MMAT) from McGill University was used to evaluate any

study reporting a mixed methods approach, including studies that use both quantitative and qualitative methods, yet do not explicitly state the use of a mixed methods design (Hong et al., 2018). The CASP (2018a) checklist for cohort studies examines studies for criteria that include validity of results, appropriate recruitment strategies and consideration of confounding factors. The CASP (2018b) checklist for qualitative studies examines criteria such as the validity of results, appropriateness of methodology, suitable recruitment strategy, and clear statement of research findings. The MMAT evaluates a study's methodology by looking at the following: adequate rationale for using this design, integration of study components to answer research question, interpretation of qualitative and quantitative results, explanation for any divergences between qualitative and quantitative data, and whether each method adhered to the quality criteria of their tradition (Hong et al., 2018). The MMAT was used to assess the quality of the three papers that reported using both qualitative and quantitative methods (Morandi et al. 2015a; Toye et al. 2014; Yevchak, 2013). Certain aspects of the MMAT, specifically appropriateness of statistics and measurements, were also used as criteria to evaluate the quantitative studies by Grossi et al. (2020) and Fong et al. (2019). The seven included articles had methodological strengths and limitations, with details of quality ratings provided in Appendix B.

### ***Strengths***

A strength of the literature was the rich description of the qualitative findings about caregivers' experiences in most of the included studies that used qualitative methods (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). In these articles,



the qualitative approach was appropriate for the stated research questions and there was sufficient detail in the descriptions of the qualitative data analysis, with appropriate references to previous methodological literature (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013). The themes were well described and supported by relevant quotes. In addition, these studies were situated within relevant background literature (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013).

The participant inclusion criteria were clear in most of the studies (Day & Higgins, 2015b; Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013). Validated tools (e.g., Confusion Assessment Method), evidence-based diagnostic criteria, and medical chart review were used to confirm the diagnosis of delirium and dementia in the included studies (Day & Higgins, 2015b; Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013). In addition, most of the authors provided details about the caregiver participants' characteristics (e.g., age, gender, education level, relationship to older person), which allows readers to assess the generalizability or transferability of their findings to caregivers in other contexts (Day & Higgins, 2015b; Grossi et al., 2020; Morandi et al., 2015a; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013).

### ***Limitations***

A limitation of the included literature was that sample sizes were small in three articles that included a quantitative component in relation to the question being addressed (Grossi et al., 2020; Morandi et al., 2015a; Yevchak, 2013). The prospective cohort study reported by Grossi et al. (2020) and Morandi et al. (2015a) only had a sample size of 33

with no power size calculation presented. Yevchak (2013)'s descriptive, exploratory study determined that a sample size of 200 participants was required, yet this study was only able to recruit a sample size of 38 caregiver-patient dyads. Three studies (Morandi et al., 2015a; Toye et al., 2014; Yevchak, 2013) claimed to use both quantitative and qualitative methods, with one claiming to use a descriptive mixed methods design (Toye et al., 2015). However, there was little integration of both quantitative and qualitative findings in the discussion of these three studies (Morandi et al., 2015a; Toye et al., 2014; Yevchak, 2013). None of the authors stated if the studies had a primary focus on the quantitative or qualitative design (Morandi et al., 2015a; Toye et al., 2014; Yevchak, 2013).

There was a lack of detailed rationale for the selected sampling, data collection, and data analysis procedures in studies that had a qualitative component, including how the qualitative tradition guided the decision-making throughout the research process (Morandi et al., 2015a; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013). In three articles, there was no explicit statement about the qualitative design that was used (Morandi et al., 2015a; Toye et al., 2014; Yevchak, 2013). In addition, there was a lack of in-depth description of the qualitative data about caregivers' experiences of delirium in the two studies that had DSD as its main focus (Morandi et al., 2015a; Yevchak, 2013). For instance, in the study by Morandi et al. (2015a), participants' experiences were categorized into themes and accompanied by quotes, yet there was little explanation about the themes and sub-themes, and how they answered the research question.

### **Findings from Studies with a Focus on Caregivers of Older Persons with DSD**

Results from the studies with a focus on caregivers of older persons with DSD were organized according to the following sections: (a) experiences of caregivers of hospitalized older persons with DSD, (b) role of caregivers in the detection of DSD and care of older persons with DSD, and (c) types of supports recommended by caregivers of hospitalized older persons with DSD.

#### ***Experiences of Caregivers of Hospitalized Older Persons with DSD***

Two sub-themes describing caregivers' experiences with DSD were identified from the findings of the four studies (Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Yevchak, 2013): (a) caregivers' experiences of distress from DSD and (b) caregivers' limited communication with the health care team.

**Caregivers' Experiences of Distress from DSD.** Findings from four studies reveal that witnessing a hospitalized older family or friend with DSD is often distressing, resulting in anxiety, fear, distress, disruption, and worries about the future (Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Yevchak, 2013). The older person with DSD may exhibit behaviours distressing to their caregivers, which include wandering, sudden confusion, hallucinations, lethargy, and resistance to care (Fong et al., 2019; Morandi et al., 2015a; Yevchak, 2013). Caregivers experienced more distress when the older person had more severe symptoms of delirium, which included restlessness, shifting attention, apathy, hallucinations, disturbance in consciousness, orientation, and anxiety (Grossi et al., 2020). Caregivers also felt anxiety, fear, and depression associated with seeing the older person with DSD (Morandi et al., 2015a). Although both caregivers and

health care team members experienced distress when caring for an older person with DSD, caregivers experienced more distress than staff and may continue to experience distress even one month after the delirium resolved (Grossi et al., 2020; Morandi et al., 2015a). During the DSD episode, caregivers expressed concerns about the present situation and the future (Morandi et al., 2015a). Caregivers were concerned about the future, with many worrying about the permanency of cognitive changes and the possibility of the older person being transferred to another institution instead of being discharged home (Morandi et al., 2015a). Findings from these studies illustrate the distress and emotional burden experienced by caregivers of persons with DSD.

One descriptive correlational study (Fong et al., 2019) compared the delirium burden in caregivers of older persons with pre-existing dementia (i.e., DSD) to that of caregivers of older persons without baseline dementia. The authors found that delirium was equally stressful to caregivers of both groups, regardless of baseline dementia status (Fong et al., 2019). The authors concluded that caregivers' familiarity with caring for a person with cognitive and functional impairments related to dementia does not alleviate the additional burden from delirium (Fong et al., 2019). The authors also state that factors determining caregiver burden associated with delirium may be affected by underlying dementia, which is an area for research (Fong et al., 2019). This study demonstrates the importance of assessing caregivers of older persons with DSD for distress and supporting them during the experience, as their previous experience caring for an older PLWD does not mitigate the distress brought by delirium (Fong et al., 2019).

**Caregivers' Limited Communication with the Health Care Team.** One exploratory study utilizing descriptive and comparative statistics, and thematic analysis briefly described caregivers' experiences with health care team members in an acute care hospital (Yevchak, 2013). In this study, the caregivers reported limited communication between caregivers and staff about DSD and the plan of care. A few caregivers reported having positive experiences communicating with staff, who tried to learn their names and engage them in conversations, although these experiences were atypical (Yevchak, 2013). Caregivers stated that communication was often lacking, and staff were often focused on tasks. Caregivers expressed a desire for more information and increased participation in care (Yevchak, 2013). This study illustrates the influence of caregiver-staff relationships on caregivers' experiences of DSD and suggests that the quality of the relationship can influence the distress associated with DSD.

***Role of Caregivers in the Detection of DSD and Care of Older Persons with DSD***

Two sub-themes related to the role of caregivers in the detection of DSD and care of older persons with DSD were identified in study findings: (a) caregivers' role in the detection of DSD and (b) caregivers' role in DSD symptom management.

**Caregivers' Role in the Detection of DSD.** One descriptive study with both quantitative (i.e., descriptive and comparative statistics) and qualitative components (i.e., thematic analysis) explored the role of caregivers in detection of DSD in hospitalized older persons (Yevchak, 2013). This study examined the agreement between research staff's and caregivers' assessment of delirium using the Family Confusion Assessment Method (FAM-CAM) (Yevchak, 2013). The FAM-CAM is a tool that provides a

systematic method for clinicians to obtain information from families to improve recognition of delirium (Flanagan & Spencer, 2016; Inouye et al., 2012; Steis et al., 2012). The FAM-CAM is based on the Confusion Assessment Method (CAM), a widely used bedside tool to screen for delirium (Inouye et al., 2014). The results of this study showed that there was poor agreement between research assistant and caregiver ratings of delirium. However, there was 100% agreement on two specific FAM-CAM items, acute change and inattention. Acute change and inattention are considered as hallmark features of delirium, suggesting that caregivers could potentially assist the health care team in detecting delirium (Yevchak, 2013).

**Caregivers' Role in DSD Symptom Management.** Only one of the four studies hinted at the caregivers' role in DSD symptom management (Morandi et al., 2015a). Morandi et al.'s (2015a) prospective cohort study used both quantitative descriptive and qualitative content analysis methods. In this study, both caregivers and health care providers were interviewed. Some of the health care provider participants reported that the older persons with DSD may benefit from the presence of caregivers. The caregivers' presence may assist the health care providers in helping the older person with DSD cooperate with care tasks (Morandi et al., 2015b). The authors did not further elaborate on these findings. Nonetheless, the findings suggest that caregivers can play an important role helping manage symptoms of DSD.

***Types of Supports Recommended by Caregivers of Hospitalized Older Persons with DSD***

Only one of the four articles reported types of support recommended by caregivers of older hospitalized persons with DSD (Yevchak, 2013). Recommendations from this article included the following sub-themes: (a) improve communication between the health care team and caregivers and (b) increase caregiver participation in care.

**Improve Communication Between the Health Care Team and Caregivers.**

Caregivers desired regular and empathetic communication from the health care team about the older person's health status, the delirium and the plan of care (Yevchak, 2013). Although some caregivers recognized the fast-paced nature of the hospital and that staff shortages could occur in the hospitals, they still hoped that the health care team would set aside time to communicate to them about the plan of care and the older persons' status (Yevchak, 2013). Given that many caregivers voiced concerns about the future (e.g., discharge planning, risk of institutionalization, symptom persistence) during the delirium episode, frequent and supportive communication may help to alleviate their distress (Yevchak, 2013)

**Increase Caregiver Participation in Care.** Most caregivers in Yevchak's (2013) study expressed a desire to be a more active participant in the care of the hospitalized older person with DSD. Many of these caregivers also wished to be more involved in identifying a plan of care. Interestingly, while Yevchak's (2013) study explored caregivers' role in DSD detection, the caregivers did not mention hoping to learn about identifying delirium in the older person with dementia. It was unclear if the absence of

explicit statements about wanting to be involved in delirium detection reflected the caregivers' limited knowledge about their potential role in caring for the older person with delirium or their lack of engagement with the health care team members. In fact, Yechak (2013) found that only two of the 23 (8.7%) caregiver participants reported that they were consulted about changes in the older person's cognition, even if the caregivers were aware of the changes. These findings suggest that although many caregivers want increased participation in care of the hospitalized older person with DSD, they may not always have this opportunity.

### **Findings from Studies That Combined Caregivers of Older Persons with DSD and Caregivers of Older Persons with Delirium Only**

The results from the three studies that combined caregivers of older persons with DSD and caregivers of older persons with delirium only were similar and complemented the findings from studies that examined only caregivers of persons with DSD as discussed in the previous section. These three studies all had an important qualitative component (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019). The results are organized according to the following themes: (a) caregivers' relationships with the health care team, and (b) types of supports recommended by caregivers of hospitalized older persons with DSD and delirium.

#### ***Caregivers' Relationships with the Health Care Team***

Similar to previously discussed studies with an emphasis on DSD (Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Yevchak, 2013), findings from these three studies also found that the caregivers experienced distress when the older person



experienced delirium (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019).

Witnessing the sudden changes in personality and behaviour in the older person with delirium caused feelings of shock in the caregiver (Day & Higgins, 2015b; Schmitt et al., 2019). These three studies also further elaborate on caregivers' relationships with the medical team (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). The findings can be divided in the following sub-themes: (a) limited communication and education from the health care team and (b) caregivers felt dismissed by the health care team.

**Limited Communication and Education from the Health Care Team.** Similar to findings in Yevchak's (2013) study, many caregivers reported a lack of communication between the health care team and caregivers (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019). Caregivers desired ongoing information about the older person's status, especially as the older person was in a vulnerable state (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019). Caregivers also discussed how it was difficult to be able to speak with a doctor at a convenient time, as they were also balancing other responsibilities (Toye et al., 2014).

Many caregivers also reported that they did not receive enough information about delirium from the health care team, particularly its causes and treatment (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019). Due to their lack of knowledge about delirium, caregivers reported feeling in the dark, which increased their uncertainty about the experience (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019). In fact, some caregivers coped with the lack of information by looking for information about

delirium on the Internet (Toye et al., 2014). These findings indicate that in addition to limited communication about the older persons' health status and care plan, caregivers also did not receive sufficient education on delirium.

**Caregivers Felt Dismissed by the Health Care Team.** Some caregivers reported feeling dismissed by health care team members during the older person's hospitalization (Day & Higgins, 2015b). Caregivers' trust in health care team members eroded when they were not actively engaged in the care or did not perceive that their knowledge was being valued, further increasing their distress in an already stressful situation (Day & Higgins, 2015b; Toye et al., 2014). Some caregivers reported feeling marginalized or dismissed by the health care team during the older person's care (Day & Higgins, 2015b). For example, one caregiver reported that when she tried to speak to the health care team about the older person's delirium, she felt that she only received a "pat on the head", and that the team saw her as "just the relative", thus "what would she know"? (Day & Higgins, 2015b, p.1708). Nonetheless, some caregivers reported positive experiences with the health care team, feeling reassured by observing competent care and regular communication from the staff (Toye et al., 2014; Yevchak, 2013). These findings suggest that relationships between caregivers and the health care team have an impact on the caregivers' experiences, with poor relationships having a negative influence on caregivers' experiences at the hospital.

***Types of Supports Recommended by Caregivers of Hospitalized Older Persons with DSD and Delirium***

Findings from the three papers also provide recommendations on supports recommended by caregivers of hospitalized older persons with DSD and delirium (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). Two sub-themes emerged from these findings: (a) provide regular communication and delirium education to caregivers and (b) increase caregiver participation in the care of older persons with delirium. Recommendations are similar to those presented in the previous section from Yevchak's (2013) study, which had a primary focus on caregivers of persons with DSD.

**Provide Regular Communication and Delirium Education to Caregivers.**

Caregivers desired regular and empathetic communication from the health care team about the plan of care and the status of the hospitalized older person with delirium (Day & Higgins, 2015b; Schmitt et al., 2019). Lack of regular communication with the health care team further decreased caregivers' understanding of the situation, which in turn increased their emotional distress about the situation (Day & Higgins, 2015b). Caregivers stressed that regular, ongoing communication with the team would make them feel better supported during the delirium experience (Toye et al, 2014).

Caregivers would have liked more education about delirium, specifically its management and treatment (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). For example, some caregivers stated that they would like to learn more about symptoms associated with delirium, rationale for tests to screen for delirium, or the use of antibiotics for an infection associated with the condition. Other caregivers expressed that

they would like to have known that delirium was a possibility during the hospitalization (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). It is important to educate caregivers about delirium, as most had limited understanding of delirium, which can worsen their feelings of helplessness with the situation (Schmitt et al., 2019; Toye et al., 2014). Possessing insufficient information about delirium could add to the caregivers' concerns, with some caregivers stating that it increased their worries about the future (Day & Higgins, 2015b). Caregivers were also unsure how to best manage the behaviours in their family or friend, and worried about the older person's safety (Schmitt et al., 2019).

Although caregivers stated that they desired more information about delirium, similar to Yevchak's (2013) study, they did not mention hoping to learn about identifying delirium in the older person (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). Again, it is not clear whether the lack of explicit desire to be involved in delirium detection was due to caregivers' limited knowledge about their potential contributions to care or lack of communication with the staff.

#### **Increase Caregiver Participation in the Care of Older Persons with Delirium.**

— Similar to findings from Morandi et al.'s (2015a) study, two papers found that caregivers played an important role in the management of behaviours associated with delirium or DSD (Day & Higgins, 2015b; Toye et al., 2014). Caregivers relayed how they were asked by staff to watch the older person with delirium or help keep them calm, as the older person tended to be more cooperative when a familiar person was present (Day & Higgins, 2015b). By involving the caregiver in the management of the older person's

behavioural symptoms, the health care team were able to complete other tasks, such as medication administration (Day & Higgins, 2015b). In addition, some caregivers reported being asked to bring in photos or personal possessions to assist the health care team in communicating with the older person (Toye et al., 2014). Yet, caregivers continued to feel that they did not have enough opportunity to become involved with the care of the older person (Day & Higgins, 2015b; Toye et al., 2014). Some caregivers stated that they felt that they were dismissed by the health care team, despite their greater familiarity with the person with delirium (Day & Higgins, 2015b.). The caregivers also found that when they offered information to assist the health care team in personalizing their care to the older person, the health care team members were slow to integrate the information in the older person's care plan (Toye et al., 2014).

The literature suggests that the health care team could improve the experience of caregivers of hospitalized older persons with DSD or delirium by increasing caregiver participation in the older person's care (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). Several caregivers indicated that they wanted to help the older person with delirium and become an active participant in their care (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). All three studies suggest that involving caregivers in the care helps caregivers feel emotionally supported during the situation (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). By involving caregivers as active care partners in the care of older person, the health care team could also reduce their distress in the current situation, as they are relaying to the caregiver that their knowledge about the older person with DSD or delirium is valuable (Day & Higgins, 2015b; Toye et al., 2014).

In addition, health care team members could engage caregivers in the management of delirium by obtaining their input on care decisions or sharing their knowledge about the older person (Day & Higgins, 2015b; Toye et al., 2014). For example, some caregivers informed the health care team about the older person's preferences (e.g., likes and dislikes) to help personalize the care provided to the older person; the opportunity to provide input into the care was highly valued by caregivers (Toye et al., 2014).

### **Comparison of Findings in the Literature**

A comparison of the two groups of studies revealed similarities and overlaps in the findings. Table One summarizes the findings between the two groups of studies and indicates which findings were present in each group. Four studies that focused on caregivers of older persons with DSD will be referred to as "Group One Studies". Three studies that combined caregivers of older persons with DSD and caregivers of older persons with delirium in analyses will be referred to as "Group Two Studies." Both sets of studies found that caregivers felt DSD was a distressing experience and that caregivers often found that communication from the health care team was lacking. Group two studies, which included more qualitative analyses, also found that caregivers felt a lack of acknowledgment and dismissed by the health care team. Group two studies also found that many caregivers desired more education about delirium. On the other hand, group one studies found that caregivers can potentially assist the health care team in detecting DSD. Finally, both sets of studies found that caregivers can assist the health care team in managing behaviours associated with delirium and DSD.

**Table 1**

***Comparison of Findings Between Group One Studies and Group Two Studies***

<b>Type of Studies</b>	Caregivers felt DSD was a distressing experience	Caregivers felt unacknowledged or dismissed by the health care team	Caregivers found that communication from the health care team was lacking	Caregivers wanted more education about delirium	Caregivers can potentially assist the health care team in DSD detection	Caregivers can assist in managing behaviours associated with delirium and DSD
Group One Studies n=4	✓		✓		✓	✓
Group Two Studies n=3	✓	✓	✓	✓		✓

**Note:** Group One Studies included studies examining caregivers of older persons with

DSD only; Group Two Studies included studies that combined caregivers of older persons with DSD and caregivers of older persons with delirium in analyses

**Summary of Literature Gaps**

Overall, findings from both sets of studies reveal significant gaps in the literature regarding caregivers’ experiences with DSD in older persons, specifically: (a) caregivers’ experiences with DSD in acute care hospitals, (b) caregivers’ roles in the management and detection of DSD, and (c) the type of supports needed to improve the experience of caregivers of hospitalized older persons with DSD or to help the caregiver support the older person. Each of these is described in the following section.

Only one of the five studies that had a qualitative component focused specifically on caregivers’ experiences with DSD in older persons in an acute care hospital (Yevchak, 2013). Three of the five studies involved caregivers of older persons who either had DSD

or delirium without pre-existing dementia, yet did not report the findings separately for caregivers with delirium from those with DSD (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). The remaining study by Morandi et al. (2015a) specifically focused on caregivers' experiences of DSD, but was conducted in a rehabilitation setting within a skilled nursing facility, not an acute care hospital. Therefore, the unique experience of caregivers of older persons with DSD in acute care hospitals has not been extensively described nor explored. Distinguishing the experience of caregivers of hospitalized persons with DSD from caregivers of older person with delirium alone or other chronic conditions is important. Caregivers of older PLWD may have unique experiences and needs, as they provide more hours of care and are at higher risk for physical and emotional burden than caregivers of other older persons (Brodaty et al., 2014; CIHI, n.d.a; CIHI, n.d.b.; Pinguart & Sørensen, 2003; Seidel & Thyrian, 2019). Furthermore, previous experience caring for an older PLWD does not necessarily mitigate caregivers' distress associated with DSD (Fong et al. 2019).

The literature review also revealed that there is a lack of information on how caregivers can be better involved in the detection of DSD within acute care hospitals. This information is important because although delirium is common in hospitalized older persons, it is frequently unrecognized. Caregivers, with their in-depth knowledge of the PLWD's cognitive baseline, are well-positioned to assist staff to detect delirium. The literature suggests that caregivers of PLWD can observe a sudden change in cognitive status (Morandi et al., 2015a; Yevchak, 2013). Yet, the findings suggest that caregivers' role in DSD detection is not fully realized (Yevchak, 2013). Furthermore, findings from



Day and Higgins' (2015b) study point out that caregivers are often in the margins of care and may not be involved in DSD detection. Additionally, it is unknown whether caregivers are aware of the appropriate action to take once they detect a change (e.g., report to a health care provider). It is possible that caregivers may believe that the correct action involves waiting for a specific amount of time, instead of immediately contacting a health care provider (Bull, et al., 2016). Further research needs to be conducted on caregivers' role in detection of DSD in order to facilitate prompt treatment of the condition.

