

**EXPLORING OLDER ADULTS' EXPERIENCES WITH THE NURSE CONTINENCE  
ADVISOR ROLE IN RESIDENTIAL LONG TERM CARE**

by

Jasjit Gill

BSN, The University of British Columbia, 1996

A THESIS SUBMITTED IN PARTIAL FULLFILLMENT OF THE REQUIREMENTS FOR  
THE DEGREE OF  
MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

March 2017

© Jasjit Gill, 2017

## **Abstract**

**Background:** It is estimated that 60% of older adults living in Residential Long Term Care (RLTC) experience urinary incontinence that impacts them physically, psychosocially, emotionally and financially. Urinary incontinence can be an embarrassing and devastating experience that impacts older adults' dignity and quality of life. Nurse Continence Advisors (NCA), experts in incontinence, are independent practitioners that can add value to quality of life who are unknown and under-utilized to health care teams as there is little information about them and so few practice in RLTC. **Purpose:** To understand the older adults' experiences working with the NCA and their role and the potential of this role within the RLTC sector.

**Sample/Methods:** Interpretive Description was the method of inquiry and multiple case studies were used to explore the older adults' experiences of working with an NCA about their incontinence. A purposive sample of three older adults who worked with an NCA were interviewed using a semi-structured process. Data were collected through 1:1 interviews with the older adults and 1 staff member, chart and supporting document reviews. **Results:** All three participants revealed intense impact of UI on their quality of life, overall day to day function and embarrassment. The involvement of the NCA was positive leading to significant improvements in UI for all three participants affecting their quality of life. The study revealed added value to having NCA involved in UI issues such as UI knowledge, consistent documentation and assessment and strategies to improve UI. **Implications:** This study revealed the need for the NCA role within the RLTC sector and provides a closer and personal understanding of the impact of UI on older adults. It provides novel insights from the older adults' experiences towards the broader knowledge of the NCA role that will assist health care providers in gaining knowledge about ways that UI affects older adults' living in RLTC.

## **Preface**

This is an independent interpretive description study that used multiple case study design to gather qualitative information. I recruited the study participants, collected and analyzed the research data, and wrote the entire thesis with guidance from my supervisor, Dr. Jennifer Baumbusch, and committee members, Dr. Alison Phinney and Jo-Ann Tait. The UBC Behavioral Research Ethics Board provided ethical approval for this study, certificate number H15-00993.

## Table of Contents

<b>Abstract</b> .....	ii
<b>Preface</b> .....	iii
<b>Table of Contents</b> .....	iv
<b>Acknowledgements</b> .....	viii
<b>Chapter 1: Introduction</b> .....	1
1.1 Background .....	1
1.2 Significance.....	2
1.3 Statement of the problem: .....	5
1.4 Study purpose.....	5
1.5 Chapter summary .....	5
<b>Chapter 2: Literature review</b> .....	6
2.1 Conducting the literature review .....	6
2.2 Nurse continence advisors .....	7
2.2.1 The NCA role.....	7
2.2.2 Outcomes of NCA practices .....	9
2.3 The population of residential long term care (RLTC) .....	11
2.4 Urinary incontinence (UI) in RLTC.....	12
2.4.1 Types of UI and contributing factors .....	12
2.4.2 Consequences of UI .....	14

2.4.3 Management of UI .....	16
2.5 Summary and gaps in the literature.....	16
<b>Chapter 3: Methods</b> .....	<b>18</b>
3.1 Research questions.....	18
3.2 Interpretive description (ID) .....	18
3.2.1 Study setting.....	19
3.2.2 Study participants.....	19
3.2.3 Study procedures.....	20
3.2.4 Trustworthiness and rigor .....	23
3.2.5 Ethical considerations .....	25
3.3 Chapter summary .....	26
<b>Chapter 4: Findings</b> .....	<b>27</b>
4.1 Introduction.....	27
4.2 Experiences before the NCA referral .....	27
4.2.1 The participants UI concerns .....	27
4.3 Other findings .....	32
4.3.1 UI practices and knowledge .....	32
4.3.2 Documentation .....	34
4.4 Experiences with the NCA.....	35
4.4.1 Participant specific impact .....	35

4.4.2 Enhancing staff knowledge.....	38
4.5 Experiences after NCA consult.....	39
4.5.1 Outcomes for participants .....	39
4.5.2 The role of NCA .....	41
4.5.3 Change in staff knowledge.....	43
4.6 Summary .....	44
<b>Chapter 5: Discussion and recommendations .....</b>	<b>46</b>
5.1. Continence education and knowledge.....	46
5.2 Continence assessment and documentation .....	47
5.3 NCAs within RLTC .....	48
5.4 Impact of UI through personal stories.....	49
5.5 Recommendations for nursing education.....	50
5.6 Recommendations for nursing leadership.....	51
5.7 Recommendations for nursing practice.....	51
5.8 Recommendations for nursing research.....	52
5.9 Limitations .....	53
5.10 Conclusion .....	54
<b>References .....</b>	<b>56</b>
<b>Appendix A: Letter to residential long term care managers/leader .....</b>	<b>63</b>
<b>Appendix B: Invitation to participate letter .....</b>	<b>64</b>

<b>Appendix C: Consent form for older adult .....</b>	<b>65</b>
<b>Appendix C1: Consent form for family member .....</b>	<b>68</b>
<b>Appendix C2: Consent form for staff.....</b>	<b>71</b>
<b>Appendix D: Older adult participant demographic information.....</b>	<b>72</b>
<b>Appendix E: Family participant demographic information.....</b>	<b>73</b>
<b>Appendix F: Staff participant demographic information.....</b>	<b>74</b>
<b>Appendix G: Interview guide for older adult.....</b>	<b>75</b>
<b>Appendix H: Interview guide for families.....</b>	<b>76</b>
<b>Appendix I: Interview guide for staff.....</b>	<b>77</b>
<b>Appendix J: Translator confidentiality agreement.....</b>	<b>78</b>
<b>Appendix K: Chart audit tool.....</b>	<b>79</b>

## **Acknowledgements**

I would first like to thank my advisor Dr. Jennifer Baumbusch with great gratitude and appreciation for her guidance and encouragement throughout every step of the way towards finishing my thesis. Her patience, expertise, direction and support made it possible for me to continue with finishing my thesis without giving up. I am forever grateful from the bottom of my heart.

I would like to thank my committee members Dr. Alison Phinney and Jo-Ann Tait who encouraged me to think critically and reach for the real meaning behind this study. I appreciate your time, experience and feedback throughout this process ultimately giving me direction towards a paper that has true meaning for me.

I extend my gratitude for the financial assistance from Vancouver Coastal Health, University of British Columbia, and British Columbia Nurses Union to complete my studies.

My greatest thank you goes to my family who supported and encouraged me in my pursuit of continuing studies and for being my cheering squad when I ran out of steam. I am especially grateful to my husband Mike, boys Davin and Rajan, sister Harjit, my parents and in laws and my friend Emillie for urging me on to finish, make my days easier by picking up the slack and continuing for giving me strength. I could not have completed this paper without your support.



## **Chapter 1: Introduction**

### **1.1 Background**

The need for Nurse Continence Advisors (NCA) in Residential Long Term Care (RLTC) is crucial with a growing aging population and older adults moving into RLTC where we see an increase in incontinence due to age related changes to lower urinary tract function predisposing older adults to urinary incontinence from functional decline, comorbidities and complexities, hence it is not a normal part of aging (Doughty, 2006; Shakepeare, K., Barradell, V., & Orme, S. 2011). Incontinence, whether urinary or fecal, is a devastating problem affecting a majority of older adults in in RLTC (Doughty). Urinary incontinence involves having little or no control with urination; fecal incontinence involves having little or no control with bowel movements and results in involuntary leakage in both cases (Getliffe & Dolman, 2007). Griebling (2009) estimated that among adults over 65 who live in RLTC, the prevalence of incontinence is 60% compared to 10% of older adults in the general Canadian population. Women, over the age of 65 living in RLTC settings are affected by incontinence twice as much as men (Al-Hayek and Abrams, 2005). Yet, the exact prevalence rates of incontinence in RLTC may be underestimated as it is an embarrassing, undignified, stigmatized and taboo condition that is under-reported, under-diagnosed and under-treated (The Canadian Continence Foundation [TCCF], 2009; Edgley, 2002; Wallner et al. 2009).

One way to address incontinence issues in RLTC is through the use of NCAs who are valuable resources. An NCA is an independent continence practitioner who is certified after completing a 1 year continuing education program at a university with specialized training on urinary and fecal continence assessment, conservative treatment measures and evaluation using best practices (Milne & Moore, 2003; Skelly & Kenny, 1998). NCAs also have specialized

knowledge about incontinence management devices, and therefore can assist in ordering supplies and managing the related costs. NCAs may have clinical roles with patient caseloads or provide consultation and education to others (Skelly & Kenny, 1998). Currently, according to the Canadian Nurse Continence Advisor Association 2014 Member Directory, there are 91 practicing NCAs registered in Canada various settings. NCAs work in clinics or hospitals with a broad spectrum of age groups such as children and young adults and a few work with elders in RLTC. Given the relatively small number of NCAs, their distribution amongst various care homes, and the prevalence of incontinence in RLTC, it is important to focus on NCAs in RLTC.

## **1.2 Significance**

Multiple studies show the significant impact of incontinence on the older adult's quality of daily life, leading to complications such as depression, low self-esteem, dependence and social isolation (Al-Hayek & Abrahms, 2005; Edgley, 2002; Molander, Sundh & Steen, 2002; Sinclair & Ramsay, 2011; Wallner, 2009). Emotionally, being incontinent can expose older adults to embarrassment as wearing a "diaper" can be seen as degrading (Edgley, 2002; Hajjar, 2004, Teunissen, Bosch, Weel & Largro-Janssen, 2006). Researchers have shown that the loss of dignity is associated with odours from incontinence that can be overwhelmingly distressing causing older adults to become socially isolated and alienated (Doughty, 2006; Edgley, 2002; Getliffe & Dolman, 2007; Hajjar, 2004). Incontinence can cause mental or emotional distress, social limitations and sleep disturbances (Doughty, 2006). Losing control over their bladder and bowels impacts older adults' independence and requiring assistance creates anxiety (Edgley, 2002). In turn, self-esteem and self-confidence can deteriorate with increased incontinence episodes (Edgley, 2002). All this is made more challenging because the stigma associated with

incontinence stops older adults from seeking help, which delays treatment (Sinclair & Ramsay, 2011).

Physically, incontinence associated dermatitis (IAD) is one of the leading and most painful consequences of incontinence, and is characterized by inflammation of the skin with redness, edema, and vesicles (Beldon, 2012; Gray et al., 2007). Constant presence of urine or feces on the skin can cause incontinence associated dermatitis, which is not only painful but has a slow recovery period. Treatment of this condition requires nursing care, skin care products, incontinence products and topical medications.

Urinary tract infections (UTIs) and dehydration are other physical consequences that can result when older adults restrict fluid intake in an effort to decrease urine leakage and toilet visits (Doughty, 2006). Concentrated urine and urinary retention, which produces urinary stasis and bacterial overgrowth, can result in UTIs in older adults.

Another consequence of incontinence is the increase in the number of falls and injuries that may lead to hospitalization requiring treatment (Wenger et al., 2009). According to Doughty (2006), approximately 20% to 30% of older adults get up two to three times at night to void as they experience increased nocturia. This predisposes them to falls, as it can be difficult to manoeuvre at night with minimal lighting or obstacles on the way to the bathroom. The result of frequent falls or skin breakdown increases the need for nurses to monitor the individual more frequently.

Injuries from falls and UTIs can increase trips to the emergency department and possible admissions to acute care resulting in a financial burden for hospitals (Wenger et al., 2009; Wilson, Brown, Shin, Luc and Suback, 2001). The burden of this condition for people over 65

costs the health care system approximately \$26 billion in the United States and over \$1.9 billion annually in Canada which includes amounts spent on incontinent products, laundry costs, staff cost and other supplies [TCCF, 2009]. Similarly in Australia, the cost of incontinence was estimated at \$1.6 billion dollars in 2010 for older adults living in Residential Aged Care facilities (Deloitte Access Economics, 2011).

In RLTC, interdisciplinary teams (comprising nursing, physiotherapy, occupational therapy, social work, medicine, pharmacy, dietary, and rehabilitation) provide care to older adults to support their complex and diverse health needs. One study by Mathis et al. (2013) concluded that 38% of Registered Nurses had a lack of knowledge about assessing, implementing and evaluating incontinence, which is a barrier to appropriate continence care. NCAs could potentially support the staff in RLTC facilities by providing comprehensive assessments and conservative measures in managing incontinence to improve residents' quality of life. These interdisciplinary perspectives can be very beneficial however there is insufficient best practice knowledge in assessing and managing incontinence (Doughty, 2006).

It is significant that continence experts exist in the health care system but there are little known about whom they are, what their role is and where they work. Very few NCAs practice in clinical settings, especially in RLTC, as their roles entail other responsibilities is not solely focused on incontinence. Generally, continence experts, such as NCAs, are not fully integrated into the interdisciplinary team and therefore are utilized minimally in RLTC where there is little awareness of their role, function and skills. This is supported by the so few and current studies or information available on the NCA role.

### **1.3 Statement of the problem:**

To date, older adults' experiences with and understanding of the NCA role have not been explored in RLTC. By generating understanding from older adults' experience of being consulted by an NCA, in-depth personal experiences can provide valuable insight about this role on health and quality of life outcomes for older adults living in RLTC (McGloin, 2008).

### **1.4 Study purpose**

The purpose of this study is twofold: to understand a) older adults' experiences of the Nurse Continence Advisor (NCA) role and b) clarify the potential of this role within the RLTC sector.

### **1.5 Chapter summary**

Incontinence poses a significant problem to older adults who are living in RLTC. Incontinence impacts the older adult physically, psychosocially, and financially. NCAs are useful independent practitioners who can alleviate these consequences and increase older adults' quality of life through assessment, interventions and evaluation. The role and function of NCAs have not been explored fully within RLTC, therefore this study will add to the literature on the value of NCAs to maintain continence.

