THE IMPLEMENTATION OF A DELIRIUM KNOWLEDGE TRANSLATION PRODUCT FOR FAMILIES OF THE ELDERLY

by

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Abstract

Family members are in an optimal position to identify changes in behaviour of loved ones suffering from delirium. To date there are no known studies on educational interventions specifically targeting families of the elderly related to delirium outside of the hospital setting.

Using the Knowledge to Action Process, families became involved in the development of a knowledge translation product related to delirium. It was found from two focus groups that participants’ knowledge of delirium was limited. Also, it was determined that participants were most interested in receiving an educational session in a group setting. The education session was developed using feedback from the focus groups as well as evidence based resources. The focus for the education session was on prevention and identification of delirium.

There were a total of seven education sessions held and 16 eligible participants. In each session a pre and post-test for delirium knowledge was given to the participants. There was a significant increase in scores on the post-test following the session. Participants were also given a post session questionnaire to evaluate the education session. Overall the session was well received; participants were often interested in learning more about delirium. Half of the participants felt they would be able to identify delirium in someone close to them. The majority of participants thought that it is important for other families of the elderly to receive a similar session on delirium.
Four to six weeks following the education session, semi-structured telephone interviews were conducted with five participants from the second phase in order to receive further feedback on the intervention. Most participants were able to recall information related to risk factors and signs of delirium. Three participants stated that the education sessions should be longer in order to provide more time for discussion. Participants still thought they would be able to recognize delirium as long as they were close to the person experiencing it. Since the education session none of the participants had witnessed anyone who was delirious.
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Chapter 1

Introduction

In 1921, approximately 1 in 20 people in Canada were over the age of 65 years. By 2001, the proportion of the elderly population grew to 1 in 8, and it is projected that by 2041, approximately 1 in 4 Canadians will be over the age of 65 years (Health Canada, 2002). Increased age is a risk factor for delirium, thus as the Canadian population continues to age, it is likely that delirium will become a larger problem, suggesting the need for a proactive, preventative approach. (Kalisvaart, Vreeswijk, de Jonghe, Gool, & Eikelenboom, 2006; Kolbeinsson, & Jonsson, 1993).

Estimates of prevalence rates of delirium in the long term care setting range up to 57.9% (Caccione, Culp, Dyck & Laing, 2003; Culp et al., 1997; Fries, Mehr, Schneider, Foley, & Burke, 1993; Laurila, Pitkala, Strandberg, & Tilvis, 2004; Sandberg, Gustafson, Brannstrom, & Bucht, 1998; Voyer, Richard, Doucet, Danjou, & Carmichael, 2008). Recent studies have shown that delirium is also quite prevalent in the community in those with dementia. In this population prevalence rates are between 10 and 21.6% (Vilalta-French, Linas-Regla, Lopez-Pousa, & Garre-Olmo, 2008; Fick, Kolanowski, Waller, & Inouye, 2005; Folstein, Bassett, Romanoski & Nestadt, 1991; Rahkokonen et al., 2001; Lerner, Hedera, Koss, Stuckey, & Friedland, 1994).

In the elderly, delirium has been associated with increased risk of death, institutionalization, hospital admission, and has even been linked to the development of dementia (Andrew, Freter & Rockwood, 2006; George, Bleasdale & Singleton, 1997;
Inouye, Rushing, Foreman, Palmer & Pompei, 1998; Kakuma, et al., 2003; Kolbeinsson & Jonsson, 1993; McCusker, Cole, Abrahamowicz, Primeau & Belzile, 2002; Rahkonen, et al., 2001; Rockwood, et al., 1999; Vilalta – French, et al., 2008). In a five year Canadian study by Andrew et al. (2006), it was found that the elderly who experienced delirium, without signs of dementia, had a significantly lower survival rate compared to persons who had not experienced delirium. Eighteen percent of those with delirium survived compared to 70% survival for those without delirium. Delirium is reversible and often times the most common cause of delirium in the elderly population are infections, such as septicaemia, pneumonia or urinary tract infections (Kolbeinsson, & Jonsson 1993). Older adults and family members can be taught the common risk factors for delirium and how to be proactive in the prevention and identification of delirium.

Key to the identification of delirium is the ability to notice behavioural changes from baseline and to act on these changes. In all settings, family members of the elderly are in an optimal position to identify changes in behaviour from baseline thus playing an important role in the detection of delirium. Yet only one study to date has attempted to educate families of the elderly about delirium (Gagnon et al., 2002). A pamphlet was developed and given to families of end-stage cancer patients. Although due to the timing of the intervention many participants did not utilize the materials with which they were provided. Delirium is prevalent in all health care settings, especially in persons with dementia, though whether or not an educational intervention for families of the elderly would be effective in increasing knowledge about prevention and identification of
delirium is unknown. Keeping in mind the negative health outcomes associated with the
development of delirium, families are an underutilised resource. Families of the elderly
hold the potential to aid in the prevention and identification of delirium across health care
settings.

One way to prepare family members to aid in the prevention and detection of
delirium is to provide them with best practice knowledge regarding the symptoms of
delirium as well as factors related to onset. Knowledge translation tools (or products) are
short, easy to read laminates, toolkits, brochures or educational sessions that translate
best practice knowledge so that health professionals and others are able to apply this
knowledge in their everyday work and lives. Graham et al. (2006) created a conceptual
framework which explains the knowledge translation process called the Knowledge to
Action Process. Education of family members based on the Knowledge to Action Process
(Graham et al., 2006) could be beneficial in the prevention, and identification of delirium.
Knowledge to Action is a framework that is used to bring evidence based knowledge
translation products to key stakeholders with the end goal of changing behaviours. One of
the strengths of this framework is that it takes into consideration the cultural context of
the key stakeholders in the implementation of the knowledge translation product. For this
reason the Knowledge to Action Process was used to guide the implementation of a
knowledge translation product with the input of key stakeholders (family members of the
elderly) to enhance knowledge acquisition related to delirium. It was the hypothesis of
this study that a knowledge translation product for this population would increase knowledge related to prevention and identification of delirium.

The following review of the literature will examine the prevalence and risk factors of delirium in the elderly, the impact of delirium on family members and available knowledge translation products. Following the review of the literature, the study design will also be presented. Additionally, the findings from this study will be presented and discussed.
Chapter 2

Literature Review

A review of the current literature was completed in order to determine the state of knowledge surrounding prevalence for delirium outside of acute care, how delirium affects the individual who experiences it and their family, and to determine what knowledge translation products are available for families of the elderly. Several databases were searched including, Ovid SP MEDLINE, CINAHL as well as Google Scholar.

Definition of Delirium

According to the Confusion Assessment Method, delirium is characterized by acute onset, inattention, disorganized thinking and an altered level of consciousness (Inouye, et al., 1990). There are three main types of delirium: hyperactive, hypoactive and mixed. Hyperactive delirium is characterized by agitation and vigilance and hypoactive delirium is characterized by lethargy and decreased motor activity; the third is a combination of the two (Inouye, 2006).

Risk Factors for delirium

Delirium is preventable and reversible. It is brought on by an underlying condition, which can be identified with a proper physical assessment and thorough history taking. Some of the causes of delirium are urinary tract infection, pneumonia, stress, surgery, pain, cognitive impairment or medications that possess anticholinergic properties and benzodiazepines (George et al., 1997; Kolbeinsson, & Jonsson, 1993; Lerner, et al., 1994). In a study by George et al. (1997), patients that met the criteria for
the diagnosis of delirium were compared to a paired control group without delirium. A total of 171 patients with delirium and 95 controls were enrolled in this study. Participants underwent visual and auditory assessments to determine any deficits in these areas. The researchers were able to show that visual impairment was an independent risk factor for the development of delirium. By teaching families the importance of wearing prescription glasses this risk factor could possibly be modified and delirium could be prevented.

In a study to create a predictive model for the development of delirium two cohorts of seniors 70 years and older were assembled (Inouye, Viscoli, Horwitz, Hurst, & Tinetti, 1993). In the first cohort there were a total of 107 hospitalized general medicine patients who did not have a diagnosis of delirium or severe dementia at baseline. The second cohort was assembled to test the model that was developed with the first cohort; there were a total of 174 patients enrolled for this purpose. All patients were screened daily from admission to discharge for delirium using the Confusion Assessment Method and any suspected cases were confirmed by the principal investigator. The risk factors that were included in the final predictive model included: vision impairment, severe illness, pre-existing cognitive impairment, and dehydration. If a participant was identified as having one or more of these risk factors at baseline then they were more likely to develop delirium. A strength of this study is that there were two cohorts, one to gather information for a predictive model and one to test the validity of that model. As well, assessments for delirium occurred daily and were confirmed by a physician.
In another study based on the predictive model mentioned in the previous study, Inouye, et al. (1999) developed a multi-component intervention in an inpatient acute care hospital. The interventions were targeted towards preventing known risk factors for delirium. A total of 426 pairs of patients over the age of 70 years were enrolled in this study. Patients were matched based on age, sex, and baseline risk of delirium. This study targeted interventions towards risk factors for delirium which included: cognitive impairment, sleep deprivation, immobility, visual impairment, hearing impairment and dehydration. To counteract these risk factors multiple interventions were undertaken, including: cognitively stimulating activities, non-pharmacological sleeping aids, increased mobilization, use of visual and hearing aids, and encouragement of fluids. They found that when these preventative measures were implemented to counteract known risk factors for the development of delirium, the incidence of delirium was significantly lower when compared to a control group (Inouye et al., 1999).

The most common cause of delirium is infection (Kolbeinsson & Jonsson, 1993). This could include urinary tract infections which are easily prevented or treated with a course of antibiotics. Families can be taught the common risk factors for delirium and how to be proactive in preventing the development of delirium in elderly persons.

**Prevalence of Delirium**

Inconsistent data exists concerning the prevalence of delirium among the elderly living in the community. To date there has only been one investigation in Canada to study the prevalence of delirium in the community (Andrew et al., 2006). This study was a secondary analysis that was completed using participants from The Canadian Study of
Health and Aging. Information was gathered from participants starting in 1991, then repeated at five and ten years later. Information that was presented in this article was from the first two time points. In this analysis participants who had a complete clinical assessment at the first and second time points were included. This came to a total of 1,658 community dwelling seniors who were over the age of 65 years as well as 1672 seniors who lived in long term care institutions. From these two independent measurements the researchers found the prevalence of delirium in individuals without dementia to be <0.5% (Andrew et al., 2006). The results from this study were gathered using participants who lived in the community and did not have a history of dementia, thus limiting their findings. This would also underestimate the true prevalence of delirium in the entire elderly population in Canada since delirium is more common in those with dementia.

In a case-control study conducted in the United States, Fick et al. (2005) used a database from a large managed care organization to study the prevalence of delirium in a community dwelling population. They studied a population of people over the age of 65 years (n = 76,688) for a total of three years and found that a diagnosis of delirium alone accounted for 1% of their study population at a given point in time (Fick et al., 2005). A total of 7,347 participants had dementia in this study and among these participants delirium had a prevalence of 13%. Participants were diagnosed using the International Classification of Diseases, Ninth Edition Clinical Modification code for delirium or delirium with dementia.
It is important to note that in Canada half a million people have Alzheimer’s disease or a related dementia and it is estimated that one million Canadians will have dementia within the next 25 years (Alzheimer’s Society of Canada, 2009). When participants with dementia are included in the estimation of prevalence rates for delirium in the community, these rates increase dramatically. In such studies prevalence rates have ranged between 10 and 21.6% (Vilalta et al., 2008; Fick et al., 2005; Folstein et al., 1991; Rahkokonen et al., 2001; Lerner et al., 1994). Most of these studies examined cohorts both retrospective and prospective and were conducted outside of Canada. Delirium in the community is quite common among the elderly with dementia, yet no studies could be found to date with the goal of prevention in this population.