The role of caregivers in management of DSD in acute care hospitals, and the supports they require in order to become involved in DSD management is also undetermined. There were references to caregivers contributing to certain aspects of care such as watching the person or bringing in personal items, but there was little description of staff actively involving caregivers in delirium management (Morandi et al., 2015a; Toye et al. 2014). Furthermore, there were no specific recommendations for optimally increasing caregivers' involvement in the management of DSD. This omission is important given that family presence has been shown to mitigate distress in persons with delirium or DSD, which can reduce risk of unsafe behaviours (e.g., exit-seeking, climbing out of bed unsafely, pulling lines, hitting staff members) (Instenes et al., 2019; Lingehall et al., 2015; Morandi et al., 2015b; Pollard et al., 2015; Schmitt et al., 2019). More information is required about caregivers' role in the older persons' care in order to facilitate improved management of DSD.

Lastly, none of the studies were conducted in Canada, so we cannot be sure that findings are applicable to the Canadian context. An understanding of caregivers' experiences with DSD in hospitalized older persons can lead to development of relationship-centred strategies to support caregivers that are both based on participants' recommendations and applicable within the Canadian health care system. Furthermore, conducting research on caregivers' experiences can provide insight on the individuals' experiences within the health care system and help identify solutions to complex health problems (Kuluski et al., 2017).

### **Research Question**

Based on the identified knowledge gaps, the following research question was identified: *What are the experiences of caregivers of hospitalized older persons with DSD in Canadian acute care hospitals?* Experiences in this study will be defined as caregivers' feelings and emotions associated with the experience, their role in the care of the older person with DSD, and the types of support required to improve the experience of caregivers of hospitalized older persons with DSD or to help the caregiver support the older person (Day & Higgins, 2015b; Kuluski et al., 2017, Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013). The findings will be used to identify recommendations for improving caregivers' experiences.

## **CHAPTER FOUR: METHODS**

### **Introduction and Overview of Chapter**

In this chapter, I describe the qualitative research design used for this study and the rationale for choosing this approach. This chapter also contains a discussion of the study setting, sampling, recruitment strategies, data collection, data analysis, and ethical considerations. Finally, I conclude this chapter by describing the strategies employed to promote rigour and trustworthiness in this qualitative study. The methods are reported using the Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups to ensure comprehensive reporting (Tong et al., 2007).

### **Rationale for Interpretive Description as Research Design**

I used a qualitative research design, specifically Dr. Sally Thorne's (2016) interpretive description (ID), in this study. A qualitative research design enables researchers to study the complexity of human interactions and phenomena in natural settings (Jack, 2006; Pope & Mays, 1995). In contrast to quantitative methods, which use a positivistic paradigm and aim to understand causal relationships and identify trends within the population, qualitative research uses a naturalistic paradigm to understand phenomena from participants' perspectives (Jack, 2006). Within the health sciences, qualitative researchers study human experiences of health and its meaning to them, including the participants' beliefs, attitudes, and perceptions of these experiences (Jack, 2006; Pope & Mays, 1995). Qualitative health research has been used to describe and explain health, illness, health services, and health policy (Luciani et al., 2019).

The selection of a qualitative research design in this study was driven by my aim to gain a deeper understanding of caregivers' experiences when their care recipient is hospitalized with DSD. The interpretive descriptive approach was used to address the research questions. As discussed in the literature review, caregivers of persons with DSD have demonstrated distress during this acute condition and expressed concerns about the future (Fong et al. 2019; Morandi et al., 2015; Yevchak, 2013).

ID is a qualitative methodology grounded within the epistemological orientations of the applied health disciplines; it is aligned with the health sciences' mandate of identifying solutions for everyday clinical problems (Thorne et al., 1997; Thorne, 2016). The ID methodology includes a set of assumptions, influenced by the naturalistic inquiry tradition and its origins in the health disciplines (Thorne, 2016). Within the ID approach, it is assumed that multiple realities exist and are constructed by humans; these realities are influenced by the time and context of the individual (Thorne, 2016). Therefore, studies using ID methodology are conducted in naturalistic contexts that capture the person's subjective experience as a fundamental source of knowledge (Thorne, 2016). Additionally, ID studies examine the similarities between different individuals' experiences of the same phenomenon (Thorne, 2016).

As a nurse, I specifically chose ID because it offers a rigorous research methodology that will allow me to identify pragmatic solutions that can be used to support caregivers who care for hospitalized older persons with DSD (hereafter referred to as "older person") (Thorne et al., 2004). These solutions may be applied by nurses and

other acute care staff who work closely with families, as well as the organizations they work in. The ID approach was used to guide sampling, data collection, and analysis.

### **Setting**

Participants were recruited from four medicine units and one alternate level of care (ALC) unit from two teaching hospitals within an academic health sciences network in Southern Ontario. Both sites employ a mix of Registered Nurses and Registered Practical Nurses within their units. Both hospitals have emergency departments that have been frequently observed to experience gridlock, during which the emergency room reaches full capacity. The lack of capacity in the emergency room impacts the hospital bed flow, with some older persons being relocated to transitional units, hallways and patient lounges in order to increase bed capacity. These hospitals also have special units that are intended for use by patients in the emergency room who are waiting for a bed in an inpatient unit, or who are expected to stay in the hospital for only a short period of time. These units help increase capacity in the emergency room.

Three of the four medical units and the ALC unit were in a hospital with over 200 beds. One general medicine unit did not yield any eligible participants. These units typically admit patients with acute medical conditions such as diabetes, stroke, heart failure, pneumonia, and myocardial infarction. The ALC unit serves patients with complex or ongoing care needs yet have medically stable conditions who no longer require acute care and are waiting to be discharged to the following settings: home with increased supports, convalescent care, rehabilitation, retirement home, or long-term care. Some patients in the ALC unit have been transferred from the general medicine units of

the hospital. The fourth medical unit was in another hospital that is also a regional trauma centre with over 600 beds.

## **Sampling and Recruitment**

### ***Sampling Strategies and Sample Size***

Purposeful sampling, specifically criterion sampling, was used to reflect expected and emerging variations in the phenomenon under study (Thorne et al., 2004; Thorne, 2016). Purposeful sampling involves selecting participants who can provide rich information about the topic of interest (Patton, 1990). Criterion sampling aims to recruit participants that meet predetermined criteria. Participants were deemed eligible if they met the following criteria: (a) 18 years of age and older, (b) is caring for a community-dwelling person aged 65 years and older who has been diagnosed with any stage of dementia, (c) English-speaking, and (d) cared for the older person who experienced DSD during the current hospitalization or within two weeks of discharge of the most recent hospitalization. For the purpose of this study, caregivers were defined as a family member (e.g., spouse, child, sibling, relative) who provides physical and/or emotional support to the older person.

Thorne (2016) does not prescribe a specific sample size for ID studies. A sample size of nine caregivers was recruited. This sample size is consistent with previous studies employing ID that have ranged from 6 to 32 participants (Teodoro et al., 2018; Thorne, 2016). Recruitment ended prematurely because of restrictions surrounding the COVID-19 pandemic during the data collection period.

### ***Recruitment Strategies***

Various recruitment strategies were used to obtain a purposeful sample of caregiver participants. I contacted the clinical managers of the hospital units to share information about the study and obtain permission to recruit from their units. I obtained permission to recruit from four medical units and one ALC unit.

Potential caregiver participants were identified by a nurse who was part of the older person's circle of care. After obtaining permission from managers, I shared information about the study with the staff members during their safety huddles. I also discussed the inclusion criteria of the study and asked the staff to identify potential participants in their care. I circulated flyers and sent emails to the staff to further disseminate information about the study. I also communicated with the unit charge nurses to check if there were any patients who had eligible caregivers and then communicated with the patient's primary nurse. The charge nurse or the older person's primary nurse would confirm whether the patient's caregiver met the inclusion criteria. The diagnoses of dementia and delirium were confirmed by the health care team members who identified potential participants for the study. These health care team members referring the participants were members of the older person's circle of care and thus possessed knowledge of the PLWD's medical history.

Whenever a patient's nurse identified a potential caregiver, I asked them to approach the individual in person or by phone to share information about the study and obtain their verbal consent to be contacted by the PI about the study. If the caregiver could not be reached by phone and was expected to visit the unit within that shift, I asked

the primary nurse to provide the caregiver with a flyer about the study and ask if the caregiver was willing to share their contact information with me. If the caregiver agreed, the nurse filled out the participant contact form and dropped it off at a locked box at the nursing station, which I would pick up the next day. Nursing staff were given a \$25 gift card for referring at least one participant enrolled into the study.

Once potential participants provided their verbal consent to be contacted, I met with them in person or contacted them by phone to share relevant information about the study (i.e., purpose, data collection, benefits/risks). I then set up a time for a 60-minute in-person or telephone interview at a time and location convenient to the participant. All participating caregivers were provided with a \$25 gift card as a token of appreciation and to reimburse them for any inconvenience experienced from participating in the study.

### **Data Collection**

The principles of ID design guided data collection (Thorne, 2016). According to Thorne (2016), data collection methods should be selected based on their ability to allow the researchers to record the subjective experience of participants as closely as possible. Thorne (2016) recommends researchers select data collection methods based on what is available to the researcher and the nature of the information. With these principles in mind, I used interviews and field notes to gather data from participants.

### ***Interviews***

Interviews were used for data collection due to their ability to access the participants' first-hand experiences and subjective knowledge of the phenomenon of



interest (Thorne, 2016). Semi-structured interviews were specifically selected, because they use a set of pre-determined open-ended questions that allow participants to openly discuss their experiences, while enabling them to focus on the topic of interest (DiCicco-Bloom & Crabtree, 2006).

All interviews were conducted in person except for two telephone interviews. Most in-person interviews were conducted within the hospital (e.g., cafeteria, waiting area). One in-person interview was conducted in a restaurant in close proximity to the hospital and one was conducted at a participant's home following her father's discharge. The hospital and its surrounding areas were commonly used for the interviews, as it was convenient for caregivers, who would participate prior to or during a visit to the older person. Private rooms for interviews were not available due to limited facilities for non-hospital employees. The interviews were conducted during less busy times such as 3:00 PM or on a weekend to ensure privacy when there were fewer people present in the cafeteria or when the waiting area for a clinic was empty, because the facility was closed.

Telephone interviews were arranged with participants when they could not find a time for an in-person interview. There were also instances when interviews had to be rescheduled to accommodate changes in the participant's schedule due to changes in their responsibilities (e.g., work meetings, medical emergencies).

Demographic data about the caregivers were also collected during the interview (See Appendix C). The interview guide was developed based on: (a) a review of previous literature about caregivers' experiences with DSD and delirium (Day &

Higgins, 2015b; Fong et al., 2019; Grossi et al., 2020; Morandi et al., 2015a; Schmitt et al., 2019; Toye et al., 2014; Yevchak, 2013); (b) literature on relationship-centred care (Brown Wilson et al., 2009; Nolan et al., 2006; Tresolini & Pew-Fetzer Task Force, 1994); and (c) discussion with supervisory committee members (See Appendix D for the interview guide). Literature on relationship-centred care was considered, as the literature review suggested that relationships between caregivers and staff may have an impact on the caregivers' experiences (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019; Yevchak, 2013). The interviews were an average of 60 minutes in duration and were conducted from January to April 2020. All interviews were audio-recorded with the participants' written consent.

### ***Field Notes***

Field notes were taken during and after interviews with caregivers (Phillippi & Lauderdale, 2018). Field notes recorded the setting of the interview (e.g., geographic context, type of setting) and participant demeanour (e.g., nonverbal behaviours) (Phillippi & Lauderdale, 2018). Field notes can improve the depth of the qualitative findings and can add context to findings from interviews (Phillippi & Lauderdale, 2018; Sandelowski, 1994). In addition, field notes were used to provide thick descriptions of the research process and to critically reflect on my personal influences on the data collection, which can increase trustworthiness of the research (Krefting, 1991).

### **Data Analysis**

Thematic analysis was used to detect commonalities in the data (Braun & Clarke, 2006). Thematic analysis was selected because it has been used to report the meanings

and experiences of participants. Braun and Clarke's (2006) method was specifically chosen as it outlines a clear step-by-step process that can be conducted inductively, and is aligned with ID (Thorne et al., 1997; Thorne, 2016). Braun and Clarke's (2006) approach to thematic analysis includes the following steps: (a) familiarizing one's self to the data, (b) generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining and naming themes, and (f) producing the report.

***Step One: Familiarizing One's Self to the Data***

I listened to all audio-recordings at least three times and transcribed all data verbatim to facilitate immersion in the data prior to coding (Thorne, 2016). This approach is consistent with Thorne et al.'s (1997) recommendation for repeated immersion in the data prior to coding in order to facilitate synthesizing and recontextualizing data. The field notes accompanying each recording were reviewed alongside the transcript to ensure the context of the data was considered within the analysis (Sandelowski, 1994; Thorne et al., 2004). I shared transcripts and notes with my supervisor who I consulted with throughout the entire analysis process.

***Step Two: Generating Initial Codes***

Coding is a process that identifies semantic or latent features of the data that appear to be the most basic aspect of the information to be assessed (Braun & Clarke, 2006). I specifically conducted open coding, which involved line-by-line coding, breaking the data into discrete parts, and examining these parts for similarities and differences (Thorne, 2016). This process allowed me to distinguish conceptual units in the data and organize them into thematic categories (Thorne, 2016). The generation of initial

codes was conducted in collaboration with my thesis supervisor, as we independently coded three transcripts. We then met to review the codes and created a combined coding tree that was used in future coding.

Coding was done inclusively (i.e., extracts of the surrounding text included) to preserve the context (Braun & Clarke, 2006). In accordance with ID, concurrent data analysis and constant comparative analysis were conducted (Thorne et al., 1997; Thorne et al., 2004; Thorne, 2016). Concurrent data analysis was carried out by transcribing and analyzing data while interviews were being completed. In using constant comparative analysis, each newly collected transcript was compared with previously coded transcripts during data analysis in order to identify relationships within the data (Thorne, 2016).

### ***Step Three: Searching for Themes***

This step is focused at a broader level of themes and was conducted after all data were coded and a list of all codes was available (Braun & Clarke, 2006). In accordance with Braun and Clarke's (2006) method, codes were sorted into themes. The initial sorting and organization of data was executed using the NVivo 12 software program (QSR International, 2020). Certain themes were also collapsed into a single theme and sub-themes were also identified (Braun & Clarke, 2006). I held regular meetings with my supervisory committee members throughout the data analysis process to receive their feedback on the emerging codes and themes from the data. My committee assisted in identifying higher level concepts, under which themes could be collapsed and sorted.

***Step Four: Reviewing Themes***

I reviewed the list of themes with my supervisory committee members during a number of meetings. In accordance with Braun and Clarke (2006), I reviewed each theme at two levels: (a) I reviewed the data coded under each theme to determine if they formed a clear pattern, and if not, I determined why and, in some cases, created a new theme; and (b) I reviewed the theme's relevance in relation to the data set (i.e., does it make sense in the context of the whole data set?).

***Step Five: Defining and Naming Themes***

This step involved writing a detailed analysis of all themes and preparing a final list of themes ready for a written report (Braun & Clarke, 2006).

***Step Six: Producing the Report***

The final report involved drafting this master's thesis under the guidance of my supervisor and supervisory committee members. Additionally, consistent with ID, the themes were situated within related literature on caregivers' experiences with DSD (see discussion chapter) (Thorne, 2016). Findings from this ID study were grounded within existing disciplinary knowledge in order to explicitly position implications arising from the study's findings (Thorne, 2016).

**Strategies to Promote Rigour and Trustworthiness**

The rigour of this study was maintained using trustworthiness criteria, which represent merit and methodological strength within qualitative research (Guba, 1981). According to Lincoln and Guba, (1985), trustworthiness includes the following criteria: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability. This section

outlines strategies used to promote rigour during the conduct of the study. It is important to note that some strategies may address more than one criterion (Lincoln & Guba, 1985).

### ***Credibility***

The criterion of credibility refers to the confidence in the truth of the findings (Lincoln & Guba, 1985). Credibility can be increased through: (a) interview techniques and (b) investigator triangulation. Interview techniques that build rapport with participants can minimize social desirability bias within interviews, in which participants give an answer to please the interviewer, but may not reflect what they think (Krefting, 1991). During the interviews, I minimized social desirability bias, by building rapport prior to the beginning of the interviews and also by informing the participants of the strategies to be taken to protect their confidentiality, in order to encourage them to give answers reflective of their thoughts and experiences. When in-person interviews were conducted in a public area (e.g., hospital cafeteria), I selected a time when fewer people were present and conducted the interview at a distance from other people in order to maintain privacy. Investigator triangulation, involving at least two researchers within the same study, brings greater breadth and credibility to the findings, because it allows for the confirmation of conclusions and the integration of different perspectives (Carter et al., 2014; Krefting, 1991). I consulted my supervisor and supervisory committee members throughout the study and involved them in data analysis and interpretation of results.

### ***Transferability***

This criterion evaluates the findings in regard to their applicability to other contexts (Lincoln & Guba, 1985). To increase transferability of the study's findings, I

included a description of the participant characteristics (e.g., education level, age, relationship to the older person) as well as a description of the acute care settings including the unit, type of hospital, and geographical context (Krefting, 1991).

### ***Dependability***

This criterion assesses whether the findings are consistent and can be repeated. To increase this study's dependability, I provided a detailed description of the study methods in this chapter (Lincoln & Guba, 1985; Thorne, 2016).

### ***Confirmability***

Confirmability evaluates the study in terms of how the findings are shaped by researcher bias and interests. Confirmability was maintained in the study through the use of: (a) reflexivity and (b) an audit trail. Reflexivity will alert researchers if any of their biases have influenced the data analysis and interpretation (Gentles et al., 2014; Krefting, 1991). Reflexivity was maintained by keeping a field journal on my reflections and observations during data collection and analysis. I also maintained an audit trail, which involved keeping records of the research and included raw data, field journal, study proposal, notes, analytic decisions and other documents (Lincoln & Guba, 1985; Krefting, 1991).

### **Ethical Issues**

This study was conducted in accordance with the Tri-Council Policy Statement, *Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and

Humanities Research Council of Canada, 2018). Institutional ethics approval was obtained from the Hamilton Integrated Research Ethics Board (#7996).

### ***Informed Consent***

Informed consent was treated as an ongoing process to ensure participants were involved throughout the process (Richards & Schwartz, 2002). When the caregiver consented to being approached and met eligibility criteria (as identified by the nurse), I contacted them and discussed potential enrollment. I explained the study's purpose, question, data collection methods, how the results would be used, and potential benefits/risks (Richards & Schwartz, 2002). A copy of the informed consent form was given to potential participants to review prior to the interview. Written informed consent was obtained prior to all in-person interviews. For phone interviews, a copy of the informed consent was sent to participants by email or regular mail. Participants who had phone interviews were given the opportunity to email or mail a copy of the consent prior to the phone interview and a self-addressed envelope with a postage stamp was made available to any participant who did not have access to email, prior to the interview. However, both participants who participated in phone interviews declined to send written consent in advance, thus, verbal consent was obtained and noted prior to the phone interview. Appendix E contains a copy of the informed consent.

### ***Confidentiality***

Various safeguards were put in place to protect participants' confidentiality and privacy. Consent forms were locked in separate file cabinets in the university office, which can only be accessed by key by myself. or my supervisor. In addition, all



transcripts were de-identified and assigned a participant code (Richards & Schwartz, 2002). Finally, consent forms and other information with identifiable information will be locked for a maximum of two years, before they are destroyed. Participants were also given the option of withdrawing data from the study up to 30 days after their interview was conducted.

### *Distress*

As the nature of qualitative studies involves in-depth exploration of the participants' experience, the process occasionally provoked distress in participants, who may have to relive unpleasant experiences during the interview (Richards & Schwartz, 2002). Participants were given the opportunity to pause or take a break during the interview, if they experienced distress. Caregiver participants were also informed of counselling, support groups, and other community services (e.g., Alzheimer Society) that they could access as necessary.

## **CHAPTER FIVE: RESULTS**

### **Introduction and Overview of Chapter**

This chapter is a report of the study's findings and is divided into two sections. The first section is a description of the demographic characteristics of the caregivers included in this study. The second section includes a description of the themes and sub-themes derived from the data. Direct quotes from caregivers are included and are labeled with the letters *CG* followed by the caregiver's study ID number.

### **Social and Demographic Characteristics of Caregivers**

A total of nine caregivers caring for eight older persons consented and participated in the study. Eight interviews were conducted because two caregivers cared for the same older person and were interviewed together; their data were labelled and reported separately as CG5 and CG6. The mean age of the caregivers was 63.8 years ( $SD=9.87$ ) (Table 2). All caregivers were Caucasian and almost all (88.9%) were female. Caregivers included four daughters, three spouses, one son and one daughter-in-law. Three of the nine caregivers lived with the older person. Three caregivers had finished high school while four had a college diploma. Most caregivers (55.5%) were employed, and almost half worked part-time (44.4%). Five caregivers (55.6%) reported that they had been a caregiver for one year or less, one was a caregiver for two to three years (11.1%) and three (33.3%) were caregivers for four to five years.

**Table 2**

*Social and Demographic Characteristics of Caregivers (n=9)*

<b>Characteristics</b>	<b>n (%)</b>
<b>Age of the Caregiver in Years [Mean (SD)]</b>	63.8 (9.87)
50 - 60	4 (44.4)
61 - 70	2 (22.2)
71 - 80	3 (33.3)
<b>Sex</b>	
Male	1 (11.1)
Female	8 (88.8)
<b>Highest Education Level Completed</b>	
High School	3 (33.3)
College Diploma	4 (44.4)
Bachelor's Degree	1 (11.1)
Master's Degree	1 (11.1)
<b>Employment</b>	
Part-time	4 (44.4)
Full-time	1 (11.1)
Retired	4 (44.4)
<b>Years of Caregiving</b>	
≤ 1	5 (55.6)
2 to 3	1 (11.1)
4 to 5	3 (33.3)
<b>Relationship with the PLWD</b>	
Spouse	3 (33.3)
Daughter	4 (44.4)
Son	1 (11.1)
Daughter-in-law	1 (11.1)
<b>Do you live with the PLWD?</b>	
Yes	3 (33.3)
No	6 (66.7)

<b>Characteristics</b>	<b>n (%)</b>
<b>Does someone help you care for the older person?</b>	
Yes	8 (88.9)
No	1 (11.1)
<b>Type of Assistance Received by Caregiver</b>	
Formal assistance	4 (44.4)
Both formal and assistance from family, friends, neighbours, etc.	4 (44.4)
No assistance	1 (11.1)

Table 3 provides a summary of the social, demographic, and clinical characteristics of the older persons at the time of the interview. The average age of the older person was 85.3 years. The older persons were hospitalized for several reasons, including heart failure, urinary tract infection, delirium, falls and dehydration. The mean length of their current hospital stay was 43.5 days with a median stay of 30.0 days. Six of the eight older persons (75%) were still hospitalized at the time of the interview with the caregiver. The remaining two caregivers were interviewed 6-14 days after the older persons' hospital discharge. Although these caregivers were interviewed at home, the interview was focused on their experience during the hospitalization. Almost a third (37.5%) of the older persons were first diagnosed with dementia during their hospitalization.