## **Chapter 2: Literature review**

Existing literature on Nurse Continence Advisors (NCAs) explored their roles in various settings from the time NCA resources were established in the early 1970s. This literature review on NCAs will focus on understanding the role, and the impact of NCAs on incontinence. To understand RLTC, the literature review will focus on this sector and its geriatric population that is affected by incontinence. In addition, the literature review will highlight the complex ailments associated with incontinence.

### **2.1 Conducting the literature review**

To get a better understanding of the existing research on NCAs, RLTC, and incontinence a thorough search of the literature was performed using Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline (OvidSp), and manual searches from reference lists looking at timeframes from 2004-2014. To explore the role of continence experts, the following search terms were used: Nurse Continence Advisors, continence experts, continence nurses and continence nurse specialists. This search revealed the latter terms were not widely used, therefore the research was expanded using search terms such as: consultants, specialists, experts, leaders, advanced practitioners and resource nurses who specialize in continence care. This search revealed studies that integrated continence experts within various settings and the outcomes of this resource, as well as studies exploring how a lack of incontinence knowledge among nurses impedes proper continence care. Included also were articles describing continence expert education and training, highlighting the specific knowledge obtained through continence curricula.

To further focus on the older adult population in nursing homes, key terms included: older adult, long term care, nursing homes, extended care, residential long term care, residential care,

older adult, and seniors were used. To increase understanding about incontinence, key terms included: continence, incontinence, urinary incontinence, and fecal incontinence. As there was so much information available on incontinence, the search focused on urinary incontinence (UI) to: impact of incontinence, consequences of incontinence, management of incontinence, and gaps in incontinence knowledge. Since there was overwhelming information on UI in the older adult, to keep within my study parameters, I narrowed my search to UI in older adults using key words such as: UI in long term care, seniors in nursing homes and UI, UI in frail older adults and UI in the elderly.

## **2.2 Nurse continence advisors**

### **2.2.1 The NCA role**

The Nurse Continence role was seen as important due to the rise in incontinence issues as discussed in many foundational studies in Australia, Canada, and United States (Addison, 1996; Bates & Porter, 2002; Rhodes & Parker, 1994; Skelly & Kelly, 1998). These studies were completed at a time when the role was new and little known about the NCA function. The NCA role has evolved over the years from when it was first established in the early 1970s, and NCAs focused on incontinence product use and saving costs to organizations (Addison, 1996; Milne & Moore, 2003). Initially the NCAs' practice focused primarily on providing advice and training mainly for professionals with smaller numbers practicing in management and research (Rhodes & Parker, 1994). In the early years of the NCA role, there was no formal requirement of qualifications because there was no academic course of studies related to incontinence care (Rhodes & Parker, 1995). The role has changed over the years, encompassing the clinical expert in continence management.

Currently NCAs practice independently after completing a University based curriculum. One example is the McMaster University NCA course in Canada established by Jennifer Skelly in the 1990s (CNCA, 2012; Milne & Moore, 2003). This course emphasises the NCA as an independent continence practitioner who is certified after completing a one year continuing education program at a university with specialized training on urinary and fecal continence assessment, conservative measures and evaluation using best practices (Milne & Moore, 2003; Skelly & Kenny, 1998). NCA education consists of bowel and bladder function, types of incontinence, various options for treatments and evaluation of care plans. Knowledge of bowel and bladder function, internal exams, use of bladder scanners and biofeedback machines, pharmacological treatment of urinary and fecal incontinence, and incontinent products are specialized to NCAs (CNCA, 2012). The NCA program focuses on refining skills on continence assessment, interventions and evaluation through case studies, problem based learning and preceptorship. The preceptorship component consists of partnering with a NCA mentor to complete 150 hours of clinical time and 15 full assessments (CNCA, 2012). Clinical experience, ongoing education and professional development are necessary for renewing the NCA certification. NCAs also have specialized knowledge about incontinence management devices used and can assist in ordering supplies and managing the related costs. NCAs may have clinical roles with patient caseloads or provide consultation and education to others. (Skelly & Kenny, 1998).

As the NCA role is seen to be clinically relevant and demand is increasing, there has been an increase in NCA certified practitioners within Canada. In 2011, there were 73 NCAs in Canada registered in the Canadian Nurse Continence Association member directory with 14 NCAs in British Columbia. In 2013 and 2014, Canada had 91 registered NCAs who are practicing with



differing skills and in various clinical settings (Canadian Nurse Continence Advisor Association, 2014).

The few studies found on the NCA role date back to the early 1990s and those that are available in later years represent populations outside of RLTC. The NCA role has not been explored in depth currently within any clinical setting that can provide an understanding of their function. Due to the difficulty in finding current research about NCAs, one of the conclusions made is that a lack of understanding continues to exist about NCAs and the literature on the NCA function remains undetermined and undefined as evidenced by the lack of articles found on this topic. However an example of NCA integration is a study by Klay & Marfyak (2005) which aimed to determine if the number of incontinence episodes for an older adultly female population in an extended care facility could be decreased by using continence nurse specialists. This study found a decrease in the number of UTIs, pressure ulcers and falls (Klay & Marfyak). Another example is a study by Festen, Duggan & Coates (2007) which found that the cost of nurse-led continence treatment is lower than physician-led continence therapy in relation to comprehensive assessment, decreased wait times, treatment options, using existing protocols and ongoing follow ups. This suggests that the NCA role has good potential within the LTRC section, although there is a need for research to define, clarify, and customize the NCA role so that it can be consistent and functional in this context.

### **2.2.2 Outcomes of NCA practices**

What was evident in the literature was the positive impact of NCAs on continence management. A foundational study initiated by Skelly & Kenny in 1998 started the work on the impact of NCAs on continence management. Skelly & Kenny (1998) initiated a study in home care that revealed that NCAs resolved many cases of incontinence and decreased the cost

associated with treating incontinence. In this study, 54 men and 120 women were seen by NCAs over a 6 month period. After completing a questionnaire, 42% of the patients' incontinence had improved with continence expert support. These findings also indicated a positive correlation between the number of NCA visits and a better overall outcome for incontinence. The greatest impact was the participants' increased awareness of incontinence they learned from the NCA which improved their ability to manage and cope with incontinence. Even though this study took place in home care services, the same outcomes could apply to RLTC.

Klay & Marfyak (2005) described that as a result of using NCAs within their extended care facility, the resident population had decreased falls, UTIs and skin breakdown. Extensive educational workshops and in-services on the urinary system and incontinence were provided to staff and families on a regular basis, and the NCA assessed and executed individualized care plans with interventions over a 1 year period with 27 residents. The authors documented a 50% decrease in falls, UTI incidences decreased by 20%, and the number of pressure sores also declined. Other outcomes of this study were better quality of life, decreased incontinence costs and increased knowledge of staff and families about incontinence.

In addition to NCAs generating positive outcomes physically, continence experts also affect emotional changes. A study by Festen, Duggan & Coates (2008) found that NCAs increased quality of life in adults experiencing incontinence as they were better able to understand and cope with their incontinence issues. They evaluated the effect of conservative therapy by a continence nurse practitioner on the quality of life of 115 community-dwelling adult women or women admitted to the hospital for childbirth or surgery with UI. This 16 month study used the King's Health Questionnaire (KHQ) to evaluate quality of life for these women. With the treatments put into place, the results were an improvement of wetness episodes, understanding

and dealing with the incontinence issues. Overall, the conservative treatments offered by continence experts to these women also resulted in an increase in them recommending continence experts to their friends, as the continence experts were seen as a valuable resource. The power of education and continence expert follow through was evident in both studies and increased incontinence knowledge to both groups.

In summary, there are a small number of studies showing that the outcomes of NCA practice are significant, however only one study was found that took place in a RLTC setting. This suggests that the impact of NCA practice has not been researched thoroughly, resulting in a gap in understanding of its relevance and potential impact within the RLTC setting.

### **2.3 The population of residential long term care (RLTC)**

Residential Long Term Care (RLTC) refers to government funded and regulated long term care facilities with four or more beds that provide 24 hour services to adults over the age of 65 (Ministry of Health, 2013). The resident population in RLTC consists of a higher proportion of women than men, who are physically dependent, have unstable health, mental health illnesses, and responsive behaviors (Estabrooks et al., 2013; IRRP Study, 2011; Shah et al., 2010). Older adults living in RLTC typically have complex and significant medical needs with a high prevalence of dementia and incontinence (Estabrooks et al., 2013; Shah et al, 2010).

Looking at the reasons for admission to RLTC, it was evident that a common impetus for an older adult to move to RLTC is UI (Doughty, 2006; Shakespeare, Barradell, & Orme, 2011; The Canadian Continence Foundation, 2009). Urinary incontinence affects about 60% of this population and can be due to the age related changes in the older adult such as smaller bladder capacity, impaired functional ability and cognitive impairment (Al-Hayek & Abrams, 2005; Griebing, 2009). For example, the inability to get to the toilet on time can cause leakage or the

inability to remove clothes and use the toilet correctly increases incontinence. UI is not a normal part of aging, but the consequences of age-related changes that impact the urinary system can cause incontinence (Doughty, 2006).

The older adult in RLTC is affected by many ailments that put him or her at risk for incontinence. Dementia, one of the most prevalent diagnosis in RLTC, increases the risk for the older adult of incontinence (Price, 2011). Changes in cognitive functioning such as cognitive impairment, losing ability to find the toilet, losing control over bowels and bladder and the inability to vocalize the need to go to the bathroom increases incontinence risk. Price (2011) reports prevalence of UI in people with dementia was 53% compared to those without dementia at 13%.

## **2.4 Urinary incontinence (UI) in RLTC**

### **2.4.1 Types of UI and contributing factors**

Urinary Incontinence has 5 classifications with associated specific risk factors for the older adult; stress, urge, overflow, mixed and functional (Doughty, 2006; Griebing, 2009; Shakespeare et al., 2011). Any one of these types of UI can affect the quality of life of the older adult so it is important to understand the classifications and how they impact the older adult.

Stress UI is urinary leakage that occurs during activities such as coughing, sneezing, laughing and exercising that increase abdominal pressure (Doughty, 2009; Griebing, 2009). Weak pelvic floor muscles cause the inability to hold urine with increased abdominal pressure resulting in leakage (Griebing, 2009). Stress UI can be contributed to trauma on muscles during pregnancy, childbirth and menopause in women or enlarged prostate in men which impacts them in older age (Shakespeare et al., 2011). Stress UI impacts more older women than men, but is less prevalent than urge, overflow and functional UI.

Urge UI is associated with a sudden onset of a sensation to void with involuntary loss of urine occurring before the person gets to the toilet (Doughty, 2009; Griebling, 2009). Urge UI is referred to as an “overactive bladder” and causes urgency and increased frequency to void over a 24 hour period. Nocturia, waking one or more times to void at night, is a common complaint of urge UI and occurs in more than 50% of older adults (Shakespeare et al., 2011). This can disturb sleep and increase risk for falls at night. Risk factors for urge UI include neurological disorders such as multiple sclerosis, Parkinson disease, spinal cord injuries and dementia.

Overflow UI is associated with poor bladder muscle contractility and incomplete bladder emptying causing continuous loss of small volumes of urine resulting in constant dribbling (Griebling, 2009; Shakespeare, 2011). In older adults, the bladder capacity decreases requiring the need to frequently void and experience constant bladder contractions. Overflow UI results in the need to void around the clock including at night, similar to urge UI.

Functional UI refers to urinary leakage that occurs as a result of factors not related directly to the lower urinary tract (Doughty, 2006; Griebling, 2009; Shakespeare et al., 2011). Contributing factors of functional UI are such things as mobility, environmental factors, medications, lighting, and other co-morbidities. As seen in RTLTC, older adults are affected by immobility, environmental limitations, vision problems, side effects of medications, and inability to transfer which puts them at risk for functional UI (Griebling, 2009).

Mixed UI refers to a combination of more than one type of UI at one time. Stress and urge UI is the most common types of mixed UI. With mixed UI, the older adult experiences urgency and frequency caused by abnormal bladder contractility.

## **2.4.2 Consequences of UI**

### **2.4.2.1 Physical consequences**

The person experiencing UI can have many consequences such as physical, psychosocial and financial. Urinary infections, falls and skin breakdown are the most prevalence physical consequences of UI (Doughty, 2009). Incontinence associated dermatitis (IAD) is a very painful and debilitating problem which is characterized by inflammation of the skin surface with redness, edema and vesicles (Gray et al., 2007). These symptoms resulting from IAD can lead to isolation, anxiety and depression (Beldon, 2012). Another physical consequence is urinary tract infections (UTI) that can cause discomfort and puts older adults at risk for delirium which is a medical emergency. UTIs can result from urinary retention, concentrated urine and indwelling catheters (Doughty, 2006). Catheters can increase the infection risk, cause discomfort, restrict activities, and act as a physical restraint (Doughty, 2006). UTIs affect eating and drinking habits, toileting habits, and can restrict normal day-to-day function.

Falls, another consequence of UI, is a major problem for older adults who are at risk as the need for voiding at night increases (Doughty, 2006; Wegner et al., 2009). Nocturia can predispose the older adult to falling as they try to maneuver to the bathroom with minimal light (Doughty, 2006). Dementia, medication, other co-morbidities and functional UI can predispose the older adult to falls as the processes of voiding are interrupted (Doughty, 2006; Wegner et al., 2009).

### **2.4.2.2 Psychosocial consequences**

Even though the physical consequences are significant, the psychosocial impact on the older adult of incontinence can greatly affect one's quality of life and sense of dignity (Hajjar, 2004; The Canadian Continence Foundation, 2009). For example the need to wear a "diaper" can

be degrading to one's self esteem. Embarrassment is a common feeling among older adults who are incontinent especially if an accident occurs in public. The odor from urine can lead to social isolation and withdrawal from activities (Hajjar, 2004). UI continues to be a taboo subject with a stigma attached to it resulting in negative impacts on the older adult's social and emotional well-being.