In the long term-care sector, estimates of the prevalence of delirium have also been quite high. In the only Canadian study to date, researchers found the prevalence of delirium to be 45.8% (Voyer et al., 2008). This prospective study comes from the Quebec City area and took place in three long-term care facilities and one long-term care unit of a hospital. This study had a total of 155 participants and they were all over the age of 65 years and had a diagnosis of dementia. A limitation of this study is that of the initial sample that was approached, only 54.6% were enrolled in the study. A notable strength of this study is that participants were observed by a trained research assistant for 7 hours on two occasions to detect delirium. In other studies on prevalence the information to classify someone as delirious was taken from a secondary data set (Fries et al., 1993; Mentes, Culp, Maas, & Rantz, 1999). Despite the limited amount of research related to
prevalence of delirium in long term care, it is apparent that delirium does occur in this area.

Studies of the people who presented to emergency departments with delirium show that often people are sent back home without admission or the physician even realizing the patient is delirious. In one Canadian study, 20% of physician detected delirium cases and 29% of undetected cases were discharged home from hospital even though these elderly patients were still delirious (Élie, et al., 2000). This leaves the responsibility of detecting delirium and pursuing further medical assistance in part up to family members. Delirium is a manifestation of another underlying health issue. If left undetected delirium often leads to negative health outcomes. Thus teaching families how to prevent and identify delirium could be beneficial. Although many studies implicate the need for preventative nursing interventions, such as further education of families, only one study could be found with the purpose of educating families about delirium.

**Consequences of Delirium**

Many studies have demonstrated that delirium can cause several negative health outcomes for the individual who experiences it. In one Canadian prospective cohort study the researchers followed patients who were 65 years or older for one year following admission to an acute care hospital (McCusker, et al., 2002). Individuals were excluded if they had a primary diagnosis of stroke or had been admitted to an oncology unit. Additionally, those who were admitted to intensive care or required cardiac monitoring for more than 48 hours were excluded. A total of 243 patients had prevalent or incident
delirium and they were matched with 118 controls that did not have delirium. All participants in this study were screened at baseline and monitored weekly during their hospital stay, at 8 weeks after discharge and at 6 and 12 months after enrolment. After adjusting for multiple variables, researchers found that delirium was independently associated with a two fold increase in death within a 12 month follow up period.

Strengths of this study include that the researchers controlled for comorbidities as well as illness severity. Furthermore, the follow up period was continued until 12 months after enrolment which gives one an idea of the effects of delirium following hospital admission and in the longer term. The study included interviews of family members as well as observation of participants at multiple time points. However, due to the gaps in observation it may have been possible for some of the controls to have developed delirium and gone unnoticed.

Another study to determine the effects of delirium was undertaken at three hospitals in the United States (Inouye, et al., 1998). All sites enrolled elderly persons who were admitted to these acute care hospitals but excluded those who were admitted to intensive care or if they were terminally ill. All participants were interviewed upon admission and discharge as well as 3 months after enrolment. If participants were not able to complete interviews themselves, surrogates were interviewed in their place. In this prospective cohort study a total of 727 patients aged 65 years or older were enrolled and a total of 12% of these patients had delirium on admission. By the three month follow up the patients who had experienced delirium were more likely to experience poor
outcomes, such as a new nursing home placement, or a decline in ability to perform activities of daily living. These results were statistically significant even after controlling for age, gender, diagnosis of dementia, severity of illness and baseline activities of daily living and instrumental activities of daily living scores. A limitation of this study is that the researchers only measured delirium at the baseline interview and did not report on whether there were any incident cases after admission.

Multiple studies have shown that a person who has had delirium is more likely to experience poor health outcomes, including death, new nursing home placement, and a decline in ability to perform activities of daily living. It is necessary that delirium be prevented in order to maintain the health of elderly persons who are at risk for becoming delirious. Families can play a large role in the prevention and identification of delirium thus preventing the negative health outcomes associated with becoming delirious.

**The Role of Family**

The negative outcomes related to delirium are not limited to the person experiencing it. Research has shown that caregivers of the delirious person can also be affected adversely. Two studies showed that caregivers frequently experienced high levels of distress when their family member became delirious (Breitbart, Gibson & Tremblay, 2002; Morita, Hirai, Sakaguchi, Tsuneto & Shima, 2004). The study by Breitbart et al. (2002) recruited a total of 101 hospitalized patients with cancer who had recovered from delirium. All patients had a confirmed diagnosis of delirium according to the DSM IV. The Memorial Delirium Assessment Scale (MDAS) was used to measure
the severity of the delirium, the subtype and to determine if the delirium episode had resolved. The MDAS is a scale that can be used by clinicians to diagnose and rate the severity of delirium in medically ill patients. The Delirium Experience Questionnaire (DEM) was used to assess recall of the delirium experience and the level of distress related to the delirium experience and was administered to patients, families and nurses. The DEM was created for the purposes of this study and was found to be face valid by the investigators. A total of 53.5% of the patients were able to recall their delirium experience. Furthermore, 80% of patients who experienced delirium reported it as severely distressing, additionally, 76% of spouses/caregivers and 73% of nurses reported severe levels of distress. Spouses/caregivers were found to be significantly more distressed than the patients themselves or the nurses providing care. This level of distress in families related to a delirium episode is concerning. It is important that families are educated about delirium so that they may contribute to the prevention and identification of delirium. This education could prevent the stress and negative outcomes that are associated with families as well as the person experiencing delirium.

In the study by Morita et al. (2004) a mailed survey was sent nationwide to families who had experienced a death to evaluate palliative care services in Japan. In the second portion of the survey, families were asked to report the frequency of 12 delirium related symptoms and level of distress they experienced related to each. The symptoms were selected from the MDAS, the Delirium Rating Scale and from interviews with palliative care nurses and bereaved family members. A total sample of 195 surveys were
used for analysis. Participants were asked to rate levels of distress for each symptom on a
5 point likert scale ranging from “not distressed at all” to “very distressed”. More than
two thirds of the family members found all symptoms except for somnolence to be
“distressing or “very distressing” when they occurred “often” or “very often”. A notable
limitation of this study is that they did not confirm the diagnosis of delirium.
Additionally, 38% of persons returned consent forms to participate, and of that sample,
65% returned the surveys. However, despite the limitations of this study it begins to give
insight into how delirium may affect people close to the person experiencing it.

In a recent secondary analysis completed by Buss et al., (2007) the link between
delirium and the mental health of caregivers was explored. Caregivers (n=200) were
asked to report if their family member was experiencing confusion or symptoms of
delirium; to control for the fact that patients were not actually assessed for delirium, the
patient’s score on the Short Portable Mental Status Questionnaire (SPMSQ) was taken
into consideration. In addition patients with baseline cognitive impairment were
excluded. They found that caregiver report of delirium was linked with a lower score on
the SPMSQ which supports a diagnosis of delirium. As well, a caregiver who perceived
delirium was 12 times more likely to have generalized anxiety symptoms. Adding to
these results, the researchers found that there was no relationship between anxiety in
caregivers and their report of observing the patient in pain, choking or thinking the
patient was dead. This suggests that the perceived delirium was the most significant
contributor to caregiver anxiety. The explanation for the anxiety in caregivers given by
the authors was that delirium interrupts the normal relationship between the caregiver and
the patient; the caregiver becomes unable to predict their family member’s behaviour
resulting in the experience of anxiety.

These three studies are the only ones available to date that show a relationship
between delirium and negative outcomes for caregivers of people affected by delirium.
Though the studies have methodological limitations, the studies outline some of the
negative effects that delirium can have on their caregivers. The results suggest that
studies on prevention of delirium could be beneficial for the families’ mental health as
well as the health of their loved one.

In the community, family members may be in the most frequent contact with
elderly persons. In a report from Statistics Canada (2003), one can gain a picture of the
current state of seniors and the care they receive. According to estimates from the 2001
Census, less than 10% of senior women and approximately 5% of senior men live in a
health care institution. This leaves the majority of elderly persons in Canada living in the
community setting. Based on the 2002 General Social Survey approximately one million
Canadians over the age of 65 years who lived in the community reported that they
received care due to a long term health problem. This total accounts for 32% of women
and 21% of men over the age of 65 years. In this report it was found that almost half of
seniors received all of their care from family and friends. This means that a lot of the time
the family may be the only ones managing the health of the elderly adult. Even if there is
home care, the elderly individual may not be in frequent enough contact with a health care professional for them to notice delirium due to its fluctuating nature.

Dellasega and Stricklin (1992) showed in a study of 100 patients admitted to a home health care agency that 50% of people who were cognitively impaired were living on their own. In some cases elderly individuals who were cognitively impaired were living with a partner who was also impaired. In this study, the researchers were unable to differentiate between cognitive impairment and delirium but there is evidence that persons who are cognitively impaired are at a higher risk of developing delirium. Families need to be informed of measures that can be taken to prevent delirium as well as how to recognize it, as they may be the only ones in a position to take action. Through the implementation of a knowledge translation product that could provide this education, families could be given the necessary resources to prevent and identify delirium.

Knowledge Translation Framework

The purpose of knowledge translation is to provide the results of evidenced based research to key stakeholders with the goal of changing behaviours (Davis et al., 2003). Often the research is presented in the form of knowledge translation products and it is these practical adaptations of research that are meant to improve health outcomes and efficiencies of the health care system (Graham et al., 2006). A knowledge translation product takes evidence based knowledge and presents this information appropriately for its target audience. It is important that the information is appropriate for the target audience so that they are able to understand the content of the product and hopefully
apply what they have learned in real life situations. These products can come in the form of brochures, education sessions or any number of formats in order to educate persons about a topic. For the purposes of this study families were given evidenced based information in the form of a knowledge translation product with the goal of providing them with the knowledge they require to aid in the prevention and identification of delirium in their elderly family member.

A conceptual framework was developed by Graham et al. (2006) which clarifies the process of knowledge translation. The Knowledge to Action model is divided into two main categories: knowledge creation and the action cycle (see Appendix A - permission was received to use model). An overview of the framework will follow, with a focus on the action cycle. The omission of knowledge creation in this study’s intervention is intentional as this was less relevant to this particular study.

In the Knowledge to Action Process, the action cycle is an illustration of the implementation and application of knowledge. First a problem is identified and knowledge is selected in order to address this problem. Knowledge can come in the form of practice guideline or findings from relevant research studies. This knowledge is then adapted so that is appropriate for the setting and target audience. Before implementing any interventions barriers to implementation need to be assessed. From the information gathered here, an intervention can be selected, refined and implemented in a way that is tailored to the target audience. From this point on, knowledge use can be monitored, outcomes are evaluated and knowledge use is sustained over time. It is important to note
that these stages are not always linear and may occur at many points throughout the cycle.

Knowledge translation is not specific to health care providers. The users of knowledge translation products can include patients, family members, policymakers, and health care professionals (Graham et al., 2006). The principles remain the same no matter which group forms the target audience. Knowledge translation targets the needs and contextual influences of the target audience. The current study used the process of knowledge translation as outlined in Graham et al. (2006)’s Knowledge to Action Process to guide the implementation of a knowledge translation product related to delirium for family members of the elderly.