**Table 3**

*Social, Demographic, and Clinical Characteristics of Older Persons (n=8)*

<b>Characteristics</b>	<b>n (%)</b>
<b>Age of Older Person in Years [Mean (SD)]</b>	85.3 (3.87)
<b>Sex</b>	
Male	4 (50.0)
Female	4 (50.0)
<b>Type of Dementia as Reported by the Caregiver</b>	
Alzheimer’s disease	2 (25.0)
Vascular dementia	1 (12.5)
Fronto-temporal dementia	1 (12.5)
Lewy body dementia	1 (12.5)
Not sure	3 (37.5)
<b>Stage of Dementia as Reported by the Caregiver</b>	
Early	2 (25.0)
Middle	2 (25.0)
Late	1 (12.5)
Not Sure	3 (37.5)
<b>Received dementia diagnosis during current hospitalization</b>	
Yes	3 (37.5)
No	5 (62.5)

<b>Characteristics</b>	<b>n (%)</b>
<b>Reasons for Current Hospital Admission as Reported by Caregivers</b>	
Fall	3 (37.5)
Delirium	1 (12.5)
Dizziness	1 (12.5)
Heart failure	1 (12.5)
Dehydration	1 (12.5)
Urinary tract infection	1 (12.5)
Pneumonia	1 (12.5)
Sudden change in mobility, stroke like symptoms	1 (12.5)
<b>Length of Current Hospital Stay at Time of Interview (Days)</b>	
Mean (SD)	43.5 (46.7)
Median	30.0
<b>Length of Current Hospital Stay at Time of Interview (Days)</b>	
0 to 10	2 (25.0)
11 to 20	2 (25.0)
21 to 50	1 (12.5)
51 to 60	2 (25.0)
> 61	1(12.5)
<b>Was older person hospitalized at the time of the interview?</b>	
Yes	6 (75.0)
No	2 (25.0)
<b>If discharged at the time of the interview, how long has it been since the hospital stay? (Days)</b>	
0 to 7 days	1 (12.5)
8 to 14 days	1 (12.5)
N/A	6 (75.0)

**Note:** Early stage refers to mild impairment, middle stage describes a greater decline in the PLWD’s cognitive and functional abilities, and late stage refers to the stage when the PLWD can no longer communicate verbally or care for themselves (Alzheimer’s Society of Canada, n.d.)

## Introduction to Themes

Four themes were identified that describe caregivers’ experiences with DSD: (a) caregivers found DSD to be an overwhelming experience, (b) caregivers were concerned about the quality of care that the older person received, (c) caregivers’ experiences were influenced by the nature of their relationship with the health care team, and (d) caregivers can play an important role in the detection and management of DSD. Table 4 lists the four themes and related sub-themes, which are discussed in the next section.

**Table 4**

### *Summary of Themes and Sub-themes*

<b>Themes</b>	<b>Sub-Themes</b>
<b>1) Caregivers found DSD to be an overwhelming experience</b>	<ul style="list-style-type: none"> <li>a) Caregivers experienced distress, sadness, helplessness, and shock at seeing the older person with DSD: <i>“It’s soul-destroying”</i></li> <li>b) Caregivers felt that they lacked information about DSD: <i>“I like approaching things if I can understand it and I can react to it better”</i></li> <li>c) Caregivers were overwhelmed and struggled to balance multiple responsibilities: <i>“Everything’s snowballed on me at once”</i></li> </ul>
<b>2) Caregivers were concerned about the quality of care that the older person received</b>	<ul style="list-style-type: none"> <li>a) Caregivers were distressed that the health care team used chemical and physical restraints to manage DSD: <i>“Sometimes they restrain him so he doesn’t harm himself, so he’s not going to fall”</i></li> <li>b) Caregivers felt that frequent and poorly executed transitions exacerbated delirium and dementia in the older person: <i>“They moved her in the night, which was very upsetting for her”</i></li> <li>c) Caregivers were not hopeful that the quality of care could be improved: <i>“I don’t know if they could have done anything different or helped”</i></li> </ul>
<b>3) Caregivers’ experiences were influenced by the nature of their</b>	<ul style="list-style-type: none"> <li>a) Caregivers’ experiences were influenced by the quality of their communication with the health care team: <i>“They spend the time with me and try to</i></li> </ul>

<p><b>relationship with the health care team</b></p>	<p><i>explain everything. So, it's been good. It's a good experience"</i></p> <p>b) Caregivers wanted to feel acknowledged, valued, and respected by the health care team: <i>"We're kind of invisible"</i></p> <p>c) Caregivers felt disempowered in their relationships with the health care team <i>"You don't want to get kicked out!"</i></p>
<p><b>4) Caregivers can play an important role in the detection and management of DSD</b></p>	<p>a) Caregivers can be instrumental in helping to identify changes in cognition or health status: <i>"Oh she wasn't her normal self. She was seeing things, you know people"</i></p> <p>b) Caregivers actively participated in strategies to manage symptoms of DSD: <i>"I brought family photos, a blanket, some favourite food and some magazines just to help her try to gain back some of her normality"</i></p> <p>c) Caregivers assisted the health care team in the care of the older person and advocated for them: <i>"Because we could calm her down"</i></p>

**Theme One: Caregivers Found DSD to be an Overwhelming Experience**

The hospitalization experience itself was difficult for caregivers, who felt overwhelmed and experienced varying negative emotions. The hospitalization of the older person and the DSD resulted in increased stress for caregivers, who were already balancing multiple responsibilities. The following sub-themes elaborate on the caregivers' experience: (a) caregivers experienced distress, sadness, helplessness, and shock at seeing the older person with DSD, (b) caregivers felt that they lacked information about DSD, and (c) caregivers were overwhelmed and struggled to balance multiple responsibilities.



***Caregivers Experienced Distress, Sadness, Helplessness, and Shock at Seeing the Older Person with DSD: “It’s Soul-Destroying”***

Caregivers reported a variety of negative emotions, such as sadness, helplessness, and shock at seeing the older person with DSD. Caregivers were particularly alarmed when the older person displayed challenging behaviours, which are common symptoms of DSD, such as resistance to care, hallucinations, and cursing. One caregiver, after hearing her mother verbalize an expletive towards a physician, expressed her shock, stating “*My Mom would never say that*” (CG8). Another caregiver explained the shock she felt when she saw her father demonstrating behaviour unlike his usual self:

*It’s a bit of shock, because you’re like, okay, he’s totally nuts. [Laughs]. I know. And now what? I think that was where my mind was. He’s gone completely off his rocker, but he’s talking and I can hear him and he’s making sentences, but he doesn’t know where he is, doesn’t know what’s happening.* (CG1)

Caregivers were saddened by seeing the older person behave so differently compared to their behaviour prior to the hospitalization. One caregiver, after seeing her father remove his clothes in the middle of the hospital room and require the assistance of two health care team members to use the bathroom, stated “*I think because he’s been such an independent man all his life. This is hard*” (CG1). These data illustrate that the hospitalization is not only difficult for the older person, but for the caregiver as well. As one caregiver stated “*Because I know he’s going through the sickness and the family member is suffering with him too so it’s hard on us too*” (CG7), suggesting that the caregivers empathize with the older person’s suffering. Another caregiver likened the experience to a trauma, said that “*It was very traumatic*” (CG3) to see her mother in a

very drowsy state, even though this caregiver had already experienced challenging behaviours associated with her mother's dementia prior to hospitalization.

In some cases, the shock and sadness stemmed from caregivers observing the development of new behaviours in the older person. Caregivers appeared to be distressed by these new behaviours and their perceived negative impact on their relationship. One caregiver described how the change in her husband's behaviour as a result of DSD affected their relationship, as he no longer appreciated conversing with her:

*I help— I try to help him to make his day better, but sometimes it's just "Don't talk to me" or I'll get upset because he said "You talk too much" and then sometimes he didn't have the patience. He lost some patience, because before he'd love to talk and everything. It's just being, not feeling well and I understand, because at home, we did things together. So, it's been many years and now it is very hard for me and my son too. (CG7)*

Caregivers also reported feeling helpless when they tried to help the older person. This was especially true when the older person refused help or if the caregiver felt that they could not do anything to alleviate the situation, which is further demonstrated in the following quote:

*And it's soul-destroying, because you're kind of like... What can you do? Other than try to deflect or something like that. It's—it's really hard. Yeah, it's really hard. [starts to wipe her eyes, tears begin to flow]. It's really hard to see your mother like that. (CG2)*

***Caregivers Felt that they Lacked Information about DSD: "I Like Approaching Things if I Can Understand it and I Can React to it Better"***

Caregivers felt that they lacked information about DSD, which contributed to their shock and distress. Caregivers described the difficulties they faced in accessing information about DSD during the hospitalization. This lack of information may have

contributed to caregivers feeling unprepared for this experience, which led some caregivers to seek information on their own. Most caregivers verbalized that more information about DSD would have been helpful.

Caregivers explained that they did not receive education about DSD during the hospitalization. Often, caregivers were told that the older persons had delirium, but were not given any additional information. When one caregiver reported a change in her husband's cognitive status, the health care team member replied: *“Oh yeah, he’s delirious”* (CG7), yet no follow-up information was given about the condition. Some caregivers found information about DSD online, as one caregiver stated: *“When they finally said delirium, then we went home on the Internet”* (CG6). Another caregiver went online to get more information about the drug that caused her father's delirium, *“I came home and looked it up. Lorazepam, what are the side effects?”* (CG1). This finding suggests that not only was the communication of the diagnosis of delirium poor, but also caregivers were not provided with additional information about this condition. Thus, caregivers had to seek the information out themselves.

Some, but not all, caregivers asked for education specifically about DSD. Much of their desire for education stemmed from their need to care for the older person and to increase their preparedness to cope with this condition. One caregiver said *“I’m wondering what I can do for him. Am I doing all that I can do?”* (CG4). This call for more education came from the caregivers' desire to find ways to help the older person recover, as a caregiver stated *“Just, I would like to have been told more about the delirium and how to help her come out of it quicker”* (CG3).

Some caregivers requested specific information about delirium on its own. They requested information about the expected course of delirium in the hospital, as one caregiver stated *“If they could explain that, I mean, they say it’s a normal thing sometimes and they’ll have very good days and sometimes they’ll have some really bad days. As long as it’s explained to you, I don’t think you can ask for anything else”* (CG5). There were also requests for pamphlets and brochures about delirium, as one caregiver reported *“[If they] would have shared some information with me or even just some written pamphlets or something, it would have been helpful to the caregivers”* (CG7). Pamphlets on delirium were available on the unit, but they were not always given to the caregivers. One caregiver described finding a pamphlet on delirium by chance in the hospital:

*The first couple of days, I just happened to walk down another hallway and noticed this brochure on the wall nobody told me about [shows a yellow brochure for patients and families on delirium] and that helped me and if I hadn’t seen that, I might not have noticed some of the tips in the brochure [caregiver starts flipping through the brochure and pointing out delirium prevention and management strategies listed in it] bringing family photos to reacclimate your loved one to where they are and time, make sure her glasses were near her table, and what else did I do? I brought a blanket from home just for comfort and a reminder of some of her favourite things, magazines, but if this had been given to me in the ER even or the first day on the ward, that would probably have helped me a bit more.*  
(CG3)

Other caregivers requested information about dementia. One caregiver whose husband had been diagnosed with dementia during the current hospitalization reported that she did not receive any information from the health care team about dementia or even direction towards resources from the Alzheimer’s Society, even after her husband was discharged home. This caregiver stated: *“Learning more about dementia, like I told you, I didn’t even*

*know that there were different kinds” (CG9). Overall, caregivers felt that they wanted more information about delirium and dementia so that they could feel better prepared to care for the older person. They felt that information on these conditions could have reduced their feelings of unpreparedness, distress, and helplessness. As one caregiver relayed “I like approaching things if I can understand it and I can react to it better” (CG1).*

***Caregivers Were Overwhelmed and Struggled to Balance Multiple Responsibilities:  
“Everything’s Snowballed on Me at Once”***

Many of the caregivers already felt overwhelmed and struggled to balance their caregiving responsibilities with childcare and other family and work responsibilities. For example, one caregiver reported that she worked two jobs as a personal support worker and cab driver, while managing her mother’s finances and appointments during the hospitalization. The hospitalization also added stress to the caregivers’ routines, as they continued to carry on their multiple responsibilities during the hospitalization. One caregiver described her busy routine, involving work and visiting her husband in the hospital:

*Yes, because I had to do cross-guard. I get up early in the morning. This was my routine before he went in the hospital. I get up in the morning, take my shower. I take about maybe about half an hour to have a coffee and then I get up. I like to do all my dishes up, and I mean my coffee cups. That’s just the way I am. I like to make my bed before I go out and then I go out and do my duty time and I’d come home and I would go up to the hospital and see him. I went up there almost everyday [...]it was very tiring, you know? (CG9)*

The above quote further underscores the multiple responsibilities that caregivers face during the older person’s hospitalization. The caregivers felt that they needed to continue

with their other responsibilities, such as childcare, as they found them essential.

Nonetheless, the caregivers also had to care for the acutely ill older person. This finding further highlights why caregivers were stressed and overwhelmed while the older person was in the hospital. One caregiver indicated that she had multiple responsibilities at work and at home, including her pet requiring urgent surgery at the same time as her mother's hospitalization. This caregiver stated: "*Yeah the cat had to have surgery and I had to medicate him*" (CG3). This caregiver also described the difficulty she experienced managing these responsibilities and said "*It's been hard for me to come work and come and drive here [hospital], park and walk in, and go back [home] trying to keep my family going*" (CG3). This quote illustrates the toll caregivers experienced from the sheer amount of essential responsibilities, which included caregiving, work, and other familial duties. Furthermore, caregivers needed to travel to the hospital from other settings, such as home and work, and depending on the distance, this extra effort added further stress to the caregiver.

Some caregivers also described strategies they used to cope with feeling overwhelmed by their responsibilities. One caregiver talked about finding support through her mother's hired formal caregiver, who was knowledgeable about dementia, and said "*Oh it's—it's really, it is tough. I'm so lucky I have a caregiver who understands what she's going through. It helps me to cope with the changes in my mom, helps me to understand*" (CG2).

## **Theme Two: Caregivers Were Concerned about the Quality of Care That the Older Person Received**

Caregivers expressed concerns about the quality of the care that the older person received, specifically in relation to restraint use and frequent transitions between and within units. Nonetheless, the findings indicate that many caregivers still had difficulty giving suggestions on how care could be improved within the hospitals. This theme is further discussed in the following sub-themes: (a) caregivers were distressed that the health care team used chemical and physical restraints to manage DSD, (b) caregivers felt that frequent and poorly executed transitions exacerbated delirium and dementia in the older person, and (c) caregivers were not hopeful that the quality of care could be improved.

### ***Caregivers Were Distressed that the Health Care Team Used Chemical and Physical Restraints to Manage DSD: “Sometimes They Restrain Him, so He Doesn’t Harm Himself, so He’s Not Going to Fall”***

Caregivers reported feeling distressed that the health care team often used chemical and physical restraints to manage risks and challenging behaviours related to DSD, such as falls and exit-seeking, rather than other more non-invasive strategies. This distress was often associated with seeing the older person feeling upset by the use of restraints. One caregiver mentioned that physical restraints, such as trays on chairs, were used for her husband, which he disliked: *“Sometimes they restrain him so he doesn’t harm himself, so he’s not going to fall [...] He doesn’t like to be confined, tray up right against him”* (CG4).

Another caregiver relayed a similar experience with his mother, describing how she was restrained to prevent her from falling and leaving the hospital:

*And then she's trying to climb out of bed. She wanted to go home. "I want to go home, I want to go home. Here help me. Get me up. Let me go home." Always grabbing and trying to pull herself, so they had to restrain her. (CG5)*

One caregiver recalled a very upsetting episode when her father was in a transitional unit between the emergency room and medical unit. Her father began demonstrating exit-seeking behaviours and was both physically and chemically restrained:

*So they had to call security and the two security guys wrestled him back to his bed and they had to tie him down. And he was so agitated and yelling that they had, the night nurse said "I think we're going to see if we could give him a shot of lorazepam, just to calm him down" and they did call my sister, she is the power of attorney for his health and she said 'you do what you have to do.' Then they called her back and said 'maybe you should come.' So she came back to the hospital at midnight and he still wasn't settling and they gave him another shot. (CG1)*

Seeing the older person restrained caused great distress in the caregivers. One caregiver indicated that it was very hurtful to see her husband in restraints, treated like a "prisoner" and said *"It hurts to see, I mean, you don't want to see anybody tied down, you feel like they're a prisoner"* (CG9).

While caregivers were distressed by seeing the older person restrained, they deemed restraints as necessary to keep the older person safe. For example, when probed on how the staff could have managed her husband's delirium without restraint use, one caregiver stated that while she was unhappy her husband had to be physically restrained, she believed it was essential: *"It hurt, but I would sooner see him tied down than end up, what he did, and broke his hip the second time"* (CG9). Another caregiver stated:



*Yeah, how do you manage the delirium, I mean? They did the best they could. I mean, when she got a little bit feisty and she tried to get out of bed, they restrained her. Like what else can you do? Because if you don't, they could hurt themselves, you know? If she climbs out of the chair and falls over. (CG5)*

When asked what the health care team could have done other than using restraints, caregivers could not identify alternatives, but instead defended the health care team and emphasized that they did what they had to do for safety reasons:

*You know, the nurses and the nurses in the [Transitional Unit], when they had to administer Lorazepam, they didn't do it just automatically. They had, I'm sure they had to get the okay from the doctor and the dosage, number one. Number two, they made a phone call to my sister and expressed—explained to her what was happening. [...] So, in that regard, I mean they were very clear, to prevent him from falling out of the bed or from running out on the street, not knowing where he was, for his safety. I think that they did what they had to do and in hindsight, when you're having to deal with someone who's psychotic, I guess you could call it that, because he was, you know? They handled it in the manner that he wouldn't hurt himself. That was paramount that they were taking care of the patient. (CG1)*

The above quote suggests that the caregiver believed that the restraints were necessary for the older person's safety and that staff did not have other options to use.

It is clear that restraint use was distressing for both caregivers and the older persons. However, it was not clear whether the health care team considered less invasive alternatives to restraints or considered the benefits and risks of the restraints versus the risk of falls and exit-seeking. One caregiver relayed how upset she was when a health care team member called security to restrain her husband, and wondered if de-escalation approaches might have resulted in a better outcome:

*I'm really embarrassed. I'm sad for him that this is happening and you're going to document it, because really this is not the kind of person that he is, but if you would have dealt with it differently to de-escalate the situation, it might have turned out differently (CG9)*

***Caregivers Felt that Frequent and Poorly Executed Transitions Exacerbated Delirium and Dementia in the Older Person: “They Moved Her in The Night, Which Was Very Upsetting for Her”***

This sub-theme describes how frequent transitions between units exacerbated symptoms of delirium and dementia in the older person. These transitions included transitions from one unit in the hospital to another, as well as transitions within hospital units (e.g., moving patients from their own rooms to a hallway location near the nursing station). Bed flow is a priority in acute care, particularly in the study setting, where it was common to have high occupancy rates in emergency rooms. In order to create additional space in the emergency rooms and ensure efficiency in bed flow, there is often a push to transfer patients from the emergency rooms to the inpatient units, leading to frequent transitions between units for older persons. Transitions also occurred as the older persons were often transferred in and out of units for medical tests. Thus, older persons experienced frequent transitions to make efficient use of hospital beds, with limited consideration of the impact of these transitions on the quality of care of older persons with DSD. For example, caregivers reported that older persons were often moved in the middle of the night to create space in the emergency department or placed in patient lounges or hallways due to lack of beds. These practices were distressing not only to the caregivers but also to the older person, who may be sensitive to sleep disruption and lack of rest that may stem from having to occupy a patient lounge instead of a quiet room. Caregivers in turn, were distressed by seeing how the environmental changes disrupted the older person’s comfort. One caregiver suggested that the sudden change in

environment, along with frequent medical assessments may have contributed to the worsening of her father's DSD symptoms:

*Yeah. Perhaps, it was an amalgamation of all the noise, the pinpricks, and the fact that he was moved again. All of that culminated into that experience for him, that again, when he woke up and he didn't know where he was. (CG1)*

In another example, a caregiver described how her mother was transferred from the emergency room to the medical unit in the middle of the night. While it was necessary to transfer her mother from the ER to a medical unit, the transfer disoriented and upset her mother, which in turn caused great distress for the caregiver:

*When —she was in the ER for overnight and the next day and they kept saying that they were going to move her. I was there the whole day. They didn't move her. I had to go home and they moved her in the night, which was very upsetting for her. She was really disoriented. She was put up on the ward, which is a good thing. But she really felt that —I would lose her, that I wouldn't be able to find her. She was terrified. When I came in the next morning, she was literally in tears. She said "I'm so happy to see you. I never thought you'd find me,—" [voice begins to break and caregiver holds back tears]. It's not a fun thing. (CG2)*

Although transferring patients across the busy hospital in the night distressed older persons with DSD and their caregivers, the practice continued. In fact, the lack of beds in the hospital meant that older persons had to occupy spaces, such as stretchers and hallways, which may contribute to the worsening of their cognitive status. Another caregiver stated that her mother was initially placed in a tight cubicle in the emergency room. When the older person was sent for a test, she lost the cubicle due to another patient admission and thus was placed in front of the nursing station in the middle of a busy hallway. This incident caused distress for both the older person and the caregiver. The caregiver observed that this was practice was contrary to what she read about the

management of delirium. The caregiver implied that placing her mother in that hallway could have exacerbated her mother's delirium:

*Well in the ER, it was very traumatic for both of us, because she was first of all in a cubicle with a curtain and then she had to go get a test, perhaps it was a CAT scan. And when we came back, there was no room available. They put her right in front of the nurses' station in a busy hall corridor with bright lights which is the total opposite of what this brochure mentioned you should do for someone with delirium. You should keep them in a quiet, darker place, like not have so many stresses of people walking about so I found that very uncomfortable for both of us really. So, that was difficult. (CG3)*

One caregiver reported how several older persons were placed within the team's watchful eye at the nursing station to prevent exit-seeking, instead of providing a quiet environment without sensory overload for the older person and other patients in the unit. This practice distressed the caregiver, who worried that the older person's cognitive status might worsen:

*So far, like you talk about the hospital atmosphere, especially for people if they have this type of diagnosis, it's just not—what would you do with all these people? I know everyone feels that their loved one needs attention. But if you got somebody that's beside you, "Well, I want my tray. Well, I want my tray" and you have somebody that's quiet and like, I don't mean—you can't just segregate them I guess? Like they're all sitting there in front of that [nursing station]. And just, I think, somebody that's not too bad, they're sitting there, they'll get worse. But what could you do? (CG4)*

This example notes that while this practice was done for safety reasons, it could worsen the older person's cognitive status due to overstimulation (e.g., disruptive behaviours of other patients, noise from the hallway).