### **2.4.2.3 Financial consequences**

At the systems level, UI can be very costly to the health care system. One study estimated that UI and related conditions in the United States totalled \$32 billion annually (The Canadian Contenance Foundation, 2007). Furthermore, the cost of an older adult with UI living in a RLTC can average \$3,000-\$10, 000 per year for supplies and nursing care (TCCF, 2009). In total, incontinence will cost Canadians over \$5.5 billion per year (TCCF, 2009). People living in Canadian RLTC, incontinence will cost the health care system over \$1.9 billion per year (TCCF, 2009). Similarly, a report from Australia in 2011 estimated the UI cost in RLTC to average about \$1.6 billion in 2010 (Contenance Foundation of Australia, 2011). The differences in costs are attributed to the varied population numbers existing in these three countries; 33 million in Canada, 300 million in United States and 20.2 million in Australia [TCCF, 2007]. Direct costs such as containment products, managing complications and nursing care are areas where cost is high. Other direct costs are resources utilized for evaluating and managing incontinence such as specialists, diagnostic tests, equipment, supplies and laundry costs. Indirect costs, which are difficult to determine due to underreporting, are pain and suffering, emotional distress, complications and treatments (TCCF, 2009).

### **2.4.3 Management of UI**

It is important to obtain a comprehensive history from the older adult that includes an extensive interview and a physical exam (Shakespeare et al., 2011). Griebling (2009) recommends conservative treatments for management as they can yield significant improvements of UI. Conservative measures refer to those interventions that are simple, non-invasive and do not cause detrimental or traumatic effects to the older adult (Getliffe & Dolman, 2007). Examples of these strategies are voiding diaries, adequate fluid intake, decrease caffeine, prompted voided, toileting plan or pelvic floor exercises (Doughty, 2006; Griebling, 2009; Shakespeare et al., 2011). For the older adult, multiple small improvements with their UI can lead to significant results (Griebling, 2009). A few specific measures for UI such as vaginal cones, bladder retraining, prompted voiding and pharmacological therapies can be recommended by a someone who has had specialized training such as urologist or NCA (Getliffe & Dolman, 2007; Shakespeare et al., 2011).

### **2.5 Summary and gaps in the literature**

The review of the literature revealed that there are very few current studies of the NCA role in RLTC. This role was supported by research in the 1990s in which many articles discussed the role of NCAs. However in recent literature, one article profiling NCAs was found with no other current research located. With so few articles available on NCAs, a considerable gap still exists to understand how NCAs function within health care teams. In reviewing the outcomes of NCA practices, articles from the early 2000s were located, however no current research was found, which limits our understanding of the potential impact of their roles currently in Canada.

Another gap was the lack of studies or articles about NCAs in the RLTC sector. Many articles highlighted the prevalence of UI in the older adultly population; however it was difficult



to find articles related to NCAs working in RLTC. Given the physical, psychosocial and financial impact of UI, this is a significant gap in knowledge. Research is clearly needed in this area.

This study will add to the body of primary research on the function and role of NCAs within the RLTC sector. Creating this new knowledge about the NCA role will help to inform care providers and decision makers about the potential importance of this role in the context of RLTC.

## **Chapter 3: Methods**

This study used an Interpretive Description (ID) methodology that employed multiple case studies in order to explore older adults' understanding and experiences of the NCA role in RLTC (Baxter & Jack, 2008; Thorne, 2008). This approach generated knowledge that was relevant to NCA practice, nursing and continence care by providing in-depth experiences from real-life cases (McGloin, 2008). Participants were recruited using a purposive approach (Polit & Beck, 2012; Robinson, 2013). The data collection strategy was semi-structured interviews that generated in-depth knowledge and understanding through participants' subjective experiences (Thorne).

### **3.1 Research questions**

Two primary questions guided the study:

1. What are the experiences of older adults consulted by a Nurse Continence Advisor (NCA) within RLTC?
2. Do these experiences support the need for NCAs within the RLTC sector?

### **3.2 Interpretive description (ID)**

An Interpretive Description (ID) approach using multiple case studies was used to explore older adults' understanding and experience of the NCA role (Anthony & Jack, 2009; Baxter & Jack, 2008; McGloin, 2008; Polit & Beck, 2012). This methodology is useful in healthcare for "making sense of research participants' experiences and perceptions." (Jirwe, 2011, pg. 4). Using the ID approach, new insight and linkages were generated about the NCA role from the older adults' subjective experiences working within the RLTC setting (Jirwe, 2011; Thorne, 2008). Thorne's ID methodology allowed for generating in-depth knowledge and understanding of the role of NCAs within the nursing discipline. Using a case study approach

focused on multiple cases captured the complexity of the phenomenon through descriptive and exploratory knowledge (Baxter & Jack, 2008; Hyett et al., 2014, McGloin, 2008). Triangulation of data sources to understand each case provided a rich and in-depth picture of the phenomenon from multiple perspectives (Baxter & Jack, 2008; McGloin, 2008).

### **3.2.1 Study setting**

The study took place at two RLTC homes in Vancouver, Canada where the NCA was supporting the older adults. The staff team consisted of Registered Nurses, Licensed Practical Nurses, Resident Care Aides, Allied Health Team members and Physicians. These care homes had the same designated NCA since 2010 who provided continence support through the Vancouver based Continence Promotion Program for Residential Care. A Continence Clinical Practice Guideline from 2012 provided staff evidence informed guidance in assessment, interventions and evaluation.

### **3.2.2 Study participants**

For this study, a purposive sample of older adults who were consulted by a NCA was recruited (Robinson, 2013). Recruitment strategies focused on three older adults: Mary, Victoria and Wan and these are pseudonyms in order to ensure participants' confidentiality. All three were living in RLTC and had been consulted by an NCA between 2012-2015 for their incontinence issues which included initial assessment, follow up visits, progress and evaluation. Connections were made via phone calls, face to face visits and email ranging from six months to one year. For recollection purposes, those participants who recalled information and could verbalize their experience were recruited into the study. This specific sampling method was best suited for participants in the study as they helped us understand the impact and outcomes of them

being seen by a NCA from their personal experiences through their willingness to engage with the researcher (Thorne, 2008).

### **3.2.3 Study procedures**

#### **3.2.3.1 Recruitment strategies**

First NCAs who practiced in RLTC, other than myself, needed to be recruited to get their list of possible participants. Two NCAs working in RLTC were approached by the researcher with the study information and an invitation but yielded no interest. Both NCAs were in leadership positions which provided them minimal time to practice within their NCA role from 2012-2015. It was a challenge to recruit a NCA who was willing to participate and forward older adults' names for this study. Unable to find a practicing NCA in RLTC who was interested in participating, the researcher of this study who is a NCA recruited participants.

Second, the Resident Services Manager (RSM) and/or Administrator at four RLTC homes were approached where a letter was provided to them outlining the study purpose and the time commitment (see Appendix A). Three of the four RLTC homes granted permission and one did not as the older adults did not meeting the criteria. At the homes where permission was granted, the NCA consulted with the Resident Care Coordinator (RCC) or Director of Care (DOC) in identifying older adults for this study using the criteria and invitation letter to participate (see Appendix B). If older adults had a substitute decision maker or family then either one were included in sharing the study information (see Appendix C1). Robinson (2013) recommended that disseminating information face to face is beneficial to create trust, relieve anxiety and give opportunities to ask questions which gains interest and participation. One participant identified had progressive dementia who could not vocalize or recall her experience hence, not fitting the criteria. Three older adults fit the criteria and agreed to participate; they

were provided with the consent form which was reviewed describing the purpose, process of the interview; risks, benefits and maintaining confidentiality (see Appendix C). Three participants were recruited: Wan, Mary and Victoria.

Lastly, in recruiting staff the DOC and RCCs reviewed the documentation to find staff who were present during the consults. Staff were approached to find those who worked at the time when consults occurred. Challenges that were found in recruiting staff included their availability for the interview due to time constraints, staff no longer working at the care home and there was no interest in participating. One Registered Nurse (RN) whose pseudonym is Krista, was willing to participate as she worked with one of the participants during the timeframe stated. She cared for Victoria when she moved into the care home. Krista was a Resident Care Coordinator who was responsible for the overall function and flow of the neighborhoods where Victoria lived and continues to work there currently. Krista's perspective was relevant to understanding the case, shedding light on the participant's experience with UI and ways that the NCA's support was provided. She was provided with the consent form (see appendix C2). The researcher's contact information was included so that participants could contact her directly. Once the participants were recruited, next steps were followed in collecting and analysing data, and collating findings of the study.

### **3.2.3.2 Data collection**

Data were collected through multiple sources such as interviews with the identified participants, a staff person, charts, and health records (see appendices D, E, F, G, I, and J) (Baxter & Jack, 2008; McGloin, 2008). While interviews with family members were planned, this proved to not be possible in these three cases. Mary's family member was phoned and a voice message was left to participate in the study with no response returned. Wan had no family

members that could participate and Victoria did not want anyone contacted about this study as she felt embarrassed by her incontinence issues. Semi-structured one on one interviews were conducted using a variety of open-ended questions (Baumbusch, 2010; Thorne, 2008). To keep within the designated timeframe of 30 minutes (based on feedback from the participants due to their available time, ensure engagement and avoid fatigue), the questions were offered in advance to the participant so they would be ready for the interview. Each participant chose the timing and location at their convenience to ensure complete participation and to avoid disruptions; a quiet environment was advised (Polit & Beck, 2012). To keep on track, an interview guide and a checklist of points were created which was reviewed by my thesis committee (Baumbusch, 2010; Thorne, 2008). Probing questions, such as “tell me more about that” or “can you describe” were included to elicit deeper conversation and opinions about the topic under study (Baumbusch, 2010). All the interviews were recorded digitally along with written field notes to capture the conversations (Polit & Beck; Whiting, 2008). Data were collected through other multiple data sources such as medical charts and supporting documentation such as voiding diaries, fluid intake and interview guides (McGloin, 2008). The data was analyzed as described below.

### **3.2.3.3 Data analysis**

The first step for data analysis was to transcribe the interviews verbatim including the observational data such as body and non-verbal expressions soon after the interview was over (Thorne, 2008). The transcriptions were analyzed using case study style analysis describing the participant’s experiences and perspectives regarding their consultation by a NCA. Each transcript was read over three to four times to ensure accuracy and credibility of the information shared, and to highlight key words and phrases (Whiting, 2008). Then transcripts were examined for

emerging themes using a detailed approach with coding schemes to identify commonalities and differences (Thorne, 2008). Information from charts or health records were gathered focusing on the incontinence consult information and recorded on a table. Final themes were reflected upon, analyzed and interpreted in consideration of the research questions.

### **3.2.4 Trustworthiness and rigor**

An essential part of this qualitative study was to achieve trustworthiness and rigor of the data collected and analysed. Using Lincoln and Guba's (1985) framework for trustworthiness and rigor, Cope (2014) describes the same criteria: credibility, transferability, dependability, confirmability and authenticity. These criteria were even more important to abide by as the NCA within this study was the researcher. Credibility refers to the truth of the data and the participants' viewpoints ensuring real representation of the information (Cope, 2014). To achieve credibility, the participants' interviews were transcribed verbatim including direct quotes. When unsure of the participants' answers, the participants were asked to clarify or repeat the comments through member checking (Thorne, 2008). Maintaining an audit trail of thorough notes about my decisions, assumptions, interview transcripts and process notes enforced credibility (Houghton, Casey, Shaw, & Murphy, 2013; Morse, Barrett, Mayan, Olson & Spiers, 2002). Through triangulation of collected data, data credibility was enhanced to reach a holistic understanding of older adults' experience under study (Baxter & Jack, 2008).

Confirmability refers to demonstrating that the data is strictly representative of the participants' responses without the researcher's biases and viewpoints (Cope, 2014). Directly quoting the participants and reflecting their voice in the interpretation was essential especially as the researcher was the NCA in this study (Thorne, 2008). My relationship with the participants was unique as I was the one who worked with them initially and now am interviewing them for

this study. This was maintained by using direct quotes from the participants and using the information from documents. Separating own biases, knowledge, perceptions and thoughts through a personal journal expressed reflexivity (Graneheim & Lundman, 2003; Houghton et al., 2013). As the NCA, avoiding subjectivity during interviewing and analysis by tracking my reflections into a personal journal contributed to reflexivity. Documenting how conclusions and interpretations were established demonstrated confirmability.

Dependability refers to the stability and constancy of the data that if replicated with similar participants, findings would be consistent (Cope, 2014). Dependability was achieved through documentation of the process, rationales and descriptions of the study through a comprehensive audit trail (Houghton et al., 2013). Making these notes about the decisions about the process provided a tracking tool and background to the end product. Similar to confirmability, a reflexive journal reflected my personal responses and challenges, thoughts, and ideas (Graneheim & Lundman, 2003; Morse et al., 2002). Houghton et al., noted that a reflexive diary can illustrate transparency in the development of themes to enhance dependability.

Transferability refers to the applicability of the findings to other settings, groups or situations while persevering the meaning of the study (Cope, 2014). Transferability was represented in the study setting and participant section that was relevant and applicable to other groups and settings as noted by Cope (2014). By providing detailed descriptions of research methods, decision making and examples of raw data, readers can decide if transferability exists (Graneheim & Lundman, 2003; Houghton et al., 2013).

Authenticity refers to the ability of the researcher to express the feelings and emotions of the participants' experiences in a true and faithful manner (Cope, 2014). Using a descriptive approach in expressing participants' feelings and emotions in a faithful manner, authenticity of



the information transcribed was maintained through verbatim quotes (Cope, 2014; Jirwe, 2011). I quoted participants to capture their voice and to portray their subjective reflections of their experiences (Polit & Beck, 2012). To capture the information from the participants' perspectives, the researcher used an interview guide to question the participants.

### **3.2.5 Ethical considerations**

Ethical approval for this study was obtained from the University of British Columbia Research Ethics Board and the relevant health authority. Information was provided to all participants that included the purpose of the study, their rights as a participant, benefits and risks, time commitment, contact information and consent (Thorne, 2008). All participants had the right to refuse to answer any questions or withdraw from the study at any point in time without affecting their living situation or their care. Participants were provided with a consent form to review on their own or with a substitute decision maker and a process to return the consent form to the researcher in a confidential manner. Informed written consent was obtained from the participants before any data was collected. Participant identifiers were kept confidential as they were not required to write their name or personal information on the consents.

