THE DEVELOPMENT OF AN EDUCATIONAL RESOURCE MANUAL ON SEXUALITY AND DEMENTIA FOR NURSING STAFF WORKING IN LONG TERM CARE FACILITIES

By © Karla Oates A Practicum report submitted to the School of Graduate Studies

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Abstract

Background: Sexuality is a basic human need that begins at birth and continues throughout the lifespan. Every individual, regardless of age, has a need for love, intimacy and companionship; this does not change as people grow older and is no different for individuals living with dementia (Hajjar & Kamel, 2003). On a provincial level, little has been done in long term care [LTC] facilities to create environments conductive to or supportive of expression of sexuality for residents with dementia. Upon encounter of sexual expression, nursing staff are continuously reporting experiencing difficulties, distress, and confusion in relation to how they should respond (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). **Purpose:** The purpose of this practicum project was to develop an educational resource manual on sexuality and dementia for nursing staff working in LTC facilities. **Methods:** A comprehensive review of the literature was conducted. Consultations consisting of face to face semi structured interviews were conducted with key members of the healthcare team. **Results:** Findings supported that development of an educational resource manual would best meet the learning needs of nursing staff. A manual consisting of five self-paced modules was developed using Knowles' Adult Learning Principles (1984) and Morrison, Ross and Kemp's (2013) Instruction Design Model. **Conclusion:** Although intended for nursing staff this manual may also be used by other members of the healthcare team who work with or are interested in learning more about expression of sexuality in this population.

Keywords: sexuality, intimacy, dementia, long term care facilities, older adults

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First, I would like to thank my family including my two daughters Kaylee & Anna, for all their understanding and patience. This degree would not have been possible without their support. Next, I would also like to thank the nursing staff at the Agnes Pratt Home who helped and contributed in the development of this educational resource manual. I would also like to thank my colleagues Shawna Delaney Martin and Elizabeth Graham and the Administrator of the home, Annette Morgan for all their guidance and encouragement along the way. Lastly, I would like to thank my supervisor Dr. Crenia Twomey for all her ongoing support, feedback and expertise.

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Sexuality is a basic human need that begins at birth and continues throughout the lifespan. It is an important component of one's identity and is positively linked to overall physical and psychological well-being (Hajjar & Kamel, 2003; Ogden, 2001). Every individual, regardless of age, has a need for love, intimacy and companionship; this does not change as people grow older and is no different for individuals living with dementia (Hajjar & Kamel). Promoting an environment where the sexuality needs of residents can be expressed appropriately without compromising the safety of other residents requires nursing staff have a thorough understanding of sexuality and dementia and how to appropriately respond to expressions of sexuality amongst these residents.

Background

On a provincial level, little has been done in long term care [LTC] facilities to create environments conductive to or supportive of expression of sexuality for residents with dementia (Tarzia, Fetherstonhaugh, & Bauer, 2012). Upon encounter of sexual expression, nursing staff are continuously reporting experiencing difficulties, distress, and confusion in relation to how they should respond (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). Currently LTC, Eastern Health has no widespread policy in place on responding to expressions of sexuality in this population.

Rationale

The Agnes Pratt Home [APH], a LTC facility within Eastern Health, recently developed their own written protocol to be used by nursing staff at the home as a guideline in responding to expressions of sexuality in residents with dementia (Delaney-Martin, 2016). Following implementation of this protocol, although beneficial in guiding nursing staff's responses the protocol was short and task oriented. Furthermore, it was evident that nursing staff working in

the home had only a vague understanding of sexuality and dementia and the need for expression of sexuality in these residents. It was felt that the development of an educational resource manual to compliment the currently existing protocol, consisting of for example interactive learning activities, would not only help to engage nursing staff in applying recommended nursing responses, but would also help to increase their understanding in relation to sexuality and dementia and create an impetus for further dialogue in this area.

Practicum Goal/Objectives

The main goal of this practicum project was to develop an educational resource manual on sexuality and dementia for nursing staff working in LTC facilities within Eastern Health. The key objectives were as follows:

1. Conduct an integrative literature review on sexuality and dementia in LTC facilities.
2. Collaborate and consult with key members of the healthcare team in the development of an educational resource manual for nursing staff on sexuality and dementia working in LTC facilities.
3. Utilize Knowles' (1984) adult learning principles and Morrison, Ross and Kemp's (2013) instructional design model in the development of a learning manual for nursing staff on sexuality and dementia working in LTC facilities.
4. Demonstrate advanced nursing competencies in the development of a learning resource manual for nursing staff on sexuality and dementia working in LTC facilities.

Methodologies

To identify and explore the need for the development of an educational resource manual two main methods were used: an integrative review of the literature and consultations with key

members of the healthcare team. Below a summary of key findings from each method will be provided.

Literature Review

Search methods. The search engines used to conduct the literature review included CINAHL and Pubmed. Initially a search was conducted using a combination of key words: 'sexuality', 'intimacy', 'expression of sexuality', 'dementia', 'long term care facilities', and 'older adults' which yielded an abundance of articles. An advanced search of 'sexuality and dementia' combined was then performed to narrow the search yielding a total of 188 articles in CINAHL and 410 articles in Pubmed. Articles were analysed based on title, abstract and content to determine applicability. A total of 16 English written articles were chosen for inclusion with publication dates ranging between 1997 -2016. Theses articles consisted of six quantitative studies, six qualitative studies, one mixed method study and three systematic literature reviews. All studies were critiqued and incorporated into a literature review summary table. Quantitative articles were critiqued using the Public Health Agency of Canada's Infection Prevention and Control Guidelines: Critical Appraisal Tool Kit [PHAC] (2014). Qualitative articles were critiqued using the Critical Appraisal Skills Programme [CASP] (2013).

Findings: The four main themes that emerged from the literature included: attitudes, beliefs, and misconceptions, appropriate versus inappropriate expressions of sexuality, consent and capacity, and forming of new relationships/pre-existing relationships. An overview of each theme will be provided below.

Negative attitudes, beliefs, and misconceptions of nursing staff. Several studies revealed that negative attitudes and beliefs are directly related to how nursing staff perceive and respond to expressions of sexuality in residents with dementia. Feelings of discomfort, unpreparedness,

anger, embarrassment, powerlessness, and disgust in relation to sexual expression were associated with sexual expression being viewed as disruptive, problematic and of no benefit to the resident with dementa (Benbow & Beeston, 2012; Ehrenfeld, et al., 1999; Gott, Hinchliff, & Galena, 2004; Mahieu, Elssen, & Gastmans, 2011). To assist nursing staff in identifying and responding effectively to the sexuality needs of residents negative attitudes and beliefs must be addressed and nursing staff given the opportunity to evaluate their own attitudes and beliefs.

Appropriate versus inappropriate sexual behaviours. The literature revealed that distinguishing appropriate from inappropriate sexual behaviour can be a very challenging process for nursing staff (Kamel & Hajjar, 2003). There is limited consensus on classification and terminology between the two types of behaviours resulting in lack of clarity between the two (Benbow & Beeston, 2012; Kamel & Hajjar; International Longevity Center [ILC], 2011). Expressions of sexuality and sexual behaviour often become labelled problematic when residents express their sexual desires or feelings in inappropriate places and inappropriate ways for example masturbating in the hallway or public exposure of breasts and genitalia, touching staff or other residents against their wishes and using foul language (Burke, Yaari, Tariot, Fleisher, Hall, & Brand, 2013; ILC). There is no single answer to how these behaviours should be managed; each individual case will be different with some more challenging than others (Benbow & Beeston). Alagiakrishnan et al. (2005) and Kamel & Hajjar state the most effective method is verbal and/or physical redirection and target behaviour interventions. Nursing staff need to be provided with education on such interventions which will result in managing and responding to inappropriate sexual behaviours in a professional and timely manner.

Consent and capacity. This was identified as one of the biggest challenges pertaining to sexuality and dementia (Tarzia, Fetherstonhaugh, & Bauer, 2012). Due to impairments

associated with dementia in relation to communication, understanding and reasoning, consent to engage in a relationship is often quite difficult to obtain (Villar, Celdran, Faba, & Serrat, 2014). Just because a resident has been deemed incompetent to make medical decisions does not mean that all competency is diminished. For example, a resident's preference for a lover or friend may be quite evident despite their poor performance upon assessment of capacity (Kuhn, 2002). Studies have shown that to eliminate risk and protect residents nursing staff tend to take an 'extreme cautionary stance' or an all or nothing approach, resulting in the preclusion of all forms of sexual expression (Villar et al.). Taking such an approach is not supported in the literature. Villar et al. state that encouraging expressions of sexuality in a safe and effective way is recommended instead of attempting to eradicate all forms of expression.