As demonstrated in the above quote, caregivers observed that the physical environment was not conducive to older persons with DSD, as tight spaces, bright lights, and loud noises may worsen their symptoms. Few modifications were made to the older

person's physical environment to reduce exacerbation of symptoms from DSD. One caregiver discussed how the noise from the nursing station affected her father. She felt that her father's room was not conducive to his cognitive status, due to the noise coming from the nearby nursing station:

*And it was noisy, because he was outside of the nursing desk. So that was not a good experience. If I have to say anything about how this might be better, possibly semi-private, which I know is not always possible. Possibly, not across from the nurses' desk, where there's a lot of commotion and talk, and changeover of shifts and people have to talk. I can understand that, but because he was in this altered state, he didn't understand it. So maybe if the dementia was recognized right away or taken into account, perhaps he could have been in a quieter space in that ward. (CG1)*

One caregiver stated that her husband's mental status improved after he was transitioned to another unit that had more space, which further demonstrates the impact of the hospital environment on the older person's health and the caregiver's experience:

*And now it's a more open area so he's got more room to move around and now we can go downstairs on a wheelchair, go to the hallway. So, it's an area almost everyday, twice we go downstairs or three times to the spiritual centre or just to the front hallway, walk down to the basement and now he's getting stronger and I think his mind it's getting a little bit better. (CG7)*

Caregivers also experienced poor and fragmented communication when the older person was transferred between units. For example, an older person's discharge plan had to be restarted after he moved to a new unit although most of the care had already been set up for the person's discharge home. Moreover, no one had informed the caregiver about the transfer beforehand:

*And the social worker called me in the morning and said "Oh did anybody tell you that your husband was transferred?" I said no. She said "Oh, we should have." And then so there's a whole new set of people again. Different social worker, there was a different doctor again— different charge nurse, different OT, different PT. A whole new set of more people again, sitting down again, discussing how*

*many hours [of home care] we are gonna get [when he goes home], and that kind of thing. (CG4)*

No explanation was given to the caregiver on why the discharge planning process had to be repeated when the older person was transferred. Further fragmented communication was revealed when the caregiver received a call from a care worker from the community home care organization, who had not been informed about the older person's delayed discharge:

*Yeah, but I don't know for sure, like I know when—they [home care] used to do that in the morning too. Like if they were coming at eight o'clock, you would get a call at quarter to eight saying they're on their way and they're coming, okay. But we're not even home,— I don't know. The system is so, so fractured. It's just, and it's so many pieces. You wonder why there's no money, because too many hands. (CG4)*

The above quotes suggest that poor communication during the care transition can create additional stress for caregivers. There also can be a lack of coordination and communication of care post-hospital discharge. One caregiver relayed how she did not receive all the important information about her husband's care when he went home, such as his incontinence or medications:

*And then what they did, the coordinator and all of them on the phone there, the speakerphone, like I said, "Oh we got somebody coming in" and I said "Oh fantastic. Thank you very kindly" and they said "No problem and we're sending him home tomorrow" and—the only thing they suggested was a—wheelchair taxi, because he wasn't able to get in the car. So, that was the only thing they suggested. They never told me he was incontinent. They never told me about the medications. We did get the prescription from the doctor, but then they, my son went over and got the medication, but it wasn't all the medication he was supposed to get so I had to look after that, run over. (CG9)*

***Caregivers Were Not Hopeful that the Quality of Care Could Be Improved: “I Don’t Know If They Could Have Done Anything Different or Helped”***

Despite the negative emotions they experienced, the lack of information they received, and their concerns about the older person’s care, caregivers struggled to identify ways that the care could be improved. Findings suggest that caregivers were not hopeful that the care could be improved due to resource constraints within the acute care setting. These caregivers discussed how health care team members were often busy and lacked time. For example, when asked how the health care team could have further involved her in her mother’s care, one caregiver stated;

*Yes, I mean it’s hard to say what they could have done for me or offered me advice, but I suppose I’m asking for things that’s not possible because I know they’re strapped for time, resources. (CG3)*

Another caregiver indicated that she did not know what else the health care team could have done to improve her experience at the hospital and said “*I don’t know what they would have done. They are very busy people*” (CG7). One caregiver also emphasized that there were other patients that the team had to look after and said “*Yeah, as there are times when you feel things are moving too slowly. But you also have to understand that you’re not the only patient in the hospital*” (CG2). In another example, a caregiver described how her request for more staff would only be possible in a “utopian world” with more resources:

*Oh gosh, in a utopian world, more staff. [Laughs] You know the usual stuff and really what can you say in that context? Um, you know, I bet you everybody had more staff. I bet you, you know if they—people get sick, staff is short, short-staffed. They’re trying to cope. (CG2)*

The above quote shows the caregiver's awareness of how resource constraints affected the quality of care. The caregiver's awareness of limited resources did not make her hopeful that quality of care could further improve.

Caregivers also affirmed that they hoped to see the nurses more often, but stated that it would be "*impossible*" (CG5) and that "*You would have to talk to the government about that*" (CG6) to improve staffing within acute care. Another caregiver also stated that the nurses did their best within the limitations of the acute care environment and that "*I had nothing against the nurses, they did their best. They gave us as much information as they could. They're not doctors, but they did what they could*" (CG9). Another caregiver further emphasized the lack of resources and the multiple responsibilities held by the team:

*"Like I know that there's not much that you can do. There are too many people to look after. You know everybody's busy with their jobs. They're doing more than their regular job, right? They're doing plus, plus"* (CG8).

These findings indicate that caregivers were not hopeful that the quality of care received by the older person could improve due to limited resources within the hospital, such as staffing and time.

### **Theme Three: Caregivers' Experiences Were Influenced by the Nature of Their Relationship with the Health Care Team**

Caregivers' experiences were influenced by the nature of their relationships with the health care team. The quality of their relationships was influenced by the caregivers' perception of the quality of communication with the health care team, the extent to which they were acknowledged by the team members, and the perceived power hierarchy



between the caregivers and the health care team. The following sub-themes elaborate on these findings: (a) caregivers' experiences were influenced by the quality of communication with the health care team, (b) caregivers wanted to feel acknowledged, valued, and respected by the health care team, and (c) caregivers felt disempowered in their relationships with the health care team.

***Caregivers' Experiences Were Influenced by The Quality of Communication with the Health Care Team: "They Spend the Time with Me and Try to Explain Everything. So, It's Been Good. It's a Good Experience"***

Caregivers' perception of the quality of their communication with the health care team had an influence on their experiences. Clear, consistent, and empathetic communication had a positive impact on caregivers' experiences and their relationships with the health care team, and left caregivers feeling supported. For instance, one caregiver appreciated how team members reacted to her mother's yelling, '*But they were very, come to think of it, they were very "Don't worry. It's okay. We know. We understand she's got dementia, but she's all right now. She's all right now. Okay?" It was calming*' (CG2). The caregiver felt calmed as a result of the health care team member's empathetic communication. This example demonstrates that when health care team members demonstrated understanding of the older person's dementia, they felt supported. Another caregiver stated that she appreciated it when the health care team member presented information to her in a way that did not blame her husband for his behaviours. In contrast, caregivers felt additional stress when health care team members

communicated in a manner suggesting that the older person was a “bother to them” (CG4) as relayed on the following example:

*You know what I don't like to hear. Nobody likes to hear anything negative. I think there's a way of presenting the information like if I hear—like I'm always worried about did he sleep during the night? Was he trying to get out of the bed? The way some of them present what happened during the night [...] Some of them, just the way they tell you, they just have a way of telling you of what went on, without you feeling upset about it [...] like even just the tone of voice [...] It's just the way they present the information. It doesn't make you feel like you own it. It's your fault. It's his fault” (CG4).*

Caregivers also felt supported when health care team members took the time to explain the situation to them or answer their questions. One caregiver indicated that she felt reassured when a physician took the time to explain her husband's medications, “*He took a lot of time to speak to us and he assured me*” (CG4). Another caregiver expressed his appreciation when team members took the time to respond to his questions, which had a positive impact on his experience, stating “*Anytime I ask them a question, they're more than happy to answer. They spend the time with me and try to explain everything. So, it's been good. It's a good experience*” (CG5). His wife corroborated the statement, and said that the health care team's responsiveness to their questions made them comfortable and that they felt more confident about the older person's care, “*and it made us feel comfortable, at least a little bit more assured that she was being cared for properly*” (CG6).

There were instances when the health care team member did not take the time to speak to the caregivers due to the pace and resource constraints in acute care. However, one caregiver explained that she still felt supported even when health care team members

were busy and could not respond immediately, as long as they felt heard and were given a sense of when they could expect a response:

*Like the ER nurse, when I kept going back and I said “Have you heard from the doctor? Have you heard from the doctor?” and the one ER nurse said to me “I’ve got two more things I have to do then I will look after that. I promise I will be back with you.” I said “That’s all I need to hear” and I went in the room. I think that’s calming, a calming activity. It gives you a sense of “You’ve heard me” and you will respond to me,” and she did. (CG2)*

Additionally, health care team members made a positive impact on the caregivers’ experience by showing concern for their feelings. This finding is demonstrated in the following example:

*They will just ask me if I need anything to just let them know if I need anything or if I need to go down for a coffee break or something or for lunch or something, just let them know and then to take time for myself and take care of myself, because if I get sick, who’s going to take care of him, so people, many times they were concerned or sometimes I was crying and they said “His sickness, don’t take it personally”, and “How are you feeling?” Some of the nurses, they give me hugs and then they said “Just hang in there. Things are gonna get better.” (CG7)*

In contrast, caregivers felt distressed when they experienced poor communication from the health care team. For example, a caregiver complained to the manager, as a nurse did not change her husband’s soiled briefs. This led to a confrontation between the nurse and the caregiver, who expressed concerns regarding her husband’s care:

*Well, he must have been [went through tests and wasn’t changed], because she didn’t change him when he went and had his tests and stuff done. And then—she had attitude. she said in front of my son and myself “Well, I was told not to change him.” What I said was “He’s sleeping right now. Don’t wake him to do that.” Because as I said, he’s difficult to wake. And he’s better if you just leave him. But she could have [changed him] at some point when he came back and yet she didn’t. [...] she should understand that I’m looking for the best care possible. She could have said to me “You know, I’m really sorry. Oh I’m sorry that you were concerned that he wasn’t changed.” And they don’t want him to end up with something else too, because he wasn’t changed or whatever right? (CG4)*

Another caregiver provided an example of poor communication with a nurse, prefacing her example with the statement “*I don’t understand some nurses, how they become nurses. When you become a nurse, you really got to have a lot of compassion—to the patients, right?*” (CG9). The caregiver relayed that some nurses communicate in a manner that indicated that they did not have time to talk to the older person or caregiver. This caregiver also talked about a time when a nurse, frustrated with her husband’s repeated attempts to take out his saline lock, curtly asked the caregiver to tell her husband to stop the behaviour:

*Like they don’t seem to have the time or maybe they don’t have the time. I’ve seen some nurses that go in there that would talk to [husband], even talk to me, they seem to take the time to do it. And yet you see other nurses, especially the one who said “Ask your husband about why he’s keeping the intravenous out?” Like I could tell that she was [frustrated], how she became a nurse, I don’t know. But because becoming a nurse, I think you really—now and I heard somebody else say this, but it’s all for the money one. They don’t, seem to, some don’t care [...] Like she was just in and out. “Ask your husband not to take the thing out!” And then the way she went out, like you know “You talk to him! [...] Like it—like why ask me? You’re the nurse. You take care of him. (CG9)*

Poor communication, stemming from a lack of updates regarding the older person’s health status, also had an impact on the caregivers’ experience. Many caregivers reported challenges in getting updates regarding the older persons’ medical diagnoses and plan of care. In the current hospital setting, physicians often conducted morning rounds on their patients, with one resident on-call after hours. Many of the caregivers held other responsibilities (e.g., work) and had to visit after working hours when only the on-call resident was available. Caregivers found it difficult to reach the resident to get updates as they were often attending to other patients. A working caregiver relayed, “*I was never*

*able to speak to them [physicians] directly, because I would come after hours” (CG3).*

However, it was also difficult to speak to the medical team even during regular working hours. One caregiver, who often visited her mother-in-law in the day stated “*Yeah, we would come and wait and be there for three hours, and the doctor never showed up. We had to leave” (CG6).*

Even when caregivers arrived in time for rounds, the physician was not always present due to emergencies or other activities. One caregiver described her frustration in trying to communicate with a resident from the emergency room about her mother’s status.

*I said “What time should I come in to talk to the doctor and she said “Well, they start their rounds at seven” and I said “Fine, I’ll be there at seven” so that I can see the doctor. Well I did not see the doctor the whole day and I said to the nurse at least three or four times to the point where I was saying “I’m sorry to be a pest about this, but I really do want to talk to the doctor.” I didn’t see him the whole day I was there. The nurse in ER said to me “I’ve called him. He knows you’re here. I didn’t see him, didn’t see him, which kinda ticked me off [...] Yeah, in the ER and he did apologize. And he said “We were so busy that day” and I understand that, but yeah, you can see they’re busy. It’s not like these people were just idling around (CG2)*

Caregivers explained that they not only had challenges in obtaining updates in relation to the older person’s health status, but also in getting information about the plan of care from the interdisciplinary team. This caregiver described:

*But I didn’t get answers. Because all I kept getting was “One day at a time. We don’t know.” [...] All I got was “One day at a time.” I said “Well, what’s the plan? What’s going on?” “Well, we don’t know.” And that’s all I got over the many months he was in there. (CG9)*

Despite these barriers, some caregivers were successful in obtaining an update on the older person’s status. As one caregiver stated “*Well, I think anytime you’re in the*

*hospital, you have to be proactive about asking for information. I mean the staff are busy” (CG2). Another caregiver described how he obtained information from the nurses because they were often busy at rounds or with other patients: “Because sometimes they’re not there. They’re on their rounds or they’re seeing other patients. Like if I see them at the nurses’ station, I flag them down and ask them” (CG5). These findings indicate that caregivers experienced many barriers to effective communication with the health care team. Thus, they often accepted that they had to take the initiative to find the information they required themselves.*

Caregivers also experienced fragmented communication as the older person was moved between units and received care from differing health care team members. One caregiver discussed difficulty getting accurate information about her mother’s condition from the nurses. This caregiver stated that her mother had *“A different nurse everyday. That was hard, because I couldn’t follow through with something” (CG3). Not only was it challenging for the caregiver to follow through with requests, she was also unsure about the information she was receiving about her mother’s health:*

*Well, they initially hydrated her IV and I mean they did all the tests they could. I found on maybe day two, the one nurse said she had low phosphate and I wasn’t sure what that meant. She was giving her a special drink and then the next day the next nurse said she had low potassium. So, I wasn’t sure if those were two different issues or the one had said the wrong name. (CG3)*

### ***Caregivers Wanted to Feel Acknowledged, Valued, and Respected by the Health Care***

#### ***Team: “We’re Kind of Invisible”***

Caregivers wanted to be acknowledged, valued, and respected by the health care team. Caregivers felt reassured and gained trust in health care team members who

acknowledged and addressed their concerns. For example, caregivers felt supported when health care team members were readily available to support them in caring activities, as one caregiver stated: *“And every time I said “Can I get some help with my mother?” They always come. So, it’s really good”* (CG2). By acknowledging and responding to the caregivers’ concerns, health care team members built positive relationships with caregivers. Health care team members thus demonstrated that they valued the caregivers’ feelings and the quality of the older person’s care: *“She does care how I’m feeling about his care and about what they’re doing for him”* (CG4).

Another caregiver provided an example of a positive relationship with the health care team. In this example, the team responded to the caregiver’s request by assisting the caregiver in bringing her mother to a dental appointment:

*Like the other day I took her to get her dentures, I needed a list of her medications and I went there and she had all like “Yup. Okay. No problem. Printed them right off.” Both of them and then I had to go down and get my car and I’m like where can I leave my mom, because I can’t park. There’s no parking around there. I had to walk to get my van to bring it around the front for her. And I’m like where and they’re like “Oh we’ll bring her down for you. There’s no problem.” So you know it was like yes! Because I couldn’t leave her anywhere when I went to get my car. (CG8)*

The caregiver recalled that the attention the team provided to her and her mother made her feel valued and said *“That she’s important. You know and that they respect me enough to be able to have everything that I need”* (CG8). The finding illustrates that caregivers want to be valued and respected by the health care team. Positive relationships built from mutual acknowledgement and respect between health care team members and caregivers increased the caregivers’ trust in the team. The positive relationship also made caregivers feel supported during the hospitalization.

In contrast, caregivers experienced additional stress when their concerns were not acknowledged by the health care team. For example, one caregiver reported that when she told the social worker that she was upset at restraints being used for her husband, “*She asked if I needed—if I wanted to see somebody, for counselling, [I] said no*” (CG4). This example suggests that the health care team member had not listened to the root of the caregiver’s concern and had immediately offered counselling. When team members did not respond to caregiver’s concerns, they felt that they were not doing their job, as a caregiver stated ““*Yeah, it makes you feel like to me, like they’re not doing their job, like you know*” (CG9). In another example, a participant who had experienced a lack of acknowledgment from some health care team members expressed doubts about the quality of her husband’s care:

*Sometimes I come in and I’ve seen both basins, one on top of the other like they were left and I wonder if they really were, if he really was like washed enough? I question that. (CG4)*

Lack of acknowledgement for the caregivers’ role made caregivers feel invisible and contributed to poor relationships with the health care team. For example, one of the caregivers, who balanced caregiving with work and family responsibilities, reported that only one health care team member had recognized her efforts and stated that caregivers were largely invisible to the team:

*I know the lady [health care team member] yesterday said I was doing a good job, giving me a bit of positive feedback, but nobody really, I don’t think they care about the caregiver kind of thing! There’s too much going on in the ward to worry about other family members, they’re strictly concerned about the patient, but that’s why it’s stressful for caregivers as well as the patient, because we’re kind of under looked. Like we’re not, we’re kind of invisible. Well, I just meant that if they want you to do something, they might say it, but usually it’s— their job is to help the patient. They’re not really concerned if the family comes, but I think they do,*



*maybe one time they said “It’s good that you’re here. Keep doing what you’re doing to help her get out of the hospital. (CG3)*

The above quote suggests that caregivers were often overlooked by health care team members. Nonetheless, providing some acknowledgment to the caregiver, even just words of encouragement, had a positive impact. The caregiver later mentioned that the encouragement from the team had a positive impact on her, stating *“So, the little tiny encouragement the ladies gave me yesterday that was nice, it gave me a boost” (CG3).*

In contrast, one caregiver described the lack of simple acknowledgement of her presence at the nursing station:

*Oh right the nursing station and you want to ask a question or something and like then they’re right there and you’re standing here and they’re talking to each other. And you understand, sometimes maybe they’re documenting and they need a few minutes before they look at you. But I’ve seen where they don’t sort of acknowledge you and somebody from the back will come and say “Oh, can I help you or something?” You know like they don’t even make eye contact with you sometimes. They’re all busy. I know that, but even just to say “I’ll be with you in one second.” (CG4)*

The results suggest that many caregivers may feel invisible, overlooked and unacknowledged by the health care team. This experience can create feelings of disempowerment among caregivers, as further described in the next sub-theme.

#### ***Caregivers Felt Disempowered in Their Relationships with the Health Care Team:***

##### ***“You Don’t Want to Get Kicked Out!”***

This subtheme describes how many caregivers felt disempowered in their relationships with the health care team. These feelings of disempowerment could be related to the fact that caregivers were not always given the opportunity to engage in the care of the older person. For instance, the findings suggest that some caregivers felt like

outsiders and were quite conscious of disrupting health care team members when they were caring for the older person. In one example, a caregiver relayed why she did not try to help the team assist her father in the shower, *“You don’t want to be in the way. Plus, they have a way of getting people in and out of the shower that’s safe. You don’t want to try to be helpful. [Laughs] And do it wrong”* (CG1).

In another example, one caregiver expressed how she was conscious about not asking too much from the staff and stated *“I didn’t feel like you know I was out of line or I wasn’t, you know, I was asking too much or anything like that”* (CG2). Another caregiver spoke almost apologetically about disrupting the team by visiting twice daily: *“Well, just they like didn’t mind us being there, because we were there twice a day. You know? [...] We were probably in the way, a lot of times.”* (CG6).

In fact, some caregivers discussed the possibility about being “kicked out” of the hospital if they were disruptive and thus were careful about what they said to team members. One caregiver stated, *“You don’t want to get kicked out! You’re gonna get kicked out. Screaming is gonna get you kicked out. So, you have to be kind. You got to be careful of what you’re saying to people”* (CG9). Another caregiver’s comment similarly reflected a concern about being ‘kicked out’ and the team’s appreciation for care they would otherwise have to provide: *“I mean, they were accommodating to us. I mean they didn’t kick us out and stuff—They appreciated us being there”* (CG6). These examples suggest that the acute care setting was not considered a space that facilitated partnerships in care provision by caregivers and healthcare team members, which can lead to caregivers feeling disempowered.