The data collected through audiotapes or written notes were stored in a locked cupboard to ensure security (Polit & Beck, 2012; Thorne, 2008). Electronic notes, files and computers were password protected. As the research leads, myself and my thesis advisor had access to the locked cupboard and electronic files. To ensure confidentiality, the participants were not identified with personal information however were coded through a numbering system and interview number (Thorne, 2008). The notes did not have personal identifiers associated with participant identities. After completing the study, I will provide each participant a brief

overview of the study and its findings to demonstrate transparency and inclusiveness of their involvement (Whiting, 2008, Thorne).

### **3.3 Chapter summary**

In this chapter, I have discussed how ID method using multiple case study approach was used for this study to gain an understanding from the participants' perspectives about the NCA role experience. This approach was useful to get an understanding of the participants' experiences by capturing their voice about the phenomenon through their own stories. The recruitment strategies included purposive sampling, provided information about the study and the consent form. Details of the data collection included how this study met trustworthiness and rigor through confirmability, transferability, dependability, and authenticity. A semi-structured interview was used in this study to allow for some freedom of exploring questions to elicit in depth answers. The location and time was chosen by the participant and was agreed upon by the researcher. To maintain confidentiality, personal identifiers were not assigned to any interview guide. The transcriptions were translated verbatim to ensure authenticity and my own thoughts and reflections were captured in a personal journal. Ethical considerations, an important aspect of research, were explicitly described to ensure no harm to the participants and to comply with the rules of the research ethics board.

## **Chapter 4: Findings**

### **4.1 Introduction**

In this chapter, the study findings are presented about older adult's experiences of consulting with an NCA while living in RLTC. First, the study participants are described to set the stage for a person-focused understanding of each participant and their UI concerns. Then, the participants' experiences working with an NCA and the results of their current continence status will be described in detail.

### **4.2 Experiences before the NCA referral**

#### **4.2.1 The participants UI concerns**

The first participant was Mary. Mary, a retired nurse, was a 97 year old female who had been living in a care home for the past four years. According to progress notes, Mary went out on social leaves one to two times in a week and enjoyed attending church but with UI this was restricting these activities. Mary enjoyed her meals in the dining room and as the UI progressed she ate her meals more often in her own room. She was experiencing about five trips to the bathroom due to urine frequency, dependant on staff to take her to the toilet and used four incontinent briefs per day. One fall was documented in the bathroom resulting in a skin tear on her arm two weeks before the NCA consult. Mary's care plan indicated constant dribbling of urine and risk for falls. Mary indicated she was frustrated with herself and at the staff who were not attending to her when she called for them. Mary requested a thorough UI assessment at her care conference in December 2011. The interview guide used by the staff indicated Mary experienced frequent toileting, urgency and dribbling.

Victoria is the second participant. She, a retired nurse, was a 73 year old female who had been living in the RLTC home since 2014. Victoria's UI was causing painful skin breakdown so

she used a urinary catheter for urine control since 2012 according to her history data. The progress notes documented five times within two months in which her catheter was blocked, she experienced UTI symptoms, and her catheter bypassed. She required two catheter changes in a two week time span for bypassing. In March 2014, a urology consult advised the insertion of a suprapubic catheter for Victoria as a way to decrease her infections. At Victoria's care conference in April 2014, it was documented that the use of a bladder medication, Oxybutynin, was causing dry mouth and discomfort. In the interview, Victoria voiced that her quality of life was minimal as the catheter restricted her social outings. She voiced to the staff that she wanted to work on having her catheter removed.

Wan, the third participant, a 66 year old male who moved into this care home in June 2014. Wan was born in Alberta and has a Masters in Environmental Engineering. He was an active person who loved mountain biking until his accident in November 2013 that left him a quadriplegic with C3 and C4 fractured spine as he stated in his initial continence assessment interview. His UI developed after his accident as his bladder tone and control was lost requiring a urinary catheter. According to an email sent in May 2015 from his RCC, Wan's catheter was causing bladder stones, frequent catheter changes and recurrent UTIs in which he was hospitalized for urosepsis.

#### **4.2.1.1 Impact of UI from psychosocial, physical and financial perspective**

The impact of UI on all participants was devastating and traumatic. UI burdened all three of the individuals and impacted their well-being and quality of life by affecting their day to day living and hindering their usual daily routines. After approximately one to two years post consults, the interviews with the participants confirmed the consequences of UI from a psychosocial, physical, and financial perspective.

#### **4.2.1.1.1 Psychosocial consequences**

The psychosocial consequences were the most evident and affected all participants of this study. Mary experienced constant dribbling upon movement or change in body positioning such as sitting to standing up. Due to the frequent dribbling and wetness she felt embarrassed to go to the dining room to eat her meals so she was having her meals in her room instead. Mary was a social person who enjoyed her meals while talking to other people at her table but due to the urine dribbling she was isolating herself to her room. When she went for her meals in the dining room, sitting for a long time made her worried about wetting her pants and this stress left her unable to finish her meals and she left the dining room quicker than anticipated. Mary stated “when I had to go I had to go.”

Dignity was affected as all of the participants expressed in their comments and this was a common theme throughout all the interviews. Dignity was compromised resulting in embarrassment related to the lack of control of their UI especially for Victoria and Wan who needed staff to change the catheter. Mary required more assistance from the staff with toileting; Victoria and Wan needed catheter care resulting in a loss of independence. Mary reported that she had urgency and frequency which required her to get to the toilet quickly and more often. She felt stripped of choosing when she could go the bathroom as she became more dependent on staff and it depended on when they had time to take her to the bathroom. Needing her perineal area cleansed affected Mary’s dignity and self-worth as she felt like a baby who needed help as she couldn’t do it herself. She also described her UI experience as feeling hopeless and feeling like a baby as it continued for many months.

Victoria expressed her worries about her bladder function returning after years of using a catheter. She didn’t know if her bladder would function like “normal” again. When the NCA

asked during the interview about her anxiety with UTI caused by her catheter, she voiced that she was worried about subsequent infections, pain, medications and the impacts on her bladder capacity with catheter use. At one point, she saw an urologist who suggested a suprapubic catheter to minimize her infections but was unable to move ahead with this as she had excessive abdominal skin. Victoria expressed the fear she experienced with her catheter possibly falling out or being pulled during transfers and movement as it was not taped down. She described a situation where she was being transferred from her bed and when she was up in the air she needed to “hold onto the catheter for dear life” so the catheter did not get pulled out. Krista agreed that Victoria’s independence and quality of life were compromised from having a catheter that limited her socialization and going outdoors to the mall.

Wan stated he felt hopeless about his situation to the point that he thought about dying through his statement “if I had known it was going to be this bad, I would have either one not broken my neck and two made sure I would’ve killed myself.” Wan was in emotional pain from his experience and the lack of options, lack of support and lack of resources for his catheter management. He expressed the difficulty he experienced and what he perceived as a “brush off attitude” from physicians who walked away from him when consulting with physicians to explore other catheter options. He expressed his frustration with the waiting time to see an urologist that put off treatment for many months.

Wan: I was not able to meet the outcomes. Part of that is the complex environment and again dealing with ... is that it wasn’t so much... it was going from... over to talking to the urologist. There was back and forth with the urologist including one appointment which was cancelled and redone three months later which caused major problem because within that three months I had tremendous number of bladder stones, obstructions and bypassing. I was swimming in urine nightly.

In his interview he used the word “diaper” to describe his current continence management.

When he said this word, his facial expression and body language expressed disappointment and

embarrassment. Diapers are associated with young children, and when associated with adults it is deemed negative and undignified.

#### **4.2.1.1.2 Physical consequences**

The physical consequences were evident as expressed by the participants. The catheter posed a problem for Victoria and Wan causing frequent catheter changes and painful UTIs. The UTIs caused catheter blockage that required frequent catheter changes that traumatized urethral tissues. The two UTI's that Victoria experienced caused septic shock landing her into the hospital. She provided insight into this experience as one particular episode of low blood pressure, which was measured at "24/10" which put her near death. The catheter caused bladder spasms that were painful and the urine leakage causing perineal skin infections such as IAD. Krista confirmed the catheter caused bladder spasm and Victoria wanted the catheter removed. Victoria described her bladder spasms being so intense it was worse than giving birth to her child because "I have given birth piece of cake." The side effects of medications used to treat her incontinence left her with a dry mouth and damaged teeth.

Victoria: and um then I got into bladder spasm pills that worked but they gave me a terrible dry mouth. I've really have had bad damage to my teeth from the, the dry mouth. I've lost teeth, I've had other teeth moved or shovelled around and you know it's been a horror story.

Mary expressed the urgency and needing to get the bathroom quickly which caused bladder discomfort. As a result of experiencing urine dripping "all the time", Mary was at potential risk for skin breakdown and poor bladder functioning.

Wan was transferred several times to the emergency department for catheter blockages and UTIs. The chronic use of the catheter led to smaller bladder capacity and caused him to have bladder spasms resulting in taking anti-spasm medications. He experienced urinary retention, a

side effect of the medication, sending him to emergency to be re-catheterized. Wan commented on the lags in catheter care treatment that caused bladder stones, obstructions and bypassing.

Bladder medication caused side effects for this participant that caused urinary retention.

Wan: So I had about a week after I started on the medication [bladder muscle relaxant] and had an AD [autonomic disreflexia] episode and the bladder medication together clamped everything down, I couldn't drain and they couldn't get a catheter in here, over to VGH, they put in a catheter, smaller diameter, they managed to drain me, re-catheterize me, came back here and this would have been about a month ago um I was on the catheter and antibiotics for about a week.

#### **4.2.1.1.3 Financial consequences**

Through the conversations with the participants, there were inferences made to the financial burden of UI issues. It was beyond the scope of this study to undertake a full financial analysis however the potential cost factor can be explained from a clinical understanding. For example the cost to replace catheters frequently is a cost of the supplies required such as catheters, catheter trays and gloves. Victoria and Wan had several trips to the emergency room using ambulance transfers which is an additional cost. The medications that Mary, Victoria and Wan were prescribed such as bladder spasm, analgesics, antibiotics and diuretics also add to the cost. The nursing care hours that were required to change the catheters, administer medications, document, and overall catheter care all contributed to financial burden.

### **4.3 Other findings**

#### **4.3.1 UI practices and knowledge**

Mary, Victoria and Wan alluded to the need for continence specialists to assist staff who were not as knowledgeable about UI. Mary was aware the number of other people in the RLTC home that experienced incontinence and felt that if help was provided to them early then they would be able to manage incontinence. Mary mentioned that most residents have UI issues so they needed expert help when they move in.



Victoria felt that staff were unprepared to answer her questions about catheter removal and they didn't understand the steps necessary to work towards this goal. She shared that staff didn't have the necessary knowledge to deal with UI to the extent that a continence specialist did. For example, the planning that took place for Victoria would not have been initiated or executed due to the lack of knowledge. Another area of knowledge gap was not using a device for holding the catheter tubing in place therefore leaving the catheter hanging or using other adhesives. Victoria expressed her fear of the catheter being pulled as there was no device used to hold it down.

Victoria: and actually that's one thing you might want to file. I'm not sure what to do, what um want to do with it but it wasn't until I had the catheter probably a year or more, um, roughly that we, I actually got um a um device to tape it down.

Once Victoria become independent with her toileting needs, a request came forward to the NCA to look at options for female urinals as the staff did not know which company sold this device. In another case from Victoria's care home, the NCA received an email request to get information about best practices in catheter care including suprapubic catheters from one of these care homes: "we were wondering if you know what's the best practice for catheter care including suprapubic catheters in terms of how often they get changed, what to do if there is bypassing/blockage, how often do we irrigate, do we do irrigation for suprapubic catheters, and how do other site track dates for catheter changes." May 26, 2011.

Wan felt that staff lacked the knowledge about UI and did not feel confident in their attention to his goals for his catheter. He stated "the challenge was like someplace like...seems to be a dumb down, I'll be blunt, there's not much super-duper expertise here." He also felt that other professional staff also lacked the continence expertise. For example he shared that "amongst the physicians, I found that there was not the most uh education experience so having

someone who could deal specifically with the topic I thought was a good resource.” Wan shared an example when his catheter was inserted incorrectly.

Wan: I had one episode where I had a blockage uh due to an incorrectly inserted catheter that caused a blood clot. The bladder was re-enlarged and they drained about 800 ccs of urine at VGH and then it shrunk back down again. And then I had a second episode more recently where a similar thing happened.

Krista stated that staff did not have the time or the knowledge to assess and strategize for UI. She expressed that staff would not have been able to implement the required plan for catheter removal for participant two in the stages agreed upon. Krista agreed that the outcome of such success may not have been met if the continence advisor had not been involved. She also revealed that incontinence is not their area of expertise and if it had not been for the NCA the outcomes would not be successful. She stated “It would’ve been very difficult to do on our own...it not our area of expertise, yeah. I think if the likelihood of it not being successful would be much greater had we not had the support of continence advisor.” The collaboration with other team members was an important aspect to working with participant two that required OT and PT to assist in different areas. For example, the OT provided Victoria with a mattress that would increase comfort and decrease her skin breakdown. The PT worked with Victoria to strengthen her legs so she could ambulate to the toilet independently.

#### **4.3.2 Documentation**

Before the NCA involvement, there was little and inconsistent documentation on fluid intake, voiding diaries and incontinence assessment. The progress notes captured detailed UI issues, progress of UI and interventions for Victoria and Wan and less detailed information for Mary. An entry in the progress notes for Victoria on May 28, 2014 by a nurse: “Resident c/o discomfort in lower abdomen. Noted urine output is 200 cc in urine bag. No urine in tubing. Catheter irrigation done due to blockage and able to unblocked Foley catheter; draining clear

amber urine. Continue to monitor.” The care conference notes for Victoria indicated UI concerns and ways staff managed the UI. One example of inconsistent documentation was the care home specific fluid intake diary for Mary that was initiated for three days over a 24 hour period in April and May. These diaries were incomplete with blank spaces at meal time and missing subtotal and total amount information. There was no conclusion note found about the fluid intake in the documentation. Staff used an interview guide from the continence guideline for Mary to gather information about her UI but no interview guide was used for Victoria or Wan. When the staff at both RLTC homes were asked about the residential care continence clinical practice guideline or the tools that were available to them, staff at one care home were aware and at the other were not. On the other hand, the plans were well documented and communicated to staff according to the written progress notes for Victoria and Wan. Care plans for all three participants were informative and involved the team. For example, the PT was involved in making a mobility and muscle strengthening plan for Victoria that included the transfer and walking goals in collaboration with the health care team.