**Knowledge Translation Products**

To date the research in the area of educating families concerning the identification and prevention of delirium has been lacking. Only one study was found that developed something that could be considered a knowledge translation product for this population. Gagnon et al. (2002) developed a study to educate families about delirium in the acute care setting. A focus group was held with professionals who had experience in palliative care, this included, physicians, nurses, social workers, psychologists, clergymen, and volunteers. A total of 15 people from these professions attended a focus group session to determine the clinical relevance, content and type of intervention to provide to families about delirium in the palliative care setting. Additionally, 21 family caregivers were individually interviewed to ascertain their knowledge of delirium, their experiences with
confusion in family members, and what they thought about the distribution of a delirium brochure. Following the focus groups and interviews, 20 family members were given a brochure which contained a definition of delirium, information about symptoms, causes and treatments as well as how to interact with someone who has delirium. After receiving the brochure, families were interviewed to evaluate it and who they thought should receive such a brochure. Based on all of the data that was gathered the final educational brochure was developed and delivered to all family caregivers. The brochure was explained to families by a nurse. A total of 124 family caregivers were interviewed two to three weeks after the death of the patient they had cared for. In follow up, families revealed this brochure to be helpful. They stated that when they knew what delirium was, they felt more confident in making the right decisions about their family member and felt that the information should be given to all caregivers. Since the participants in this study were family members of advanced cancer patients some families later admitted to not reading the brochure at all. The authors suggested that educational interventions should be completed earlier on in the course of disease, even before hospital admission, perhaps in the home care setting. This proactive approach would be useful in the prevention and identification of delirium. Knowledge translation is an appropriate model to develop such an intervention. Early recognition of delirium is important to reduce the negative effects associated with delirium. Education needs to be provided to this group for prevention and identification of delirium to be possible.
Conclusion

From a review of the literature it can be seen that the effects of delirium are far reaching. People that have delirium experience negative health outcomes as well as the people who are close to them. Delirium is prevalent in the elderly population living in the community with dementia and in long term care facilities and it is preventable and reversible. Only one study to date has shown the benefit of educating family members related to delirium in improving health outcomes, but it was in an acute care setting. Researchers were able to show that families of the elderly are not aware of the nature of delirium or how to identify it. Through an educational intervention the participants’ knowledge was increased (Gagnon et al., 2002).

There were no other studies found that targeted families of the elderly. Yet this population, due to their frequent contact, may be in the best position to identify subtle changes in their family member’s behaviour that may indicate the onset of delirium. The implementation of a knowledge translation product for this population may be valuable for increasing the knowledge of family members concerning prevention and identification of delirium.

Research Questions

To help fill the gap in the current research, this study set out to answer the following questions: What type of knowledge translation product related to delirium would best suit the needs of family members? How can the knowledge translation product best be disseminated to family members? Is the resulting knowledge translation...
product effective in increasing family members’ knowledge related to prevention and identification of delirium?
Chapter 3
Methodology

Introduction

The purpose of this study was to implement a knowledge translation product about delirium for family members of the elderly and to explore its impact on their knowledge of delirium. As per the Knowledge to Action Process, key stakeholders (family members) were involved in the implementation of a knowledge translation product. The knowledge translation product that was implemented took the form of an educational session. Please see Figure 1 for an overview of the three phases.
Figure 1

Overview of the Study

Phase 1 ➔ Phase 2 ➔ Phase 3

Focus Groups ➔ Education Session ➔ Follow-Up Interviews

Delirium Knowledge Test
- Completed immediately before and after session

Questionnaire
- Completed following session

Follow-Up Interviews
- 4-6 weeks following education session
While guidelines from the Canadian Coalition for Senior’s Mental Health have suggested the need for family education, only one study to date has looked at the effects of an educational intervention related to delirium for this population (Gagnon et al., 2002). Thus, the knowledge translation product that was implemented required a great deal of input from family members throughout all stages of development. As such, measures were taken to determine the family member’s knowledge of delirium, opinions of the tool’s utility and to determine areas for future improvement. There were three phases completed in this study. First, a focus group was used to determine mode of delivery and educational content of the knowledge translation product. Through the focus groups it was agreed that an educational session would be most ideal. Second, the educational session was presented to participants and it was evaluated through a questionnaire. Additionally, knowledge of delirium was measured during this stage through a multiple choice pre and post-test. Third, a follow up interview was completed four to six weeks following the session to determine retained knowledge of delirium as well as to further evaluate the session.

**Ethical considerations.** Ethics approval was received from Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. Informed consent was obtained from the participants before enrolment in this study. For phase one, informed consent was obtained before starting the focus group and a copy of the consent form was given to each participant (Appendix B). In the second phase, consent was obtained before the beginning of each education session (Appendix C). At this time
participants were also asked if they would be willing to participate in the third phase of the study. If the participant provided their contact information for this purpose then they were contacted. In phase three, if the participant was contacted, the purpose of the follow up was explained again and consent was obtained over the phone. There was no known harm that can come to the participants from participation in this study. To ensure confidentiality, any recorded conversations and their transcriptions were kept on a secure computer and only accessible by the principal investigator.

**Phase 1**

**Research design.** For this portion of the study, focus groups were used to gain insight into the educational needs of the participants related to delirium education. Focus groups can be used to gather data about people’s feelings and opinions surrounding an experience, problem or other phenomenon (Basch, 1987). Groups usually consist of 6-10 participants that share a common experience (Speziale & Carpenter, 2007). It is important to make sure that focus groups are held in a physical setting that will encourage comfort and intimacy among participants to enhance discussion. A topic guide should be created to guide the discussion. Additionally, it must be made clear to the participants the purpose of the focus group in order to gather as much relevant information as possible (Basch, 1987). It was not known how much families knew about delirium and if they lacked knowledge and found it important to learn about delirium, it was not known how they would want to learn about it. Due to this lack of knowledge, holding focus groups to
gain insight into the family’s needs related to a knowledge translation product about delirium was necessary.

**Sampling procedure.** Participants for the focus groups were recruited using a convenience sample from the Alzheimer’s Society in Kingston. Two focus groups were held at the Alzheimer’s Society in Kingston. The focus groups were held there as it was the most convenient way to gather a group of families of elderly persons since they were already attending regularly scheduled meetings. To be included for this portion of the study participants were over the age of 18 years, they had an elderly family member who was 65 years or older and they were in contact with that person one or more times per week. It was a goal of this study to have 6-10 participants in each focus group to facilitate discussion amongst participants. The number of focus groups held was determined by the emergence of new themes. If no new themes were found after evaluation of the data collected from each group then this stage of the study would be complete.

**Participants.** A total of two focus groups were held, one on September 2, 2009 and the other on September 9, 2009. On September 2nd a total of eight participants attended and on September 9th there were five participants. All participants met the inclusion criteria for the first phase of this study. None of the participants had an occupational background in healthcare. Other than the criteria mentioned above no other demographic data were collected.

**Setting.** The two focus groups took place at the Alzheimer’s Society in Kingston. The focus groups were held in the same room that groups usually met in to maximize
familiarity and comfort with their surroundings. The room contained couches and a few chairs arranged in a circle for participants to sit in and a table in the centre of the room. The facility provided refreshments for the participants to have during the session.

**Focus groups.** A topic guide was developed by the principal investigator and was used (Appendix D) to lead the group in discussion. It was unknown what type of knowledge translation product participants would prefer, for example it could have been a pamphlet or an educational session. In order to determine what format would be most suitable, topics covered included baseline knowledge of delirium, individual learning styles, preferred method of delivery for the knowledge translation product, and when would be the best time to receive the product. There were two focus groups scheduled to last approximately one hour each. The first focus group took place on September 2, 2009 and the second took place on September 9, 2009. The moderator for the focus groups was the principal investigator. The principal investigator is a Registered Nurse who has experience working with families of the elderly and persons with delirium. Each focus group was recorded using a RCA digital recorder (model: RP5120-A) so that the conversations could later be transcribed verbatim.

**Data analysis.** Transcriptions from each focus group were analysed thematically by the principal investigator. The themes that emerged were used to chose the appropriate format for the knowledge translation product that would later be implemented.
Phase 2

**Research design.** For this phase of the study multiple education sessions were held with families of the elderly. It was the goal of this study to recruit 20 or more participants. A questionnaire and a pre- and post-knowledge test were used to evaluate the education sessions. By using a pre- and post-test design one can measure the change following the implementation of an intervention (Stommel & Wills, 2004). In this case the participants’ knowledge of delirium was measured with this design. Additionally, a questionnaire was used in order to evaluate the session in order to gain insight into potential areas for improvement.

**Sampling procedure.** Participants in this phase were recruited through various methods but all consisted of a convenience sample. Most participants were recruited at regularly occurring meetings at the Alzheimer’s Society. Advertisements for these sessions were given to members of the Alzheimer’s Society by their group facilitators. For sessions that were held outside of the Alzheimer’s Society participants were recruited by word of mouth and advertisements in local newspapers.

Inclusion criteria were: the participant must be an adult (≥ 18 years of age) who may or may not live with the elderly family member, the participant must have been in frequent contact with the elderly family member either through visiting the person or through speaking to them regularly. Regularly was defined as one or more times per week. Additionally, the elderly family member must have been 65 years or older. Exclusion criteria were the following: persons who were paid health care workers hired
to provide care. If the family member happened to be employed in the health care field they would be included in the study. To control for any background knowledge among participants who were also health care professionals, these individuals’ knowledge scores would be analysed separately to see if there was a difference when compared to participants in other occupations.

**Participants.** In total there were seven education sessions held from October 2009 to April 2010. Overall there were 25 people who attended the sessions. Three people were excluded as they did not have an elderly family member but they still wanted to attend the session. Four participants did not return the questionnaire following the session and two refused to participate. This left a total of 16 participants’ responses for thematic-analysis (See table 1). All participants included in the final analysis met the inclusion criteria for the first phase of this study.
Table 1

*Participants Included and Excluded from Study*

<table>
<thead>
<tr>
<th>Education Session</th>
<th>Oct 27 2009</th>
<th>Oct 28 2009</th>
<th>Nov 18 (Am) 2009</th>
<th>Nov 18 (Pm) 2009</th>
<th>Feb 26 2010</th>
<th>March 6 2010</th>
<th>April 24 2010</th>
<th>Total for all sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Included in study</td>
<td>0</td>
<td>5</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>16</td>
</tr>
<tr>
<td>Excluded from study</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Did not return questionnaire</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Refused to participate</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>
**Setting.** Educational sessions took place in multiple settings. Four of the sessions took place at the Alzheimer`s Society, three at the Kingston location and one at the Napanee location. At the Kingston location two of the groups were held in the rooms where the groups usually met and one was in a larger room to accommodate for a larger number of people. All of the rooms had chairs for the participants and table space so that participants could take notes if required. Two of the education sessions were held outside of the Alzheimer`s Society in a church located in the Kingston area. Again chairs and tables were available for the participants.

**The education session package.** Each participant was given a package of documents to supplement the education that was given. The package included consent forms, a pre- and post-knowledge test (Appendix E), a questionnaire (Appendix F), a reference card (Appendix G), and two pamphlets related to the material presented (Appendices H and I). The number of resources for families related to delirium is somewhat limited. Multiple resources from the Vancouver Island Health Authority (VIHA) were used for this phase as they contained the most relevant information for the purposes of this study and they were targeted towards a lay audience. From the limited number of resources available it was the resources from the VIHA that best met the purposes of this study.

The pamphlets given to participants were created by the VIHA and used with their permission. The pamphlet titled “Delirium in the older person: family guide” (2009) (Appendix H) was chosen because it contains a comprehensive guide for families of the
elderly on how to prevent and identify delirium as well as information about causes, risk factors, treatments and who to seek help from. It was created from multiple evidenced based resources. There is also a helpful tool on the pamphlet which allows for information to be collected about an elderly family member’s usual behaviours, medical history, any changes to medications, and cues for the signs of delirium. The reference card that was handed out to participants was modified from the tool on the VIHA pamphlet and given to the participants as a separate card. The only modification that was made to the card was to include the phone number for Telehealth Ontario since the original contact information was intended for residents of British Colombia.