Forming of new relationships/Pre-existing relationships. The forming of new relationships is not only challenging for nursing staff it can be very uncomfortable and emotionally painful for the spouses and family members of residents involved (Kamel & Hajjar, 2003; Wiskerke & Manthorpe, 2016). The situation becomes even more complex when one or both residents already have an existing spouse (ILC, 2011). For pre-existing relationships in some situations, individuals may have entered the nursing home as a couple in which one or both partner's may have dementia. In most situations, however the partner with dementia resides in the nursing home while the partner without dementia remains home (ILC, 2011). No matter what the situation there is no one more affected by the loss of what was then the healthy partner (Wornell, 2014). Educating family members and spouses on sexuality and dementia can help to avoid future conflict should issues such as the forming of new relationships occur. Educational materials such as pamphlets and video clips can be used to enhance the understanding of family members and existing spouses in preparation for what might happen. However, the process of

educating family members will not be effective unless nursing staff are educated and feel confident in discussing this topic.

Consultations

Participants: Consultations were conducted with two Registered Nurses [RNs], two Licensed Practical Nurses [LPN], and two Personal Care Attendants [PCAs]. The Resident Care Manager on the two dementia care units was also consulted. Purposive sampling was used to select permanent full time employees with one-year experience working on one of the two dementia care units

Data Collection/Management/Analysis: Data was collected using face-to-face semi-structured interviews during working hours in a private area and took approximately 20 to 30 minutes. Quality of data was further assured by verbally stating responses back to the participants during the interview process (Polit & Beck, 2012).

Data was transcribed verbatim into a word document and stored on a password protected laptop. All guiding questions for the interview were open ended. Content analysis was used to summarize the data. Emerging themes and patterns were identified and grouped into categories.

Findings: The main themes included the following: views of nursing staff, need for more education and resources, and priority learning needs. A discussion of each theme will be provided below.

Views of nursing staff. All participants agreed that sexuality is a basic human need that begins at birth and continues throughout the lifespan and does not diminish with old age or cognitive status. Half of participants felt that LTC facilities should promote environments where the sexuality needs of residents with dementia can be met. The other fifty percent although they disagreed with promoting such an environment, felt that sexual expression should not be

condoned or shamed when it does occur. Forms of sexual expression that participants felt were appropriate included holding hands, kissing, hugging, and cuddling. Forms of inappropriate sexual expressions included sexual intercourse, fondling of another resident, masturbating in public, and disrobing. All participants stated that sexual relations between residents were not wrong. However, several experienced staff voiced that some of the typical responses of their co-workers upon encounter of sexual expression in residents was negative and included shock, panic, disgust, and turning a blind eye. Despite these negative responses all participants felt that male and female residents with dementia should not be segregated onto separate units unless there is a safety issue which puts the residents or other residents at risk. Participants in support of co-ed dementia care units felt that social interaction between male and female residents is beneficial and sexual behaviours will still occur on segregated units.

Need for more education and resources. All participants stated that there is a need for more education on sexuality and dementia in their workplace setting. Fifty percent of participants stated they were aware of a guideline that was recently implemented on their unit by their resident care manager on responding to sexual expression. The other half of participants however stated that they were not aware of any policies, guidelines, educational resources or training on sexuality and dementia in their workplace. Participants voiced that majority of their skills in responding to sexual expression on dementia care units have come from their experience working with this population. Experienced nursing staff stated that some of the common concerns and questions that they have been faced with in relation to sexual expression in residents with dementia included ‘Is this allowed to happen? What do I do?, Do I separate them?, Is this legal?, ‘What do I tell families’, ‘Is the resident competent to engage in such behaviour?’ All participants agreed that there is a need for more educational resources, in-services, and

policies on responding to sexual expression in this population and felt that it should be included in orientation to LTC including cooperate and site orientation. It was further suggested that how to respond to sexual aggression should be incorporated into the gentle persuasive approach training for managing aggressive behaviours in residents with dementia.

Priority learning needs. All participants supported the development of an educational resource manual on sexuality and dementia. Some of the priority topics that participants voiced they would like to see included in an educational resource manual included: the effects of dementia on sexuality, responding to different forms of sexual expression, evidence based strategies/interventions in managing sexual expression supported by research and used in other facilities, involving and educating families on sexuality and dementia, and identifying and responding to sexual aggression.

Permission: The Health Research Ethics Authority (HREA) screening tool was used to determine if ethical approval was needed for the proposed project. Based on this screening tool it was determined that ethical approval was not required. Permission to consult with participants was obtained from the administrator of the APH and consent was obtained from participants via verbal consent. Participants were given the option to withdraw from the interview at any time.

Educational Resource Manual

Findings from the literature review and consultations with key members of the healthcare team supported the development of an educational resource manual. Throughout the literature education was identified as the most effective strategy in enhancing the knowledge of nursing staff. Development of an educational resource manual during consultations was agreed upon as the most effective method in meeting the needs of nursing staff at the APH. Training sessions can be limited by financial constraints and finding coverage to replace staff to attend training

sessions is a major challenge in LTC. An educational resource manual kept on the dementia care units would be easily assessable for nursing staff and allow them to progress through the content at their own pace.

Content included in the education resource manual was based on the literature review and findings from consultations. The education resource manual consists of five different modules each of which will be summarized below. It is intended that each of these modules be completed in sequence of the last.

Module One: Sexuality and Older Adults defines sexuality and intimacy. The focus is on understanding sexuality and distinguishing between sexual versus intimate behaviors. Emphasis is placed on exploration of common myths and misconceptions associated with sexuality in older adults which portray older adults as being asexual human beings (Allen, Petro, & Phillip, 2009; Benbow & Beeston, 2012; Bouman, Arcels, & Benbow, 2006). Healthcare providers are not immune to these negative misconceptions (ILC, 2011). Content and learning activities within this module are intended to help nursing staff evaluate their own personal attitudes and determine how they conflict with or support residents' rights to sexual expression.

Module Two: Impact of Dementia on Sexuality - What Happens to the Brain focuses on educating nursing staff on the neurobiological changes associated with dementia and their effects on sexuality. Understanding how various brain lesions associated with different types of dementia effects sexuality can help make dealing with unexpected expressions of sexuality easier.

Module Three: Dementia and Sexual Behaviors distinguishes between appropriate versus inappropriate sexual behaviors. Distinguishing inappropriate sexual behavior from appropriate sexual behavior can be a very challenging and complex process for nursing staff (Kamel, &

Hajjar, 2003). This module provides examples of case scenarios for nursing staff to work through and other learning activities to help clarify the difference between the two.

Module Four: Dementia and Relationships focuses on the impact of dementia on pre-existing relationships and development of new relationships amongst residents with dementia. This module provides nursing staff with ways in which they can help support pre-existing relationships and emphasizes the importance of educating existing partners and their families on the effects of dementia on sexuality so that they know what to expect. Perhaps one of the greatest challenges for families and nursing staff is when residents form new intimate relationships with other residents in the LTC facility, especially if one or both residents already have an existing spouse (ILC, 2011). Different issues for nursing staff to consider including ethical conflicts regarding capacity and consent and opinions of family members are discussed within this module.

Module Five: Responding to Sexual Behaviors focuses on assessment of sexual behaviours and the prevention and management of inappropriate sexual behaviours. This module incorporates several assessment tools that can be used by nursing staff including an Admission Sexual History tool, a Behaviour Assessment tool, Assessment of Awareness of Actions Tool and a guideline in determining level of risk associated with the behaviour. There is no drug currently licensed to treat problematic sexual behavior in residents with dementia (ILC, 2011). The recommended approach in the management of this type of behavior is non-pharmacological consisting of a person-centered approach. Examples of such person-centered approaches are provided for nursing staff in this module and include interventions such as music therapy, pet therapy and beauty and cosmetic services (ILC, 2011).

Theoretical Framework

Knowles' Adult Learning Principles

Within the nursing profession Knowles' Adult Learning theory has been used as a popular framework in developing educational resources for nursing staff. In 1984 Knowles applied four principles to adult leaning. Each of these principles will be discussed below along with a brief description of how they were applied in the development of the resource manual.

Adults need to be involved in the planning and evaluation of their instruction. Learners were involved in all stages of the development of the manual. The introduction to the manual specifically explains to the reader: who the manual is for, what the purpose of the manual is, and how the manual can be used. This provides a clear overview to the learner on the importance of the subject matter (Pappas, 2013).

Experience (including mistakes) provides the basis for the learning activities. The educational resource manual was based on task orientated instruction as opposed to memorization. Objectives were clearly stated at the beginning of each module and learning activities were interactive and consisted of reflective questions and real-life case scenarios. This allowed learners to apply acquired knowledge to real-life situations within the workplace (Pappas, 2013).

Adults are most interested in learning subjects that have immediate relevance and impact to their job or personal life. Although, it is recommended that each module be completed in sequence of the last, a learner with previous experience on the subject can refer to specific modules based on their learning needs. Having content separated into modules further allows for the learner to refer to certain topics in the module as a refresher when problems occur rather than having to review the entire manual (Pappas, 2013).