Caregivers were at times reluctant to speak up on behalf of the older person because of the perceived power imbalance they experienced in relation to the health care team. For example, one caregiver was hesitant to criticize the team member coordinating her mother's community care, even though he did not consider her mother's dementia during his interaction with her:

*And he [said], here's the information on heart failure and stuff like that and he wanted— he kept saying "Oh your mother will read it and everything". She can't read it. She can't comprehend stuff anymore and I kinda felt that he didn't get that she has dementia. It's not like she is going to go home and take care of herself now. So I don't think he really understood what her particular situation was. [...] No, I didn't say that to him and he was very nice, mind you. I don't want to be critical or judgmental. I just felt that he wasn't really getting the scope of what her dementia is. (CG2)*

As this caregiver said, she believed the team did their best, even though her statement suggested that she was not entirely confident that the team was always aware that her mother had DSD. This finding further demonstrates that caregivers were at times reluctant to speak up on behalf the older person and did not perceive themselves as true partners in the care of the older person. The finding indicates that the caregiver appeared to believe that the health care team knew "what was best" for her mother, suggesting that the caregiver may devalue her own knowledge about the older person:

*I think they did what they could as far as I know to help her, you know as best as I thought. I'm hoping that they knew that she had all the symptoms of delirium. I'm sure it was in her notes, so they would be the best to know how to help her, I guess. (CG3)*

Some caregivers appeared to believe that their relationship with the health care team would impact the quality of care received by the older person. This points to caregivers' perceived power imbalance between themselves and the health care team, as caregivers

may believe that the health care team had ultimate control over the older person's care. Subsequently, caregivers believed that the quality of their relationship with the team could affect the older person's care. Therefore, caregivers endeavoured to build good relationships with the team by interacting with them in a friendly manner. For example, one caregiver talked about how she tried to be pleasant with the nurses "*And the nurses, I think as my mom always says have fun with people and they'll have fun with you*" (CG2). Another caregiver stated that it was important to get along with the team, implying that the quality of their relationship could affect her spouse's care:

*I think it's your attitude towards them [health care team] too right? If they asked you to do something, you got to do it. Like you know, you just can't say "I'm not going to go and do it." I think you try to get along with them. Sometimes it doesn't work. Sometimes it does work [...] You don't wanna be...snapping at them or anything like that. You try to you know, "Good morning." You try to have a good attitude towards them. You know what I mean? You go in and "Hi. How are you today?" And they'll ask you how you're doing. Some do. Some don't. [...] You have to a—you don't go in and be a—the nurses, you know that, you don't go in there and "You're not doing that right there." You have to kind of get along with them. You know what I mean? You're trying to get along. (CG9)*

In another instance, a caregiver relayed her hesitancy in criticizing the team during the research interview for fear that this could have a negative impact on the older person's care. This example further illustrates the caregivers' feelings of lack of power in relation to the team, as she was worried that criticism could negatively impact her mother's care. The interviewer was careful to remind caregivers that the information that they shared would remain confidential and would not be shared with the health care team.

#### **Theme Four: Caregivers Can Play an Important Role in the Detection and Management of DSD**

Despite caregivers' perception that they were not engaged as true partners in the care of the older person, they made important contributions to the detection and management of DSD. This finding is illustrated in the following sub-themes: (a) caregivers can be instrumental in helping to identify changes in cognition or health status, (b) caregivers actively participated in strategies to manage symptoms of DSD, and (c) caregivers assisted the health care team in the care of the older person and advocated for them.

##### ***Caregivers Can be Instrumental in Helping to Identify Changes in Cognition or Health Status: "Oh She Wasn't Her Normal Self. She Was Seeing Things, You Know People"***

The caregivers' knowledge of the older persons' normal (baseline) cognitive status was helpful in detecting subtle cognitive and acute changes in the older person, such as delirium. Delirium is difficult to detect, particularly in older people with dementia, as many of the cognitive symptoms overlap. The caregivers' knowledge of the older persons' baseline cognitive status often resulted in the older person obtaining necessary care in the hospital as demonstrated in the following example:

*She was not in a lucid state. She was confused and the windows were—the blinds were down in her room. She was disoriented. She said her head hurt, she felt dizzy. So I determined— that her care at the moment, she wasn't at her right mind and she needed the hospital care to look at her. So that's when I made the decision to phone the ambulance. (CG3)*

This finding suggests that caregivers were instrumental in helping identify changes in the older persons' cognition or behaviour that deviated from the older person's norm. One

caregiver observed her mother was sleeping more, a possible sign of hypoactive delirium: *“Well the week prior, she seemed to be sleeping a lot more”* (CG3). This finding is important as signs of hypoactive delirium, such as increased lethargy or lack of motivation, are more difficult to observe in older PLWD, thus highlighting the role caregivers can play in delirium detection.

Another example of the caregivers’ role in delirium detection was a caregiver who appeared to intuitively know that something was different about her mother. This caregiver knew there was a concern, even though she did not know what it meant: *“Well yeah I knew something was going on with her. There was something yeah”* (CG8).

Another caregiver recalled that she noticed that her mother was becoming more disoriented to place although she did not initially attribute it to delirium:

*Yup. She usually remembers, but this, you know, kinda last month or so, she’s been having, when I think back, she’s been having more and more kind of disassociation of where she is.* (CG2)

In another example, one caregiver described how her husband talked about meeting a man who had previously died. This example highlights the caregivers’ ability to detect cognitive changes in the older person:

*Oh well, when I would go in and visited him, he seemed to be, there would be days when he recognized you, but there’d be days that he would be, say out to lunch, not there. And I know when my daughter went in to see him, he talked about [Son-in-law], my son-in-law. “This useless son of a gun!” I said “[Son-in-law Name] passed a few years ago.” And “Oh! Is that right?” I said “Yeah” and then he would talk about things, you know, years and years ago when he was a youngster and things like that.* (CG 9)

The findings suggest that caregivers are also able to detect other acute medical changes in the older person. The caregivers’ observation often led to seeking medical attention for

the older person. For example, one caregiver observed new symptoms in her husband:

*“He experienced some dizziness and his feet were swollen and that’s why he came to the hospital”* (CG7). This caregiver mentioned the symptoms to her health care provider, who advised her to bring her husband to the hospital. In another example, a caregiver observed a sudden change in his mother’s mobility, and they sought help later on after his mother’s cognitive symptoms worsened. He stated: *“And she’s always been strong. Like she never had to use a walker. Always strong on her feet. So, I find it kind of weird that she was so [weak]”* (CG5).

***Caregivers Actively Participated in Strategies to Manage Symptoms of DSD: “I Brought Family Photos, A Blanket, Some Favourite Food and Some Magazines Just to Help Her Try to Gain Back Some of Her Normality”***

Caregivers actively participated in strategies to manage the DSD. These strategies included: (a) engaging the older person in recreational activities and exercise, (b) encouraging the older person to eat, and (c) using their knowledge of the older person to support their care. To begin, caregivers tried to improve the older person’s memory in the hospital by engaging the person in cognitively stimulating recreational activities. For example, one caregiver brought photo albums to show his mother, saying *“We brought photo albums to show her if maybe that would help her kind of jog her memory”* (CG5). Another caregiver brought photos and magazines to help her mother begin to remember her life prior to her hospitalization:

*And then I mentioned that I brought family photos, a blanket, some favourite food and some magazines just to help her try to gain back some of her normality and what she remembered, what life was like before she got a bit delirious.* (CG3)

One caregiver used engaging and interactive activities to keep her husband cognitively stimulated:

*So, I kept him company to have some interaction, because otherwise, I know the nurses are very busy and would not have time to just sit with him to keep him company or talking so this way he wasn't alone, he wasn't bored. Because—nothing else was in there, just the four walls that was there for him. There wasn't any TV, no music, or nothing in there. Here in this floor, we have some music in there too, so he was listening to the music, and his own music and then he was happy. He was singing along so just I kept him more, I was entertaining him and then supporting him and then—entertaining him—maybe that's the wrong word—I just kept him company and then give a little bit for his mind to work. (CG7)*

Caregivers often knew which activities the older persons preferred due to their intimate knowledge of the older person. In the above passage, the caregiver hinted at how the lack of recreational activities in the hospital could negatively impact her husband's well-being because he was bored. She also stated that the health care team members may not have time to engage her husband in activities because they were often too busy with other tasks. Another caregiver corroborated this, stating “*The nurses can't sit and babysit you, but family can*” (CG1). This finding suggests that the health care team are often unable to provide recreational activities and cognitive stimulation, which are important in managing behaviours related to delirium.

Caregivers also actively encouraged the older person to engage in care activities to hasten their recovery, such as exercising and finishing their meals. One caregiver relayed how she and her husband (CG5) brought in different family members to improve her mother-in-law's desire to get better, saying “*And you know, maybe, make it herself decide that it's worthwhile to get better, right?*” (CG6). Another caregiver described in detail how she encouraged her mother to exercise and eat:



*Well when I came, I would converse with her till she changed her mind and remind her that there's life outside of the hospital bed. I just kept encouraging her to walk. I try to get her up to the toilet, sometimes she would, sometimes she wouldn't, said she didn't have to go. Just a couple of times, I got her to take a quick walk in the hall and then she said she was tired and wanted to go back. So, then we'd go back. I'd help her with food, like if she needed the milk put in with her tea or she needed her tea heated up, just to try and encourage her to eat and drink. (CG3)*

Several caregivers reported that they tried to bring in food that the older person preferred to encourage meal intake, as the older person did not always like hospital meals. One caregiver stated that *"I tried to bring him things that I know he really likes to eat"* (CG4). Another caregiver mentioned occasionally bringing her husband's favourite treats to the hospital *"Taking him in treats, like not everyday, but every so often, buy him a pop that he liked, buy him a Jersey Milk or something like that"* (CG9). One of the caregivers described how she would encourage her father to eat by accompanying him during lunch and bringing his preferred food:

*Well, [I], encouraged him to eat. I would bring a lunch for myself and I would go get him coffee and he likes cheese so if there wasn't something on that tray that he was particularly happy to eat, one day he had oatmeal and he's not a fan [chuckles]. He hadn't had a choice to make his choices at that point. (CG1)*

Caregivers also used their knowledge of the older person's personal preferences to help support their care and make them feel comfortable in the hospital. For example, one caregiver relayed, *"He likes to be clean, [I] shaved him, make sure he feels comfortable, the way things were at home, I continued doing it for him"* (CG7). Another caregiver reported *"Well, I tried like, I said like I will wash him, shave him"* (CG4). In another example, a caregiver brought a blanket for her mother to ensure that she was warm, *"But*

*she was cold, so I bought her a blanket, a nice furry blanket so she can stay warm, right?” (CG8).*

***Caregivers Assisted the Health Care Team in the Care of the Older Person and Advocated for Them: “Because We Could Calm Her Down”***

Caregivers described how they assisted the health care team with the care of the older person and advocated for them. Caregivers assisted with the care of the older person by assisting the health care team with carrying out various tests and treatments, as persons with delirium and/or dementia commonly resist care. For instance, a caregiver prevented her husband from attempting to remove his oxygen: *“He had his oxygen on so I was holding his hands to make sure he didn’t take his oxygen off” (CG7).* Caregivers also assisted in helping the health care team obtain the older person’s bloodwork: *“And talking to her and stuff. Even when they had to take blood from her the one time, they asked if we could stay, you know? So they could take a blood test” (CG6).*

In another example, a caregiver remained present while the health care team members changed her mother-in-law to help her cooperate:

*Sometimes it was nice that we were here to help, when she would get a little bit agitated. Because we could calm her down a little bit and they were able to change her, wash her and do that kind of thing. (CG5)*

These findings suggest that older persons tended to be more cooperative when the caregiver was involved in their care. Because the caregiver was familiar to the older person, their presence was calming and comforting.

In addition to assisting with the older person’s care, caregivers also advocated for the older person. This role included sharing information and concerns about the older

person's health with the team. For example, one caregiver said that she would make sure that the health care team members were aware that her husband also had dementia, "*I did mention to them he had dementia, so they knew*" (CG7). Another caregiver ensured that the team was aware that her mother needed mobility aids, "*I told them she needed a walker so they got the walker, but because she's a risk for, like falling over sometimes, so I had to remind her to take her walker always everywhere*" (CG3). This caregiver also reminded the health care team that her mother did not require adult briefs, because she was not incontinent and also ensured they knew that she had not urinated for a long time due to her dehydration:

*When I, you know, would mention she wasn't incontinent. She didn't need diapers or she had the first couple of days, I've reminded them she hadn't urinated for a long time, so they were trying to encourage her to drink more and get her into the toilet. (CG3)*

Caregivers played important roles in advocating for appropriate care for the older person. For instance, one caregiver notified the physician that his mother's mood was worse after a new antidepressant was started, "*Yes, that's why I wanted to talk to the doctor, because that's what I've noticed*" (CG5). In another example, a caregiver raised her concerns on whether her mother would receive necessary supports following her discharge to prevent readmission:

*I told them there was a risk that I thought she would be readmitted if it didn't work out or if she didn't eat, drink again then the same thing would happen over again and she would be back in an ambulance here, so I'm not sure if they're discussing all those issues I brought up and they're going to get back with me what their discharge plan is for her. I know the LHIN care is they're strapped for people and time and resources so that's my biggest worry and fear now. Is there going to be enough support once she is discharged while she is waiting for that crisis care bed. (CG3)*

In another example, the caregiver posted a piece of paper near her mother's bed for the health care team to see:

*I left a note above her bed saying [CG2] is at home, she's fine and I had put in, Thursday morning, [Hired Caregiver Name] will be here and [CG2] will come in the afternoon. Because I wanted, I told the nurses and I said you know this may help her calm down, if you're able to say "[CG2] is at home, she's fine. Don't worry about it. She's fine and [Hired Caregiver Name] is gonna be here tomorrow morning and [CG2] will come in the afternoon", because I think if she knows, it might help. I don't know if they did or not, to try. (CG2)*

The above example demonstrates the caregiver advocating for the older person by sharing advice with the health care team about managing her mother's behavioural symptoms, when the caregiver was not present at the hospital.

### **Summary of Main Results**

The findings demonstrated that caregivers found DSD to be a distressing and overwhelming experience. Caregivers felt helpless, overwhelmed, and unacknowledged. Caregivers were concerned about the quality of care the older person received while in the hospital. Findings indicate that health care team members often used restraints to reduce risk of falls and exit-seeking when caring for older persons with DSD. The use of restraints was upsetting to the caregivers, but caregivers were not hopeful that the quality of care could have been improved. The caregivers also found that the older person experienced frequent transitions within and between units. Transitions between units were intended to improve efficiency of bed flow and facilitate medical interventions, yet exacerbated the older person's symptoms, and causing distress for both the older person and caregiver. Yet caregivers were not hopeful that the quality of care could be improved due to resource constraints within the hospital.

The findings illustrate that caregivers' experiences were influenced by that nature of their relationship with the health care team, thus underscoring the importance of building collaborative relationships between caregivers and the team members. Positive relationships, where caregivers were valued, respected and acknowledged can help improve their experiences. On the other hand, poor communication and a lack of acknowledgement for the caregivers' role, made caregivers feel invisible and contributed to poor relationships between caregivers and the health care team, thus exacerbating caregivers' stress. Unfortunately, some caregivers felt that they were "invisible" to the team during the hospitalization, and were not consistently recognized as true partners in the care of the older person. This led to caregivers feeling disempowered, with some believing that they had little or no control over the older person's care. These caregivers were hesitant to be critical of the team and were conscious of disrupting their work. Caregivers endeavoured to build good relationships with the team, as they believed that it could affect the care provided to the older person. Caregivers identified many unmet needs for support, which include high quality communication with the healthcare team, acknowledgment of their role as a partner in care, and education regarding DSD, delirium, and dementia.

Despite the negative emotions and disempowerment experienced by caregivers, they continued to play an important role in the detection and management of DSD. Many caregivers used their knowledge of the older person to encourage them to participate in care activities and to advocate for them. In fact, caregivers demonstrated an intimate knowledge of the older person's baseline cognition and behaviours, suggesting that they

may assist in swift detection of delirium and other acute symptoms, which can lead to prompt medical intervention.

## **CHAPTER SIX: DISCUSSION**

This chapter contains a discussion of the study's overarching findings in relation to the literature. These findings include: (a) recognizing caregivers' experiences of DSD and their role in care and (b) optimizing caregivers as partners in care. In order to identify the overarching findings, study results were considered within the context of the literature and the research question. This approach is aligned with the process of interpretation of meaning described in Thorne's interpretive description (2016). Thorne (2016) states that this process requires "thoughtful examination, reflection, and reinterpretation within the context of what else is known" (p.162). The two overarching findings were identified after thoughtful reflection of the results in the context of the literature and repeated discussion with my supervisory committee. Consistent with Thorne's (2016) interpretive description approach, the findings were worded in an action-oriented manner to reflect the pragmatic demands of the nursing discipline and this study's purpose. This study aims to generate knowledge to help improve the experiences of caregivers, and improve their role in the detection and management of DSD. Thus, each finding was worded in a manner that emphasizes the action required to support and promote the well-being of caregivers of hospitalized older persons with DSD and support their role as care partners. Following a discussion of the overarching findings, this chapter concludes with a discussion of the Caregiver-Centred Framework and its relationship to the study's findings (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019), and the presentation of the study's implications, strengths and limitations.

### **Recognizing Caregivers' Experiences of DSD and Their Role in Care**

Study results indicate that it is important to recognize caregivers' experiences of DSD and their role in the older person's care. This section is divided into two sections: (a) building an awareness of the emotional toll and struggles experienced by caregivers related to DSD and (b) acknowledging caregivers as partners in care. It is important that health care team members are aware of the emotional toll and distress experienced by caregivers. This awareness is necessary to identify strategies to support caregivers and to optimize their role in the care of the older person with DSD.

#### ***Building an Awareness of the Emotional Toll and Struggles Experienced by Caregivers Related to DSD***

This section presents a discussion of the significance of developing an awareness of the emotional toll and struggles caregivers experience due to the DSD. The current study's findings illustrate that most caregivers experienced various negative emotions that included distress, sadness, helplessness, and shock at seeing the older person with DSD. In fact, one caregiver was so distressed, that she described the experience as "soul-destroying." In addition, the current study highlighted the competing responsibilities that caregivers balanced along with caregiving, which included childcare, work, and other medical emergencies. Caregivers felt overwhelmed due to these responsibilities, which only heightened the stress and emotional toll stemming from the hospitalization. This study is unique in that it provides a detailed account of the emotional toll and struggles of DSD on caregivers. While previous studies reported that caregivers of older persons with DSD experienced distress, the nature of this distress was not described in detail, as the



results were reported quantitatively (Fong et al., 2019; Grossi et al. 2019; Morandi et al., 2015a). It is important to understand the emotional toll of DSD on caregivers, as it can assist health care team members to gain insight into their experiences and respond with empathy and meaningful support (Day & Higgins, 2015b). Furthermore, there are no known previously conducted studies about caregivers' experiences of DSD in Canadian acute care settings. Thus, this study, provides a unique perspective of caregivers' experiences within the context of a Canadian health care system.

Caregivers were particularly disturbed by the behavioural and cognitive symptoms associated with delirium, which included: sudden change of behaviour, decrease in consciousness, hallucinations, yelling, and resisting care. This finding is consistent with three previous studies on caregivers of older persons with DSD, which reported the distress felt by caregivers related to witnessing cognitive and behavioural symptoms (Fong et al., 2019; Grossi et al., 2019, Morandi et al., 2015a). These cognitive and behavioural symptoms related to delirium cause the older persons to act differently than their typical selves. The loss of the familiar older person is especially distressing to caregivers, who lose a taken-for granted presence (Day & Higgins, 2015b). The current study's findings demonstrate that this loss was also present among these caregivers, who expressed sadness at seeing the older person behave differently. It is important for health care team members, especially nurses who are caregivers' first line of contact in hospitals, to recognize this distress as it can help them to communicate with compassion, offer support, and meaningfully involve the caregivers in the older person's care (Day & Higgins, 2015b).

Delirium and dementia have similar cognitive and behavioural symptoms (Inouye et al., 2006). Nonetheless, even though over half of the caregivers (55.6%) had previous experience caring for an older PLWD, they still experienced distress with DSD. This finding confirms the results of Fong et al.'s (2019) quantitative, descriptive correlational study which found that caregivers of persons with and without dementia experienced similar levels of distress when the older person was hospitalized with delirium. Both the current study and Fong et al.'s (2019) work demonstrate that previous experience caring for an older PLWD does not necessarily mitigate the distress associated with DSD. This finding can be explained by the fact that delirium is often unforeseen, sudden, and unpredictable, unlike the more progressive and predictable nature of dementia (Day & Higgins, 2015b, Fong et al., 2019, Schmitt et al., 2019). Thus, delirium may create distinct stressors for caregivers who may be more familiar with the slow and predictable cognitive decline associated with dementia (Fong et al., 2019). Therefore, it remains necessary for health care team members to recognize the caregiver distress associated with DSD, assess their needs and provide support as necessary.

### ***Acknowledging Caregivers as Partners in Care***

A key finding of the current study is that caregivers felt that they were not engaged as true partners in the care of older persons. This led to caregivers feeling disempowered, believing that they had little control over the care of the older person, in spite of their intimate knowledge of and previous experience caring for the older person.

While the caregivers did not explicitly report their recognition of this power imbalance in their relationship with the health care team, this disempowerment often

manifested itself in caregivers' efforts to build good relationships with team members. The caregivers in the current study appeared to believe that health care team held most, if not all of the power, over the older person's care. Thus, the caregivers tried to maintain good relationships with the health care team to avoid negative consequences to the older person's care. Some caregivers ensured that they were not disrupting health care team members. Some caregivers seemed to believe that they were not entirely welcome in the hospital, with a few expressing that they did not want to be "kicked out." This finding suggests that there may not be a true care partnership between caregivers and staff, with health care team members holding a certain level of power over caregivers. The finding is consistent with Day and Higgins' (2015b) phenomenological study of caregivers of older persons with delirium, which found that caregivers of older persons with delirium felt marginalized by the health care team in relation to the older person's care. The power imbalance between caregivers and the health care team has been identified in previous literature on caregiver engagement (Kuluski et al. 2019a; Kuluski et al., 2019b; Tresolini & Pew-Fetzer Task Force, 1994). Yet this finding is unique as it also demonstrates that caregivers of older persons with DSD recognize this power imbalance and react to it by building good relationships with the health care team.