The second pamphlet was titled “The 2 D’s: Comparison between delirium and dementia” (2006) and was developed by the VIHA as well (Appendix I). This information was included in the package for caregivers because many of the participants from the focus group confused delirium with dementia. This pamphlet gives multiple comparisons between delirium and dementia to illustrate how they can be differentiated.

The knowledge test was modified from a similar test from the VIHA that was intended for health care professionals. The test was revised in order to gear the content to a lay audience. The decision to modify the knowledge test from the VIHA was made since there were no other tests available that were intended for a lay audience. The test consisted of four multiple choice questions and one true or false statement. Neither test has been validated or tested for reliability. The pre- and post-tests contained identical questions.
The questionnaire consisted of 12 questions and was developed by the principal investigator. Some questions were used to determine eligibility of family members to participate in the study. Other questions were used to evaluate the study and to determine the session’s effectiveness in teaching families about delirium. Overall the questions were used to answer the research questions that were mentioned previously.

**The education session.** From the focus groups it was determined that an education session would be most appropriate to teach this population about delirium in the elderly. The education session contained information related to prevention and identification of delirium as well as what to do if a family member becomes delirious. The pre-knowledge test was administered immediately prior to the start of the session and the post-test was given immediately following the education session and included the questionnaire. However, if a participant did not have sufficient time to complete the post-test and questionnaire, they had the option to complete it at home and mail it to the principal investigator. An envelope and postage was provided if this was the case.

Each education session was delivered in a similar manner by the principal investigator. A session guide was created to ensure that topics covered would be the same in each session (Appendix J). Throughout the session participants were encouraged to ask questions and discuss material presented. Each session was scheduled to last one hour. In addition a video clip was played at each session from a DVD titled “Delirium in the Older Person: Family Guide” made by the Vancouver Island Health Authority (2007). The DVD was used to supplement the material presented and to illustrate one elderly
persons personal experience with delirium. The DVD was intended for families of the elderly, so it presents the information clearly for persons who may not be familiar with medical terminology.

**Data analysis.** Information from the questionnaire was analysed thematically by the principal investigator in order to evaluate the education session. There were 11 complete pre- and post-test knowledge test pairs. Scores from the knowledge test were compared using the Wilcoxon Signed Rank Test at an α level of .05. Since the sample was small, the calculations were completed by hand by the principal investigator.

**Phase 3**

**Research design.** For this portion of the study semi-structured telephone or email interviews were conducted with participants. This method was used to further evaluate the education session.

**Sampling procedure.** In the consent form from phase two, all participants were asked to provide contact information, either a telephone number or an email address, if they were willing to complete a follow up interview four to six weeks following the education session. Participants were contacted by the principal investigator four weeks following the session. If the participant was not reachable at that time they were contacted again each week up to six weeks following the education session or until contact was made.

**Participants.** Participants from this phase of the study all met the same inclusion and exclusion criteria as in phase two since they were the same people. A total of six
participants consented to be contacted by telephone and seven by email. Of these, five were successfully contacted by telephone; none of the participants returned the email questionnaire.

**Setting.** Interviews were arranged to take place either over the telephone or via an email questionnaire based on which option each participant chose.

**The interviews.** Participants were notified in the second phase of the study that there would be an opportunity to participate in a follow up interview four to six weeks following the education session. The option was given to each participant that if they were willing to participate the interview could be conducted on the telephone or via an email questionnaire. At the time of the telephone interview participants were again asked if they would like to participate and explained the purpose of the interview. Each telephone interview was audio recorded using an RCA digital voice recorder (model: RP5120-A). An interview guide was created by the principal investigator and participants were encouraged to share any comments concerning the session they wished (Appendix K). Topics covered included: knowledge of delirium, strengths and weaknesses of the education session, usefulness of materials given to participants, and if they thought other members should receive a similar session about delirium. Interviews were scheduled to last approximately 10-20 minutes.

**Data analysis.** Each interview was transcribed verbatim and analysed thematically by the principal investigator in order to further evaluate the education session.
Chapter 4

Results

In this section the results from each phase of the study will be reported separately. For all phases of the study, themes that arose will be explained and tables with primary and secondary codes will be provided. The results from the pre- and post-knowledge test will also be presented.

Phase One

A number of themes arose from the groups which will be described in further detail in the following paragraphs. Please note that the number tallies for each theme do not represent the number of people who stated something, instead it is the number of times the theme arose during the focus groups.

Delirium knowledge. (Table 2) Overall participants in the focus groups did not have a very clear understanding of delirium. When asked what they thought delirium was, many participants admitted that they did not know what it was. Others attempted to guess but quite often participants mistook symptoms of dementia for that of delirium, for example “My wife thinks her parents are still living sometimes and they’ve been dead for years”. Another participant stated that “I always thought it was another stage of dementia”. Other participants shared this view that dementia and delirium are the same. Despite the overall lack of knowledge concerning delirium some participants did have a partial understanding related to previous experience with delirium.
His mother was in the hospital after she had hip surgery… she broke her leg and
she was just right out of it, I mean just talking silly and nothing made sense …you
know talking about chickens and she hadn’t had chickens for how many
years…but nurses and doctors don’t know whether that was real or not…or
whether it was present time.

Another participant described it as:

My experience with delirium is when they are either getting sick and you haven’t
noticed why but they aren’t with you at all. They’re just somewhere else and
they’re very agitated often times…you know that there’s something, something
really different, something going on that you don’t know what it is.

**Preferred Learning Style.** (Table 3) Most people agreed that a combination of
approaches would be most appropriate to educate families about delirium.

I think one of the big things for me that makes things stick in my mind is
elements…so you talk about the theory and…even and visual is helpful and
having something to follow, like if I can actually refer to, cause also just talking
about something, I don’t have a framework…and then something to take home
that I can review or go through or put in my file for further reference.
### Table 2

**Themes Phase One: Delirium Knowledge**

<table>
<thead>
<tr>
<th>Secondary Code</th>
<th>Primary Code</th>
<th>Count</th>
<th>Focus Group 1</th>
<th>Focus Group 2</th>
<th>Total n=13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delirium Understanding</td>
<td>Delirium brought on by illness</td>
<td></td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Unaware of reality</td>
<td></td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Delirium Misconception</td>
<td>Dementia and delirium as one</td>
<td></td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Interchangeable with hallucinations</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>More common in younger people</td>
<td></td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Admitted to not knowing about delirium</td>
<td></td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

### Table 3

**Themes Phase One: Preferred Learning Style**

<table>
<thead>
<tr>
<th>Secondary Code</th>
<th>Primary Code</th>
<th>Count</th>
<th>Focus Group 1</th>
<th>Focus Group 2</th>
<th>Total n=13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Auditory Learners</td>
<td>Learning through discussion</td>
<td></td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Learning with movies</td>
<td></td>
<td>7</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Visual Learners</td>
<td>Learning through handout/checklist</td>
<td></td>
<td>8</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Auditory/Visual Learners</td>
<td>Combination of handout/discussion</td>
<td></td>
<td>1</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
Most participants felt that “…a discussion is much better because over the past few years I have had so much paper work handed to me and I personally don’t get time sometimes to even read it”.

To accommodate multiple learning styles it was agreed upon by both focus groups that an education session would be the best format to learn about delirium. This way there would be information geared towards both auditory and visual learners through a combination of methods including, discussion, a video clip and handouts for future reference.

**Useful Resources.** (Table 4) When participants were asked what would be a helpful resource in the case of emergency, most often participants requested a reference card. They wanted something that they could put by their phone or on their fridge so they could have a reminder about the symptoms of delirium. One participant stated:

I have it right on the side of my fridge I have the…symptoms of a heart attack and stroke what you look for…I sort of study all of this stuff and I sort of get an idea of just what to look for right off the bat.

In addition to a reference card people wanted more information about resources available on the internet. They wanted to know about reliable sites that are available to learn more about delirium. Participants also wanted to learn about who they could talk to if they suspected that their family member had delirium.
Table 4

*Themes Phase One: Useful Resources*

<table>
<thead>
<tr>
<th>Secondary Code</th>
<th>Primary Code</th>
<th>Count</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Focus Group 1</td>
<td>Focus Group 2</td>
<td>Total n=13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n=8</td>
<td>n=5</td>
<td></td>
</tr>
<tr>
<td>Resources for Emergencies</td>
<td>Reminder beside phone</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Fridge Magnet</td>
<td>4</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Call Family</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Telehealth</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Go to emergency</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Family Dr</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Call 911</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Additional Resources</td>
<td>Interest in internet resources/other resources</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

*Note.* Additional resources reflect items not included in resources for emergencies.
Factors Affecting Attendance. (Table 5) Participants were asked what they thought would be useful to draw people to an education session. Participants stated often that they had very busy lives with many responsibilities related to caring for their elderly family member. They felt that they needed to know that learning about delirium was a priority before attending a session. One participant stated that:

…if people know that it’s important to them, they will come. So, if I just see the word delirium and I don’t even know what it means, I don’t know if I’ll go if I don’t think it’s important, or if it’s significant.

Another participant explained:

There are so many things you can go to and that’s what I find is really the hardest part about being a caregiver is too many things and you have the full responsibility for everything, including looking after the place, outside work and everything.

It was agreed upon by most people that holding the information session on a Saturday would be appropriate. During the week people had varying schedules and no one day could be agreed upon other than Saturday. This was found to be the best way to accommodate multiple schedules. Participants also felt that it would be very easy for them to have the education session during their regularly scheduled support group meetings.

In general, it was agreed upon by participants that having multiple education sessions at different times of the day and week would be most accommodating to
everyone’s busy schedules. Additionally, it was important that potential participants understand the personal significance of delirium to increase interest in attending an education session.
Table 5

Themes Phase One: Factors Affecting Attendance

<table>
<thead>
<tr>
<th>Secondary Code</th>
<th>Primary Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Focus Group 1 n=8</td>
</tr>
<tr>
<td>Barrier to Attendance</td>
<td>Busy Schedule/overwhelmed</td>
<td>0</td>
</tr>
<tr>
<td>Facilitate Attendance</td>
<td>Access to car</td>
<td>Not asked</td>
</tr>
<tr>
<td></td>
<td>Understanding Importance to them personally before attending</td>
<td>2</td>
</tr>
<tr>
<td>Scheduling</td>
<td>Day</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Fall/spring</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>During support group</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Weekday</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Saturday</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Afternoon</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Between Meals</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Multiple dates/times</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Evening</td>
<td>0</td>
</tr>
</tbody>
</table>
Phase Two

In the second phase of this study participants were asked to complete a questionnaire as well as a knowledge test before and after the education session. All participants who completed the questionnaire also completed at least one or both of the knowledge tests. All of these results are presented below.