Adult learning is problem-centered rather than content oriented (Kearsley, 2010). The manual is aimed at self-directed learning which allows learners to discover knowledge for themselves at their own pace. The manual is intended to be used by nurses in LTC facilities working with dementia residents who are motivated and interested in enhancing their knowledge-base in this area (Pappas, 2013).

Instructional Design Model

Morrison, Ross and Kemp's (2013) Instructional Design Model is a popular model used in the creation of educational resources. The model is composed of nine elements. Each of these elements will be discussed below and how they were applied in the instructional design process of the resource manual.

Instructional problems. Instructional problems were identified, and a goal and objectives set prior to the development of the manual (Giles, 2013).

Learner's characteristics. During the planning stage of the manual learner characteristics were examined including prior skills and education, and learning style. Instructional strategies took into consideration these characteristics (Giles, 2013).

Task analysis. Subject content for the educational resource manual was identified and task components analyzed based on goal and learning objectives (Giles, 2013).

Instructional objectives. Instructional objectives were developed and stated at the beginning of each module within the manual for learners (Giles, 2013).

Content sequencing. Content sequencing was used to manage content. Each unit flowed from one to the next and went from basic to more comprehensive material (Giles, 2013).

Instructional strategies. Strategies of learning were selected and designed to allow learners to meet outlined objectives for each module. Instructional strategies were creative and

innovative with the intention to keep learners interested and actively involved in the learning process (Giles, 2013).

Designing the message. The instructional message was delivered to learners through use of pictures, quotes, and word text incorporated throughout the modules (Giles, 2013).

Instructional delivery. Content and instruction was reviewed and feedback obtained to ensure the education resource manual was effectively ready for distribution (Giles, 2013).

Evaluation instruments. Evaluation instruments testing the learner's knowledge were included at the end of several modules (Giles, 2013).

Advanced Practice Nursing Competencies

Competencies are "the specific knowledge, skills, judgment and personal attributes required for a registered nurse to practice safely and ethically in a designated role and setting" (Canadian Nurses Association [CNA], 2010, p 15). In 2008 the CNA developed a national framework for Advanced Practice Nursing [APN] which included competencies specific to APNs. Competencies were separated into four categories: clinical, research, leadership, and consultation and collaboration. A discussion of how each APN competency was demonstrated during completion of this practicum project will take place below.

Clinical

Application of knowledge gained through clinical experience as clinical coordinator at the APH and my nursing background in psychogeriatrics was of great value in completing this practicum project. Integrating my clinical experience with research to identify and address an unmet need demonstrated application of this competency (CNA, 2008).

Research

Research is central to APN and is demonstrated through the generation, synthesization, and utilization of evidence based research (CNA, 2008). A comprehensive review of the literature was conducted to justify and support the need for an educational resource manual. Articles were analyzed based on title, abstract and content to determine applicability. Main themes emerging from the literature were identified and incorporated into a literature review report. Content included in the educational resource manual was based on the emerging themes identified ensuring accuracy and reliability of information.

Leadership

Being a leader involves APNs acting as agents of change within their organization and community to improve nursing practice and quality of care (CNA, 2008). By taking necessary steps to identify the learning needs of nursing staff in my area and developing an educational resource manual to meet their needs I effectively demonstrated this competency.

Consultation and Collaboration

Consulting and collaborating with members of the healthcare team is an important aspect of enhancing nursing practice (CNA, 2008). Throughout this practicum project I consulted and collaborated with key members of the healthcare team, including frontline nursing staff to identify learning needs and validate the need for an educational resource manual. Main themes emerging from consultations were incorporated into a consultation report and reflected in the content of the educational resource manual. During each stage of this practicum project I further consulted with my practicum supervisor, Dr. Crenia Twomey, for guidance, expertise and scholarly input.

Next Steps

Following development of the education resource manual a copy was given to nursing staff and management to review and provide feedback. A copy was also provided to the regional LTC committee. Based on feedback provided, any necessary modifications identified will be made and the implementation process will follow.

The final product will be presented to the administrator and resident care managers of the APH during a scheduled management meeting where approval to implement the final product on dementia care units will be discussed. Once the approval is given the resource manual will be introduced to nursing staff. This will occur during a scheduled unit meeting so that all existing employees are aware of the resource manual and its purpose. A discussion will be further held with the administrator and resident care managers to have the manual added to the site orientation checklist so all new employees hired for the home, especially the dementia care units, are aware of the manuals existence.

Conclusion

Sexuality in residents with dementia, although a topic of great significance, has remained a neglected area in many LTC facilities. Education on sexuality and dementia has been limited to non-existent for nursing staff working on dementia care units. Completion of this practicum course taught me the necessary skills required to address this ongoing need.

At the beginning of this practicum course the goal to develop an educational resource manual on sexuality and dementia for nurses working in LTC facilities within Eastern Health was set. Four key objectives were put in place to help meet this goal including conducting an integrative review of the literature, collaborating and consulting with key members of the healthcare team, utilizing Knowles' adult learning principles and Morrison, Ross and Kemp's

instructional design model as the theoretical foundation of the development of the manual, and demonstration of APN competencies. By the completion of this practicum project the main goal and each of the four objectives were successfully met.

The APN skills acquired throughout completion of this practicum project will be of great value to me throughout the remainder of my nursing career. Completion of this practicum project helped me to become an effective agent of change contributing to improved nursing practice and enhanced quality of care for dementia residents residing in LTC facilities.

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Appendix A

Literature Review

Sexuality and Dementia in Long Term Care Facilities: An Educational Resource Manual for Healthcare Providers

Integrated Literature Review

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With the rapid aging of the baby boomer population and continuing rise in life expectancy rates it is anticipated that the number of older adults with dementia living in long term care facilities is only expected to dramatically increase over the next decade (Mahieu, Elssen, & Gastmans, 2011). Sexuality is a basic human need that begins at birth and continues throughout the lifespan. It is an important component of one's identity and is positively linked to overall physical and psychological well-being (Hajjar & Kamel, 2003; Ogden, 2001). Every individual, regardless of age, has a need for love, intimacy and companionship, this is no different for individuals living with dementia (Hajjar & Kamel).

Nursing staff, caring for residents with dementia in long term care facilities [LTC], have an obligation to maintain the dignity of residents while at same time ensuring the protection of the residents from neglect and abuse (Wornell, 2014). Promoting an environment where the sexuality needs of residents can be expressed appropriately without compromising the safety of other residents requires nursing staff have a thorough understanding of sexuality and dementia and the need for expression of sexuality in residents with dementia (Kamel & Hajjar, 2003). The purpose of this paper is to provide evidence to support the need for the development of an educational learning resource manual for nursing staff on sexuality and dementia. This paper will include an overview of the topic background and importance, a review of the literature search process and selection of studies, followed by a discussion on the main themes that emerged from the literature and a critique of limitations and strengths of selected studies.

Topic Background and Importance

On a national level little has been done in LTC facilities to create environments conductive to or supportive of expression of sexuality in residents living with dementia (Tarzia, Fetherstonhaugh, & Bauer, 2012). Upon encounter of sexual expression, nursing staff are

continuously reporting experiencing difficulties, distress, and confusion in relation to how they should respond (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). Currently LTC, Eastern Health has no widespread policy in place on responding to expressions of sexuality in residents with dementia. The Agnes Pratt Nursing Home [APH], a LTC facility within Eastern Health recently developed their own written protocol to be used by nursing staff at the home as a guideline in responding to expressions of sexuality in this population (Delaney-Martin, 2016). Following implementation of this protocol, although beneficial in guiding nursing staff's responses the protocol was short and task oriented. Furthermore, it was evident that nursing staff working in the home had only a vague understanding of sexuality and dementia and the need for expression of sexuality in these residents. It was felt that the development of an educational resource manual to compliment the currently existing protocol, consisting of for example interactive learning activities, would not only help to engage nursing staff in applying recommended nursing responses, but would also help to increase their understanding in relation to sexuality and dementia and create an impetus for further dialogue in this area.

Integrated Literature Review

The search engines used to conduct this literature review included CINAHL and Pubmed. Initially a search was conducted using a combination of key words: 'sexuality', 'intimacy', 'expression of sexuality', 'dementia', 'long term care facilities', and 'older adults' which yielded an abundance of articles. An advanced search of 'Sexuality and Dementia' combined was then performed to narrow the search yielding a total of 188 articles in CINAHL and 410 articles in Pubmed. Articles were analysed based on title and abstract and following critical appraisal of selected articles a final total of 16 articles were chosen for inclusion with publication dates ranging between 1997 -2016. The four main themes that emerged from the literature included:

Attitudes, beliefs, and misconceptions, appropriate versus inappropriate expressions of sexuality, consent and capacity, and forming of new relationships/pre-existing relationships. These themes will each be discussed below.