#### **4.4 Experiences with the NCA**

##### **4.4.1 Participant specific impact**

All three participants were referred to the NCA by the Director of Care or Resident Care Coordinator for continuous incontinence issues. The staff had worked on several interventions with each of the participants but the issues continued for many months with little or no change. The staff exhausted all known management strategies; they felt they needed more help. Referrals were made to the NCA via email or phone calls using a continence referral form.

Mary was seen by the NCA in April 2012. Her main urinary incontinence issue was stress incontinence experiencing constant dribbling which worsened when she stood up, coughed or

shifted her position. The NCA spend approximately two hours with Mary to interview her, the staff and read through her chart about her UI. The physical assessment revealed a positive stress test of dribbling urine upon coughing. Her pelvic floor muscles were weak when strength testing was done which pointed to stress incontinence. Mary felt that her sphincter was not working as it supposed to. She wore a yellow pad insert in her underwear as she wanted to keep dry during the day with getting to the toilet. She was drinking less than five glasses of fluid because with more fluid intake she needed to get to the bathroom more often. She had a fear of falling due to leg weakness and balance. She was embarrassed and upset at her dribbling which affected her daily activities, routines and social life. The following plan was suggested for Mary: get a water bottle of her choice and to drink an additional three glasses of water, start a new voiding diary for one week, complete a fluid intake diary for three days, Kegal exercises four times in a day with five sets of five, add fruit laxative for bowel management, night staff to toilet Mary using a commode and a follow up with the NCA in one month. One month post first visit, Mary reported she did not notice any difference with her dribbling but she was drinking more fluids in a day. As per progress notes, staff were toileting Mary two to three times on night shift. Mary fell twice while staff assisted her as her knees were sore. She was finding it difficult to pull up her pants by herself which required attention from staff. The plan was to continue with previous plan with additional assistance at night time and a change in her type of pad which Mary refused. The third visit one month later found that the staff had difficulty on night shift toileting resident due to her weak legs therefore they decided to check in on her every two hours to ensure dryness.

Victoria's referral to NCA occurred in August 2014. The NCA spent about one hour interviewing Victoria and reviewing her chart. Her main incontinence concern was her urinary catheter which was inserted in 2012 for her continuous perineal skin breakdown and the inability

to get to the toilet on time. There were four documented times in the progress notes that Victoria's catheter was bypassing or required changes within two months. Victoria stated she drank well and her fluid intake was about 5500 mls/day. She was working with PT for mobilization and safe transfers. Her goal was to be free of her catheter, get in and out of bed with minimal assistance, manage self-care and use the toilet. The following plan was put in place for Victoria: Phase one was for one month to increase her mobility, strength and confidence with PT, kegal exercise one set of 10 three times a day and NCA to follow up in one month. Phase two was set for one month to work on self-transfer and walking to the bathroom, sitting on the toilet or commode and self-clean, PT would look into self-cleaning devices to help gain Victoria's independence and evaluate her readiness to move onto phase three, catheter removal, after one month. On the second visit, Victoria continued to experience bladder spasms, frequent catheter changes, pain from her catheter and catheter blockages as noted in her progress notes. The PT was working with Victoria on the mobilization and transfer plans where Victoria was progressing well according to the progress notes. Victoria was following the Kegal exercise regime and her skin was healing. She expressed concerns about the heaviness of her catheter bag, the need for a raised toilet seat and the difficulty of reaching behind herself to self-clean. The following recommendations were written: look at other leg bag options, extender for wiping perineum area, a spray bottle to help clean skin with a follow up in one month. Follow ups were done via email to the nurse and participant. In November 2014, the catheter was removed as Victoria met her identified goals. PT continued to work with her mobility, nursing worked to control her diabetes, OT assisted with adequate wheelchair cushion and toileting aides such as wiping extender and raised toilet seat. In total, there were six follow ups via phone, email and visits.

Wan was seen by an NCA in August 2015 where an initial assessment was completed with an interview that took about 2.5 hours. His main incontinence concern was the frequent UTIs, catheter blockages and bladder stones experienced with his Foley catheter which was inserted in 2013. He experienced numerous bladder spasms which he was prescribed medications. He was transferred to acute care frequently for antibiotics and catheter changes for reoccurring catheter blockages and UTIs. The plan for Wan included: fluid intake diary, Kegal exercises, trial of hydrophilic or antimicrobial infused catheter to minimize UTI symptoms and review the outcomes of Kegal exercise at the next urology appointment with urodynamic testing and NCA to follow up in six weeks. Over the next few weeks, the RCC informed the NCA that there was difficulty in finding a company who supplies specialized catheters. In the meantime urology suggested to Wan in trialling removing the catheter. PT also worked with Wan to strengthen his leg and arm muscles in possible self-catheterization trial. The NCA provided the staff with a plan over the phone on steps to remove his catheter and to watch for urinary retention using a bladder scanner. The Foley catheter was removed in April 2016. Wan experienced urinary retention as noted in the progress notes and an intermittent catheter was used once to remove his urine otherwise he was incontinent in his pad. He was working on strengthening his sphincter to regain control. The NCA connected with Wan via email about his progress which continued.

#### **4.4.2 Enhancing staff knowledge**

During the consults with all three participants, the NCA supported the staff in spreading knowledge about UI, assessment tools and evaluation. For example, the NCA shared that Mary's dribbling was caused by increased pressure in the abdomen called stress incontinence. Through the information shared about Mary's UI situation and the impact of UI on Mary the staff were

more aware of ways in which UI affected Mary. During the consults, the continence clinical practice guideline was shared and reviewed with staff paying attention to the tools that could be used. The NCA educated the staff on completing the voiding diary, fluid intake and interview assessment guide through 1:1 and group sessions. The DOC, RCC and Educator from these care homes took the responsibility of supporting their staff in completing the tools. With each consult the NCA documented a detailed assessment, management strategies and an evaluation which included the staff involvement and planning. The NCA provided the staff with company lists who sold catheters so they were aware of these agencies. In speaking to the PT working with Victoria, the kegal exercises were presented step by step in detail so that PT could continue helping Victoria in completing these exercises.

## **4.5 Experiences after NCA consult**

### **4.5.1 Outcomes for participants**

Throughout the interviews, the participants expressed ways the NCA helped them with their incontinence issues revealing a positive impact. In this section, the outcomes are divided into three main points as described by the participants: feeling heard, comprehensive assessment and changes to their incontinence reflective in their quality of life.

#### **4.5.1.1 Feeling heard**

One area that was profound in the interviews was the participants felt heard and had a chance to voice their issues to someone who spent focused time with them listening and documenting their concerns. Nurses and other staff were busy day to day with their responsibilities so they had minimal time in their busy day to perform a urinary assessment. The NCA had focused time to spend with each of the participants to hear and understand their story, review the chart and supporting documents, plan with the staff and suggest management

strategies. As Wan stated “and having somebody you can say yes speak to me.” Victoria appreciated that someone could answer her questions about her catheter and the plans she had in mind for options for her catheter. She stated “because there was just a whole new field, a whole new subject and, and I didn’t really, I don’t think really the staff uh here never really uh prepared to understand or understood or prepared and to, to answer those questions.”

#### **4.5.1.2 Changes to incontinence**

The most powerful outcomes were the positive results that each participant experienced giving them a sense of dignity, freedom and control over their UI. In the interview with Mary, she managed to sit through lunch in the dining room without wetting herself giving her a sense of accomplishment and enjoyment. The kegal exercises may have strengthened her pelvic muscles giving her control over her bladder leakage as she mentioned in her interview. Mary also indicated that she was happy that she was able to minimize her dribbling to enjoy her socialization. Mary continues to struggle with UI but staff are more aware of assistance she needs with the plan to take her to the toilet when she requires.

Victoria successfully discontinued her catheter which was causing her so much distress, infections and pain. She expressed her gratitude for getting more information about options for her catheter in her interview. The three phase approach was doable and set achievable goals which she met as per Victoria. Krista expressed the value of having a step by step approach and collaborating with the health care team such as OT and PT. Victoria’s willingness and energy to meet her goal of catheter removal set the stage for her achievements. She worked hard with the PT in strengthening her leg muscles enough for her to walk using the walker to the toilet with minor setbacks of health deterioration. The kegal exercise may have strengthened her pelvic muscles and bladder. Once the catheter was removed she did not need the bladder spasm



medications, antibiotics or the diuretic which caused several side effects. Her Lasix was decreased from 80 mgs to 40 mgs with a plan to decrease possibly to 20 mgs. She no longer needed catheter changes nor be worried about it being pulled out. Her skin was in good health with no breakdown. She was going out more to the mall and outdoors. As per the nurse, her quality of life had improved “remarkably” that made the participant very happy.. On February 2015, the NCA received an email from Victoria outlining her progress with her UI: independent with her toileting, purchase of a wand to help with cleaning, no further pain, holding her urine for up to four hours, continuing with strengthening her pelvic floor muscle skin remained less irritated and diuretic medications decreased. Victoria also expressed “It’s been a lovely process, I am so happy about the whole effort, and thank you and everyone else who has been involved. They’ve all been great and so supportive, I’ve been a lucky, lucky woman indeed.”

Wan had his catheter removed and found a sense of relief from UTIs, catheter changes, and bypassing. He found kegal exercises did help with regaining bladder function. He now wears an incontinence pad which he is not happy with however he feels it is better than the consequences of a catheter. He is no longer burdened with transferring to acute care for bladder infections or difficult catheter changes. His dose of Baclofen was decreased from 95 mg a day to 25 mg a day which also has minimized the side effects for him. Linking to other resources for catheter care has given him opportunities and support systems to discuss his concerns. Wan is a quadriplegic and the urinary catheter caused autonomic disreflexia episodes which can be dangerous for him. Now having the catheter removed he is less at risk for these episodes.

#### **4.5.2 The role of NCA**

When participants were asked the questions about their opinion about continence specialists’ involvement, all agreed that this resource was helpful and important. Mary expressed

that if continence specialists were involved early for UI issues then people would get the help they need. Victoria shared her thought of the need for more involvement from the continence specialist in her plan for catheter removal to support staff and follow the plan without delay. Involving a continence specialist into one of the participant's care allowed for her questions to be answered and to validate her goal of removing the catheter.

One of the roles of the NCA is to involve the health care teams and to link people to resources for further assistance. The work on Victoria's catheter removal plan was a collaborative involvement from different areas. The PT worked on her walking and transfers, nursing was managing her skin breakdown and the continence advisor supported her with a catheter removal plan. Kegal exercises were effective as per the first two participants as they were able to gain control of their bladder by making her bladder stronger. When Victoria's catheter was removed she was able to manage her own toileting by walking to and from the bathroom, using a wiper extender to clean herself and to use the toilet when she needed. The removal of the catheter posed another advantage for Victoria as the signs and symptoms of infection according to Victoria's comment "I knew what the potentials were, so I sit now no open areas and no areas with infection and uh one bit of eczema on my one part of my upper thigh but it's not, you know we treat that".

Wan stated that having a resource that had the continence knowledge relieved him. He was able to regain some bladder control and have his catheter removed through kegal exercises. The continence nurse could be a link to connect residents with other resources and support systems. He reported that the continence nurse provided him with "intellectual stimulation" by spending focused time and talking about his continence issues. He felt heard by the NCA who

gave him time to voice his issues and frustrations versus feeling ignored by the other health professionals.

The role of the NCA in all three cases played a critical and crucial part in working with incontinence issues. The continence expertise and skills that the NCA has are unique to this role that other professional staff do not bring. In all three cases, the outcomes were positive leading to increase quality of life for the residents. These measures not only returned their dignity but their independence, control, comfort and freedom. The consults with an NCA provided these opportunities and possibilities. This role is an added value to the health care team as evidenced by each case study and its findings.

### **4.5.3 Change in staff knowledge**

#### **4.5.3.1 Documentation**

When the NCA consulted with the team, a comprehensive assessment was used to gather UI information from the chart, other supporting documents and interviewing the resident and staff who provided a detailed story of the participants' UI issues. After the assessment, tools were further suggested from the guideline such as the voiding diary and fluid intake to get a picture of the participant's current state. Three voiding diaries were initiated in a four month consultation for Mary which assisted in understanding her voiding pattern and resulted in a concrete and individualized toileting plan for her. These voiding diaries were completed with concrete data and for every shift with minimal missed times. Another example of using a consistent tool from the guideline to collect fluid intake for Mary was using the fluid intake diary which provided a better understanding of the amount she drank over a three day period in 24 hours. The NCA educated the staff on how to fill out the fluid intake and the voiding diary which then was then analysed with the staff after its completion. After this education, the fluid intake,

voiding diary and supporting documents are being completed before sending the referral to the NCA.

#### **4.5.3.2 Comprehensive assessment**

Another outcome was using a comprehensive assessment to understand the incontinence issues that delved deeper into these issues gathering information that includes the issues they face, ways incontinence impacts them, setting goals, fluid intake, contributing factors and current medication list. The NCA's knowledge and expertise in assessing the participants using the comprehensive assessment is specialized training that nurses don't get in nursing school. This added knowledge for the NCA allowed her to ask questions, look into management strategies and link in with resources. As Wan stated, "And that sort of thing um in invaluable. I think one thing, the, the outreach point is I would suggest is that the continence nurse do is certainly some liaison with the ICORD and the Rick Hansen institute" which are agencies supporting people with spinal cord injuries. This assessment provided staff with a better understanding of the reasons possibly causing incontinence, how incontinence impacted each participant and how incontinence affected their day to day living. This information was shared with the staff so that the team would understand the reasons for UI, agree upon the recommended treatment plan with an evaluation date. In using the continence clinical practice guideline and referring to it often during the consult, the staff are aware of this document and its' tools.