Participants. (Table 6) None of the participants had an occupational background in healthcare. Five of the participants had also participated in the focus groups from phase one. In total there were ten participants living with their elderly family member. Of the other elderly family members four lived in nursing homes, one lived in a retirement home, and one lived alone in their own home. All the participants who did not live with their elderly family member were in contact with them at least once per week.
Table 6

Phase Two: Participants

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Session</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your occupation? If you are retired, what was your occupation?</td>
<td>No health care background</td>
<td>1 n=5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 n=7</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 n=1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 n=1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5 n=2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total</td>
<td>16</td>
</tr>
<tr>
<td>Did you attend the focus group session with Shannon Parry in September 2009?</td>
<td>No</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>No answer</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Is the person you are caring for over the age of 65?</td>
<td>No</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Do you live with the person you are caring for?</td>
<td>No</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>If you do not live with the person you are caring for, where do they live (ie. In a nursing home/retirement home, in their own home)?</td>
<td>Nursing Home</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Retirement Home</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Own home</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>If you do not live with the person you are caring for, how many times per week are you in contact (by phone or in person) with the person you care for?</td>
<td>One or more times/week</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Not applicable</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>
**Retained knowledge.** (Table 7) There were three answers that stood out when participants were asked what the most important thing was that they had learned. First, four participants described that delirium had a rapid onset. Second, four participants described various risk factors for delirium. For example one participant stated that “Knowing the list of things that could put them at risk (or at the very least compromise their abilities) ex. Meds – such as gravol, pain meds, sleeping pills. –hydration, sleep, hearing, vision, stress, blood sugar, infections etc”. Third, three participants stated that now they knew what they needed to do if their family member became delirious.

**Strengths/weaknesses of session.** (Table 8) When participants were asked what else they would like to learn about delirium most said they wanted to learn more about the causes of delirium. The same number of people stated that the session was very informative as it was. Two participants requested that the handouts be numbered so they could know which handouts were to be completed first. When asked if there are any additional handouts that they thought would be useful three participants stated that they did not think that they required any additional material. Two participants said that they would like to have additional materials related to more specific causes and prevention techniques. For example one participant requested a “list of meds that may be problematic and the reasons why they are of concern.”

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Table 7

Themes Phase Two: Retained Knowledge

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>What was the most important thing you learned about delirium today?</td>
<td>Rapid Onset</td>
<td>2 1 0 0 1 4</td>
</tr>
<tr>
<td></td>
<td>Changes in Attention</td>
<td>1 0 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>Risk Factors</td>
<td>2 1 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>What to do if delirium</td>
<td>0 3 0 0 0 3</td>
</tr>
<tr>
<td></td>
<td>suspected</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Behaviour changes</td>
<td>1 0 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>Hallucinations</td>
<td>0 1 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>Have dealt with delirium</td>
<td>0 1 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>before but unaware at the</td>
<td></td>
</tr>
<tr>
<td></td>
<td>time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Does not apply to my wife</td>
<td>0 1 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>Can happen to anyone</td>
<td>0 1 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>Presents in various ways</td>
<td>1 0 0 0 0 1</td>
</tr>
<tr>
<td></td>
<td>Familiar with delirium</td>
<td>0 0 1 0 0 1</td>
</tr>
<tr>
<td></td>
<td>Treatable</td>
<td>0 0 0 1 0 1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>What was the most important thing you learned about delirium today?</td>
<td>Total n=16</td>
<td></td>
</tr>
</tbody>
</table>
Table 8

*Themes Phase Two: Strengths/Weaknesses of Session*

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Session 1</td>
<td>Session 2</td>
<td>Session 3</td>
<td>Session 4</td>
<td>Session 5</td>
<td>n=16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n=5</td>
<td>n=7</td>
<td>n=1</td>
<td>n=1</td>
<td>n=2</td>
<td></td>
</tr>
<tr>
<td>What else would you like to learn about delirium?</td>
<td>Causes</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Prevention</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Process of Delirium</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Statistics of people affected</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Possible interventions</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Session very informative</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Any other comments/suggestions?</td>
<td>Number the handouts</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Enjoyed the video clip</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Nothing</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Enjoyed presentation</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>What other materials related to delirium would you like to receive?</td>
<td>Material on causes and prevention</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Fridge magnet</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Nothing Else</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Anything</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>No answer</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
**Self efficacy.** (Table 9) A total of eight participants felt that if their elderly family member became delirious that they would be able to recognize it. One participant stated “Yes, I feel the checklist is very helpful and I will know what situations I need to be more alert eg. operation, stress etc”. Three participants were unsure if they would recognize delirium “I’m not sure as I am in the early stages of Alzheimer’s with my husband and there is so much to learn”.

**Value of session.** (Table 10) Ten of the 16 participants felt that it would be important for other families of elderly persons to learn about delirium. Three people stated that it would be important so that they had a better understanding of what was happening to someone who was experiencing delirium. Two participants thought that it would be helpful so that families could differentiate delirium from dementia. One person stated “There can be a lot of confusion especially when the dementia is involved”. Three participants thought that it would be important for families to know how to identify delirium and “because the symptoms too easily be dismissed or mistaken for something else”.
Table 9

*Themes Phase Two: Self Efficacy*

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Session 1 n=5</th>
<th>Session 2 n=7</th>
<th>Session 3 n=1</th>
<th>Session 4 n=1</th>
<th>Session 5 n=2</th>
<th>Total n=16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think that you would be able to recognize if someone had delirium? Please Explain.</td>
<td>Yes</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>No answer</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>
### Table 10

*Themes Phase Two: Value of Session*

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think other caregivers of the elderly could benefit from an education session like this? Why?</td>
<td>Yes</td>
<td>4  4  0  0  2  10</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>0  0  0  0  0  0</td>
</tr>
<tr>
<td></td>
<td>Possibly</td>
<td>0  0  0  1  0  1</td>
</tr>
<tr>
<td>No answer</td>
<td></td>
<td>1  3  1  0  0  5</td>
</tr>
<tr>
<td>To differentiate from dementia</td>
<td>1  1  0  0  0  2</td>
<td></td>
</tr>
<tr>
<td>To learn to identify</td>
<td>2  1  0  0  0  3</td>
<td></td>
</tr>
<tr>
<td>To understand what is happening</td>
<td>0  1  0  0  2  3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Session 1 n=5</th>
<th>Session 2 n=7</th>
<th>Session 3 n=1</th>
<th>Session 4 n=1</th>
<th>Session 5 n=2</th>
<th>Total n=16</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**Knowledge test.** (Table 11) The participants of the educational session took part in both a pre- and a post-test to measure a change in knowledge of delirium. Each participant was given a mark out of five for the knowledge test. A higher mark on the test suggests a greater knowledge of delirium. There were a total of 11 out of 16 complete pre- and post-knowledge tests. Five of the participants only completed the pre-test and were dropped from the analysis. The median score on the pre-test was 2, the median score on the post-test was 3. Using the Wilcoxon Signed Rank Test this difference was found to be statistically significant when \( W=0, p = <0.05 \).

**Phase Three**

Follow up interviews were completed with each participant who consented to be contacted from phase two. All participants were contacted between four and six weeks following the education session they attended.

**Retained knowledge.** (Table 12) Overall participants had retained some of what they had learned from the education session. Four participants were able to recall information related to risk factors for delirium as well as the signs of delirium. When asked about risk factors for delirium one participant stated that “infections, medications side effects, worsening of illness, dehydration, malnutrition…um grief and stress” could put someone at risk for delirium.
Table 11

*Phase Two: Knowledge Test Scores*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pre test</th>
<th>Post Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>16</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>19</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>20</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>25</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

*Note.* Scores from both the pre and post-test are out of five marks.

Table 12

*Themes Phase Three: Retained Knowledge*

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What do you think puts someone at risk for getting delirium?</td>
<td>Delirium Understanding</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Delirium Misconception</td>
<td>1</td>
</tr>
<tr>
<td>2. Do you remember any of the signs of delirium?</td>
<td>Delirium Understanding</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Delirium Misconception</td>
<td>1</td>
</tr>
</tbody>
</table>
**Strengths/weaknesses of session.** (Table 13) From the interviews a variety of strengths and weaknesses arose. Three participants stated that there was nothing else that they would have liked to learn about delirium. One person had made prevention practices for delirium part of their routine for their elderly family member. Four of the participants thought that the reference card was a good tool. One participant stated that “I think it is good because…if you are aware of someone having it, you could just grab that off the fridge door”. Four participants were unsure of any additional material that they would have liked to receive. Three participants stated that having longer education sessions would be an area for improvement. One participant stated:

> I think the only thing was and this happens to us all the time, for most sessions, is we get going in a discussion or people have questions and we get feel like cut off or you get cut off… it’s really healthy when the group starts to say, hey this happened and this happened, because it makes it more meaningful.

Two additional participants stated that it would be an improvement to have more discussion and time for questions. One participant in phase two had suggested that PowerPoint may have been a helpful tool to use during the education session. When participants were asked in phase three about their opinion on this three of them did not know what PowerPoint was. After an explanation was given three participants thought that it might be helpful.

**Self Efficacy.** (Table 14) Participants were asked if they thought they would be able to determine if someone had delirium. Two participants thought they would be able
to recognize delirium. The other three thought they would be able to recognize delirium in someone that they were close with but they were not certain of this. One participant stated:

If I knew how they normally are, had a comparison, yes….I might suspect if I didn’t know and I saw some extreme behaviours I might suspect it and then suggest, but if I knew the person it would probably be quite um, obvious.
Table 13

Themes Phase Three: Strengths/Weaknesses of Session

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Was there anything else you would have liked to learn about delirium?</td>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Gained a mental image of person with delirium</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Made prevention part of routine care</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Unsure</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>6. In what way was the yellow/red card helpful?</td>
<td>Signs/symptoms to watch for</td>
<td>1</td>
</tr>
<tr>
<td>Should be a magnet</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Liked the card</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Good reference tool</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Information to present to health care professional</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>7. What other materials would have been helpful to receive?</td>
<td>Unsure</td>
<td>4</td>
</tr>
<tr>
<td>Received enough material</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Tool for reference</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>9. In what ways could the education session you received be improved?</td>
<td>Unsure</td>
<td>1</td>
</tr>
<tr>
<td>Enjoyed the video</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Make session longer</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>More sharing of experiences</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Longer video</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>10. Would you have liked to have a power point presentation?</td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Maybe</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Not familiar with power point</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>12. Any other comments/suggestions?</td>
<td>Enjoyed session</td>
<td>2</td>
</tr>
<tr>
<td>Learned importance of prevention</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Good refresher</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Table 14

Themes Phase Three: Self Efficacy

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Do you think that you would be able to tell if someone had delirium?</td>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
<td>3</td>
</tr>
</tbody>
</table>

Usefulness of Session. (Table 15) Participants were asked if they had used any of the materials they were given. Two participants had not used any of the materials and two had filed them away for future reference. Since the education sessions no participants had witnessed delirium in anyone that they knew. When participants were asked if other caregivers should receive delirium education all participants said yes. Two participants thought it would be helpful for family to learn the difference between delirium and dementia. One participant stated “well maybe they wouldn’t be hasty to say, well oh she’s got Alzheimer’s and they’ll sort of watch and get them to the doctor”.

In summary, the findings of this study covered three phases of the process. In the first phase of this study a lot of useful data was gathered to build an education session to meet the needs of this population. In phase two and three an evaluation of the session was undertaken. Overall the education session was well liked by participants. Important feedback was received from participants to improve the education session that was delivered.
Table 15

*Themes Phase Three: Usefulness of Session*

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Since you attended the education session have you used any of the materials that were given to you?</td>
<td>Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Filed away for later reference</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Need to learn to manage information</td>
<td>1</td>
</tr>
<tr>
<td>8. Since having the education session, do you think you have had any experiences with delirium? If yes, how did the education session prepare you for this?</td>
<td>No experience with delirium</td>
<td>5</td>
</tr>
<tr>
<td>11. Do you think other caregivers of the elderly could benefit from an education session like this? Why?</td>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Learn difference between dementia/delirium</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Learn that it is an emergency</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Don’t learn things unless in situation</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>To know what to expect</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>To learn how to help</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Revisit past behaviours</td>
<td>1</td>
</tr>
</tbody>
</table>

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Chapter 5

Discussion

Overall useful information was learned from this study that could be used to establish a knowledge translation product for families of the elderly in the future. In the following sections the discussion addresses each phase of the study, as well as examining the findings as they relate to the Knowledge to Action Process and the literature.