Sexuality and Dementia

Sexuality is a term that is often difficult to define and therefore commonly misunderstood by many nursing staff (Dementia Training Study Centres, 2013). Sexuality is an integral aspect of being human extending throughout the lifespan encompassing sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction (World Health Organisation, 2002). Sexual behaviour is perceived by many as the central concept of sexuality. However, sexuality consists of many interconnected concepts and includes more than just physical 'sexual' behaviour, it has many psychological and social aspects (Dementia Training Study Centers).

Although it is evident throughout the literature that sexual activity decreases with age many older individuals still engage in sexual behaviour (Trudel, Turgeon, & Piche, 2000). Residents living in LTC facilities, despite having a diagnosis of dementia or another cognitive impairment, have been found to continue to have intimate and sexual desires (Ehrenfeld et al, 1999). Sexual behavior is overt and in most cases is directly linked to satisfying sexual desire. Expression of sexual behaviours include but are not limited to flirtatious behaviour, gestures of romance, oral sex and sexual intercourse and can be carried out by oneself or with another individual (Dementia Training Study Centers, 2013). When sexual behavior is no longer possible or desirable emotional connectedness with another is often achieved through intimacy. In one study it was found that up to 70 percent of couples reported continual engagement in intimate activities with each other despite one partner having a diagnosis of dementia (Davies, Sridhar, Newkirk, Beaudreau, & O'Hara, 2012). Expressions of intimacy include but are not limited to

touching, hugging, kissing, cuddling, empathetic understanding and comforting and are often carried out between two or more individuals (Bauer, Nay, & McAuliffe, 2007; Benbow & Beeston, 2012; Hajjar & Kamel, 2003). Recognizing that expression of sexuality not only involves sexual behaviours but that it also involves intimate activities such as wanting to feel close to someone is important in understanding the sexuality needs of residents with dementia (International Longevity Center [ILC], 2011).

Dementia is a disease that affects the brain and is characterized by a decline in memory and increase in cognitive impairments (Higgns, Barker & Begley, 2004). As the disease progresses and cognitive impairments worsen a move into a more protective setting such as a LTC facility is often necessary (Roelofs, Luikx, & Embregts, 2014). As stated above, the need for expression of sexuality does not change for individuals with dementia upon admission into a LTC facility (Bauer, Nay, & McAuliffe, 2009; Di Napoli, Breland, & Allen, 2013; Shuttleworth, Russell, Weerakoon, & Dune, 2010; Tarzia, Fethersonhaugh, & Bauer, 2016). However, due to cognitive impairments these residents often have trouble verbalizing their needs resulting in identification of their needs, including sexual needs, becoming highly dependent upon nursing staff (Roelofs, Luikx, & Embregts).

Attitudes, Beliefs, and Misconceptions

Sexuality in the elderly is an issue that is seldom spoke about openly and constructively in Western Society (Bauer, Nay, & McAuliffe, 2009; Higgins, Barker & Begley, 2004; Mahieu, Elssen, & Gastmans, 2011). One explanation for this is media's portrayal of older adults as being asexual human beings. This ageist stereotype has resulted in many negative public misconceptions including older adults are unattractive and sexually undesirable, sex is for younger individuals, and older people are incapable of sex (Allen, Petro, & Phillips; Benbow &

Beeston, 2012; Bouman, Arcelus, & Benbow, 2006). Restrictive attitudes towards late-life sexuality have been found to not only be evident among younger adults but also middle aged adults approaching older adulthood within the next decade (Allen, Petro, & Phillips).

Healthcare providers are not immune to these negative misconceptions and attitudes. Comments such as 'I have always thought of older people as being sexless' and 'touching and cuddling is ok, but I am not sure about anything else' are not uncommon to hear amongst nursing staff working in LTC facilities (Benbow & Beeston, 2012; International Longevity Center, 2011). Throughout the literature negative attitudes and perceptions of nursing staff have been found to be directly linked to how they perceive and respond to expressions of sexuality (Benbow & Beeston; International Longevity Center). In several studies evaluating the attitudes and experiences of nursing staff working on psychogeriatric units it was found that upon encounter of sexual incidents nurses reported feelings of anger, embarrassment, powerlessness, and even disgust (Ehrenfeld, et al., 1999; Mahieu, Elssen, & Gastmans, 2011). Given these negative attitudes it is not surprising that expression of sexuality in residents with dementia is primarily viewed as distributive and problematic to the nursing unit and is rarely viewed as positive or beneficial to the residents well being (Ehrenfeld, et al., 1999). In another study conducted by Gott, Hinchliff and Glena (2004) it was found that general practitioners did not consider sexual health as a legitimate health topic to discuss with older adults and reported feelings of unpreparedness and discomfort in this area. These findings provide evidence that education is warranted to eliminate potential ageist stereotypes amongst healthcare providers so the sexual needs of older adults are not compromised (Allen, Petro, & Phillips, 2009).

Education level, years of work experience and gender have all been found to be directly linked to and highly influential on the attitudes of nursing staff (Kamel & Hajjar, 2003; Tzeng,

Lin, Shyr, & Wen, 2009). Di Napoli, Breland, & Allen (2013) found a positive correlation between years of education and positive attitudes towards sexuality in older adults. In another study conducted by Bouman, Arcelus, & Benbow (2006) it was found that negative attitudes towards expression of sexuality in residents were more prevalent in employees with less than five years work experience compared to more experienced employees. However, Napoli, Breland, & Allen found that caregivers employed with a facility for a longer period of time had more negative attitudes. Furthermore, it has been found that negative attitudes are more prevalent amongst female caregivers compared to male caregivers (Tzeng, Lin, Shyr, & Wen (2009). It is essential when providing education to nursing staff that extra vigilance be taken to ensure that employees most prone to negative attitudes do not fall between the cracks.

Appropriate versus Inappropriate Expressions of Sexuality

Sexually inappropriate behaviors, although a fairly uncommon occurrence within LTC settings, have been found to be most common amongst cognitively impaired residents (Kamel & Hajjar, 2003). Distinguishing inappropriate sexual behavior, also referred to as 'sexual disinhibition', 'improper behaviour' or 'hypersexuality' from appropriate sexual behaviour can be a very challenging and complex process (Kamel, & Hajjar). There is limited consensus on classification and terminology in relation to what constitutes appropriate versus inappropriate behavior resulting in lack of clarity between the two (Benbow & Beeston, 2012; Kamel & Hajjar; ILC, 2011). Expressions of sexuality and sexual behaviour often become labelled problematic when residents express their sexual desires or feelings in inappropriate places and inappropriate ways for example masturbating in the hallway or public exposure of breasts or genetilia, touching staff or other residents against their wishes and using foul language (Burke, Yaari, Tariot, Fleisher, Hall, & Brand, 2013; ILC). In a retrospective cross sectional study

conducted by Alagiakrishnana et al. (2005) in Canada it was found that sexually inappropriate behaviour both verbal and physical was significantly higher in males compared to females. This finding is consistent with that of an earlier study conducted by Archibald (1998) where managers of residential care facilities reported most incidents of sexual expression involved male residents with dementia. This is an interesting finding as majority of residents in LTC facilities are generally female. Archibald states this may be attributed to the paternalistic attitude of staff members who often view women as lacking autonomy and in need of protection resulting in incidents of sexual expression in women being underreported.

Although disruptive, burdensome and problematic just because a behavior is inappropriate does not mean that it is necessarily abnormal. Sometimes behavior interpreted by nursing staff as abnormal in nature, may to the resident with dementia, hold a completely different meaning (Kamel, & Hajjar, 2003). For example, two residents lying together in the same bed may not necessarily be sexual in nature; the intention may stem from the need for intimacy and reassurance created by fear of loneliness (Ehrenfeld et al, 1999; Kuhn, 1998). Furthermore, residents with dementia may engage in behaviours such as masturbation in public places, which would be considered normal if performed in private, due to an unawareness of their surroundings (Kamel & Hajjar). In some cases, residents with dementia may even mistaken another resident or staff member as their significant other and as a result try to engage in relations with them similar to that of a married couple (Kamel & Hajjar). This behavior was found to be one of the main reasons for initiation of sexually-based interactions by women with dementia (Ehrenfeld et al.).

Many healthcare providers refer to problematic sexual behaviour as a medical problem that should be controlled with medication (Parker, 2006). Aside from the ethical issues

associated with this there is no drug currently licensed to treat problematic sexual behaviour in residents with dementia (ILC, 2011). The recommended approach in the management of this type of behaviour is non-pharmacological consisting of a person-centred behaviour management approach (Alagiakrishnan et al, 2005; ILC). A person-centered approach involves treating residents as "individuals regardless of their age and health status, adopting the point of view of the person with dementia and taking into account his/her unique needs and feelings (including sexuality and dementia) as the basis on which to provide as personalized care as possible" (Villar, Celdran, Faba & Serrat, 2013, p 404).