#### **4.6 Summary**

Through the utilization of multiple case studies of Mary, Victoria and Wan, the experiences being seen by a NCA was explored. The analysis revealed three consistent categories with the NCA experience such as the impact of UI, gaps in staff knowledge and the impact of the NCA role on continence issues. The older adults' perspectives through these

interviews provided a rich and deep understanding of their own experiences with incontinence and the outcomes of the NCA involvement. It was evident that Mary, Victoria and Wan experienced psychosocial, physical and financial consequences of incontinence. In other findings, the lack of UI knowledge amongst staff was expressed by both Victoria and Krista. The lack of timing and resources available, hindered attention to their UI concerns. Mary, Victoria, and Wan expressed the importance and value that continence experts brought to their incontinence and the positive outcomes they experienced. Krista also saw the value to staff in involving the NCA in the ways she educated, trained and supported them. Having a resource available, such as an NCA, to work with people experiencing UI would be invaluable from understanding the causes of UI to looking at conservative measures by listening to the issues that they are dealing with. These three case studies reached a deeper understanding on the relevance of the NCA role as they expressed their experiences through their stories. Given that NCAs roles exist but are underutilized, it is important to understand the potential role of NCAs in RLTC, and how they can integrate best practices in continence care. There are no studies currently available that explore nurses' perspectives of the NCA role in RLTC. In exploring older adults' perspectives about this role, it will assist in defining and clarifying the NCA role as it fits within the RLTC sector and assist in customizing the NCA role so that it can be consistent and functional. This study provides justification for the NCA role to be a part of RLTC resources through the positive impact on each person's UI and a better quality of life.

## **Chapter 5: Discussion and recommendations**

The purpose of this study was to explore older adults' experiences in working with a Nurse Continence Advisor in RLTC. The case study method provided critical insights from the older adults' experiences towards understanding the impact of UI on their quality of life and the NCA role as a resource. The interviews and supporting documents shed light on older adults' experiences, assessments and the outcomes they achieved. From these findings, there is a strong case to hear from individuals experiencing UI in understanding the value of the NCA role as a key member of the health care team. The results of this study reflect the participants' perceptions and experiences of working with a NCA and the impact of UI on their quality of life. The limitations will be presented along with implications of the NCA role from the education, practice, leadership, and research domains.

### **5.1. Continence education and knowledge**

Through the exploration of the older adults' experience and the nurse's feedback, it was evident that there are gaps in staff continence knowledge. This is evidenced in Victoria's case where the staff had difficulty in planning her catheter removal as they had little knowledge about the process and initiation of this intervention. Krista felt that nurses did not have enough skill about incontinence to be successful. Mathis, Ehlman, Dugger, Harrawood and Kraft (2013) supported this in their quasi-experimental, within-subject, longitudinal (two time points) study to understand nursing home staff knowledge about UI. This study revealed approximately 50% of staff lacked UI assessment and implementation knowledge. All study participants received the same intervention of education on types of incontinence and treatment over a 6-week period. The study showed that after education was provided to staff, there were improvements in staff knowledge about the types of incontinence and treatment options of UI which resulted in the

appropriate identification of incontinence issues. Similarly, Keilman and Dunn (2010) concluded that advanced practice nurses also had difficulty applying UI knowledge to assessing, treating and managing UI related to inadequate skills and experience within their preceptored curriculum. This study suggested that nurses not only receive theoretical UI information in their curriculum but clinical experiences to enhance their skills.

## **5.2 Continence assessment and documentation**

The importance of a comprehensive assessment cannot be overemphasized. This study found gaps in regards to assessing the older adult for UI. As the participants indicated, incontinence caused them embarrassment and humiliation which may have delayed reporting. As Wallner et al. (2009) discovered, this delay can have substantial impact on quality of life. A high majority of older adults in RLTC experience some form of incontinence pointing to the importance of assessment (Griebing, 2009). As Keilman & Dunn (2010) confirmed nurses do not ask older women about urine leakage or offer intervention and evaluation as UI was considered a normal part of aging, a common belief. Assessing continence is essential upon moving into RLTC to understand a person's baseline and functionality (Price, 2011). Interviewing the older adult, reviewing their chart and supporting documents such as diaries and fluid intake are a few examples of initiating a comprehensive assessment to get the whole story from the older adult. According to Prideaux (2011), having structured and consistent documentation can improve care by eliminating vagueness and variations of narrative styles by nurses.

It was evident through the review of the supporting documentation that there was missing information about the participants' progression of incontinence. There were many inconsistencies in the documentation such as variations in the tools used for assessment and tracking, incomplete

fluid intake and voiding diaries, and inadequate documentation in progress notes. Voyer et al. (2014) conducted a prospective, observational study in seven RLTC homes in Canada collecting data on nursing documentation on delirium. The results concluded that 7.6% nurses documented about delirium in the progress notes leaving gaps in information for other health care team members and physicians thus leading to an unclear picture of residents' health progress. As Inan & Dinc (2013) concluded, inadequate and incomplete documentation can threaten the continuity of care and person's safety.

### **5.3 NCAs within RLTC**

One of the key findings was that the NCA role was unknown to staff and participants living in RLTC. Reasons for this may be the lack of information disseminated and communication to care homes and staff which potentially impacted accessibility. Mary and Victoria had the NCA involved after several weeks to months of their UI issues starting as staff were not aware that a NCA existed in RLTC. Victoria explained that the NCA only got involved after she consistently pursued the need to have her catheter removed and was being vocal of her goal. This waiting may have led to the delay in putting the plan in place and this participant dealt with ongoing UTIs and discomfort. Mary stated that she recommended that the specialist get involved quickly with UI issues before it progresses. The literature supports this claim that there is little known about NCAs by staff as found in the minimal articles found on this role. The few articles located about the NCA role, as mentioned before, were from 15 to 20 years ago (Austin, 2003; Festen, Duggan & Coates, 2007; Skelly & Kenny, 1998). The NCA brought a continence specialist lens with skill and knowledge that others did not have. Skelly & Kenny (1998) found the NCA role significantly contributed to resolving UI issues and decreased cost of continence care. Bates & Porter (2002) concluded that UI can be managed and treated with the involvement



of NCAs by performing a thorough assessment. In reaching the outcomes, the NCA was able to work with each individual and staff to assess, plan, implement and evaluate strategies for their incontinence. Overall, the quality of life for older adults living with UI was improved or maintained with the involvement of a NCA. Klay and Marfyak (2005) study proved the value of a NCA being involved which improved UTI, skin integrity, falls and reduced cost of care. This role is instrumental in working with a variety of incontinence issues, educating staff and older adults about incontinence and potentially decreasing costs on the health care system. In this study, the continuous collaboration with the NCA provided staff with a resource and support to follow the steps suggested to work with all three participants. The multiple case studies add to this evidence that NCAs are valuable to the team and participants.

#### **5.4 Impact of UI through personal stories**

The most overwhelming and informative aspect in this study was engaging participants in sharing their experiences about UI. Before the interviews, there was documentation about the physical impact of UI on each participant and what was missing was the emotional and psychosocial impact of UI. NCAs bring the knowledge and understanding of incontinence therefore NCAs can provide opportunities for individuals to express their UI experiences (Keilman & Dunn, 2010). Giving the participants the time to voice their experiences builds trust and relationships to honor the individual in care. Johnson (2016) drew from patient and family centered personal stories to focus on collaboration and involvement to promote knowledge, values, beliefs, perspectives, dignity and respect. His recommendations of promoting personal stories help build meaningful partnerships with patients and families at all levels of health care. Interviewing the participants and hearing their stories allowed for a personalized and heartfelt understanding of their experiences with UI. Harrison & Frampton (2016) focused on resident

centered care by asking the residents in United States nursing homes about their choice in wake and bed times. Residents expressed their beliefs that their voices and opinions were being heard and taken seriously, an example of asking individuals. Similarly Smitha and Kreklewetz (2015) provided evidence that resident life stories are a useful method in learning about residents and providing care. Nursing aides were exposed to three modes of communication in sharing a resident's life story: (1) resident intake form (2) typed story and (3) video relaying life story. Nurses' aides found the story and video to be useful, helpful and far more superior in learning about the resident than the form. Personal stories allow for expressions of experiences, feelings and self-reflection.

## **5.5 Recommendations for nursing education**

Continence education is an integral first step in understanding continence which involves assessment, planning, treatment and evaluation. In conjunction with education, the NCA can support the application of learning by assisting staff to initiate and complete assessments, analyze the information, implement interventions and evaluate the interventions. Mathis, Ehlman, Dugger, Harrawood and Kraft (2013) found a value in creative, evidence-based education programs to improve staff knowledge about UI to improve quality of care for residents. Providing continence education would not only benefit the staff but in turn benefit those experiencing incontinence. Increasing staff knowledge about the types of UI and different management strategies may result in improved understanding and knowledge. An important point found by Klay and Marfyak (2010) was that staff were taught that incontinence is not a normal part of aging which impacted staff belief and attitude towards older adults. Taking another look and reviewing current continence education for staff and proposing an education program focusing on incontinence is recommended. NCAs would be an ongoing resource to

provide education and skill to health care teams including the use of consistent tools and guidelines.

### **5.6 Recommendations for nursing leadership**

It has been suggested from the little research in this area that there is lack of understanding and awareness of the NCA role and this may lead to their ineffective use. As the NCA communities are growing, this role needs to be advertised and utilized more within clinical settings. Accessibility to health care teams needs to be further explored in ways to make this resource more available than it has been currently. This needs to start from the health care organizations and agencies. Clinical leaders can be instrumental in working towards supporting health care teams in advocating for NCA resources within RLTC. Bringing the NCA role to light can be advantageous to the people experiencing incontinence, health care teams and the public. NCAs can empower the health care team by providing guidance for working through incontinence issues, problem solving and working together to reach individual specific goals. With such a valuable position and the possible positive impacts of this role, the NCA role needs to be advertised, shared and spread throughout the RLTC community. This role would bring not only benefit to the team but the older adults themselves as shown in this study.

### **5.7 Recommendations for nursing practice**

It was well evident in this study that nurses had gaps in UI knowledge and practices in using tools and assessing were varied. It was clear that discussing the impact of UI on older adults is a crucial step that must be part of assessment and evaluation. A key theme that was evident in this study was that the participants did not feel heard by specialists, staff or other individuals due to the time factor or because they had little knowledge about the issues. A crucial part of understanding the full picture is listening to the person who is experiencing the problem,

in this case the older adult. Keilman & Dunn (2010) found that demonstrating care and concern through emotional support for the older person experiencing UI will become paramount in promoting their quality of life. Shakespeare, Barradell and Orme (2011) concluded that appropriate goal setting be realistic, achievable and subjective to the individual and be based on maintenance and improvements versus cure.

Using the consistent tools within the Continence clinical practice guideline (CPG) for interviewing and gathering information allowed for an in-depth assessment of incontinence. These tools can be used by the staff consistently for all older adults requiring an incontinence assessment while it helps guide the staff use simple strategies for management. Using the same tools repeatedly gives staff the confidence in the information required and ensures similar steps are taken for a complete data collection. Within the CPG are management strategies, medications for UI and evaluation tools. For a more detailed assessment, the NCA utilizes a more comprehensive assessment form to gather detailed incontinence information. This assessment has categories for incontinence issues, contributing factors, medications and treatment plan which are a specialized assessment tool that the NCA uses. Educating staff on using these tools is a role that the NCA can take part in as the continence specialist. Not only would training staff to use these tools boost efficient continence assessment skills, it will create a standard workflow for all continence assessments.

### **5.8 Recommendations for nursing research**

There is limited literature about NCAs currently that has led to little or no awareness of the NCA role. Further research is needed with NCAs sharing their work with UI in informing the health care sectors on the value and function of this role to fully understand it. Hearing from older adults on their personal experiences with UI and working with an NCA must be pursued

further to provide more insight to their UI issues. Future research needs to be broader to include NCAs and older adults from other health authorities, sectors and regions to get a wider variety of experiences with UI and measurable outcomes of the impact of NCA involvement.

## **5.9 Limitations**

While the results from this study are promising, there are several limitations. Limitations of this study can be attributed to the small sample of participants who took part in this study.

There were three participants who took part in this study. Another limitation was this study took place in two organizations under one health authority versus expanding the study to other areas.

All three participants in this study worked with the same NCA which did not allow for perspectives from older adults who worked with other NCAs to be included. The timing of the interviews, approximately 1-2 years after the initial NCA consultation, may have impacted their true recollection of emotions and information.

During recruitment, there were challenges in finding older adults living in RLTC who worked with an NCA, could recall their experiences and agreed to be involved in the study.

Challenges found in recruiting participants were progression in their dementia, inability to recall and verbalize experiences, move to another care home, deceased and very few older adults had

NCA involvement. When reaching out to family, one participant was embarrassed to have them involved and the other participant's family did not respond. This study was not able to capture

perspectives from family members which would have provided another view of understanding.

When reaching out to other NCAs in RLTC for this study, they were not actively practicing in their NCA role, had no time or participants who wanted to participate. The NCA in this study

was the researcher and this may suggest a possibility of bias as the NCA was well known to the

staff and participants. Recruiting staff for interviews was difficult due to staff turn overs and willingness to participate in this study hence only one staff member participated.

Little is known about the NCA role due to the limited literature to help understand this role; it was difficult to gain knowledge about the functions of NCAs. Research available on this role was in the early 1990s and earlier making it difficult to get up to date information. No literature was found on older adults' experiences working with NCAs providing no comparative information as a starting point. Even though this is truly a limitation, this study took place in hopes to inform and share the true findings of older adults voicing their experiences through their work with an NCA.

## **5.10 Conclusion**

In conclusion, this multiple case research study provided an understanding of older adults' experiences of working with an NCA in RLTC. The findings reveal several gaps that need focus such as continence education, documentation and the NCA role which can add value to the quality of life of residents. Consistent tools need to be used to ensure the correct information is being gathered for UI issues. With practice and UI education, nurses will become better at assessing and managing UI. Becoming familiar and using the Continence CPG will not only ensure staff are using best practices but this document is a guideline for managing and maintaining continence. All three participants provided their stories on their experiences in working with an NCA which proved to have positive results. Above all, the participant perspectives highlighted many areas of their struggles and successes with UI that were evident in their comments and shared experiences. The participants' will and commitment in meeting their goals were not only a result of their own desire but were attainable by the support in collaborating with the NCA. All though this is a small sample, the three case studies provided a

reason for further studies with a larger sample size to be completed as the impact of UI was evident as well as the importance of the value that the NCA brought to lives of Mary, Victoria and Wan.