Phase One

In keeping with the Knowledge to Action Process it was important to include participants in the implementation of the education session; this is why focus groups were used in the beginning of this study. The main findings from the focus groups were that participants did not have a good understanding of delirium, they wanted to be educated about delirium in the format of an education session, participants wanted multiple sessions at varying times and they wanted a reference card about delirium. These results are consistent with the study by Gagnon et al. (2002), who found that prior to their intervention, participants lacked knowledge concerning delirium. In the current study, since many people were unfamiliar with delirium, participants explained that it would be important to inform families of its applicability to them. Based on this recommendation, a flyer was created and posted in multiple settings in order to inform people of the sessions and the health implications of delirium.

In the focus groups, participants mentioned that they were usually bombarded with pamphlets and information. For this reason, materials that were given to supplement
the education session were kept to a minimum. The reference card was important because it could be easily accessible and it had important information for the participants to refer back to when needed.

One of this study’s strengths is that participants were asked for input, through the use of focus groups, to determine the most appropriate way to implement the education session. A limitation of the focus group is that the principal investigator lacked experience in the role of a moderator. However, a great deal of useful information was gained from the participants to create an education session that was ultimately well received.

In the study by Gagnon et al. (2002), the educational intervention consisted of two parts in order to address the learning needs of the participants. Participants were able to learn about delirium from a nurse as well as from a brochure. This study by Gagnon et al. (2002) was successful in some aspects. Caregivers in the intervention group had a higher level of perceived confidence and thought that all family caregivers should receive a similar intervention. The benefit of the current study is that participants were educated about delirium, given reference materials and allowed to discuss experiences. Most participants from the current study requested that a combination of methods be used to learn about delirium, including, discussion, movies, and handouts. This accommodation of various learning styles was intended to increase the likelihood of the participants’ comprehension of educational material provided.
Phase Two

Recruitment for the education session was the largest barrier to this study. Initially participants were recruited through the Alzheimer’s Society in Kingston. When this was no longer possible other avenues needed to be explored. Advertisements were placed at a local church as well as in a local newspaper. One participant was recruited from advertisements and two by word of mouth, the rest of the participants came from the Alzheimer’s Society. Originally the goal was to recruit 20 participants. While 25 people attended, there were only 16 people who agreed to participate and qualified for the final analysis. Due to time constraints during the education session, which were held at the Alzheimer’s Society, it was not possible to allot time for participants to fill out questionnaires following the session. This led to many participants not returning the questionnaire or knowledge test. Additionally, since many of the education sessions were held during regularly scheduled support group meetings anyone who wanted to learn about delirium was invited to stay and participate in the study if they wished, even if they did not meet the inclusion criteria for this study. This is why even though 25 people attended the sessions only 16 were included in the final sample for analysis.

While recruitment numbers was a limitation for this study, other researchers have conducted studies over longer periods of time and were able to compile larger samples. However there were still problems with retention of participants (Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007; Hepburn et al., 2005). There are many potential barriers to recruiting families who provide care for an elderly family member. In a study
by Connell, Shaw, Holmes & Foster (2001) 50 family caregivers of elderly persons with dementia were interviewed about the barriers and facilitators to participating in research studies. Caregivers liked the support and interpersonal contact they received from research staff. Barriers to their participation included the perception that the research was not applicable to their situation, the inconvenience related to participation, as well as not having the time or resources to arrange for frequent visits to the study site. Participants from the current study listed some similar barriers to participation especially related to the issue of time. Families that are caring for an elderly person are busy and if they do not understand the applicability of the research to their unique situation they may choose not to participate. This in part explains why recruitment was an issue for the current study, due to the general lack of knowledge of delirium in families of the elderly.

Results from phase two of this study show that half of the participants felt they would be able to identify if a family member was delirious. In the interviews from the third phase the number of participants who felt this way did decrease. Whether or not this confidence truly does decrease over time would need to be determined in a larger study, especially considering the attrition rate between phases two and three of this study. However, this is still a considerable finding especially since baseline information gathered from focus groups suggests that there was not a good understanding of delirium. Additionally, in the study by Gagnon et al. (2002) they also found that the participants who had received their intervention had a greater perceived competence.
The results from the knowledge test show that there was a significant increase in the scores from the pre- to post-delirium test. However, due to the small sample size and the lack of a validated knowledge test for this population whether this increase can be attributed to an actual increase in knowledge of delirium cannot be determined. Another limitation of a pre- and post-test in an educational intervention is that the pre-test may sensitize a participant to the intervention and change the way that they would respond to the intervention if there had been no pretest at all (Stommel & Wills, 2004). If there were a separate control group this effect could be controlled. The use of a control group to control for this effect would have required more time for recruitment, as it would have required an even larger sample size. Due to time constraints this would not have been possible for this study.

Most participants from both follow up questionnaires felt that other families should be educated about delirium. Similarly, Gagnon et al. (2002) found that participants who received an educational intervention more often stated that all caregivers should receive a similar intervention related to delirium. This suggests that families from both studies valued the education they received about delirium. In order for education sessions such as this to work in the future it is essential that families feel that delirium education is important.

Another point that participants brought up was that the session was not long enough and consequently there was not enough time for discussion and sharing of experiences. Participants would have benefitted from additional discussion; it may have
assisted in identifying with the reality and severity of delirium, as quite a few participants had an experience with delirium in the past.

**Phase Three**

In the third phase of the study, only five participants were successfully contacted for follow up, thus limiting the generalizability of the results from this section. Four of the five participants were able to describe delirium which suggests they had retained some of what they had learned in the weeks following the session. It was interesting to see that one participant had made delirium prevention part of their routine care. It would have been interesting to know if any of the other participants from phase two had done this as well. Allowing a longer time for follow up and increased participant retention may have produced additional useful results. For example, none of the participants had interacted with anyone who was delirious since the education sessions. With a longer follow up they may have encountered delirium while caring for their family member and would have been able to describe whether this intervention had prepared them for this.

**Knowledge to Action Process**

This study was guided by the Knowledge to Action Process by Graham et al. (2006). This is a conceptual model that was developed in order to clarify the subject of knowledge translation. For the purposes of this study the focus was on the action cycle of the Knowledge to Action Process. How this process was used to shape this study will be presented in the following paragraphs.
In the first phase of the action cycle a problem needs to be identified. Through the use of focus groups, it was determined that families of the elderly lacked an understanding of delirium. The focus group was also used to gain insight into how to tailor the intervention to families of the elderly and assess barriers to implementation of an education session.

For the second phase of the study, existing educational resources were gathered and appraised for their level of appropriateness for a lay population and the best available resources were chosen. Such resources included pamphlets and a video from the VIHA. Additionally, a review of the literature was completed to ensure that families would be educated using up to date information concerning the prevention and identification of delirium. This gathering and synthesis of the available research and resources would represent the identification, review, and selection of knowledge stage from the action cycle of the Knowledge to Action Process. Once the review of the literature and resources was complete, the education session was implemented. Information that was given to the participants was adapted to their needs and cultural context which is an important stage of the action cycle. Following each education session a knowledge test and a questionnaire was completed by participants. Responses on the questionnaire were used to further tailor the intervention to the needs of the participants. The knowledge test was used to determine if participants had acquired knowledge following the intervention.

The purpose of the third phase of this study was to further receive feedback in order tailor the intervention to the participants, monitor knowledge use, and evaluate
outcomes. It is important to ensure that participants perceive that there is a benefit to adopting knowledge translation products (Berwick, 2003). The participants in this study did say that they thought it would be important for other caregivers to learn about delirium, suggesting they valued the education. To further evaluate this education session it would have been beneficial to understand whether or not participants applied what they had learned and why they chose to or not. This further insight into participant’s perceptions would prove useful in further work with delirium education in this population. Additionally, further research will be needed in order to determine whether knowledge use can be sustained over time.

**Implications for Practice**

Education of nurses concerning delirium is a vital step in the future education of families related to delirium. Nurses in many settings often provide health education to families of the elderly. Organizations have recognized the need for the integration of delirium education, including the Registered Nurses’ Association of Ontario (RNAO) and the Canadian Coalition for Seniors’ Mental Health (CCSMH). The CCSMH has released national guidelines pertaining to the assessment and treatment of delirium in the elderly population (CCSMH, 2006). It has been suggested by the CCSMH that health care teams include families in the care of a person with delirium and that they are provided with education concerning this topic. It is this alliance between health care workers and families that would improve the care for an elderly person with delirium. In addition the RNAO has a best practice guideline titled “Screening for Delirium Dementia and
Depression in Older Adults” (RNAO, 2010). Both of these publications are excellent tools for nurses to begin the enhancement of our knowledge of delirium. It is important that the guidelines from these documents be incorporated into nursing practice through the use of knowledge translation in order to improve prevention and identification of delirium in all practice settings.

Research suggests that nurses may be lacking in knowledge related to delirium. In one study by Milisen et al. (2002), researchers found that nurses underreported cases of delirium in their documentation. False negative documentation ranged respectively from 87.5% to 50% on the first and twelfth day postoperatively. The nurses were also more likely to document delirium if the patient was expressing symptoms of the hyperactive form. This suggests that perhaps nurses are unaware of the symptoms of the hypoactive form and these patients may be labelled as being tired or even depressed and would not receive the same attention as someone with the hyperactive form of delirium. Delirium in the nurses’ charting was often referred to as “acute confusion” or “confusion”; nurses were asked to define these terms and were not able to clearly explain them. In the medical documentation there was no formal diagnosis or charting of any of the common signs of delirium, suggesting more attention needs to be paid to the patient’s mental health by the health care team.

In another study by Inouye, Foreman, Mion, Katz, and Cooney (2001) researchers found that nurses only recognized delirium in 31% of 131 delirious patients. There were four independent risk factors that were found to contribute to this under recognition;
these included, if the patient had hypoactive delirium; 80 years of age or more; visual impairment; and dementia. If a patient had all of these risk factors nurses were 20 times more likely not to recognize delirium.

These studies provide evidence that nurses require additional education concerning delirium. Nurses need further education in this area so that they can educate the public. It is important that the evidenced based knowledge is incorporated into various organizations. It would also be beneficial for nurses to learn more about knowledge translation techniques so that they can take what they have learned about delirium and tailor it to their unique target population. Just as individuals and families respond to a variety of educational methods and tools, nurses also may need a variety of tools and educational approaches in order to make use of the guidelines put forward by the CCSMH and the RNAO.

Families can offer a wealth of information concerning baseline characteristics of their elderly family member which would aid in the identification of delirium. If nurses themselves do not recognize the cues of delirium how can they evaluate the information they are given by families? Nurses can also learn much from the Knowledge to Action Process which would enable them to better inform families of evidence based research related to key health issues such as delirium. It is also concerning to see that nurses are more likely to not recognize delirium in a patient with dementia when this is the group that will experience much higher rates of delirium. If nurses were to receive more education about delirium they would in turn be able to pass this knowledge on to families.
of the elderly. Perhaps this education of nurses needs to be more integrated into education at the undergraduate level in multiple areas of the curriculum. Nurses frequently work with the elderly persons and delirium is a prevalent condition in this population. More attention needs to be paid to this issue throughout the nursing community. Improved prevention and identification of delirium by families as well as nurses is possible through further education of nurses. This additional education will be vital in the coming years.