When managing sexually inappropriate behaviours there is no single answer every individual case will be different with some more challenging then others (Benbow & Beeston, 2012). Recommended nursing interventions and responses to managing inappropriate sexual behaviours often include verbal and physical redirection and target behaviour interventions (Alagiakrishnan et al, 2005; Kamel & Hajjar, 2003). Examples of verbal and physical redirection include firmly but gently informing the resident that their behaviour is unacceptable or physically assigning manual tasks such as folding towels to divert their attention away from for example exposing and fondling genitals (Alagiakrishnan et al.). An example of a targeted behavior intervention would involve seating male residents with a history of making sexually inappropriate gestures towards female residents away from them during social gatherings such as meal times (Kamel & Hajjar). Helping residents meet their sexuality needs is also an important component in the management and prevention of problematic sexual behaviors. When the sexuality needs of residents are not met they are more likely to engage in physically aggressive sexual behaviours (Alagiakrishnan et al.; Kamel & Hajjar). Promoting an environment where the sexuality needs of residents can be met can include for example use of 'do not disturb signs on

doors', allowing conjugal and home visits, encouraging hugging and kissing during family visitation, and having beauty and cosmetic services available (Kamel & Hajjar).

Consent and Capacity

Perhaps one of the biggest ethical challenges pertaining to sexuality and dementia has to do with capacity and consent (Tarzia, Fetherstonhaugh, & Bauer, 2012). In a study conducted by Allen, Petro, & Phillips (2009) evaluating the attitudes of young adults it was found that level of acceptance of sexuality greatly declined when older adults were physically and cognitively impaired compared to older adults who were physically and cognitively well. Due to impairments associated with dementia such as communication, understanding and reasoning, consent to engage in a relationship is often difficult to obtain and in some situations cannot be assured (Villar, et al., 2013). Just because a resident has been deemed incompetent to make medical decisions does not mean that all task specific competency is diminished (Kuhn, 2002). Wilkins (2015) argue that in situations where residents lack capacity but continue to display interest in expression of sexuality a committee approach should be taken to advocate for the residents right to sexual expression, autonomy and dignity while at the same time ensuring the safety of the resident.

However, in an effort to eliminate risk and protect residents nursing staff tend to take an 'extreme cautionary stance' or an all or nothing approach, resulting in the preclusion of all forms of sexual expression (Villar, et al., 2013). Paternalistic attitudes, overprotective behaviours and restrictive behaviours are not consistent with a person-centered care approach and can be attributed to the vague understanding of nursing staff in relation to sexuality and dementia (Mahieu, Van Elssen, & Gastmans, 2011; Villar, et al.). Taking such an approach is furthermore not supported throughout the literature. It has been found that perpetrators of sexual abuse are

more likely to be staff or visitors than other residents residing in the long term care facility (Burgess, Dowdell, & Prentky, 2000). Focus must therefore be placed on a shift from eradicating all forms of expressions of sexuality to encouraging expressions of sexuality in a safe and effective way (Villar, et al.).

Forming of New Relationships/Pre-Existing Relationships

One of the greatest challenges for nursing staff in relation to sexuality and dementia is when residents form new intimate relationships with other residents in the LTC facility (ILC, 2011). Integral to this process is the resident's capacity to consent to the relationship. If two residents are able to consent to a relationship and are enjoying each others company, there is no reason they should not be able to engage in a relationship with each other (Kamel & Hajjar, 2003). Hindering or preventing such a relationship from happening would be in violation of their right of expression of sexuality potentially placing them at risk both mentally and physically (Kamel & Hajjar). Unfortunately for residents with dementia as discussed above consent is often difficult to obtain and often cannot be assured raising many ethical issues (Kamel & Hajjar). For example, a resident's preference for a lover or friend may be quit evident despite their poor performance upon assessment of capacity (Kuhn, 2002).

The forming of new relationships becomes even more challenging for residents with dementia when one or both residents already have an existing partner not residing in the long term care facility (ILC, 2011). The forming of new relationships can be very uncomfortable and emotionally painful for the existing partner and their families (Kamel & Hajjar, 2003; Wiskerke & Manthorpe, 2016). Conflict may arise between family members in relation to the appropriateness and the necessity of the relationship (Kamel & Hajjar; Wiskerke & Manthorpe). In an observational study conducted by Ehrenfeld et al, (1999) it was found that in majority of

cases where a woman was found actively engaging in sexual behaviour with another resident family members immediately reacted with anger and demanded nursing staff protect the resident. Families need to be educated on expression of sexuality in residents with dementia in an effort to avoid conflict (Kamel & Ramzi, 2003). Educational materials such as pamphlets on sexuality and dementia can be used to aid in this process. However, before nursing staff can educate family members it is essential they are educated themselves. If conflict continues to remain unresolved following family education an ethics consultation may be the next necessary step (Kamel & Hajjar).

Implications for Nursing Staff and LTC Facilities

Education

Education has been identified as one of the most effective strategies in enhancing the knowledge of nursing staff in relation to sexuality and dementia (Kamel & Hajjar, 2003; McAuliffe, Bauer, & Nay, 2007). It has been found that nursing staff do not have the proper knowledge to identify and respond to the sexuality needs of residents (Bauer, Nay, & McAuliffe, 2009). Staff education is needed to promote an understanding of the need for expression of sexuality in this population of residents. However, increased knowledge and level of awareness does not necessarily mean a positive and accepting attitude (Allen, Petro, & Phillips, 2009; Hillman & Stricker, 1994; Langer-Most & Langer, 2010). A positive attitude towards sexuality in later life has been linked to a greater level of acceptance towards sexual expression in older adults regardless of health or cognitive status (Allen, Petro, & Phillips). It is therefore essential that educational resources not only focus on improving the knowledge of nursing staff but also the attitudes of nursing staff. Shifting attitudes in regards to sexuality in later life in cognitively

impaired older adults is not an easy task but is essential in order to provide the best quality of care to residents (Allen, Petro, & Phillips; Di Napoli, Breland, & Allen, 2013).

Assessment

Sexuality should be discussed just as commonly as any other aspect of health in residents with dementia, with assessment of sexuality beginning immediately upon admission into a LTC (Hajjar and Kamel, 2003). However, research has shown that assessment of sexual functioning is limited to non-existent in many LTC facilities (Villar, et al., 2014). Questions regarding sexuality in relation to history of past and present sexual behaviours, interests and attitudes should be asked in a forthright and dignified way and not followed by an apology as suggested by Hajjar and Kamel (2003) which signifies embarrassment and shame. Several sexuality assessment tools have been developed to help nurses in gathering background information on a resident's social and sexual history however they are rarely implemented (ILC, 2011). It has been suggested this could be related to feelings of discomfort and unpreparedness of nursing staff (Bauer, Nay, & McAuliffe, 2009).

Policy development

The absence of polices on sexuality and dementia has been found to be prevalent within LTC (Archibald, 1998). It has been argued that policies are not needed in relation to addressing natural behaviours such as expression of sexuality; however, lack of policy has been stated to result in increased conflict and dissatisfaction of nursing staff and residents (Cornelison & Doll, 2012). Expression of sexuality has been identified as a basic human need, having a direct influence on an individual's quality of life, and was further identified by Maslow (1943) as a fundamental component of the hierarchy of needs. Increased emphasis needs be placed on the development of policies that will help guide nursing staff in the identification and management

of sexual expression which in turn will help to improve the quality of life of residents (Yelland & Hosier, 2015).

Critique of Studies

Overall, there has been limited research conducted on appropriately responding to expressions of sexuality in residents with dementia residing in LTC facilities. Majority of studies included in this paper strongly emphasize the need for more research in this area. All studies were extensively critiqued and incorporated into a literature review summary table (See appendix B). There were six quantitative studies, six qualitative studies, one mixed method study and three systematic literature reviews in total.

Data for the qualitative studies came from several sources including informal and semi-structured interviews and observation of behaviour. All studies adhered to ethical principals and all except for one specified that ethical approval was obtained from an ethics review board. The major limitation noted for the qualitative studies was the small number of participants. An increased number of participants would have helped to enhance the understanding of phenomena being studied however none the less findings were valuable to the topic under review.

Data for quantitative studies were collected via screening of resident charts, online surveys, and postal questionnaires. Several of the quantitative studies used the same outcome measurement tool, the Aging Sexual Knowledge and Attitude Scale [ASKAS], in which previous establishment of reliability and validity was assured (Allen, Petro, & Phillips, 2009; Bouman, Arcelus, & Benbow, 2007; & Langer-Most & Langer, 2010). This allowed for easy comparison of results. Ethical approval was indicated for all studies except one. The major limitation noted for quantitative studies was also in relation to small sample sizes. The small samples sizes along with characteristics of study sample decreased generalizability of findings.