## References

- Addison, R. (1996). The changing role of the continence advisor. *British Journal of Nursing*, 2(6), 361-363.
- Al-Hayek, S., & Abrahams, P. (2005). Incontinence in the elderly. *Women's Health Medicine*, 2(6), 46-50.
- Anthony, S., & Jack, S. (2009). Qualitative case study methodology in nursing research: an integrative review. *Journal of Advanced Nursing*, 65(6), 1171-1181.
- Bates, F., & Porter, G. (2002). The role of the Nurse Continence Advisor in a urology wellness clinic. *Urological Nursing*, 22(1), 23-26.
- Baumbusch, J. (2010). Semi-structured Interviewing in Practice-Close Research. *Journal for Specialists in Pediatric Nursing*, 15(3), 255-258.
- Baxter, P., & Jack, S. (2008). Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report*, 13(4), 544-559.
- Beldon, P. (2012). Incontinence-associated dermatitis: protecting the older person. *British Journal of Nursing*, 21(7), 402-407.
- Canadian Nurse Continence Advisor Association. (2012) <http://www.cnca.ca/>  
Retrieved April 20, 2014
- Cassells, C., & Watt, E. (2003). Impact of incontinence on caregivers. *Journal of Advanced Nursing*, 42(6), 607-616.
- Cope, D. (2014) Methods and Meanings: Credibility and Trustworthiness of Qualitative



- Research. *Oncology Nursing Forum*. 41(1), 89-91.
- Deloitte Access Economics (2011). The economic impact of incontinence in Australia. Contenance Foundation of Australia Retrieved April 20, 2014 from [http://www.contenance.org.au/data/files/Access\\_economics\\_report/dae\\_incontinence\\_report\\_19\\_april\\_2011.pdf](http://www.contenance.org.au/data/files/Access_economics_report/dae_incontinence_report_19_april_2011.pdf)
- Doughty, D. (2006). *Urinary & Fecal Incontinence: Current Management Concepts*. (3rd Ed). Mosby Elsevier: USA.
- Ehlman, K., Wilson, A., Dugger, R., Eggleston, B., Coudret, N., & Mathis, S. (2012). Nursing home staff members' attitudes and knowledge about Urinary Incontinence: The impact of technology and training. *Urological Nursing*, 32(4), 205-213.
- Edgley, J. (2002). The psychosocial impact of incontinence on older people: a review. *Nursing Older People*, 14(1), 17-19.
- Estabrooks, C., Poss, J., Squires, J., Teare, G., Morgan, D., Stewart, G.,... Norton, P. (2013). A Profile of Residents in Prairie Nursing Homes. *Canadian Journal of Aging*, 32(3), 223-231.
- Festen, L., Duggan, P., & Coates, D. (2008). Improved quality of life in women treated for urinary incontinence by an authorized continence nurse practitioner. *International Urogynecology Journal*, 19, 567-571.
- Getliffe, K., & Dolman, M. (2007). *Promoting Continence: A Clinical and Research Resource*. (3rd ed.). Elsevier Limited.

- Graneheim, U.H., & Lundman, B. (2003) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- Gray, M., Bliss, D., Doughty, D., Ermer-Seltun, J., Kennedy-Evans, K., & Palmer, M. (2007). Incontinence-associated Dermatitis. *Journal of Wound Ostomy Continence Nurse*, 34(1), 45-54.
- Griebing, T. (2009). Urinary Incontinence in the Elderly. *Clinical Geriatric Medicine*, 25, 445-457.
- Hajjar, R. (2004). Psychosocial impact of urinary incontinence in the elderly population. *Clinics in Geriatric Medicine*, 20, 553-564.
- Harrison, J., & Frampton, S. (2016). Resident-Centered Care in 10 U.S. Nursing Homes: Residents' Perspectives. *Journal of Nursing Scholarship*, 49(1), 1-9.
- Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*, 20(4), 12-17.
- Hyett, N., Kenny, A., & Dickson-Swift, V. (2014). Methodology or method? A critical review of qualitative case study reports. *International Journal of Qualitative Studies on Health and Well-being*, 9, 1-12.
- Inan, N., & Dinc, L. (2013). Evaluation of nursing documentation on patient hygienic care. *International Journal of Nursing Practice*. 19, 81-87.

- Jirwe, M. (2011). Analyzing qualitative data. *Nurse Researcher*, 18(3), 4-5.
- Johnson, B. (2016). Promoting Patient- and Family-Centered Care Through Personal Stories. *Academic Medicine*, 91(3), 297-300.
- Keilman, L., & Dunn, K. (2010). Knowledge, attitudes, and perceptions of advanced practice nurses regarding urinary incontinence in older adult women. *Research and Theory for Nursing Practice: An International Journal*, 24(4), 260-279.
- Klay, M., & Marfyak, K. (2005). Use of a Continence Nurse Specialist in an Extended Care Facility. *Urologic Nursing*, 25(2), 101-108
- Mathis, S., Ehlman, K., Dugger, B., Harrawood, A., & Kraft, C. (2013). Bladder Buzz: The effect of a 6-week evidence-based staff education program on knowledge and attitude regarding urinary incontinence in a nursing home. *Journal of Continuing Education in Nursing*, 44(11), 498-506.
- McGloin, S. (2008). The trustworthiness of case study methodology. *Nurse Researcher*, 16 (1), 45-55.
- Milne, J., & Moore, K. (2003). An exploratory study of continence care services worldwide. *International Journal of Nursing Studies*, 40, 235-247.
- Ministry of Health – Province of British Columbia (2013). Retrieved March 2013 from: <http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-residential-care>
- Molander, U., Sundh, V., & Steen, B. (2002). Urinary incontinence, its influence on daily

life, and use of continence aids in two cohorts of 85/86-year-old free-living men and women, born 10 years apart. *Archives of Gerontology and Geriatrics*, 35, 275-281.

Morse, J., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002) Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*. 1(2), 13-22.

National Association for Continence (2014). Retrieved April 20, 2014 from

<http://www.nafc.org/media/statistics/>

Polit, D., & Beck, C. (2012). *Nursing Research: Generating and Assessing Evidence for Nursing Practice* (9th ed.). Philadelphia, PA: Wolters Kluwer Health & Lippincott, Williams & Wilkins.

Price, H. (2011). Incontinence in patients with dementia. *British Journal of Nursing*, 20(12), 721-725.

Prideaux, A. (2011). Issues in nursing documentation and record-keeping practice. *British Journal of Nursing*, 20(20), 1450-1454.

Rhodes, P., & Parker, G. (1994). Profile of an advisor. *Nursing Times*, 90(4), 75-78.

Rhodes, P., & Parker, G. (1995). The role of the continence advisor in England and Wales. *International Journal of Nursing Studies*, 32(5), 423-433.

Robinson, O. (2013) Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative Research in Psychology*, 11(1), 25-41.

Shah, S., Carey, I., Harris, T., DeWilde, S., Hubbard, R., Lewis, S., & Cook, D. (2010).

- Identifying the clinical characteristics of older people living in care homes using a novel approach in a primary care database. *Age and Ageing*, 39, 617-623.
- Shakespeare, K., & Barradell, V., & Orme, S. (2011). Management of urinary incontinence in frail elderly women. *Obstetrics, Gynecology and Reproductive Medicine*, 21(10), 281-287.
- Sinclair, A., & Ramsay, I. (2011). The psychosocial impact of urinary incontinence in women. *The Obstetrician & Gynecologist*, 13, 143-148.
- Skelly, J., & Kenny, K. (1998). The impact of the nurse continence advisor on continence care. *Clinical Effectiveness in Nursing*, 2, 4-10.
- nursing home residents? *Archives of Gerontology and Geriatrics*, 49, 278-283.
- Smith, M., & Kreklewitz, C. (2015). Can resident life stories help nursing aides learn about residents? A pilot study. *The Journal of Nursing Home Research Sciences*, 1, 81-83.
- Teunissen, D., Bosch, W., Van Weel, & Largo-Janssen, T. (2006). “It can always Happen”: The impact of urinary incontinence on elderly men and women. *Scandinavian Journal of Primary Health Care*, 24, 166-173.
- The Canadian Continence Foundation (2007). Incontinence: A Canadian Perspective  
Retrieved April 2014 from  
<http://menopauseandu.ca/documents/IncontinenceCanadianPerspectiveContinenceFound.pdf>
- The Canadian Continence Foundation (2009). Impact of Incontinence in Canada

Retrieved April 2014 from

<http://www.canadiancontinence.ca/pdfs/impacts-of-incontinence-in-canada.pdf>

Thorne, S. (2008). *Interpretive Description*. Left Coast Press Inc. Walnut Creek, California, USA.

ISBN 978-1-59874-330-2

Voyer, P., McCusker, J., Cole, M., Monette, J., Champoux, N., Ciampi, A., ...Richard, S.

(2014). Nursing Documentation in Long-Term Care Settings: New Empirical Evidence Demands Changes be Made. *Clinical Nursing Research*, 23(4), 442-461.

Wallner, L., Porten, S., Meenam, R., Rosetti, M., Calhoun, E., Sarma, A., & Clemens, J.

(2009). Prevalence and Severity of Undiagnosed Urinary Incontinence in Women. *The American Journal of Medicine*, 122 (11), 1037-1042.

Wenger, N., Roth, C., Shekelle, P., Young, R., Soloman, D., Kamberg, C., Chang, J.,

Louie, R., Higashi, T., MacLean, C., Adams, J., Min, L., Ransohoff, K., Hoffing, M., & Reuben, D. (2009) A Practice-Based Intervention to Improve Primary Care for Falls, Urinary Incontinence, and Dementia. *Journal of American Geriatrics Society*, 57(3), 547-555.

Wilson, L., Brown, J., Shin, G., Luc, K., & Subak, L. (2001). Annual Direct Cost of

Urinary Incontinence. *Obstetrics and Gynecology*, 98(3), 398-406.

Whiting, L.S, (2008). Semi-structured interviews: guidance for novice researchers. *Nursing*

*Standard*. 22(23), 35-40.

## Appendix A: Letter to residential long term care managers/leaders



### Exploring Older Adults' Experience about the Nurse Continence Advisor role in Residential Long Term Care

July 13, 2015

To: Residential Long Term Care Managers/Leaders

Re: Permission Request to Recruit Research Participants

I, Jasjit Gill, am a graduate nursing student at the University of British Columbia seeking permission to engage older adults in a research study that will contribute to my thesis work in the Masters of Science in Nursing Program.

The purpose of the study is to explore the experience of being consulted by a Nurse Continence Advisor (NCA) from the older adults' perspective who are living in a Residential Long Term Care (RLTC) home. This study aims to provide insight to health organizations on the value of Nurse Continence Advisors and their impact on the quality of life of older adults who experience incontinence.

Background: The role of the NCA in RLTC is an important area of research. Urinary incontinence affects residents physically, emotionally and socially impacting their quality of life. NCAs play a vital role in assessment, interventions, care planning and evaluation of continence issues. Understanding the real life experience of older adults who were consulted by a NCA within RLTC will inform the impact of this role on their quality of life and possibly the importance of this role in RLTC.

I am hoping to recruit 3 older adults living in RLTC that have been consulted by a NCA. Older adults will be participating in a 30 minute interview which can be facilitated in-person at a time and place of convenience to participant. These interviews will be audio-taped and field notes will be taken. Information will be gathered using charts and health records if needed. There will be no personal information shared or documented on any of the information provided by the participant. My advisor and Principal Investigator, Jennifer Baumbusch, and I from the School of Nursing will be the only 2 people who will have access to the information that you provide.

I hope that you will support this study by assisting me in sharing the following documents: invitation to participate letter, consent, and demographic information with potential participants.

I appreciate your support.

## Appendix B: Invitation to participate letter



### Invitation to participate: Exploring Older Adults' Experience about the Nurse Continence Advisor (NCA) role in Residential Long Term Care

To: potential participants

As a graduate nursing student at the University of British Columbia I, Jasjit Gill, am seeking participants for a research study that will contribute to my thesis work in the Masters of Science in Nursing Program.

The purpose of the study is to explore experiences about the NCA role within RLTC from the older adults' perspective. The goal of the study is to provide useful information to health organizations of the value of NCAs on the quality of life of older adults living with incontinence issues.

Background: The role of the Nurse Continence Advisor (NCA) in RLTC is an important area of research. Urinary incontinence affects residents physically, emotionally and socially impacting their quality of life. NCAs play a vital role in assessment, interventions, care planning and evaluation of continence issues. Understanding the real life experience of older adults who were consulted by a NCA within RLTC will inform the impact of this role on their quality of life and possibly the importance of this role in RLTC.

I am hoping to recruit 3 older adults living in RLTC that have been consulted by a NCA. Older adults will be participating in a 30 minute interview which can be facilitated in-person at a time and place of convenience to participant. These interviews will be audio-taped and field notes will be taken. Information will be gathered using charts and health records if needed.

This opportunity allows older adults to share their experiences of being consulted by a NCA. There will be no personal information shared or documented on any of the information provided by the participant. My advisor and principal investigator, Jennifer Baumbusch, and I from the School of Nursing will be the only 2 people who will have access to the information that you provide.

If you are interested in participating in this study, please contact me at 604-992-6808 by (2 weeks of receiving letter). The enclosed consent and demographic information is requested to be completed prior to the interview date and forwarded to me via fax at 604-730-7660 or in person.

Thank you for your support.

Jasjit Gill (Co-investigator)



## Appendix C: Consent form for older adult



# EXPLORING OLDER ADULTS' EXPERIENCES WITH THE NURSE CONTINENCE ADVISOR ROLE IN RESIDENTIAL LONG TERM CARE

The researchers involved in this study include:

**Principal Investigator:**        **Jennifer Baumbusch, PhD**  
School of Nursing  
University of British Columbia

**Co-Investigator(s):**        **Jasjit Gill, BSN**  
School of Nursing  
University of British Columbia

### **Why am I doing this study?**

The purpose of the interview is to understand the participants' understanding and experience about the Nurse Continence Advisor (NCA) role in managing continence in the older adults living in Residential Long Term Care (RLTC). You are invited to participate in this study because you have been consulted by an NCA. This study will contribute to my graduate thesis work in the Masters of Science in Nursing Program at University of British Columbia.