**Role of Family**

Families have a wealth of information related to the normal behaviours of the elderly family members. Since delirium is represented by a change in the normal behaviours of a person, the knowledge that a family member possesses about what is baseline for that individual is quite valuable. According to the General Social Survey from 2002 the majority of elderly persons live in the community setting (Statistics Canada, 2003). Additionally, 32% of women and 21% of men over the age of 65 years reported receiving care for a long term health problem. Among this group, almost half reported that they received all of their care from family or friends. Since many elderly persons are living outside of health care institutions and receiving care from family and friends this leaves these caregivers in the best position to be able to identify delirium. Even if someone did receive home care, due to the fluctuating nature of the symptoms of delirium, it may go unrecognized. In the current study families were able to acquire knowledge related to the prevention and identification of delirium and were able to retain this knowledge after a 4-6 week period. Further education of this population should be a
priority for health care professionals as they could play an integral role in the prevention and identification of delirium across health care settings. It will also be important in the future to determine whether or not education of this population related to delirium does in fact prevent delirium or increase the identification of delirium.

Delirium does not only affect the person who is experiencing it. Two studies were able to show that caregivers frequently experienced high levels of distress when their family member became delirious (Breitbart et al., 2002; Morita et al., 2004). It is important that we take advantage of the information that families possess in order to prevent the negative outcomes associated with delirium for the person who is experiencing it and the families. It is imperative that we take advantage of the knowledge they have of baseline behaviours of elderly persons, as too often the signs of delirium are dismissed by health care professionals. By using the knowledge they have, we may be able to increase the identification of delirium and hopefully increase prevention in the future.

**Implications for Future Research**

To the author’s knowledge, this study is the first to attempt to design a delirium educational product for families of the elderly outside the hospital setting. Despite the small sample size valuable lessons can be learned for future studies in this area. Future studies could work to improve the education session that was developed in this study as it is important that this type of product be disseminated. To increase sample size it may be beneficial to partner with organizations in communities who already work with families
of the elderly in order to sample from their membership. Sessions should be made longer to facilitate discussion among participants as learning through sharing of experiences will make delirium seem more relevant to families of the elderly and hopefully solidify what they had learned. Greater numbers of participants will be needed in order to determine if an education session such as this is enough to increase delirium knowledge. Also it would be beneficial to determine if educating families about delirium decreases rates of delirium or increases identification of delirium. This would need to be a longitudinal study which was not possible in this case.

**Conclusion**

It is important for future research to focus on this population related to education about delirium. Families of the elderly are the common link between all healthcare settings. They possess invaluable knowledge related to the baseline behaviours of their loved ones and they are in the ideal position to identify changes in these behaviours that could be a result of delirium. In the coming year’s further education of nurses will also be necessary. As the population continues to age, delirium rates in all settings will only increase unless something is done to increase prevention and identification. Finding a way to educate families about the identification and prevention of delirium may be the key to preventing delirium and its negative outcomes in multiple settings. As health care professionals we must find a way to ease the burden on the health care system that delirium causes; in the years to come this will become increasingly apparent.
References


Appendix A

Knowledge to Action Process


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Appendix B
Phase One: Consent Form

Information and Consent Form: Phase 1

Title: The Effects of a Knowledge Product on Family Caregiver Knowledge about Delirium

You are invited to participate in a research study directed by Shannon Parry to evaluate the usefulness of education related to delirium knowledge. Shannon Parry will read through this consent form with you and describe procedures in detail and answer any questions you may have. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

1. The purpose of this study is to determine if education has any effect on knowledge related to delirium. You will be considered for the study if you are 18 years or older, and are in contact with an elderly family member (65 years or older) one or more times per week.

2. You will participate in a focus group to aid in the development of an educational product related to delirium.

There are no known risks associated with participation in this study.

By participating in the focus group you may be considered for following phases of the study which would include evaluation of the tool developed. This study will also be used to build future tools for other families related to delirium.

You will not be considered for this study if you are a hired health care worker for the person who is receiving pay for providing care.

The focus group session will be audio recorded. All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. Data will be stored in password protected computer files and will be available only to Shannon Parry and her faculty supervisor. You will not be identified in any publication or reports.
Your participation in this study is voluntary. You may withdraw from this study at any time.

Statement of Participant:

I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

If at any time I have further questions, problems or adverse events, I can contact:

Shannon Parry RN, BNSc at shannon.parry@queensu.ca
or
Dr. Diane Buchanan, RN, PhD at 613-533-6000 extension 78907.

If I have questions regarding my rights as a research subject I can contact:

Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 613-533-6081

By signing this consent form, I am indicating that I agree to participate in this study.

_______________________  ____________________
Name and Signature of Participant  Date

_______________________  ____________________
Name and Signature of Witness  Date

STATEMENT OF INVESTIGATOR:
I, or one of my colleagues, have carefully explained to the subject the nature of the above research study. I certify that, to the best of my knowledge, the subject understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_______________________  ____________________
Signature of Principal Investigator  Date

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Information and Consent Form: Phase 2

Title: A Knowledge Product on Delirium for Family Caregivers

You are invited to participate in a research study directed by Shannon Parry to evaluate the usefulness of education related to delirium knowledge. Shannon Parry will read through this consent form with you and describe procedures in detail and answer any questions you may have. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

1. The purpose of this study is to determine if education has any effect on knowledge related to delirium. You will be considered for the study if you are 18 years or older, and are in contact with an elderly family member (65 years or older) one or more times per week.

2. You will receive an educational session. Prior to the session you will be asked to fill out a questionnaire. After the session you will be asked to fill out a questionnaire immediately following the session and again 4-6 weeks later.

There are no known risks associated with participation in this study. You will learn about delirium and how to identify and prevent it. This study will also be used to build future tools for other families related to delirium. You will not be considered for this study if you are a hired health care worker for the person who is receiving pay for providing care. All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. Data will be stored in password protected computer files and will be available only to Shannon Parry and her faculty supervisor. You will not be identified in any publication or reports. Your participation in this study is voluntary. You may withdraw from this study at any time.

Statement of Participant:
I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.
If at any time I have further questions, problems or adverse events, I can contact

Shannon Parry at shannon.parry@queensu.ca
or

Dr. Diane Buchanan, RN, PhD at 613-533-6000 extension 78907.

If I have questions regarding my rights as a research subject I can contact

Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 533-6081

By signing this consent form, I am indicating that I agree to participate in this study.

_________________________  _________________________  _____________________
Name of Participant       Signature of Participant       Date

_________________________
Signature of Witness

Date

STATEMENT OF INVESTIGATOR:
I, or one of my colleagues, have carefully explained to the subject the nature of the above research study. I certify that, to the best of my knowledge, the subject understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_________________________  _____________________
Signature of Principal Investigator       Date

Note: If you are able to complete a short follow up questionnaire 4-6 weeks following the education session, please provide your contact information below.

Please indicate whether you would prefer to be contacted by phone or email.
Phone: _______________________

OR

Email: _______________________

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Appendix D

Phase One: Topic Guide

2. How do you remember things you might need in an emergency?
3. What would be helpful for you to learn about delirium?
4. Do you watch videos?
5. Do you attend classes?
6. Do you use a calendar at home?
7. Would you be interested in attending a free educational session on delirium?
8. What time of the week/day would you most likely be able to attend a session on delirium?
Appendix E

Phase Two: Delirium Knowledge Pre and Post-test

1. Someone that has delirium will have:
   a) Sudden confusion, sometimes confused and sometimes okay, normal attention, sleepy
   b) Sudden confusion, behaviour does not change, having trouble paying attention, seeing and hearing things that aren’t there
   c) Sudden confusion, sometimes confused and sometimes okay, having trouble paying attention, having trouble staying awake
   d) Slowly becoming more confused, trouble paying attention, seeing and hearing things that aren’t there, forgetful

2. Which of the items below increase the risk for delirium?
   a) Age 75 or older
   b) Has dementia
   c) Has an infection
   d) Takes many medications
   e) Change of surroundings (ex. New home, being in hospital)
   f) All of the above

3. True or False: Delirium is a medical emergency ______

4. Which of these items **DOES NOT** help prevent delirium?
   a) Offering fluids, and eating well
   b) Encouraging the use of glasses if needed
   c) Promoting healthy hearing
   d) Making sure the person stays in bed until they are better
   e) Talking about current events and surroundings

5. What should you do if you think your family member is delirious?
   a) Take them to your family doctor
   b) Wait to see if they get better
   c) Give them a sleeping pill to help them relax
Appendix F

Phase Two: Post Session Questionnaire

Please complete the following questionnaire. If you do not have enough time to complete this during the education session please insert the questionnaire in the self addressed pre paid envelope that was provided to you. If you have any questions you may contact Shannon Parry by email at shannon.parry@queensu.ca

1. What is your occupation? If you are retired, what was your occupation?
2. Is the person you are caring for over the age of 65?
3. Do you live with the person you are caring for?
4. If you do not live with the person you are caring for, where do they live (ie. In a nursing home/retirement home, in their own home)?
5. How many times per week are you in contact (by phone or in person) with the person you care for?
6. What was the most important thing you learned about delirium today?
7. What else you would you like to learn about delirium?
8. Do you think that you would be able to recognize if someone had delirium? Please Explain.
9. What other materials related to delirium would you like to receive?
10. In what ways could the education you received today be improved?
11. Do you think other caregivers of the elderly could benefit from an education session like this? Why?
12. Any other comments/suggestions?
Appendix G
Handout From Phase Two: Reference Card

**Is it Delirium?**
If you suspect delirium, please fill out both sides of this checklist and take it to your healthcare provider (e.g., family doctor, emergency ward, etc.). You can also call Telehealth Ontario 1-866-797-0000

- [ ] Unable to pay attention?
- [ ] Restless and upset?
- [ ] Sleepy, then alert?
- [ ] Speech slurred?
- [ ] Not making sense?
- [ ] Sees or hears things not there?
- [ ] Mixes up days and nights
- [ ] Unable to concentrate?
- [ ] Doesn’t know where they are?
- [ ] Can’t stay awake?

**Medical History**
- [ ] Dementia?
- [ ] Depression?
- [ ] Previous delirium?
- [ ] New illness?

List medications, both prescribed and over-the-counter, include herbal remedies.

1. ____________________________
2. ____________________________
3. ____________________________
4. ____________________________
5. ____________________________
6. ____________________________
7. ____________________________
8. ____________________________

List any medications that have been recently started or stopped.

1. ____________________________
2. ____________________________
3. ____________________________
4. ____________________________
5. ____________________________
6. ____________________________
7. ____________________________
8. ____________________________

When did you first begin to notice a change in behaviour? ____________________________

**My family member’s usual behaviour:**

**Thinking ability:** How is the person’s usual concentration, attention, memory, problem-solving, ability?

Thinking ability: ____________________________

**Daily routines:** Describe the person’s housekeeping, meal prep, social contacts, transportation routines.

Daily routines: ____________________________

**Communicating:** What is their style of self-expression? Can they use the telephone, computer, or write letters?

Communicating: ____________________________

**Mood:** Is the person easy-going or a worrier, optimistic or pessimistic?

Mood: ____________________________

**Sleep habits:** Describe the person’s usual pattern, and remedies that help them sleep.

Sleep habits: ____________________________

**Note:** If the person has dementia, please describe their abilities before the beginning of delirium symptoms.
Appendix H
Handout From Phase Two: Delirium in the Older Person

My family member’s usual behaviour:

Thinking ability: How is the person’s usual concentration, attention, memory, problem-solving ability?

Daily routines: Describe the person’s housekeeping, meal prep, social contacts, transportation routines.