In relation to the caregivers' feelings of disempowerment, another finding of this current study is that caregivers were reluctant to criticize the health care team, as it could negatively affect their relationship, and in turn impact the older person's care. In fact, one caregiver relayed that she feared that criticizing the staff would affect the support services her mother would receive after discharge. Further, some caregivers were hesitant to

criticize the health care team's use of restraints, even though they found the experience very upsetting. Some caregivers reported that they did not think there was another alternative to restraints and that they were necessary for patient safety. Caregivers' lack of hope that the quality of care could be improved may reflect a lack of preparation and knowledge of DSD, delirium and dementia (which will be discussed in the next section), specifically less invasive alternatives to restraints. Nonetheless, findings may also reflect caregivers' fear of criticizing the health care team, again suggesting the lack of a true care partnership between caregivers and health care team members. This finding is in contrast to Kuluski et al.'s (2019a) recommendations on caregiver engagement which was based on a Pan-Canadian meeting of caregivers, health care team members, researchers and other stakeholders. According to Kuluski et al., (2019a), to engage caregivers in care and research, they must have a comfortable space to voice their concerns and experiences. This safe space was not evident in the findings of the current study.

Caregivers' feeling of disempowerment may be heightened by a lack of acknowledgement of their caregiving role and responsibilities. Most caregivers visited regularly, managed the older person's affairs outside the hospital, and engaged the older person in care activities (e.g., encouraging meals, exercise, personal care). Moreover, caregivers carried out these activities while balancing other responsibilities. Yet, some caregivers reported that they felt invisible in the hospital, with some reporting that their presence and efforts were not acknowledged by the health care team. While there were a few reported instances when the caregivers were recognized for their efforts in caring for the older person, this was rarely seen in the interview transcripts. These results are similar

to qualitative literature on caregivers' experiences of delirium, which found that caregivers' contributions to care were often unrecognized, with caregivers desiring acknowledgment, and yet being relegated to the margins of care (Days & Higgins, 2015b; Toye et al., 2014; Yevchak, 2013). Research on caregivers in the community also illustrates that caregivers are often unrecognized as team members and were also not offered appropriate supports for their role (Change Foundation, 2016; Jeffs et al., 2017; Kuluski et al., 2019a). Possible factors contributing to the lack of recognition of caregivers within hospitals may include the fast pace of work, limited staffing levels, heavy workload, and disease-oriented focus of the health care team (Hynninen et al., 2014; Nilsson et al., 2013; Nolan et al., 2006, Tresolini & Pew-Fetzer Task Force, 1994; Yevchak, 2013; Yous et al, 2019). Thus, the health care team members may be focused on completing tasks, as opposed to building partnering relationships with caregivers, which was seen in the current study.

The feelings of disempowerment and lack of recognition experienced by the current study's caregivers are concerning, because they suggest the lack of a true care partnership between caregivers and the health care team. A growing body of literature supports the impact of building partnerships with caregivers within health care, as they hold critical knowledge of the care recipient (Kuluski et al., 2019a; Kuluski et al., 2017; Nolan et al., 2006). The current study's results also diverge from the relationship-centred approach to care, which states that building collaborative relationships between staff, patients and caregivers can lead to improved standards of care and caregiver experiences in acute care and in the community (Nolan et al., 2006). In fact, Nolan et al.'s (2006)

Senses Framework, states that caregivers must feel a sense of belonging and be encouraged to participate which indicate that caregivers be encouraged to participate in care as appropriate.

Best practice guidelines indicate that collaboration between caregivers and the health care team can help manage the cognitive and behavioural symptoms associated with delirium and DSD (Day & Higgins, 2015b; RNAO, 2016). Furthermore, previous literature on caregivers' role within the health care system suggests that encouraging caregivers to participate in care can improve both the experience of caregivers and older persons, while simultaneously acknowledging, rather than ignoring, caregivers' contributions to care and providing them with educational supports (Day & Higgins, 2015a; Kuluski et al., 2019a; Rosenbloom & Fick, 2015). The next section will further elaborate on issues that need to be addressed in order to optimize caregivers as partners in care.

### **Optimizing Caregivers as Partners in Care**

A finding of this current study is that many caregivers expressed a desire to become more informed about and involved in the older person's care. Caregivers wanted to be informed about DSD, and specifically how they could help the older person recover. These findings are consistent with previous literature on delirium, which suggests that involving caregivers in the care of the older person can reduce their distress (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). The current study's findings are also consistent with work on relationship-centred care, which found that caregivers, who are active care partners with the health care team, can obtain a sense of continuity and

improved experience of care (Nolan et al., 2006). This section is divided into the following segments that indicate steps that are necessary to optimize caregivers as partners in care: (a) improving quality of communication with caregivers and (b) enhancing caregivers' abilities in caring for persons with DSD, delirium, and dementia.

### ***Improving the Quality of Communication with Caregivers***

The quality of communication had an impact on the caregivers' experiences of DSD and relationships with the health care team. The results suggest that the quality of the communication between caregivers and older persons was influenced by: (a) nature of communication and (b) access to information about the older person's care. Clear, consistent and empathetic communication left the caregivers feeling supported and reassured about the older person's care. Caregivers experienced added stress when communication lacked empathy or when they had difficulty accessing information about the older person's care. The current study's findings illustrate that caregivers believed that positive communication involved a compassionate manner, regular interactions, and reassurance of their concerns, as discussed in the subsequent paragraph.

The findings of the current study demonstrate that the quality of caregivers' communication with the health care team influenced their experience. Some caregivers reported positive communication with the health care team. For instance, one caregiver reported that the nurses offered her comfort and reassurance while another reported feeling that her concerns were acknowledged by the team. Caregivers who had positive relationships with the health care team felt supported, heard, and reassured that the older person was receiving good care, thus, improving the caregivers' experiences during a

stressful time. The findings of the current study are similar to other studies on caregivers' experiences caring for a hospitalized person with DSD or delirium. These studies found that caregivers who experienced compassionate communication from the health care team felt supported and reassured about the older person's care (Day & Higgins, 2015b; Toye et al., 2014; Yevchak, 2013).

In contrast, some caregivers reported feeling ignored by or had tense communication with the health care team. For example, a few caregivers reported having curt discussions with health care team members whose communication style suggested that they did not like caring for the older person. These caregivers appeared to have poorer relationships with health care team members, with one caregiver merely describing their relationship as "cordial" and one caregiver wondering why certain health care team members chose their profession. Caregivers with poorer relationships with the team appeared to experience additional stress due to the quality of the relationship and expressed more doubts regarding the older person's quality of care. The current study's findings are consistent with studies on caregivers' experiences of DSD and delirium (Day & Higgins, 2015b; Yevchak, 2013). These studies found that health care team members whose communication lacked compassion, left caregivers feeling troubled and frustrated (Day & Higgins, 2015b; Yevchak, 2013). Day and Higgins' (2015b) qualitative phenomenological study found that when staff communicated in a manner that signaled displeasure in caring for the older person, caregivers experienced additional stress. The confrontational nature of these experiences made it harder for caregivers to care for the older person (Day & Higgins, 2015b).



One key finding from the current study is that many caregivers had difficulty accessing information about the older person's status and plan of care, and acquiring information about DSD. Many caregivers also had difficulty accessing information from the physician about the older person. This challenge was especially poignant among working caregivers, who could not always be present when physicians conduct patient rounds during working hours. Caregivers who had difficulties obtaining information often felt additional stress. For instance, one caregiver expressed frustration regarding the lack of updates regarding her husband's discharge plan after his prolonged hospital stay and believed that the social worker was merely repeating platitudes to her (e.g., "one day at a time") instead of giving her a concrete update.

In contrast, caregivers who reported receiving clear communication from the health care team related a more positive evaluation of the care. For example, one caregiver reported that she felt reassured when the physician took time to explain and answer her questions about her husband's care. Furthermore, findings of the current study suggest that even when health care team members did not have time to respond to the caregiver, merely acknowledging their request and stating that they would address it, left caregivers feeling reassured.

The communication difficulties experienced by caregiver is concerning. Some caregivers reported that more information could have better prepared them for the DSD hospital experience, and, thus possibly improved their experience. The current study findings regarding the communication challenges that exist between caregivers of persons with DSD and the health care team are similar to previous literature on caregivers of older

persons hospitalized with DSD and delirium (Day & Higgins, 2015b; Toye et al., 2014; Schmitt et al., 2019; Yevchak, 2013). In these studies, caregivers reported that communication about the older person's health status was lacking, with many expressing a desire for increased communication from the team. Caregivers in Toye et al.'s (2014) descriptive mixed methods study of family caregivers of older patients with delirium also reported difficulty reaching the medical team and reported that ongoing communication about the older persons' status would make them feel better supported.

Current study findings also suggest that many caregivers were proactive in seeking information about DSD from the health care team or the Internet. This finding is similar to a grounded theory study on the care of hospitalized older persons with cognitive impairment (Nilsson et al., 2013). This study revealed that family members also had difficulty obtaining consistent and clear updates about the older persons' care, with caregivers reporting that the responsibility for initiating communication with the health care team and staying informed was left to them (Nilsson et al., 2013).

The current study's findings in relation to communication is concerning, because previous literature indicates that maintaining compassionate and regular communication with caregivers is important in order to optimize their role as care partners (Kuluski et al., 2019a; Nolan et al., 2006). Active listening and compassionate communication are important, because they help build a therapeutic relationship between caregivers and the health care team (Kuluski et al., 2019a). This therapeutic relationship is the foundation of a collaborative care partnership between caregivers and the health care team (Nolan et al., 2006). Furthermore, regular communication with caregivers is important, as caregivers

can only be equal and empowered partners if they are fully informed about the older persons' health and care (Change Foundation, 2016; Jeffs et al., 2017; Kuluski et al., 2019a; Nolan et al., 2006). Thus, this current study's findings demonstrate that caregivers of hospitalized older persons with DSD experience a number of challenges communicating with the health care team. Improving the quality of communication between caregivers and the health care team is important to optimize caregivers as partners in care.

***Enhancing Caregivers' Abilities in Caring for Persons with DSD, Delirium, and Dementia***

A key finding of this current study is that most caregivers demonstrated the potential to make valuable contributions to the care of the older person, particularly DSD detection and symptom management. Nonetheless, findings from the current study illustrate that many caregivers still desired more education about DSD, delirium and dementia.

Study findings indicate that caregivers can play an important role in the detection of DSD. The results demonstrated that many caregivers were able to observe subtle changes in the older person's cognitive status from their baseline, such as increased lethargy or hallucinations, which were later confirmed as delirium. An acute change in baseline cognition is a key diagnostic feature of delirium (Inouye et al., 2014). This finding from the current study is similar to the results of Yevchak's (2013) study on caregivers' recognition of DSD symptoms, which also reported that caregivers were able

to detect hallmark features of delirium in older persons, specifically, an acute change in cognitive function, even without prior training.

The findings of the current study that suggest that caregivers are able to recognize acute changes in cognition is important, as previous literature demonstrates that delirium is often under recognized by health care team members in hospitals as much as 75% of the time (El Hussein et al., 2015; Rice et al., 2011). Evidence demonstrates that delirium is underrecognized by acute care staff, as its cognitive symptoms can be mistaken for dementia or as part of aging (El Hussein et al., 2015; Rice et al., 2011). As the cognitive and behavioural symptoms are similar to dementia, delirium is difficult to recognize in older persons with dementia if the assessor is not familiar with the older person's baseline cognition (El Hussein et al., 2015; Inouye et al., 2014; Rice et al., 2011). Caregivers are often familiar with the older person's baseline cognition and behaviour, and thus can help detect DSD (Bull et al., 2017; Yevchak, 2013). Bull et al. (2017) conducted a quasi-experimental, pre-post study and found that caregivers' knowledge and recognition of delirium improved after receiving short telephone-based educational modules. Caregivers were also able to identify corresponding actions in the face of delirium (Bull et al., 2017). Considering the previous literature, the findings of the current study further demonstrate that caregivers, with their experience and knowledge of the older person, can assist in detection of DSD. It is possible that, with appropriate training, caregivers can be trained to identify DSD and improve detection of DSD in hospitals.

A unique contribution of the study is that caregivers can play a critical role in DSD symptom management. Earlier literature on DSD has suggested that caregivers can

assist the health care team in helping the older person with care tasks but did not elaborate on this in detail (Morandi et al., 2015b). Findings of the current study demonstrate that caregivers frequently engaged the older person in activities, such as mobilization, encouraging meals, reminiscence, and recreational activities that were tailored to the older person's preferences. For example, one caregiver reported playing her husband's favourite music in order to stimulate his mind. These activities are valuable, as best practice guidelines on delirium state that aside from treating the underlying cause of delirium, implementing tailored non-pharmacological interventions, such as those carried out by the current study's caregivers, may reduce the severity and length of delirium (RNAO, 2016). In addition, the study's caregivers also assisted the health care team in situations where the older person resisted care due to the DSD. For example, one caregiver reported that her presence helped her mother-in-law cooperate with the nurse during a body wash. Caregivers also intervened in immediate situations, such as convincing the older person to take medication or stopping them from removing their oxygen lines. This finding is consistent with previous studies that have found that caregivers can help calm older persons with delirium and help them cooperate with care (Morandi et al., 2015a; RNAO, 2016). Therefore, in addition to DSD detection, caregivers can play an important role in DSD symptom management.

Despite the caregivers' potential to play an important role in DSD detection and management, the findings of the current study illustrate that most caregivers were not engaged as partners in care. Caregivers in the current study did not receive adequate education regarding DSD in the hospital. In fact, many caregivers reported wanting more

information about DSD and how they could support the older person's recovery from the DSD. The lack of information about DSD left caregivers feeling unprepared and overwhelmed about their experience. Findings from the current study also suggest that receiving appropriate education could have decreased caregivers' distress, as it could have prepared them for the unforeseen occurrence of DSD and provided them with strategies to assist the older person's recovery. This finding is consistent with previous literature on caregivers' experiences of delirium, with many caregivers reporting that information about delirium was often lacking (Day & Higgins, 2015b; Schmitt et al., 2019; Toye et al., 2014). The lack of information about delirium may increase caregivers' feelings of uncertainty and stress (Day & Higgins, 2015b).

Findings from the current study also suggest that few caregivers reported receiving information about delirium. In addition, while educational material on delirium was present on acute care units, it was not disseminated to the caregivers. For instance, one caregiver reported seeing a pamphlet about delirium for family members in the unit and obtained it herself. However, none of the caregivers in the study reported receiving this pamphlet from the health care team. According to Day and Higgins (2015b), this finding can be explained by the fact that delirium may be "taken-for granted" by the health care team. While delirium is new and distressing to caregivers, this condition is often familiar to health care team members. Thus, health care team members may believe that the diagnosis and cause of delirium is enough information to communicate to the caregiver (Day & Higgins, 2015b). Nonetheless, the lack of delirium education reported in the study is concerning, as caregivers can benefit from tailored education regarding

delirium, including its trajectory, family roles in care and potential long-term outcomes (Toye et al., 2014).

Results of the current study also suggest that caregivers who received a new diagnosis of dementia in the older person during hospitalization lacked information about dementia. For example, three caregivers who received the dementia diagnosis during the hospitalization were unaware of the type of the dementia the older person had. In one instance, a caregiver reported that the discharge education she received was lacking, as she went home with her husband, without knowing his dementia subtype or the level of assistance her husband required. This caregiver also did not receive referrals to appropriate community resources, such as the Alzheimer's Society. This caregiver voiced frustrations in her husband's transition home as she found herself as her husband's sole caregiver and lacked education about his level of care and condition. This finding was not present in previous literature about DSD or delirium, but is consistent with McCusker et al.'s (2020) study on unmet needs of family caregivers of older persons with chronic conditions preparing for discharge home from the hospital, which reported that caregivers required more medical information and clarification about their roles. McCusker (2020) suggests that lack of communication in relation to discharge education of caregivers of older persons is common in acute care. The lack of educational support is concerning as evidence demonstrates that providing caregivers of older persons with information and linkages to resources can improve their resilience and help them cope with this new diagnosis (Brodaty & Donkin, 2009; Logsdon et al., 2007; Peckham et al., 2017; Whitlach & Orsulic-Jeras, 2018).

### **Caregiver-Centred Care Competency Framework**

The study's findings are consistent with the Caregiver-Centred Care Competency Framework (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019). The Caregiver-Centred Care Framework was developed in collaboration with the University of Alberta and Covenant Health Network of Excellence in Seniors' Health and Wellness (2019). This framework defines caregiver-centred care as care that involves a collaborative partnership between families and the health care team, with the team supporting caregivers in their role, recognizing their needs, and meaningfully involving them in care planning for the older person (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019).

The Caregiver-Centred Care Competency Framework identifies the following competencies necessary for caregiver-centred care: (a) recognizing the caregiver role, (b) communicating with family caregivers, (c) partnering with family caregivers, (d) fostering resilience in family caregivers, (e) navigating the health and social systems and accessing resources, and (f) enhancing the culture and context of care (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019). These competencies allow health care team members to establish collaborative, working relationships with caregivers as partners in care (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019).

Both the findings of the current study and the caregiver-centred care competency framework illustrate steps in building collaborative relationships between caregivers and the health care team (Covenant Health Network of Excellence in Seniors' Health and



Wellness, 2019). The caregiver-centred care competency framework was used to discuss implications of the study findings for practice, education, policy, and research

## **Implications**

### ***Practice***

According to the caregiver centred care competency, “recognizing the caregiver role”, it is important to recognize the caregivers’ experiences and become aware of their roles and responsibilities to support them in their care of the older person (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). This study highlights how caregivers found the DSD hospital experience distressing and overwhelming. This experience can be impacted by their relationship with the health care team, which can help relieve or exacerbate the distress. The negative emotions felt by caregivers were magnified by a perceived lack of information about DSD. Therefore, the health care team, particularly nurses who spend the most time with patients and families, must assess caregivers’ well-being. Nurses must avoid making the assumption that a caregiver will not find DSD distressing because they have previous experience caring for an older PLWD (Fong et al., 2019)

According to the caregiver-centred care framework (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019), health care team members demonstrate competency in communicating with family caregivers when they communicate with compassion, respect and empathy. The inconsistency in the quality of communication between caregivers and the health care team found in the current study signifies a need for improved communication between health care team members and

caregivers. Health care team members who are competent in this domain provide timely information to caregivers. It is also important that nurses and health care team members communicate with caregivers in a manner that demonstrates respect, empathy and compassion as the quality of their communication can impact the experiences of caregivers (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019). Health care team members, with organizational support and education, are ideally placed to establish collaborative relationships with caregivers and ensure that they feel welcomed in hospital settings.

Nurses and other health care team members must also ensure that caregivers feel that their concerns are heard and that they are appreciated for their contributions to care (Kuluski et al., 2019b). While the fast-paced nature of acute care hospitals can make it difficult to immediately respond to caregivers' concerns, health care team members should recognize that acknowledging caregivers' concerns and the possible delay in response, can still make caregivers feel heard. This study also demonstrates that caregivers often face difficulties accessing information about the older person's health status and care plan. Thus, nurses and other health care team members must initiate communication with the caregiver, without leaving the responsibility of staying informed on the caregiver (Nilsson et al., 2013). Caregivers must receive timely and reassuring information about treatment plans for the older person and must be involved in the plan of care (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019; Grossi et al., 2019; Morandi et al., 2015a).

Caregivers should also receive education regarding the older person’s delirium and dementia so they can better support the older person with DSD. This action is consistent with the caregiver-centred care competency, “fostering resilience in family caregivers”, which indicates that it is important to enhance caregivers’ skills and abilities through education and support (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). Improving caregivers’ skills not only builds caregivers’ capacity as care partners, it also promotes their resilience (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019; Peckham et al., 2017; Whitlach & Orsulic-Jeras, 2018). Education can involve dissemination of educational brochures and in-person teaching.

The findings also illustrate that caregivers of older persons often do not receive enough education about DSD or are consistently engaged in the care. This finding is in contrast to the caregiver-centred care competency, “partnering with family caregivers”, which indicates that it is important and beneficial to include caregivers’ knowledge of the older person in assessments and care planning (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). In fact, findings of the current study demonstrate caregivers’ ability to assist in managing DSD symptoms and their potential in helping detect DSD. Thus, education about DSD should include information about what DSD is, and how caregivers can identify and manage symptoms of DSD. This education should include implementation of opportunities for caregivers to participate in care according to their preference (Day & Higgins, 2015; Rosenbloom & Fick, 2015). Education should be

provided to caregivers in lay terms to support their participation in care (Boltz et al., 2015).

In addition, findings of the current study demonstrate that even though educational brochures on delirium were available (containing information about detection, prevention and management), they were not distributed to caregivers by the health care team. Therefore, this education should be implemented as a standard hospital practice, with brochures widely available in units with high prevalence of DSD to promote consistencies in care. Furthermore, to involve caregivers systematically in the detection of delirium, units can implement tools, such as the FAM-CAM, which involve obtaining caregivers' input on the assessment of delirium and educating them about the appropriate corresponding actions (Bull et al., 2017; Shankar et al., 2014). The FAM-CAM is based on the Confusion Assessment Method (CAM), which is a widely used tool to detect delirium in acute care settings (Inouye et al., 2012; Inouye et al., 2014).

Consistent with the caregiver-centred care competency, “navigating health and social systems and accessing resources”, caregiver education should also include facilitating links with community resources, such as the Alzheimer’s Society (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). As caregivers’ roles do not end with the hospitalization, acute care organizations and their staff are in a unique position to ensure that caregivers of older persons with DSD receive the necessary education and supports prior to discharge to the community or to another setting. When discharging an older person from the hospital, it is important to communicate relevant

patient information, provide emotional support, and direct caregivers to appropriate resources (McCusker et al., 2020; Nolan et al., 2006).

### ***Education***

The caregiver-centred care competency, “enhancing the culture and context of care” recognizes that caregiving is often affected by societal views that include stigma and discrimination (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). Consistent with this competency, curricula for nursing students and other health care students (e.g., physicians, personal support workers, occupational therapists, physiotherapists) should include education on delirium, dementia, and DSD. This education should also include education about caregiver-centred care and include encouragement of self-reflection to improve their support of and interactions with caregivers (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). Educating health care students will ensure that future health care team members will be equipped with the appropriate knowledge to detect, prevent, and manage delirium or DSD.