Data for the mixed methods study was collected through focus groups and a questionnaire. This study also used the Aging Sexual Knowledge and Attitude Scale as an outcome measurement tool. Adherence to ethical principals were discussed however it was not indicated whether or not ethical approval was obtained for this study. The richness and quality of the findings was a major strength for this study.

Lastly, data sources for the Systematic literature reviews included various databases (CINAHL, Pubmed, Psychinfo, Web of Science, Philosphers Index, Google Scholar, Invert, Medline, and Embase). Ethical approval was not required for these studies. The major limitation associated with these studies was each included empirical research over several decades. Attitudes and perceptions pertaining to sexuality and older adults may have evolved over such a time period. Furthermore, the methodological challenges of combing findings from several studies can present many challenges.

Conclusion

Education is the single most effective way to provide nursing staff with the knowledge and skills required to assertively respond to expressions of sexuality in residents with dementia (Ehrenfeld, et al., 1999). It is evident throughout the literature that there is a widespread need for the provision of staff education within LTC facilities in this area. The proposed development of an educational resource manual, aimed at overcoming many of the challenges faced by nursing staff discussed throughout this paper, will help to enhance the knowledge of nursing staff, creating an environment where expression of sexuality can occur in a safe and effective way (Di Napoli, Breland, & Allen, 2013).

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Appendix A

Protocol for Responding to Sexual Behaviors between Residents with Dementia at the Agnes Pratt Home

Protocol for Responding to Sexual Behaviors between Residents with Dementia at the Agnes Pratt Home

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February 2016

Introduction:

Human beings require companionship, affection and intimacy at all ages (Kuhn, 2002). People with dementia are no different in that many still have sexual urges and desires. However, dementia can alter the ways in which sexuality is expressed. This is largely due to the disinhibition and loss of executive cognitive function that often accompanies dementia. These sexual urges are often ignored, denied, and stigmatized (Heath, 2012). Despite the theoretical focus on sexual disinhibition, it is important to note that this affects only a minority of persons with dementia (Higgins et al, 2004; Subramani et al, 2011).

It is often difficult for caregivers, staff and families to remain non-judgmental in such cases. There is often conflict among staff in terms of their need to support a resident's right to sexual expression and their need to protect vulnerable residents. It raises many ethical, legal, and practical challenges and how we respond to it is dependent on many factors as every situation is unique. Staff often look for guidance on how to manage inappropriate sexual behaviors, or ISB. However, it is difficult to develop a comprehensive protocol to deal with all potential situations and there is little literature on the management of ISB and the few existing studies on the subject have limitations. Nonetheless, guidance can be extrapolated from other research on the pharmacological and non-pharmacological management of other behavioral and psychological symptoms of dementia (Joller et al, 2013).

Nursing Response: The Basics:

Essentially, staff must remain compassionate to all residents involved and remember that sexual expression is a normal behavior. It is critical that staff guide their response to the behavior from the perspective that every behavior of a cognitively impaired person is the result of an unmet need and that all human behavior is purposeful (Kitwood, 1997). When a person displays ISB, it is our responsibility as caregivers to find out the meaning behind it. It is also important to remember that not all residents are heterosexual. Staff must respond in a respectful and non-punitive manner and not make the person feel shameful or embarrassed when displaying ISB. Staff must also not breach confidentiality and must ensure that the resident's privacy and dignity are respected. Only team members within the circle of care should be informed of the behavior and the care plan as necessary. All assessments and interventions must be documented as per Eastern Health policy. A Focus note and CSRS to be completed by staff on discovery of suspected incident or unwelcomed sexual activity involved in consultation with Charge RN and/ or Manager (if available) as per Eastern Health Policy.

The following information must be clearly documented:

1. Exact date and time of the incident.
2. Residents involved (in each residents chart only).
3. Factual information of what was observed by staff member including, but not limited to, amount of clothing removed if any, actual physical act observed, psychological state of residents, location of incident, physical description of the residents location/position at time of incident, physical assessment findings.
4. Who was notified (RN / Manager / SDM) and when.
5. Nursing interventions implemented.
6. Strategies to reduce immediate risk.
7. Decision to notify MD or not with rationale.
8. Plan for follow up.

Documentation must be clear, concise and factual. Opinions and assumptions are not appropriate to be included in narrative notes. For example, statements such as "resident was observed crying or screaming 'get away from me'" is preferable to "resident appears fearful and traumatized" or resident "seems not herself today". Be careful of the choice of words. For example, it is not appropriate to write "Resident was a victim of sexual assault" if there is no evidence to support this as it carries with it many legal and inflammatory connotations.

The Nursing Care Plan and Kardex must be updated by the end of shift to include interventions and strategies implemented in response to the incident. These include, but are not limited to, the level of observation required, distraction techniques, and safety plan in place.

Determining Capacity to Consent

When two residents with dementia are mutually attracted to one another and form a new relationship many assume they are not capable of consenting to sexual activity. This may or may not be the case as a resident may perform poorly on a mental status test but their willingness to participate in a relationship may be quite evident. Consent between two residents can be implied and professionally acceptable when neither resident protests, even if cognitively impaired. They may protest verbally by saying "No" or by shouting or crying, or they may protest non-verbally by pushing someone away. Unfortunately, it is often difficult to determine if the persons involved have limited, partial or full capacity to make such decisions. An "all or nothing" approach to determining mental capacity is not useful. (Kuhn, 2002). Residents with dementia can be vulnerable to abuse if they are unable to refuse unwanted sexual advances or communicate their refusal. We as caregivers have a duty to protect those vulnerable residents and ensure their safety. While a resident may have a right to sexual expression, this must be balanced with the potential risks of harm for others.

So how do we determine whether or not a resident has the capacity to consent to sexual activity? Lichtenberg (1997) and Lichtenberg and Strzepek (1990) suggest the following considerations be made to determine capacity:

1. Are they aware of the relationship?
    - To what extent are the residents involved able make their own decisions?
    - Do they recognize the other resident with whom they have the relationship?
2. Are they able to express their wishes either verbally or non-verbally?
    - Can they say no to unwanted sexual contact?
    - Do they know what it means to be sexually active?
    - Are they able to express what level of sexual activity or behavior they are comfortable with?
3. Are they able to avoid exploitation?
    - How will they react if the relationship ends?
    - Are they aware of the potential risks?

An Interdisciplinary Conference including the family should be held to discuss the resident's capacity to consent and what is in their best interests. Not surprisingly, there is often disagreement between parties on their determination of capacity and how to proceed. A care plan must be developed to satisfy all parties yet focused on the best interests of the residents involved. However, if it is determined that the individual(s) lack capacity to consent, the Home has a duty to ensure they are protected from harm.

Assessment:

A thorough and accurate assessment of the behavior is required. This can be done through Dementia Observation Scale (DOS) Charting and discussion with ALL team members within the circle of Care. The following must be considered when assessing the behavior of concern:

1. Is the behavior mainly verbal or physical?
2. What is the meaning behind the behavior? For example….could it be a physical problem? UTI? Med Change? Or is it likely due Loneliness? Boredom? Grieving?
3. How frequently is it happening and when?
4. Is there potential for harm or injury, either physical or emotional?
5. What options are available to meet the resident's needs? (Distraction, therapy, privacy)
6. Are any family members available to consult with?
7. Is the behavior an actual problem? If so, to whom?

A thorough assessment will reveal if the ISB is actually problematic and only then can a determination be made if any intervention is necessary. For assessment purposes, the behavior should then be classified in one of five categories, depending on the level of risk involved.

These Levels are categorized as:

Level 1	Verbal sexual talk, flirting, use of sexually explicit language. Non aggressive, non-physical. Not upsetting to others. No risk of harm.
Level 2	Verbal sexual talk that is upsetting to others, but is easily redirected. Non-physical, Low level of risk.
Level 3	Physical Behaviors of Intimacy/Courtship –like behavior such as kissing, handholding, hugging, hugging, touching of others. It is consentual and there is low risk of harm. Mutual consent is implied by the behavior towards each other.
Level 4	Physical sexual behaviors that are self-directed (Masturbation) or directed at others (exposing oneself to others). May or may not be upsetting to others. Moderate risk of harm.
Level 5	Physical sexual behaviors directed towards others that are unwanted and causes distress. These are aggressive, repetitive sexual behaviors that are unwelcomed and rejected by others. High risk of harm.

Nursing Interventions:

Accordingly, the response to the ISB and the interventions implemented are dependent on the level of risk.