Communicating: What is their style of self-expression? Can they use the telephone, computer, or write letters?

Mood: Is the person easygoing or a worrier, optimistic or pessimistic?

Sleep habits: Describe the person’s usual patterns, and remedies that help them sleep.

If the person has a dementia, please describe their abilities before the beginning of delirium symptoms.

Will my family member return to normal?

For many people, delirium can clear in a few days or weeks. Others may not respond to treatment for many weeks. Some do not fully return to their normal selves. You may see some problems with memory and thinking that do not go away. Each person is different. Please talk with your health care provider about your family member or loved one.

Who should I tell?
- Family doctor
- Local health clinic
- Hospital social worker
- Home support agency
- Community nurse
- Seniors outreach program
- In British Columbia, call the BC Nursesline – dial 8-1-1.

Questions to ask the Health Care Provider:
- What is causing the delirium?
- How long will it last?
- Will my family member get better?
- How can we prevent it from happening again?
- Should changes be made in the person’s environment?
- How can we as a family help?

For more information about delirium:
www.vhha.ca/inthebasics/delirium/

Delirium in the Older Person
Family Guide

“My family member is not usually like this.”

Delirium is not Dementia
Delirium is a sudden onset of mental confusion causing changes in behaviour.
Older people are at greater risk.
Recognizing and reporting the symptoms early can save lives.
What can cause Delirium?

- An infection
- Medication side-effects
- Not taking medications as prescribed
- Recent surgery with anesthetic
- Worsening of a chronic illness
- Dehydration
- Malnutrition
- High or low blood sugar
- Constipation or diarrhea
- Pain
- Alcohol intoxication or withdrawal
- A recent injury (e.g., a fall)
- Recent move or hospitalization
- Grief and stress over a recent loss (e.g., death of family, friend, pet)
- Ill-fitting hearing aids or glasses
- Low B12

What puts my family member at risk?

Your family member is more likely to develop a delirium if he or she has:

- Had a delirium before
- Memory or thinking problems
- Severe illness resulting in hospitalization
- Dehydration
- Problems with seeing or hearing
- Taking 5 or more medications

What does Delirium look like?

People with delirium can act confused and may:

- Be restless and upset
- Stutter when speaking
- Not make any sense
- See or hear imaginary things
- Mix up days and nights
- Drift between sleep and wakefulness
- Be forgetful
- Have trouble concentrating
- Be more alert than normal
- Not know where they are
- Have trouble staying awake

How is Delirium treated?

Treating delirium means treating the underlying cause. The cause of the delirium needs to be figured out before treatment can begin. This usually means doing tests and answering questions. Once the cause is understood, treatment may include medication as well as adjustments to the elder’s environment. There are many ways to help your family member. Please talk to your health care provider about what you can do.

What can I do to help?

- Promote healthy rest and sleep:
  - Reduce noise and distractions
  - Keep light low or off when resting
  - Increase comfort with a pillow, blanket, warm drink or back rub
  - Do not use sleeping pills if possible
- Promote physical activity:
  - Help with sitting and walking
  - Talk with your health care provider about exercise and safe activities
- Promote hydration & healthy eating:
  - Encourage and help with eating
  - Offer fluids often
- Promote healthy hearing:
  - Encourage the wearing of hearing aids
  - Make sure hearing aids are working
- Promote healthy vision:
  - Encourage wearing of glasses and keep them clean
  - Use enough light
  - Consider using a magnifying glass
- Promote mental stimulation:
  - Arrange for familiar people to visit
  - Talk about current events and surroundings
  - Read out loud; try large print or talking books

Is it Delirium?

If you suspect delirium, please fill out both sides of this checklist and talk to your health care provider (e.g., family doctor, emergency room, etc.)

- Unable to pay attention?
- Restless and upset?
- Sleepy, then alert?
- Speech slurred?
- Not making sense?
- Sees or hears things not there?
- Mixes up days and nights?
- Unable to concentrate?
- Doesn’t know where they are?
- Can’t stay awake?

Medical History:

- Dementia?
- Depression?
- Previous delirium?
- New illness?

List medications, both prescribed and over-the-counter. Include any herbal remedies.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
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<tbody>
<tr>
<td>3</td>
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<td>5</td>
<td>6</td>
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<tr>
<td>7</td>
<td>8</td>
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</tbody>
</table>

List any medications that have been recently started or stopped.

<table>
<thead>
<tr>
<th>1</th>
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<tbody>
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<td>5</td>
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</tbody>
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When did you first begin to notice a change in behavior?
# Appendix I

Handout from Phase Two: “The 2 D’s”

## THE 2 D’s

Comparison between DELIRIUM and DEMENTIA

<table>
<thead>
<tr>
<th></th>
<th>Delirium</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>An acute or sudden onset of mental confusion as a result of a medical, social, or environmental condition.</td>
<td>Progressive loss of brain cells resulting in decline of day-to-day cognition and functioning. A terminal condition.</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>Hours to months, dependant on speed of diagnosis.</td>
<td>Years (usually 8 to 20)</td>
</tr>
<tr>
<td><strong>Thinking</strong></td>
<td>Fluctuates between rational state and disorganized, distorted thinking with incoherent speech.</td>
<td>Gradual loss of cognition and ability to problem solve and function independently.</td>
</tr>
<tr>
<td><strong>Mental status testing</strong></td>
<td>Testing may vary from poor to good depending of time of day and fluctuation in cognition.</td>
<td>Will attempt to answer and will not be aware of mistakes.</td>
</tr>
<tr>
<td><strong>Memory</strong></td>
<td>Recent and immediate memory impaired.</td>
<td>Inability to learn new information or to recall previously learned information</td>
</tr>
<tr>
<td><strong>Sleep-wake cycle</strong></td>
<td>Disturbed, and sleep-wake cycle is reversed (up in night, very sleepy and sometimes non-responsive during the day)</td>
<td>Normal to fragmented</td>
</tr>
<tr>
<td><strong>Hallucinations &amp; delusions</strong></td>
<td>Often of a frightening or paranoid nature.</td>
<td>Can be present. May misperceive. In Lewy body dementia, visual hallucinations present.</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>Diagnosis based on rapid onset of fluctuating symptoms. Can be mistaken for dementia progression.</td>
<td>Usually diagnosed approximately 3 years after onset of symptoms. Must rule out other cause of cognitive decline, e.g. depression or delirium.</td>
</tr>
<tr>
<td><strong>Care approaches</strong></td>
<td>Early recognition is key. Keep person safe, find cause of the delirium and treat as quickly as possible.</td>
<td>Maintain and enhance abilities that remain. Focus on the positive and support the lost abilities.</td>
</tr>
<tr>
<td><strong>Prognosis</strong></td>
<td>Treatable and reversible, especially if caught early.</td>
<td>Progression can be slowed but not reversed.</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td>Treat cause. Monitor response. Be alert for relapse.</td>
<td>Cholinesterase inhibitors slow the progression of some dementias. Symptomatic treatment with environmental &amp; staff approaches.</td>
</tr>
</tbody>
</table>

Appendix J

Phase Two: Education Session Guide

1. Give education session package (fridge magnet, pamphlet from VIHA, 2D’s, consent form, questionnaire) (5 min)

2. Discuss study and sign consent forms (10 min)
   - Explain highlighted areas
   - Remember to explain 4-6 week follow up and get contact info

3. Pre-test (5 min)
   - Circle only one answer per question
   - Don’t expect you to know the answers
   - Used to measure your baseline knowledge of delirium
   - Hand in when you are done

4. Overview of Delirium (from VIHA pamphlet) (15 min)
   - What does delirium look like?
   - Person may not have all symptoms, must have acute onset and fluctuation of symptoms and inattention and either disorganized thinking or altered level of consciousness
     - Acute change: Change from baseline that happens in a short period of time (hours/days)
     - Inattention: problems with concentration, can’t follow a conversation, easily distracted
     - Disorganized thinking: rambling, irrelevant conversation, switching from subject to subject
     - Altered level of consciousness: sleepy, hyper
   - Other symptoms:
     - Disorientation: not knowing time of day/year, where they are
     - Memory Impairment: can’t remember things that have happened to them, can’t remember instructions
     - Perceptual disturbances:
       - Seeing or hearing things that aren’t there
       - Hallucinations (sensory experiences that people believe to be real, seeing things, hearing things, smelling
things, tasting things, experiences are created by the mind but do not really exist.

- Illusions: false belief, distorted perception of reality
  - Psychomotor agitation/retardation: increased movement, picking at clothes, can’t sit still, opposite: sluggish, staring into space, staying in one position for a long time
  - Altered sleeping cycle: reversed - awake at night, sleeps during day, having trouble staying awake

- Risk Factors for delirium
  - Related to an underlying condition/medical problem
  - Infection: Urinary tract infection, pneumonia,
  - stress, surgery, pain,
  - cognitive impairment (ex. dementia)
  - medications that possess anticholinergic (ex. gravol) properties and benzodiazepines (sedatives generally end in “pam” ex. lorazepam)
  - Dehydration, malnutrition, blood sugar
  - recent move,
  - ill fitting glasses or hearing aids

- Treatment of delirium
  - Treat underlying cause
  - May include:
    - Doing tests (ex. for infection)
    - Adjusting medications
    - Adjusting the elder’s environment

- Prevention of delirium
  - Promote healthy rest and sleep
    - Reduce noise and distractions
    - Low or no light when sleeping
    - Comfort measures before sleep (ex. Massage, warm blanket)
    - Avoid using medications
  - Promote physical activity
    - Sitting up in a chair, walking
    - exercise is able
  - Promote hydration and healthy eating
    - Offer fluids frequently
• Encourage eating, help if necessary
  o Promote healthy hearing
    ▪ Wear hearing aids
    ▪ Make sure hearing aids fit properly and are working
  o Promote healthy vision
    ▪ Wear glasses and keep them clean
    ▪ Use enough light
    ▪ May need a magnifying glass
  o Promote mental stimulation
    ▪ Visiting with friends and family
    ▪ Talk about current events and surroundings
    ▪ Read out loud
    ▪ Large print books, books on tape

• What to do if family member becomes delirious
  o Call Telehealth if unsure, need some advice
  o Family doctor
  o Community nurse
  o Alzheimer’s Society
  o Emergency if necessary
• Difference between Dementia and Delirium (from VIHA “The 2 D’s”)
  o Main differences:
    ▪ Delirium:
      • the changes happen quickly as a result of an underlying condition
      • Lasts hours to months
      • The behaviours fluctuate
      • Problems with sleep-wake cycle
      • Hallucinations – this may also happen in lewey body dementia
      • Treatable and reversible
      • Treat the cause and delirium will resolve

5. Video clip (from VIHA) (5 min)
  • 2:10-7:32 for delirium and dementia, if extra time go to 8:25
6. Discussion (15 min)

7. Questionnaires/post-test (10 min)
   - Complete post-test without looking at handouts

Total: 60 minutes
Appendix K

Phase Three: Interview Guide

1. What do you think puts someone at risk for getting delirium?
2. What are the signs of delirium?
3. Was there anything else you would have liked to learn about delirium?
4. Do you think that you would be able to tell if someone had delirium?
5. Since you attended the education session have you used any of the materials that were given to you?
6. In what way was the yellow/red card you received helpful? (This question refers to the card with information about delirium and looks like a bookmark)
7. What other materials would have been helpful to receive?
8. Since having the education session, do you think you have had any experiences with delirium? If yes, how did the education session prepare you for this?
9. In what ways could the education session you received be improved?
10. Would you have liked to have a power point presentation?
11. Do you think other caregivers of the elderly could benefit from an education session like this? Why?
12. Any other comments/suggestions?