Findings of the current study show that both older persons and caregivers were distressed by the use of physical and chemical restraints. Therefore, consistent with the competency “enhancing the culture and context of care”, an important implication of this study is to provide nurses and other health care team members with education about how to provide tailored care to the older persons with DSD and their caregivers and to reduce restraint use (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). Thus, organizations must support staff education within this area. The frequent use

of restraints in the older persons are in contrast to best practice guidelines recommending they be used as a last resort to prevent physical harm to older persons (Gunawardena & Smithard, 2019; NICE, 2018; RNAO, 2016). Restraint use is discouraged because of its negative effects, which include increased anger, aggression, pressure injuries, loss of muscle tone, excessive sedation, and death (Gunawardena & Smithard, 2019; Inouye et al., 2014).

Additionally, education on restraint use should address the issues of a proactive versus reactive approach to reduce escalation of behaviours in the older person (Nilsson et al., 2013). According to Nilsson et al. (2013), hospitals' focus on efficiency and disease may cause staff to overlook unmet needs in the older person with delirium, dementia or DSD. Thus, health care team members are often reactive, instead of proactive to approaching problems. For example, older PLWD do not receive attention until they develop hyperactive delirium and begin exit-seeking or removing medical equipment. Therefore, health care team members may resort to reactive and immediate solutions when behaviours become unmanageable, such as using restraints. Therefore, staff members must learn about non-pharmacological strategies (e.g., playing music and involving families in care), rather than the use of physical and chemical restraints to manage behaviours associated with DSD (Yous et al., 2019). While there are no known specific educational modules or programs focused on DSD, standardized dementia education programs such as Gentle Persuasive Approaches to Dementia Care and P.I.E.C.E.S also cover delirium and have been implemented in some Canadian hospitals (Hamilton et al., 2010; Pizzacalla et al., 2015; Schindel Martin et al., 2016).

Given that caregivers appreciate being involved in the older person's care, and the potential contributions they can make to the care, hospitals should educate staff about how to engage and build partnerships with caregivers to increase their participation in care and promote shared decision-making (Boltz et al., 2015; Clissett et al., 2013b). This action is consistent with the competency, "partnering with family caregivers" which highlight the importance of establishing collaborative relationships with caregivers (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019). Both the Caregiver-Centred Care Competency and Senses Frameworks can provide a basis for educating staff on relationship-building strategies with caregivers of older persons with DSD in the acute care environment (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019, Nolan et al., 2006). Nonetheless, education must be accompanied by organizational interventions to ensure sustainability (Nilsson et al., 2013). Ongoing reinforcement of education (e.g., annual review) as well as an evaluation of barriers and facilitators to application of education must be implemented to improve uptake (Yous et al., 2019).

### ***Policy***

Findings of the current study illustrate that many caregivers do not feel acknowledged or recognized as partners in care, which is in contrast to the caregiver-centred-care competency, "partnering with family caregivers" (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019). Evaluating caregivers' experiences during hospitalization is necessary to evaluate whether or not the organization is establishing collaborative relationships with caregivers or is demonstrating other

caregiver-centred care competencies (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019). Nonetheless, many acute care hospitals remain efficiency and disease-focused, instead of caregiver-centred, yet as this study and the literature indicates, safe and quality care extends beyond disease management and bed flow (Kuluski et al., 2019b). There needs to be a shift in policy in order for the government to measure organizational outcomes not just by standardized indices, but also by caregiver and patient experiences (Kuluski et al. 2017; Kuluski et al., 2019a; Kuluski et al., 2019b). Patients and caregivers can be involved in identifying which indices are appropriate for evaluation of their experiences within the health care system (Kuluski et al., 2019a; Kuluski et al., 2019b).

Consistent with the caregiver-centred care competency, “enhancing the culture and context of care”, a cultural change is also required within hospitals to shift the focus beyond disease management to recognizing caregivers as partners in care (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019; Dupuis et al., 2016; Kuluski et al., 2019b). This change is particularly important in the context of DSD, as caregivers can provide valuable contributions in the detection and management of hospitalized older persons with DSD. In addition, there should be allocated funding for hospitals to allow organizations to increase bed capacity, redesign their physical environment, and increase staffing. Investing in bed capacity can reduce frequent care transitions, which can trigger delirium or exacerbate symptoms of dementia or DSD (Edvarsson & Norvall, 2008; Fong et al., 2009; Yous et al., 2019). Funding can also be used to redesign the physical environment to increase space and privacy for older persons



and their caregivers to promote a sense of security and safety within an unfamiliar environment (Nolan et al., 2006). In addition, ensuring adequate staffing levels could lead to improved communication and could free up staff to be available for families and increase staff time to encourage them to use alternatives to restraints in situations during which an older person with DSD may resist care. It may also be necessary to obtain funding for recreation therapists within the hospital, who could provide cognitively stimulating activities to older persons with DSD, as under-stimulation may trigger or exacerbate symptoms of DSD (Yous et al., 2019).

Finally, there is no documented national or provincial policy on supporting caregivers within hospitals in Canada and Ontario. In 2015, the government of Ontario (2015) released the *Patients First: Action Plan for Healthcare*, with the goal of improving patient and family experience within the health care system. While the plan included geriatric care training, there was no specific strategy to improve caregivers' experiences within hospitals (Ontario, 2015). In order to enhance the "culture and context of care" to promote caregiver well-being, coordinated policies at each level of government, from municipal to federal can be helpful to develop appropriate supports in hospitals and during transitions in care (Beed, 2018; Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019).

### ***Research***

This study highlights several areas for future research. It is important to understand the perspectives of health care team members, including nurses, and organizational leaders when hospitals attempt to implement policies to increase education

and participation of caregivers of older persons with DSD. These stakeholders may identify strategies to realistically and sustainably implement such practice changes. As discussed, “enhancing the culture and context of care” is a caregiver-centred care competency and a culture change is required in hospitals from a disease-focused perspective to one that also prioritizes caregiver-centred care and relationship-building to promote safe and effective care (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019; Kuluski et al., 2019b; Nolan et al., 2006). However, more research is required on how health care team members and nurses in particular, can work together to shift this focus, particularly within a health care system that relies on quantitative metrics for evaluation and funding (Kuluski et al., 2019b). Furthermore, this study was interrupted by the COVID-19 pandemic that necessitated visitor restrictions in hospitals across Ontario. Future research could investigate how restrictions stemming from this pandemic impacted the experiences of caregivers of older persons with DSD and their participation in care.

This study also highlights the importance of involving families in detection of DSD, which is consistent with the caregiver-centred care competency “partnering with family caregivers” (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). There is a dearth of material on this topic and little research on tools that can be used to assist caregivers in detecting DSD, such as the FAM-CAM (Yevchak, 2013). Therefore, more research needs to be conducted on the appropriate educational strategies and tools to help caregivers detect DSD in both hospitals and the community.

This study also includes the experiences of some caregivers whose care recipients were newly diagnosed with dementia. However, this study focused on the experience of DSD, rather than the diagnosis of dementia. Future research should investigate their experiences to ensure that caregivers who receive the new diagnosis of dementia in hospitals receive appropriate support at this time of transition, which is consistent with the competency “fostering resilience in family caregivers” (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019). Additionally, this study’s caregivers were all Caucasian and English-speaking. A majority of the caregivers were currently working and also identified themselves as female. Future research on caregivers’ experiences of DSD in hospitals should investigate the experiences of caregivers who are male and non-Caucasian. Conducting research on populations not well-represented in this study is also consistent with the caregiver-centred care competency “recognizing the caregiver role”, which acknowledges the diversity among caregivers (e.g., age, gender, culture) (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019).

Finally, findings of this current study can also be used to inform the design of an intervention to enhance caregiver-centred care for caregivers of hospitalized older persons with DSD. This intervention can address some, if not all of the six competency domains highlighted in the caregiver-centred care competency framework (Covenant Health Network of Excellence in Seniors’ Health and Wellness, 2019).

### **Strengths and Limitations**

Strengths of this study include the variability of characteristics of caregiver participants and the older person care recipients. Caregivers included those new to the caregiving role to those with five years of experience. Included caregivers had varying ages, education levels, employment status, and relationship to the older person. The older persons receiving care had variability in their sex, types of dementia, stage of dementia, reported reasons for admission, and lengths of stay in the hospital. The variability of characteristics of the caregivers and older persons helps increase the transferability of the study's results to similar populations and settings (Lincoln & Guba, 1985). Another strength of this study was in the use of both interviews and field notes during data analysis. The use of field notes helped strengthen the data analysis as it added information about the study's context and the caregivers' nonverbal actions during the interviews (Phillippi & Lauderdale, 2018; Sandelowski, 1994). Other study strengths included the rigorous analytic approach as outlined by Braun and Clarke (2006) and the participation of an experienced research team in data analysis.

Limitations of this study include a lack of diversity in relation to gender and race among the caregivers. All caregivers were Caucasian and English-speaking. A majority of the caregivers were female and currently working. Caregivers were also recruited from only medical units in two urban teaching hospitals. Therefore, the transferability of results may be limited to similar populations and settings. Another limitation of this study was that the history of delirium and dementia were confirmed by the nurses who had access to the patient file, which was again confirmed via self-report of the caregivers. Self-report of

diagnosis may not be as accurate as confirming the history through patients' medical charts. However, I was not allowed access to the charts by the organization due to their privacy policy. Lastly, as delirium is underrecognized and hyperactive delirium is more likely to be observed by nursing staff, the recruitment method may have missed eligible caregivers of older persons with hypoactive delirium (El Hussein et al., 2015; Rice et al., 2011).

### **Conclusion**

In summary, this study makes an important contribution to the literature by providing an in-depth description of the experiences of caregivers of hospitalized older persons with DSD. The study revealed that the caregivers experienced distress and various negative emotions associated with the experience. Caregivers' experiences were also influenced by the nature of their relationships with the health care team. While some caregivers reported positive experiences with the healthcare team, other caregivers reported feeling disempowered, unacknowledged, and lacked the information needed to be true partners in the older persons' care.

Caregivers are ideally positioned to identify delirium early and participate in care of the older person with DSD. However, findings of the current study suggest that caregivers are not engaged as true partners in the care of older persons, with some reporting that they feel invisible to the staff. Multiple practice and organizational changes must occur to increase caregiver's participation in care, which include building strong relationships between caregivers and the health care team. The Caregiver-Centred Care Competency and Senses frameworks can both provide a foundation to help health care

team members and organizations build collaborative, working relationships with caregivers caring for older persons with DSD (Covenant Health Network of Excellence in Seniors' Health and Wellness, 2019, Nolan et al., 2006). By building strong relationships and increasing caregiver participation in care, nurses, and other health care team members can support caregivers through the complex DSD hospital experience.

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**APPENDICES**

**Appendix A**

**Table A1**

*Data Extraction Table of Included Studies*

<b>Study Authors (Country)</b>	<b>Research Question (s) and/or Aim(s)</b>	<b>Setting and Sample</b>	<b>Methodology</b>	<b>Main Findings of Relevance to Present Study</b>	<b>Critique</b>
Day & Higgins 2015 (Australia)	<p><b>Research Question:</b> What is the lived experience of family members who are with an older person when the older person has delirium?</p> <p><b>Aim:</b> To explore family members' experiences during the older person's delirium.</p>	<p><b>Setting:</b> Acute hospital wards or residential aged care settings</p> <p><b>Sample:</b> Fourteen female family members between 51-74 years old. The study also included family members of persons who had delirium-only and persons with</p>	<p>Phenomenology</p> <p>In-depth interviews were conducted with participants. The first author (the primary data collector) also collected interview field notes, observations of the context and reflections on visits to acute care hospitals. Delirium-related poetry, music, images and novels were also collected.</p> <p>The first author developed and revised themes under the supervision of two study supervisors.</p>	<p>The women's experiences were best described by the following core essence: <i>changing family portraits – sudden existential absence during delirium.</i> The core essence describes how the woman suddenly loses a familiar and taken-for-granted presence of the older person, because delirium alters the nature of the person they are with. Two themes further describe the women's experience:</p> <p><b>1) Living the fragility of a older person's</b></p>	<p><b>Strengths:</b> The qualitative approach was appropriate for the study question and illuminated the women's experiences of an older person's delirium. In addition, the authors described the underpinning philosophy of the design in relation to the phenomenological approach, which was consistently applied throughout the research process.</p> <p><b>Limitations:</b> The context of the data could be further elaborated in the discussion of findings. The authors state that the</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
		delirium in the presence of dementia.		<p><b>presence:</b> Women experienced sudden changes in the older person’s demeanour and their absence from their world. This theme has the following sub-themes:</p> <p><b>a) Facing a older person’s existential absence:</b> Women experienced the sudden and unexpected absence of the familiar person during delirium.</p> <p><b>b) Living with a stranger:</b> The women felt they were with an unfamiliar person who demonstrated shocking behaviours, a stark contrast from the older person, during the delirium.</p> <p><b>2)Living life holding on:</b> This theme described women’s experiences of waiting for the older</p>	<p>participants experienced delirium in both hospital and residential aged care facilities. However, they did not describe how the context impacted the participants’ experiences. In addition, the authors could have further detailed how discrepancies in the data analysis could be resolved. Lastly, there was a lack of detail about rationale and theoretical justification for the sampling procedures.</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
				<p>person’s uncertain return from the delirium and their relationship with health care providers. This theme has five sub-themes:</p> <p><b>a) Waiting for a loved one:</b> Women continued to hold on to their memories of the older person and hoped that the unfamiliar person was temporary.</p> <p><b>b) In the dark:</b> Women perceived a lack of communication about the condition from the health care team.</p> <p><b>c) On the fringe but center stage:</b> The women felt dismissed or marginalized by health care team members during the older person’s care.</p> <p><b>d) On thin ice:</b> Women continued living on with the possibility of the unfamiliar stranger re-</p>	



Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
				<p>appearing in future episodes of delirium.</p> <p><b>e) Keeping secrets:</b> This sub-theme describes how women attempted to conceal the experience from the older person to shield them from the distress of knowing how they acted during the delirium.</p>	
<p>Fong, Racine, Fick, Tabloski, Gou, Schmitt, Hshieh, Metzger, Bertrand, Marcantonio, Jones, &amp; Inouye (USA)</p>	<p>Aim: To measure the burden of delirium in older adults with or without Alzheimer disease or related disorders (ADRDs).</p>	<p><b>Setting:</b> Inpatient hospital and participants’ homes</p> <p><b>Sample:</b> A subset of older medical and surgical patients (n=243) and their family or friend caregivers (n=214) who were enrolled in the Better</p>	<p>Quantitative, prospective, observational, cohort</p> <p>The authors measured delirium burden using the Patient Delirium Burden Instrument (DEL-B) and Caregiver Delirium Burden Instrument (DEL-B-C) and patients 1 month after hospitalization. Delirium presence and severity were assessed respectively by the Confusion Assessment Method (CAM) and the CAM-Severity. The</p>	<p>Caregivers experienced greater burden (<math>\beta[\text{delirium} \times \text{ADRD}] = -.29; P = .42</math>), when the patient developed delirium, ADRD status notwithstanding. Caregiver burden was also moderately correlated with patient Montreal Cognitive Assessment scores (<math>\rho = -0.18; P = .01</math>).</p> <p>Based on the findings, the authors concluded that delirium is equally stressful to caregivers,</p>	<p><b>Strengths:</b> The authors used validated instruments such as the CAM, MOCA and DEL-B. The DEL B instruments also had good internal consistency between patients with or without ADRD as per the Cronbach’s alpha test. The authors also controlled for confounding factors in patients, which included age, sex, years and education. There was sufficient follow-up and appropriate statistical analyses were also used.</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
		Assessment of Illness Study. Fifty-six patients had ADRDs.	severity of cognitive impairment was measured using the Montreal Cognitive Assessment (MOCA)	regardless of whether or not the older person had baseline ADRD. The authors suggested that being familiar with the burden of caring for a person with ADRD-related cognitive and functional impairment does not mitigate caregivers' distress stemming from delirium.	<b>Limitations:</b> The authors did not control for confounding factors among caregivers (e.g., age, education, sex, years of caregiving experience) that may have impacted delirium burden. The study was also done in one site, which limits generalizability of the study's findings.
Grossi, Lucchi, Gentile, Trabucchi, Bellelli, &	To identify predictors of distress in informal caregivers of older patients	<b>Setting:</b> Inpatient rehabilitation unit at a post-acute hospital	Quantitative, correlational, prospective cohort  The caregivers were interviewed 3 days after	A majority of the caregivers were female (81%). The mean age of family caregivers was 59 ( $\pm$ 13.0) years of age. The predictors of distress	<b>Strengths:</b> The authors had a meaningful follow-up time at one month after the first interview, which can prevent participants being lost to follow-up.

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
Morandi 2020 (Italy)	with delirium superimposed on dementia (DSD).	<p>in Cremona, Italy</p> <p><b>Sample:</b> Caregivers (n=33) of patients with DSD (n=33). The caregivers were family members or private caregivers who had been in contact with the client at least one hour a day.</p>	<p>the delirium resolved (T0) and at 1-month follow-up (T1) to describe their level of distress related to the delirium using a 5-point Likert scale (0= no distress, 4= extremely distressed). The authors identified predictors of caregiver distress a priori: age, sex, employment status, education level, delirium severity, delirium subtypes, type and severity of dementia, and time spent with patient during delirium episode. A linear regression was used to identify predictors of caregiver distress at T0 and T1.</p>	<p>at T0 were severity of delirium and severity of dementia. Moderate dementia was associated with lower distress (<math>p = 0.011</math>) while greater delirium severity was associated with higher distress (<math>p = 0.021</math>). The authors believe that moderate dementia may be linked to lower distress, because the caregivers would have more experience with caregiving and more honed coping strategies. On the other hand, delirium severity could have increased their perception of the situation's difficulty, therefore leading to more distress.</p> <p>At T1, older caregivers experienced higher distress (<math>p = 0.042</math>) and when they spent less time</p>	<p>The presence of delirium in the patients the participants were caring for were also confirmed by two expert geriatricians, who used previously validated scales, the modified Richmond Agitation and Sedation Scale, and the Delirium-O-Meter. The p values and confidence intervals of the variables showing significance were also reported.</p> <p><b>Limitations:</b> There was no explicit description of inclusion criteria for participants. The authors did not define the term <i>informal caregivers</i>, which seemed to include both family and caregivers privately hired by the family. This difference in caregiver status is a potential confounding factor to the level of</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
				with the patient during the delirium episode. The authors postulate that spending more time with the patient during the delirium may increase the caregivers' exposure to competent staff, who educate them about delirium and therefore increase the caregivers' perceived problem-solving abilities.	distress. There was also no detailed rationale (based on theory or literature) for the chosen predictors of distress within the analysis, which the authors chose <i>a priori</i> . In addition, the sample size was low for a correlational study (n=33) and no power calculations were presented.
Morandi, Lucchi, Turco, Morghen, Guerini, Santi, Gentile, Meagher, Voyer, Fick, Schmitt, Inouye, Trabucchi, & Bellelli 2015 (Italy)	To evaluate health care staff's and informal caregivers' experience caring for older patients with delirium superimposed on dementia in a rehabilitation setting.	<p><b>Setting:</b> Inpatient rehabilitation unit at a post-acute hospital in Cremona, Italy</p> <p><b>Sample:</b> The study included both informal caregivers (n=33) who have been in contact with the patient</p>	<p>Prospective cohort study that used both qualitative and quantitative methods</p> <p>Informal caregivers were interviewed in-person three days after the resolution of delirium in the older person (T0). Caregivers were also interviewed at a 1-month follow-up (T1) either over the phone (if the patient was discharged) or in-person (if the patient was still</p>	<p><b>Quantitative:</b> The authors found that the reported mean level of distress for informal caregivers at T0 was <math>2.3 \pm 1.1</math> and lower at T1 at <math>1.9 \pm 1.12</math>. The informal caregivers also reported higher distress than health care staff in relation to the following Delirium-O-Meter symptoms: delusions, incoherence, hallucinations, sustained attention,</p>	<p><b>Strengths:</b> The authors provided a sufficient description of the study's setting and recruitment process. Inclusion and exclusion criteria for participants were also outlined. The authors also used previously validated measurements to ascertain delirium in the patients cared for by the participants, such as the modified Richmond Agitation and Sedation Scale (m-RASS) and the</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
		<p>with delirium for at least an hour daily and health care staff (n=41, 8 nurses, 13 nurse aides, and 20 physical therapists) who have cared for the older patients for at least one shift.</p>	<p>hospitalized. Participants who were health care staff were given a questionnaire, instead of an interview, for data collection.</p> <p>The authors also gathered data about the participants' demographics. Data about caregivers' age, gender, education level and relationship to the patient were collected. The authors also collected data about the health care staff's age, gender, and work experience.</p> <p>Each participant was asked to rate their level of distress in relation to each symptom in the Delirium-O-Meter (e.g., sustained inattention, hypokinesia/psychomotor retardation, incoherence</p>	<p>hypokinesia/psychomotor retardation, and orientation. Among health care staff, the mean distress level for nurses was <math>0.8 \pm 0.7</math>; with nurse aides/health care assistants, it was <math>1.1 \pm 1.1</math>; and among physical therapists, it was <math>1.1 \pm 1.2</math>. The health care staff had lower level of distress in relation to each Delirium-O-Meter symptoms when compared to family caregivers.</p> <p><b>Qualitative:</b> Based on the two qualitative interviews at T0 and T1, the informal caregivers experience of caring for patients with deliriums could be categorized into three categories: perceived aspects of patient experience; aspects of</p>	<p>Delirium-O-Meter. In addition, the authors used similar measurements (e.g., distress scores, open-ended questions) for both health care staff and informal caregiver groups. Finally, the authors described details of the content analysis method used to evaluate the qualitative data.</p> <p><b>Limitations:</b> There was no clear definition of <i>informal caregivers</i>. Given that this group of participants included both relatives and caregivers privately hired by the older person's family, it would be useful to have a clear definition distinguishing informal caregivers from the health care staff. Furthermore, the family-hired caregivers may have different experiences of</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
			<p>on a Likert scale from 0 to 4 (0=no distress, 1=little, 2 = a fair amount, 3 = very much, and 4 = extremely distressed). Participants were also asked to rate their global level of distress using the same Likert scale. As part of the qualitative evaluation, the participants were asked to describe their overall experience of delirium with two open-ended questions: “Can you please describe, with your own words, your experience caring for the patient during the delirium episode?” and “Can you please describe what worried you the most?”</p> <p>The authors used descriptive statistics to summarize demographic</p>	<p>caregiver experience; and aspects of both the patient and caregiver experience. The perceived aspects of the patient include subcategories of cognitive impairment, aggressive behavior, and psychosis. The category, aspects of caregiver experience, is comprised of concerns about present situation, concerns about the future, awareness of change. The third category is about aspects of patients and caregiver experience, which include: emotions, physical symptoms, and care.</p>	<p>delirium compared to the relatives due to their paid role.</p> <p>In relation to the study’s quantitative strand, there was a lack of information about the validity of the distress scales used. The study had a small sample (n=33), with no power calculation presented. Subsequently, within the qualitative strand, there was a lack of in-depth analysis of the data. While aspects of the participants’ experiences were categorized into themes, there was little to no explanation about what each theme or sub-theme meant and how they answered the research question. Furthermore, the analysis could have been further deepened by comparing the experiences between informal caregivers and staff. The</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
			and quantitative data. Content analysis was used to analyze qualitative data.		quantitative and qualitative findings could have also been further integrated and discussed within the article
Schmitt, Gallagher, Albuquerque, Tabloski, Lee, Gleason, Weiner, Marcantonio, Jones, Inouye, & Schulman-Green, 2019 (USA)	To describe common burden experiences among patients, family caregivers, and nurses.  To inform the development of instruments to measure delirium burden and intervention improve delirium management.	<b>Setting:</b> Urban teaching hospital  <b>Sample:</b> Eighteen patients who had recently experienced delirium (patients who had pre-existing dementia were excluded), 16 family caregivers (of persons who had delirium with and without pre-existing dementia), and	The authors conducted semi-structured interviews about delirium burden with patients who had recently experienced a delirium episode, family caregivers, and nurses who routinely cared for patients with delirium. Following transcription of data, the authors used interpretive description to code data and identify common themes across the three groups.	The authors presented the following three major themes that described the common burden among the three groups:  <b>1) Symptom burden:</b> The patients were burdened by hallucinations, impaired communication, and changes in their personalities. Family caregivers were also worried from observing hallucinations, not knowing if symptoms would go away, inability to communicate with the older person, and seeing personality changes. Lastly, the nurses were burdened by increased workload and difficulty	<b>Strengths:</b> The work was situated within relevant background literature on delirium’s burden on patients, families, and nurses. The selected research design was appropriate for the objective and allowed the authors to describe the commonalities in delirium experience. Clear inclusion criteria were outlined and a validated method was used to screen participants for eligibility. The authors provided sufficient detail on their data collection and coding processes. The inclusion of three groups allowed the authors to compare data across groups. Investigator triangulation