Level 1	• Staff are to respond professionally in a non-punitive manner and not engage in the discussion but rather redirect the discussion to a more socially appropriate context. • Remain calm and respectful.
Level 2	• Use same approach as above but a firmer approach and some additional distraction techniques may be required. • Identify triggers if any. • Goal is to reduce the triggers to reduce the frequency and severity of the behavior and reduce co-residents exposure if upset by the behavior.
Level 3	• Goal is to provide a socially appropriate context for a relationship of companionship. • Redirect socially inappropriate behavior in a non-punitive and respectful manner. • A discussion must be held with family to disclose the behavior and determine if any

	additional interventions or education is necessary. • Document all behavior and discussions with family and document any changes to the Care Plan.
Level 4	• Staff to observe vigilantly (Close, Cluster or Constant surveillance as per Eastern Health Policy) as per RN's discretion for any signs that the behavior is unwelcomed by others. • Families of all residents are to be notified by RN/Manager as appropriate. • Solutions formulated that allow the person privacy, dignity and opportunity to engage in more socially appropriate interactions. • Documentation is critical to communicate the behavior and solutions, update the Nursing Care Plan by the end of shift. • Dr. and NP should be notified as soon as possible at the discretion of the RN.
Level 5	• The goal is to protect the resident(s) from all unwelcome gestures that are upsetting to them. • Constant surveillance to be initiated until a more long-term solution is found or behavior subsides. • Safety plan/ Nursing Care Plan to be updated by end of shift. • Families are to be notified immediately (RN to use discretion) as per Eastern Health's Disclosure of adverse Events Policy. • Interdisciplinary Team Meeting (including the family) to be held ASAP to discuss treatment options, appropriateness of referral to Psycho-geriatrician, appropriateness of resident for unit. • CSRS report to be completed by end of shift.

If staff suspect that a resident had engaged in an unwelcomed sexual act, the following is a guideline of how to respond:

1. Charge RN to be notified upon discovery of suspected incident and preliminary physical exam to be completed by RN immediately. LPN can be designated by RN to perform assessment if necessary.
2. Assessment to be done for: presence/absence of semen/ bodily fluid / genital trauma / an erection, psychological state of all residents involved.
3. Charge RN to notify RCM/CC as soon as possible. If no Manager available, RN to decide if can wait until following day to notify Manager, depending on severity and level of harm.
4. The RN may decide to contact MD without consent from SDM if assessment indicates that further examination or treatment is required. If in doubt, determination to be made after discussion with SDM if MD should be consulted for further medical examination. Goal is to not make incident any more traumatic to resident(s) involved.

5. SDM to be notified of suspected incident as soon as possible post examination. If alleged incident occurs during the night, Charge RN to determine if feasible to wait until following day to notify SDM, depending on level of risk and harm. When in doubt, notify family immediately.
6. SW to complete a report in accordance with the Adult Protection Act.

It is important to remember that this protocol is only a *guideline* for use at the Agnes Pratt Home and not all recommendations will apply in all situations. A common sense, practical approach is to be used when managing these behaviors as there are no set rules and answers and each situation is unique. And as dementia is progressive, so must the plan of care in response to it. The goal is that this protocol will improve the levels of understanding and education and help nurses make practical decisions to balance the need for resident safety and protection with their need of sexual rights and expression.

Appendix B

Literature Review Summary Table

Title, Authors, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/Limitations	Conclusion and Rating
Sexually Inappropriate Behavior in Demented Elderly People. Alagiakrishnan, Lim, Brahim, Wong, Wood, Senthilselvan, Chimich, & Kagan (2005) Study Objective(s): -Determine prevalence of abnormal sexual behaviour. -Identify aetiology, presentation, and treatment of abnormal sexual behaviour	-Canada -Charts of patients with dementia from long term care psychiatry consultation service, community based geriatric psychiatry service and inpatient dementia behavioural unit -n= 2278	-Quantitative - Retrospective cross-sectional study design - Screening of patient charts (sexually inappropriate behaviours, physically inappropriate behaviours, verbal inappropriate behaviours) -DSM IV criteria used in determining dementia dx. - Demographic data and management techniques for each type	-Verbally inappropriate behaviour found to be more common in community sample (81%) compared to nursing home sample (50%) (P=0.04) -Sexually inappropriate behaviour found to be more prevalent among male subjects (93%) - Inappropriate touching of the opposite sex was the	Strengths: -Ethical approval and site administrative approval obtained for all participating locations - No conflict of interest declared Limitations: -Potential for exclusion of data as a result of family members not reporting sexually inappropriate behaviours as frequently as health care providers working in a nursing home	-Provides valuable information for health care providers in the management of inappropriate sexual behaviours in residents with dementia

		of behaviour obtained -Continuous variables described using means and standard deviations - Categorical data described using frequencies and percentages	most common form of inappropriate sexual behaviour (87.8%)		
Factors Influencing Young Adults Attitudes and Knowledge of Late-life Sexuality Among Older Women. Allen, Petro, & Phillips (2009) Study Objective(s): - Examination of young adult's attitudes and acceptability of late life sexuality in	-United States -606 young adults between 17-36 years old from department of psychology's PY 101 subject pool -632 individuals responded to the survey - 26 Excluded	-Quantitative -Vignette methodology -Online survey -Demographic information questionnaire, The Duke University Religion Index, Aging Sexual Knowledge and Attitudes Scale, Human Sexuality Questionnaire and Vignettes -Data analysis included Mixed-model	-Young adults had a lower acceptance of late life sexuality in older women with cognitive impairment -Young adult's attitudes towards sexuality in older women predicted acceptance	Strengths: -Ethical approval obtained -Online survey maximized confidentiality and privacy Limitations: -Limited generalizability due to findings reflective only of young college student's attitudes	-Provides valuable information on attitudes of young adults in relation to sexuality in later life which can be beneficial in the development of interventions to combat negative attitudes and misconceptions

older women. - Examinatio n of younger adult's beliefs on sexual consent capacity and acceptabilit y of late life sexuality in older adults		Analysis of Variances (ANOVAs), Cohens guidelines, means and standard deviations			
Sexuality, dementia and residential care: Managers Report and Response. Archibald (1998) Study Objective(s) : - Exploration of types and prevalence of sexual expression in residents with dementia. - Exploration of manager's responses to	-Scotland -28 social work managers from 28 residential homes invited to participate -1 discarded -n=23 (85% response rate)	-Quantitative -Cross sectional survey - Questionnair e comprised with four sections: Demographi c data, Behavioral checklist, sexual expression and vignettes	-Most common form of sexual expression was male and female residents holding hands followed by fondling of female staff member's breasts by male residents and public and private masturbati on -Managers reported holding hands as most accepting	Strengths: - Confidentiality and anonymity assured - Approval to carry out study obtained with the proviso that participation was on a voluntary basis Limitations: -Small pilot study. -Limited generalizability of results	-Provides valuable informatio n on the attitudes of managers in relation to sexual expression in residents with dementia

sexual expression in residents with dementia			form of sexual expression and easiest to disclose -Managers were most concerned with sexual expression towards staff members, followed by exploitation and coercion and public expression of sexuality		
We need to Know What's Going On: Views of Family Members Toward the Sexual Expression of People with Dementia in Residential Aged Care. Bauer, Nay, Tarzia, Fetherstonhaugh, Wellman, &	-Australia -Family members from six residential care facilities who had a parent, partner, or spouse living in the facility or had lived in the facility within the last 4 years. -n=7	-Qualitative -Semi-structured interviews -Interviews audio recorded and transcribed -Constant comparative method used for data analysis -Interview texts broken down and coded	-Findings revealed three key emerging categories: 'Residents can go so far…but not all the way!', 'It's difficult for staff to cope', and We need to know what's going on'	Strengths: -Findings valuable in that there are minimal studies conducted in this area. - Ethical approval obtained Limitations: -Small number of participants -Recruited from only two resources	-Findings provide valuable information in relation to the quality of care for residents as family members are consulted and usually have decision making power over engagement of residents in