### **What happens if you agree to take part in this study?**

Three participants will be asked to share their experience of being consulted by an NCA during a 30 minute interview which will be facilitated by the co-investigator. The interview will be audio-recorded through a face to face interview and will occur at a mutually agreed upon time between yourself and the researcher. The interview will take place in a quiet and confidential environment of your choice. The researcher will be using an interview guide and will be taking notes during the interview.

Included in the interview are demographic information of each participant however no identifying information will be asked. Information will be accessed by only 2 people for this study: Jasjit Gill and Jennifer Baumbusch.

### **What are the risks of taking part in this study?**

By participating in this study, there will be minimal risk to you. The conversations will be in confidence however minimal emotional discomfort may be experienced by you when sharing experiences. If you become uncomfortable, the researcher must stop and if you agree can carry on.

### **What are the benefits of taking part in this study?**

Although there are no immediate benefits, your participation in this study will contribute to a greater understanding of NCAs with the RLTC sector. You may experience some benefit with sharing your own opinion, understanding, experience and knowledge.

### **How will your privacy and confidentiality be maintained?**

Your privacy and confidentiality will be respected. Any information resulting from this research study will be kept strictly confidential and will be protected in several ways.

- No names or other personal identifiers will be used in any research documents resulting from this research.
- Each participation will be identified by an identification number.
- No individual will be able to identify your answers to the questions in the interview as yours.
- Audiotapes will be used to record your interview. No personal identifiers will be used and only principal investigator and co-investigator will have access to this information.
- All records will be securely stored in a locked filing cabinet and/or password protected computer files.
- All data will be stored for up to 5 years as per UBC policy.

### **Will you be paid for your time or taking part in this study?**

We will not pay you for your time or provide any other compensation for taking part in this study.

### **How will the results of the study shared?**

The results of the study will be reported in a graduate thesis. The investigators of this study can provide the participants with the results of the study by providing a simplified report or through a short discussion with the participants. The main study findings may be published in journal articles.

### **Who can you contact if you have questions about the study?**

If you have any questions about the study, please contact the investigators listed at the top front page of this document.

### **How can you sign up to take part in this study?**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any point of time without jeopardy to your living or care situation. If you wish to withdraw from the study at any point your data will be removed from the study.

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study.

Yes, I understand what this study entails and I am comfortable with the procedures.

---

Participant Signature

Date

---

Printed Name of the Participant signing above

**Who can you contact if you have concerns about the study?**

If you have any concerns about your treatment or rights as a participant in this study, you may contact the Research Participant Complaint Line in the UBC office of Research Ethics at 604-822-8598 or email at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

## **Appendix C1: Consent form for family member**



### **EXPLORING OLDER ADULTS' EXPERIENCES WITH THE NURSE CONTINENCE ADVISOR ROLE IN RESIDENTIAL LONG TERM CARE**

The researchers involved in this study include:

**Principal Investigator:**        **Jennifer Baumbusch, PhD**  
School of Nursing  
University of British Columbia

**Co-Investigator(s):**        **Jasjit Gill, BSN**  
School of Nursing  
University of British Columbia

#### **Why am I doing this study?**

The purpose of the interview is to understand the older adult's understanding and experience about the Nurse Continence Advisor (NCA) role in managing their incontinence who are living in Residential Long Term Care (RLTC). You are invited to participate in this study because your loved one has been consulted by an NCA. This information for this study will contribute to my graduate thesis work in the Masters of Science in Nursing Program at University of British Columbia.

#### **What happens if you agree to take part in this study?**

Your loved one is one of three participants who will be asked to share their experience of being consulted by an NCA during a 30 minute interview which will be facilitated by the co-investigator. This interview will be audio-recorded through a face to face interview.

Similarly you will be involved in an interview for about 30 minutes that will take place in a quiet and confidential environment of your choice. The researcher will be using an interview guide and will be taking notes during the interview.

Included in the interview are your demographic information however no personal identifying information will be asked. Information will be accessed by only 2 people for this study: Jasjit Gill and Jennifer Baumbusch.

#### **What are the risks of taking part in this study?**

By participating in this study, there will be no anticipated risk to you. The conversations will be in confidence however minimal emotional discomfort may be experienced by you when sharing your experiences. If you become uncomfortable, the researcher must stop and if you agree can carry on.

### **What are the benefits of taking part in this study?**

Although there are no immediate benefits, your participation in this study will contribute to a greater understanding of NCAs with the RLTC sector. You may experience some benefit with sharing your own opinion, understanding, experience and knowledge.

### **How will your privacy and confidentiality be maintained?**

Your privacy and confidentiality will be respected. Any information resulting from this research study will be kept strictly confidential and will be protected in several ways.

- No names or other personal identifiers will be used in any research documents resulting from this research.
- Each participation will be identified by an identification number.
- No individual will be able to identify your answers to the questions in the interview as yours.
- Audiotapes will be used to record your interview. No personal identifiers will be used and only principal investigator and co-investigator will have access to this information.
- All records will be securely stored in a locked filing cabinet and/or password protected computer files.
- All data will be stored for up to 5 years as per UBC policy.

### **Will you be paid for your time or taking part in this study?**

We will not pay you for your time or provide any other compensation for taking part in this study.

### **How will the results of the study shared?**

The results of the study will be reported in a graduate thesis. The investigators of this study can provide the participants with the results of the study by providing a simplified report or through a short discussion with the participants. The main study findings may be published in journal articles.

### **Who can you contact if you have questions about the study?**

If you have any questions about the study, please contact the investigators listed at the top front page of this document.

### **How can you sign up to take part in this study?**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any point of time without jeopardy to your loved one's living or care

situation. If you wish to withdraw from the study at any point your data will be removed from the study.

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study.

Yes, I understand what this study entails and I am comfortable with the procedures.

---

Participant Signature

Date

---

Printed Name of the Participant signing above

**Who can you contact if you have concerns about the study?**

If you have any concerns about your treatment or rights as a participant in this study, you may contact the Research Participant Complaint Line in the UBC office of Research Ethics at 604-822-8598 or email at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

## Appendix C2: Consent form for staff



# EXPLORING OLDER ADULTS' EXPERIENCES WITH THE NURSE CONTINENCE ADVISOR ROLE IN RESIDENTIAL LONG TERM CARE

The researchers involved in this study include:

**Principal Investigator:**       **Jennifer Baumbusch, PhD**  
School of Nursing  
University of British Columbia

**Co-Investigator(s):**       **Jasjit Gill, BSN**  
School of Nursing  
University of British Columbia

### **Why am I doing this study?**

The purpose of the interview is to understand the older adult's understanding and experience about the Nurse Continence Advisor (NCA) role in managing their incontinence who are living in Residential Long Term Care (RLTC). You are invited to participate in this study because you provide care for the older adult who has been consulted by an NCA. This information for this study will contribute to my graduate thesis work in the Masters of Science in Nursing Program at University of British Columbia.

### **What happens if you agree to take part in this study?**

The older adult is one of three participants who will be asked to share their experience of being consulted by an NCA during a 30 minute interview which will be facilitated by the co-investigator. This interview will be audio-recorded through a face to face interview.

Similarly you will be involved in an interview for about 30 minutes that will take place in a quiet and confidential environment of your choice. The researcher will be using an interview guide and will be taking notes during the interview.

Included in the interview are your demographic information however no personal identifying information will be asked. Information will be accessed by only 2 people for this study: Jasjit Gill and Jennifer Baumbusch.

### **What are the risks of taking part in this study?**

By participating in this study, there will be no anticipated risk to you. The conversations will be in confidence. If you feel you don't want to continue, the researcher must stop and if you agree can carry on.

### **What are the benefits of taking part in this study?**

Although there are no immediate benefits, your participation in this study will contribute to a greater understanding of NCAs with the RLTC sector. You may experience some benefit with sharing your own opinion, understanding, experience and knowledge.

### **How will your privacy and confidentiality be maintained?**

Your privacy and confidentiality will be respected. Any information resulting from this research study will be kept strictly confidential and will be protected in several ways.

- No names or other personal identifiers will be used in any research documents resulting from this research.
- Each participation will be identified by an identification number.
- No individual will be able to identify your answers to the questions in the interview as yours.
- Audiotapes will be used to record your interview. No personal identifiers will be used and only principal investigator and co-investigator will have access to this information.
- All records will be securely stored in a locked filing cabinet and/or password protected computer files.
- All data will be stored for up to 5 years as per UBC policy.

### **Will you be paid for your time or taking part in this study?**

We will not pay you for your time or provide any other compensation for taking part in this study.

### **How will the results of the study shared?**

The results of the study will be reported in a graduate thesis. The investigators of this study can provide the participants with the results of the study by providing a simplified report or through a short discussion with the participants. The main study findings may be published in journal articles.

### **Who can you contact if you have questions about the study?**

If you have any questions about the study, please contact the investigators listed at the top front page of this document.

### **How can you sign up to take part in this study?**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any point of time without jeopardy to your employment. If you wish to withdraw from the study at any point your data will be removed from the study.

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study.

Yes, I understand what this study entails and I am comfortable with the procedures.



---

Participant Signature

Date

---

Printed Name of the Participant signing above

**Who can you contact if you have concerns about the study?**

If you have any concerns about your treatment or rights as a participant in this study, you may contact the Research Participant Complaint Line in the UBC office of Research Ethics at 604-822-8598 or email at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

## Appendix D: Older adult participant demographic information



Participant Demographic Form

Study Participant no. \_\_\_\_\_

This section will help in gaining some background information about the participants.

1. I have lived in this nursing care home since: \_\_\_\_\_
2. My age is: \_\_\_\_\_
3. My gender is:
  - a. Male
  - b. Female
  - c. Other (please specify)

## Appendix E: Family participant demographic information



Participant Demographic Form

Study Participant no. \_\_\_\_\_

This section will help in gaining some background information about the participants.

1. My relationship to the older adult is: \_\_\_\_\_
2. My age is: \_\_\_\_\_
3. My gender is:
  - a. Male
  - b. Female
  - c. Other (please specify)

## Appendix F: Staff participant demographic information



### Participant Demographic Form

Study Participant no. \_\_\_\_\_

This section will help in gaining some background information about the participants.

1. I work as a:
  - a. Nurse (RN/LPN/RPN)
  - b. Resident Care Aide (RCA)
  - c. Allied health
  
2. I work:
  - a. Full time
  - b. Part time
  - c. Casual
  - d. Other
  
3. My age is: \_\_\_\_\_
  
4. My gender is:
  - a. Male
  - b. Female
  - c. Other (please specify)

## Appendix G: Interview guide for older adult participant



### **Introduction:**

Acknowledge receipt of signed consent form and demographic information; confirm understanding study topic, interview procedure/process, use of data, and measures to ensure confidentiality.

Allow participant to ask questions before starting interview.

### **Research question:**

1. What is the older adults experience with the Nurse Continence Advisor (NCA) role within RTLTC?
2. What is the potential for this role within the RLTC sector?

### **Guiding questions:**

1. Can you recall how long ago you were seen by a NCA?
2. What was the main reason that you were seen by an NCA?
3. Please tell me your experience when you were seen by the NCA?
  - a. What did you find helpful with spending time with the NCA?
  - b. Did you experience any challenges or issues?
  - c. What were the outcomes of this consult?
  - d. Were you happy or unhappy with the results?
4. From this experience, what would you recommend to the health authority about this role within RLTC?



## Appendix H: Interview guide for families

### **Introduction:**

Acknowledge receipt of signed consent form and demographic information; confirm understanding study topic, interview procedure/process, use of data, and measures to ensure confidentiality.

Allow participant to ask questions before starting interview.

### **Research question:**

1. What is the older adults experience with the Nurse Continence Advisor (NCA) role within RTLTC?
2. What is the potential for this role within the RLTC sector?

### **Questions:**

1. What was the main reason on why this resident was seen by a NCA?
2. Were the interventions recommended by the NCA useful for this resident?
3. When the interventions were used for this resident, what was the impact on his/her incontinence?
4. How would you describe the resident's quality of life related to his/her incontinence issues?



## Appendix I: Interview guide for staff

### **Introduction:**

Acknowledge receipt of signed consent form and demographic information; confirm understanding study topic, interview procedure/process, use of data, and measures to ensure confidentiality.

Allow participant to ask questions before starting interview.

### **Research question:**

1. What is the older adults experience with the Nurse Continence Advisor (NCA) role within RTLTC?
2. What is the potential for this role within the RLTC sector?

### **Questions:**

1. What was the main reason for the resident to be seen by a NCA?
2. Were the interventions recommended by the NCA useful for this resident?
3. When the interventions were used for this resident, what was the impact on his/her incontinence?
4. How would you describe the resident's quality of life related to incontinence issues after the consult?



## Appendix J: translator confidentiality agreement



In consideration of my volunteer translator services for the University of British Columbia research project and to Vancouver Coastal Health (VCH) Authority, I acknowledge and agree to the following:

1. I will adhere to the VCH Information Privacy and Confidentiality Policy and related policies as amended from time to time, concerning the collection, use and disclosure of the information obtained in the course of my service;
2. I understand that all personal information concerning staff and clients that receive services from VCH is confidential and may not be communicated to anyone in any manner, except as authorized by VCH and applicable policies;
3. I understand that compliance with confidentiality is a condition of my volunteer services to the UBC research study and VCH and that a failure to comply may result in legal action by VCH and others.

I also confirm that I have read and understood the [\\..\..\Translator forms\VCH Information Privacy and Confidentiality Policy.pdf](#)

***Please use pen to complete. Confidential when completed.***

Print Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date (mm/dd/yr): \_\_\_\_\_





**Appendix K Chart audit tool**

Participant no. \_\_\_\_\_

Date of consult period: \_\_\_\_\_

Progress Record       Health Record       Other: \_\_\_\_\_

Data:	Answers:	Comments:
Was the incontinence issue documented on the chart? <i>(Yes or no)</i>		
What was the date of initial visit by NCA? <i>(Write in date)</i>		
Was a continence assessment completed by the NCA? <i>(Yes or no)</i>		
Where there interventions recommended by the NCA? <i>(Yes or no)</i>		
Which interventions were recommended? <i>(Write down all the interventions)</i>		
Which interventions were followed? <i>(Write down only the interventions used)</i>		
What were the outcomes for the resident at time of discharge? <i>(capture ways in which incontinence was affected)</i>		
Resident's incontinence issue improved? <i>(Yes or no)</i>		