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
		15 nurses who routinely care for patients with delirium		<p>providing proper care due to hallucinations.</p> <p><b>2) Emotional burden:</b> All groups felt anger, distress, fear, guilt and helplessness. Patients reported feeling frustrated with the way they were treated and felt helpless during the hospital stay. Nurses and family caregivers were frustrated with patients' behaviours and refusal of care during the delirium. All groups also felt fear. The patients felt fear that the changes in their brain and behaviour were permanent while nurses feared patient behaviours. Patients also felt guilty for disturbing the staff and their family, while nurses felt guilty for not spending enough time with the patients.</p>	<p>was applied during data analysis.</p> <p><b>Limitations:</b> Although the authors claimed to use interpretive description in their data analysis, there was little mention of how this approach was applied throughout the study. Additionally, the relationship between the study's implications and the original research objective was not clearly defined. The authors state that the study could guide the development of delirium burden measurements and evidence-based interventions to manage common burden experiences, but did not elaborate on how the study's findings could achieve these tasks.</p>



Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
				<p><b>3) Situational burden:</b>                      All groups experienced loss of control. Patients lost autonomy, family caregivers questioned if the patients were receiving the amount of care needed, and nurses felt pressure to follow treatment plans, which were being interfered with by patient’s delirium. On the other hand, patients and family caregivers perceived a lack of attention from staff. All groups reported a lack of knowledge about delirium and managing its symptoms.</p>	
<p>Toye, Matthews, Hill, &amp; Maher, 2014 (Australia)</p>	<p>To describe families’ experiences, understanding of delirium and delirium care, and support needs</p>	<p><b>Setting:</b>                      Secure, 10-bed delirium-specific unit in an Australian tertiary hospital with more than 600</p>	<p>Descriptive, mixed methods</p> <p>The authors collected the following demographic information about the carers: age, gender, education level, cultural</p>	<p>The following themes emerged from the interviews, with limited understanding of delirium and delirium care underpinning all themes:</p>	<p><b>Strengths:</b> The qualitative approach was appropriate in understanding family carers’ experiences. Furthermore, the authors provided a detailed description of the study’s context, which increased</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
	<p>in order to inform nursing practice.</p> <p>To document family carers' experiences and understandings of delirium and delirium care, in addition to their support needs and how these could be met.</p>	<p>beds. The hospital was located in city with a population of over 1.5 million people.</p> <p><b>Sample:</b> 17 family carers of older patients with non-terminal delirium answered the questionnaire. Twelve participants (11 female) also took part in the interviews.</p>	<p>background, relationship with patient, and the support they provided (type, frequency, and location) The authors gathered the following data about the patient: age, gender, and illnesses. A questionnaire survey that evaluated family carers' concerns, experiences of support from the staff, and the adequacy of information provision about delirium. In addition, the authors interviewed 12 participants about their experiences of having a relative with delirium in the unit.</p>	<p><b>1)Admission experience:</b> Overall, families felt relief at the transfer to the delirium-specific unit, because they expected expert care, but participants continued to have limited understanding of delirium.</p> <p><b>2)Worries and concerns:</b> This theme demonstrated the families' anxieties during the admission, including the behavioural changes in the patient and rushed communication with unit staff.</p> <p><b>3)Feeling supported:</b> This theme depicts participants' reflections on staff's efforts to meet their families' support needs. Family members felt reassured when they observed calm, cheerful,</p>	<p>study's trustworthiness in its qualitative results. There was sufficient explanation of the data analysis method for the interviews, with the authors using constant comparison in their thematic analysis. There was a rich description of the themes emerging from the findings with appropriate, supporting quotes from the participants.</p> <p><b>Limitations:</b> The quantitative strand of this study was poorly conducted and did not seem appropriate for the research question. The survey used had not been previously validated and poorly linked to the research purpose, which was to evaluate family carer's concerns and experiences of support.</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
				<p>and understanding care from the staff. Participants also appreciated being involved or helping personalize care, yet reported that this opportunity did not often occur. Most carers reported wanting more communication from the staff and information about delirium.</p> <p><b>4) The discharge experience:</b> This theme described that transition to either home or residential aged care happened smoothly. However, some participants were distressed due to rushed transitions or by the patient’s discharge to residential care, instead of home.</p>	<p>Rather, the questionnaires appeared to measure the participants’ level of agreement in relation to delirium and their experiences of support from the staff. Although the authors claim to be using mixed methods, findings from both the survey and interviews were not integrated in the analysis or discussion. The authors state that the interviews expand on the survey results, but the article lacked a detailed explanation of the relationship between the results, as well as any possible inconsistencies. A large proportion of the paper was allotted to the qualitative results, in spite of the stated mixed method design. The study could have further strengthened its</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
					qualitative strand by outlining the rationale for the selected sampling, data collection and data analysis procedures.
Yevchak, 2013 (USA)	<p>To compare the agreement between family caregivers' and research staff's assessment of delirium using the Family Confusion Assessment Method (FAM-CAM)</p> <p>To evaluate factors associated with family caregivers' delirium symptoms reporting</p>	<p><b>Setting:</b> The study was set in two locations in Pennsylvania: 1) general medicine unit at a regional hospital, and a 2) orthopedic unit at a county community hospital.</p> <p><b>Sample:</b> Informal caregiver and patient dyads (n=38) were included. Telephone interviews were</p>	<p>Descriptive exploratory design using quantitative and qualitative methods</p> <p>The study was embedded within a larger randomized controlled trial on nurses' detection of delirium superimposed on dementia. The author collected information about the patients' and informal caregivers' characteristics. Information was collected about the patients' demographics, presence of delirium, delirium subtype, delirium severity, and dementia stage. The author gathered data about the informal caregivers' education</p>	<p><b>Quantitative:</b> The author found poor agreement between research assistant (RA) and informal caregiver ratings of full delirium (k= -0.07) and subsyndromal delirium (k= -0.02) (subsyndromal delirium occurs when persons have two features of delirium, but do not meet the full criteria). There was only one case where the RA and the informal caregiver had agreed that the person with dementia also had delirium. However, there was 100% agreement on hallmark delirium features of acute change and inattention. Family</p>	<p><b>Strengths:</b> Strengths of this study include the detailed description of the study's setting and context. The author provided details about how participants were recruited from the parent study. The variables chosen for the logistic regression analysis (i.e., patient and informal caregiver characteristics) were based on literature. Details regarding the statistical analysis and its results (e.g., p values, kappa, confidence intervals) were reported. There was an explicit description of the thematic analysis, which involved more than one researcher.</p>

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
	To describe the hospital experience and recognition of delirium from the family caregivers' perspective via post-hospitalization telephone interviews	conducted with 23 informal caregivers.	level, previous experience with delirium, and relationship and living arrangement with the patient. The author collected information about the caregivers' recognition of delirium in the patient using the Family Confusion Assessment method within 48 hours of admission. Telephone interviews using semi-structured questionnaires were conducted with 23 informal caregivers within 7 days of hospital discharge. Not all informal caregivers interviewed had a family member with a positive delirium rating as per the research assistant assessment with the Confusion Assessment Method.	caregivers were less likely to report symptoms of delirium per FAM-CAM when the patient had hypoactive delirium (0.0540), and more severe delirium (0.0041). None of the informal caregiver characteristics were significantly associated with reporting of delirium symptoms. <b>Qualitative:</b> The following themes were identified from the interview data:  <b>1) Transitions:</b> This theme described the family caregivers' and clients' transitions of location and its difficulty (i.e., from acute care to home); the family caregivers' observations of transition in thinking; and the adjustment period.	<b>Limitations:</b> The author did not validate or pilot-test the FAM-CAM in acute care, because the tool had only been previously validated in the community setting. Another limitation was the small sample size (n=38). The study's findings are not generalizable to large urban cities with diverse populations, because a majority of the population in the study's setting were Caucasian. In relation to the qualitative data analysis, the author did not explain how they reached thematic saturation. Although the author aimed to conduct a qualitative evaluation of how family members detected delirium, much of the qualitative findings was focused on the family's experience with

Study Authors (Country)	Research Question (s) and/or Aim(s)	Setting and Sample	Methodology	Main Findings of Relevance to Present Study	Critique
			<p>The author used Kappa coefficient (using a 95% confidence interval) to measure the degree to which informal caregivers' recognition of delirium agreed with the assessments of trained research assistants. Logistic regression analysis was used to determine which patient and informal caregiver characteristics were associated with informal caregivers' reporting of delirium symptoms. Lastly, the author used thematic analysis to review the qualitative data.</p>	<p><b>2) Communication:</b> There was a lack of communication about the care plan and delirium symptoms from staff to family. The family caregiver participants expressed wanting to become active participants in care.</p> <p><b>3) Returning to normal or not:</b> This theme refers to the family caregivers' expression of an understanding of what normal behaviour is for the patient with underlying dementia, with some caregivers being able to identify potential causes of the acute change (e.g., pain medication).</p>	<p>DSD and with the health care team</p>

**Appendix B**

**Table B1**

*Critical Appraisal of Quantitative Studies Adapted from: Critical Appraisal Skills Programme (2018a) and Hong et al. (2018)*

Quantitative Studies	Study addressed a clearly focused issue	Cohort recruited in an acceptable way	Exposure accurately measured to minimize bias	Outcome accurately measured to minimize bias	Confounding factors all identified	Confounding factors taken into account in design and analysis	Sufficient follow-up	Appropriate measures	Appropriate statistical analysis
Fong et al. (2019)	Y	Y	Y	Y	N	Y	Y	Y	Y
Grossi et al. (2020)	Y	Y	Y	N	N	Y	Y	N	Y

**Table B2**

*Critical Appraisal of Qualitative Studies Adapted from: Critical Appraisal Skills Programme (2018b) and Hong et al. (2018)*

Qualitative Studies	Clear statement of aims of research	Qualitative methodology appropriate	Research design appropriate for research aims	Recruitment strategy appropriate	Data collection methods were justified	Relationship between research and participants considered	Ethical issues taken into consideration	Data analysis sufficiently rigorous	Clear statement of findings	Value of research discussed
Day & Higgins (2015b)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Schmitt et al. (2019)	Y	Y	N	Y	Y	N	Y	Y	Y	N



**Table B3**

*Critical Appraisal of Mixed Methods Studies Adapted from: Critical Appraisal Skills Programme (2018a) and Hong et al. (2018)*

Mixed Methods Studies	Clear statement of aims of research	Adequate rationale for using a mixed methods design to	Recruitment strategy appropriate	Data collection methods were justified	Measurements appropriate	Statistical analysis appropriate	Outputs of the integration of qualitative and quantitative components adequately	Divergences between quantitative and qualitative results adequately addressed	Different study components adhere to the quality criteria of the methods involved	Ethical issues taken into consideration
Morandi et al. (2015)	Y	N	Y	Y	N	Y	N	N	N	N
Toye et al. (2014)	Y	N	Y	Y	N	Y	N	NA	N	Y
Yevchak (2013)	Y	N	Y	Y	Y	Y	Y	NA	Y	Y

### Appendix C

#### Participant Characteristics Questionnaire for Caregivers

Study ID \_\_\_\_\_

1. What is your age? \_\_\_\_\_
2. What is your gender? \_\_\_\_\_
3. What is the highest level of education you have completed?  
Elementary school  High school  College diploma   
Bachelor's degree  Master's degree  PhD   
Other (Please indicate): \_\_\_\_\_
4. What is your current employment status?  
Full-time  Part-time  Unemployed   
Retired  Homemaker  Other (Please indicate): \_\_\_\_\_
5. What is the age of the person receiving care? \_\_\_\_\_
6. What is the gender of the person receiving care? \_\_\_\_\_
7. What is your relationship to person who receives care? Are you their:  
Spouse/partner  Son/daughter  Son-in-law/daughter-in-law   
Sister/brother  Friend   
Other (Please indicate): \_\_\_\_\_
8. Do you live with the person receiving care? If not, please indicate where the person currently lives: \_\_\_\_\_  
Yes  No
9. Does someone help you care for the person?  
Yes  No
10. If you answered yes to the previous question, please indicate the type of support you receive?  
Formal assistance (i.e., home care, private caregiver services, etc.)   
Assistance from family, friends, neighbours, etc.

Please indicate type of support provided: \_\_\_\_\_

11. When was your family or friend first diagnosed with dementia? Please provide the approximate month and year: \_\_\_\_\_

12. Do you know what type of dementia your family or friend has? If yes, please indicate which type.

Alzheimer's disease       Lewy-body dementia       Parkinson's dementia

Fronto-temporal       Creutzfeldt-Jakob

Other (Please indicate): \_\_\_\_\_

13. What stage of dementia does your family or friend have?

Early       Middle       Late       Not Sure

14. How many years have you provided care for this person? Please indicate: \_\_\_\_\_

15. What led to your family member or friend's hospital admission?

16. When did your family member or friend experience the delirium or sudden confusion?  
Please indicate: \_\_\_\_\_

## Appendix D

### Interview Questionnaire

#### Introduction

Hello, my name is Patricia Julian and I am a Master of Science in Nursing student at McMaster University. This study is about family or friend caregivers' experiences of having an older person with delirium and dementia at the hospital. This study aims to explore caregivers' experiences of delirium and dementia in the hospital, their role in the older person's care, and the type of support that would improve their experiences and involve them in the care of the older person with delirium. By participating in this study, your views will help us identify strategies to better support caregivers in caring for the person with delirium, ultimately to improve both the experiences of older persons and caregivers.

*If the person has passed away since the hospitalization:* I am very sorry for the loss of your (enter relationship). Can If you are willing, we can share resources in relation your loss from the Alzheimer's Society. Thank you for your consideration in participating in the study. (End interview).

#### Interview Questionnaire

During this interview, we will be talking about your experience when your family or friend was hospitalized on the medical-surgical floor (unit to be specified).

##### 1) Caregivers' Experiences of an Older Person with Delirium Superimposed on Dementia (DSD) in the Medical-Surgical Unit

- Recently your older person was in hospital with delirium and dementia, can you tell me about your experience?
- How did the experience make you feel?
- How were you involved in getting your older person to the hospital?
- What changes in your older person's health were worrying to you? When did it start?
- What are your thoughts about the care your older person received?
- Tell me about your interactions with the health care staff during the hospitalization?
- How did the staff provide care for your older person and to yourself?
- What did staff do for the delirium?

##### 2) Caregivers' Involvement in the Detection and Management of DSD

- How did you participate in the care of your older person while they were in the hospital? How did the staff involve you in the care of your older person?
- How would you describe your relationship with the staff while your older person was in hospital?

- What changes in relation to your older person's thinking or mental status did you observe?
- What was your reaction when you observed the change? What did you do next?
- How were you involved in identifying delirium of your older person?
- How were you involved in managing delirium of your older person?
- Tell me how the staff responded to your concerns? How did it make you feel?
- Tell me how the staff shared information with you about your older person while they were in hospital?

3) Recommendations to Improve Caregivers' Overall Experience, and to Support them in the Detection and Management of DSD

- What supports did you receive during the hospitalization in relation to the delirium?
- What did you think the staff did well?
- What could have been done to improve your experience when your older person was in hospital?
- How can staff assist in you identifying delirium (or sudden confusion) in your older person in the hospital ward?
- How can staff help you to manage the delirium of your older person while in hospital?
- How could staff better involve you in the care of your older person?

Is there anything else you would like to share about your experiences when your older person was in hospital with delirium and dementia?

## Appendix E

### Letter of Information/Consent - Caregivers Experiences of Caregivers of Older Persons with Delirium Superimposed on Dementia in Hospital Medical-Surgical Units: An Interpretive Description Study

#### **Investigators:**

##### **Local Principal Investigator:**

Dr. Jenny Ploeg  
Professor, School of Nursing  
McMaster University  
Hamilton, ON, Canada  
**(905) 525-9140 ext. 22294**  
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##### **Student Investigator:**

Patricia Julian  
Graduate Student, School of Nursing  
McMaster University  
Hamilton, ON, Canada  
**(416) 617-4109**  
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You are being invited to participate in a research study about the experiences of family and friend caregivers of hospitalized older people with delirium superimposed on dementia. Delirium is a medical condition that can make people confused. Delirium can change people's behaviour and mood. People with delirium may have low energy or be restless. Some people with delirium may resist care and sense things that are not there. It is important to identify delirium immediately, so it can be treated. Delirium is different from dementia, but they have similar symptoms. Delirium superimposed on dementia happens when a person with dementia also develops delirium.

This research is being conducted by Patricia Julian (Masters student) and Dr. Jenny Ploeg from McMaster University. This study is part of a Masters thesis, which has been supported with funding from the Canadian Institutes of Health Research and the Canadian Nurses Foundation. You have been asked to participate in this study, because you are a caregiver of an older person who had delirium superimposed on dementia during the hospitalization.

#### **What are we trying to discover?**

We are interested in learning about your experiences in the hospital when the older person had delirium and dementia. We also want to understand the role you play in identifying delirium and in caring for the older person during the delirium episode. This experience includes how you worked with staff in caring for your family member or friend. Lastly, we want to find out about the support you need to improve your experience when your family or friend was hospitalized

#### **What will happen during the study?**

You will be invited to a one-on-one interview with the master's student. The interview will be held at a convenient time and place for you. The interview will be about an hour long. During the interview you will be asked questions about your caregiving history. You will also be asked questions about your family or friend's health. For example, we will ask you about how long you have been caregiving. We will also ask when your family or friend was diagnosed with dementia. After collecting this information, we will ask you questions specifically about your experience when your family or friend had delirium in the hospital. For example, we will ask

you about how you were involved with the care of your older person. We will audio tape the interview and write notes with your permission.

### **Are there any risks to doing this study?**

The risks involved in participating in this study are minimal. You may find it stressful to share your experience in caring for a hospitalized person with dementia and delirium. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can also request to take a break. You may also withdraw from the study at any time and have your information removed. If you experience distress during the interview, with your permission, we will give you the contact information of your local Alzheimer's Society. The Alzheimer's Society will have a list of resources, support group and other services for caregivers.

### **Are there any benefits to doing this study?**

The research will not benefit you directly. Your participation will provide a voice for caregivers of persons with delirium and dementia who have been hospitalized. We hope that this study can better help caregivers when their family or friend is hospitalized with delirium and dementia. The study's results can be helpful in ensuring that caregivers of persons with delirium superimposed on dementia are well supported during the hospitalization.

### **Payment or Reimbursement**

Every participant will receive a \$25 gift card at the end of the interview.

### **Confidentiality**

Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. The information/data you provide will remain in a locked cabinet in the Aging, Community, and Health Research Unit, a secure office, at McMaster University. Participants will be assigned a study ID and interview transcripts will not contain any identifying information. Once audio tapes are transcribed, the audio recordings will be deleted. We may also use your quotes in the study report, but the quote will not be associated with your name. Following completion of the study, all data will be archived, kept for five years, and destroyed. Transcripts of the interviews will be kept for five years and then deleted.

### **What if I change my mind about being in the study?**

Your participation in this study is voluntary. You can decide to leave the study at any time, even after signing the consent form or after the interview. If you decide to withdraw, there will be no consequences to you. You can also request to have your data removed. You may also refuse to answer some questions during the interview, but choose to stay in the study. Your decision of whether or not to be part of the study will not affect your continuing access to services or health care.

### Questions about the Study

If you have questions or need more information about the study itself, please email Patricia Julian at juliap3@mcmaster.ca or Dr. Jenny Ploeg at ploegj@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

### CONSENT

I have read the information presented in the information letter about a study being conducted by Patricia Julian and Dr. Jenny Ploeg of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I will be given a signed copy of this form. I agree to participate in the study.

_____	_____	_____
Name of Participant (Printed)	Signature	Date

Consent form explained in person by:

_____	_____	_____
Name and Role (Printed)	Signature	Date

**If you would like to receive a copy of the final report of this study, please add your name, mailing address or email here:**