Beattie (2014) Study Objective(s): - Exploration of family member's views and attitudes towards sexuality in residents with dementia	-Purposive sampling -Recruited over a 6-month period				sexual expression with others
Nottingham Study on Sexuality and Ageing: Attitudes of Care Staff Regarding Sexuality and Residents – A Study in Residential and Nursing Homes. Bouman, Arcelus, & Benbow (2007) Study Objective(s): -Investigate attitudes of nursing staff towards	- Nottingham -495 nursing staff from 11 residential homes and 8 nursing homes invited to participate. -n=234 (Response rate 55%)	-Quantitative - Questionnaire sent to all permanent nursing staff -Ageing Sexual Knowledge and Attitudes Scale [ASKAS] and sociodemographic variables sheet	-Young age and less than five years work experience were found to be associated with more negative attitudes towards sexuality in older adults	Strengths: -Ethical Approval obtained Limitations: -None Specified	-Findings provide valuable information in relation to the provision of education to nursing staff in on sexuality and older adults residing in nursing homes

aged sexuality in residential nursing homes					
Staff Knowledge and Perceptions of Sexuality and Dementia of Older Adults in Nursing Homes. Di Napoli, Lauren Breland, & Allen (2013) Study Objective(s): -To investigate nursing staff's attitudes and perceptions of sexual expression in older adults residing in nursing homes	-Alabama -Nursing staff with minimal daily contact with residents from three nursing home facilities -Convenience sample -Sample size determined using power analysis (power level of .85 and effect size d = .60) -N=100	-Mixed Methods - Focus groups -A questionnaire via telephone or face to face -Sexuality in older adults' questionnaire; AD Knowledge Scale, Aging Sexual Knowledge and Attitudes Scale, Holmes Questionnaire, and Duke University Religion Index -Significance level of $p < .05$	-A positive correlation was found between knowledge of dementia and knowledge of sexuality ($r = .46$, $p < .01$) -A positive correlation was found between education and attitudes towards sexuality in older adults ($r = .31$, $p < .01$) -Staff strongly felt that specific instruction should be provided on how to deal with expression of sexuality in residents with	Strengths: -Informed consent obtained -Authors declared no conflict of interest Limitations: -Findings mainly correlations limiting interpretation of causation -Convenient sample limited generalizability of findings -Potential for skewed results due to more questionnaires taking place during day shift	-Findings provide valuable information supporting the need for more education in relation to sexuality and dementia and identifying nursing staff at greatest need for education

			dementia (M = .95)		
Sexuality Among Institutionalized Elderly Patients with Dementia. Ehrenfeld, Bronner, Tabak, Alpert, & Bergman (1999) Study Objective(s): - Observation and categorization of the manifestations of sexuality among institutionalized older people with dementia. -Provide an analysis of the reactions of other patients, staff and family members	- Israel - Nursing staff from Psychogeriatric Wards of 8 Nursing Homes -25 nurses and 48 psychogeriatric residents (90 % stage II dementia, 10% stage I dementia)	- Qualitative - Observational Design -Over 14-week period 25 nurses monitored the sexual behaviors of 48 residents - Checklist developed and pretested by the researchers to record observations prior to use -Data processed and grouped into three main categories love and caring; romance; and eroticism	-70 percent of sexually-based interactions occurred between men and women -In only 10 percent of cases were women the initiators of the sexually-based interactions -Staff reactions to behaviours falling into the love and caring group were mostly supportive -Staffs reactions to behaviours falling into the romance group were mixed and included amusement, treating residents like small children,	Strengths: -Approved by Institutional Ethics Committee Limitations: -Small number of participants	-Provides valuable information on the attitudes of staff members towards expression of sexuality in residents with dementia -Provides evidence supporting the increased need for education in relation to the sexuality needs of residents

			and not interfering. -Staffs reactions to behaviours falling into the eroticism group included rejection, disgust, and anger		
General Practitioner Attitudes to Discussing Sexual Health Issues with Older People. Gott, Hinchliff, & Galena (2004) Study Objective(s): - Exploration of the views and experiences of GPs' in relation to the sexual health of older adults	-Sheffield - 64 GP's from 4 Primary care practices -Purposive sampling -n=22 (13 men and 9 women) -Response rate 34%)	-Qualitative -In-depth semi-structured interviews -Analysis of data based on grounded theory principles. -Double coding of transcripts and comparing inter-rater reliability ensured reliability of analysis	-Findings reveled that the sexual health of older adults is not an issue proactively discussed -Reasons for this included sexual health is equated with younger adults, sexuality in older adults is a private topic that may offend the older adult and have a negative impact on	Strengths: -Ethical approval obtained Limitations: -Small number of participants	-Study findings provide valuable insight in relation to education and training for GPs

			the doctor/patient relationship, and discomfort in this area due to limited education and training		
Sexual Expression and Dementia - Views of Caregivers: A Pilot Study. Holmes, Reingold, & Teresi (1997) Study Objective(s): -Measure attitudes of health care staff in relation to sexuality and sexual expression in cognitively impaired residents residing in nursing homes	- USA -Staff from 300 nursing homes including: staff administration (17 %), nurses and physicians (45%), social workers (20%) and other (18%) - n=114 - Response rate 40 percent -Nursing homes randomly selected	-Quantitative -Survey -Holmes Questionnaire -Exploratory factual analysis, using principal components used to categorize data -Internal consistency	-Findings revealed that attitudes towards sexual expression were generally positive -Although not statistically significant administrators were found to be more conservative than other staff members	Strengths: -Anonymity assured Limitations: -Small sample size -Low statistical power -No follow up of questionnaire recipients which would have helped obtain an acceptable response rate. Potential for systemic bias as a result	-Findings provide valuable insight into the need for increased education and training in relation to sexual expression in residents with dementia

Aging and Sexuality: How Much Do Gynecologists know and Care. Langer-Most & Langer (2010) Study Objective(s): -Measure sexual knowledge and attitudes of sexuality in older aged women	-USA -Physicians from five hospitals (89 females, 52 males) -n=141	-Quantitative -Prospective Study -Aging Sexual Attitudes and Knowledge Scale -Previous establishment of reliability and validity of scale	-No correlation between knowledge and attitude scores (r =.06, p = .54) -No positive correlation between age and knowledge (r = .20, p = .02). -A positive correlation was found between age and attitudes (r = .20, p = .02) but not to knowledge	Strengths: -Reviewed by Institutional Review Board. Weaknesses: None identified	-Findings place emphasis on the need for educational training programs for health care providers on sexuality in older adults
Nurses Perceptions of Sexuality in Institutionalized Elderly: A Literature Review. Mahieu, Van Elssen, & Gastmans (2011) Study Objective(s):	-Final inclusion (n=18) Inclusion criteria: -Empirical research (Quantitative, qualitative, or mixed method design) - Focus on knowledge, attitudes, and	-Systematic literature review of research between 1980 and 2010 -Criteria outlined by Polit and Beck (2008)	-Attitudes towards sexuality in older adults was generally positive. -Nursing staffs had knowledge in relation to sexuality was very limited. -Nursing staff's attitudes	Strengths -Steps taken to minimize bias -No conflict of interest declared Limitations -Search included articles over several decades. Evolvement of attitudes and perceptions may have	-Provides valuable findings in relation to the attitudes and perceptions of nursing staff towards sexuality in institutionalized settings.

-Examination of the knowledge, attitudes, and experiences of nursing staff in relation to sexuality in residents with dementia residing in institutionalized settings	experiences of nursing staff in relation to sexuality. -Institutionalized elderly		were more conservative towards older adults residing in institutionalized care settings -How nursing staff responded to incidents of sexual expression were influenced by their own level of comfort and the ethos of work environment	occurred over this time -Potential for bias due to methodological challenges associated with combining various study designs	
Intimacy and Sexuality of Nursing Home Residents with Dementia: A Systematic Review". Roelofs, Luikx, & Embregts (2015)	-n = 254 articles retrieved -Final sample n=12 Inclusion criteria: -Empirical research (Quantitative, qualitative, or mixed method design) -Focus on intimacy	-Systematic literature review -Research published between 1990-2013 included in the study. -Mixed methods appraisal tool used to assess quality of studies	-Emerging themes from the included: Intimate and sexual behavior, knowledge and attitudes, capacity to consent and care culture, and staff training and guidelines	Strengths: -No conflict of interest declared Limitations: -Search included articles over several decades -Small number of publications. -Small number of searched databases (Majority of articles retrieved from	-Findings support the need for increased education and training for nursing staff in relation to expression of sexuality in residents with dementia

Study Objective(s): -To provide an overview of healthy and normal forms of sexuality and intimacy in residents with dementia residing in nursing homes	and sexuality and staff member's attitudes on intimacy and sexuality in residents with dementia residing in institutionalized settings -Peer reviewed			PsychInfo, CINAHL not included) - Potential for bias due to methodological challenges associated with combining various study designs	
"Sexual Behavior of Institutionalised Residents with Dementia – A Qualitative Study". Tzeng, Lin, Shyr, & Wen (2009) Study Objective(s): - Exploration of characteristics and contexts of	-Taiwan. -12 formal caregivers (3 registered nurses and 9 nursing aids) from dementia units of 3 long-term care facilities -12 institutionalized male with dementia	-Qualitative -Grounded Theory Design -Purposive sampling -Study took place from November 2002-August 2003 - Observation, informal interviews, and in-depth interviews - Observations were recorded and interviews tape	- Predisposing factors for sexual behaviour included opportunity, a cooperative target, and personal space without privacy -Three types of sexual expression emerged from the findings physical intimate	Strengths: -Ethical approval obtained Limitations: -Purposive sampling may have lead to exclusion of potential participants -All residents in the study were male affecting representativeness and generalizability	-The findings from this study provide evidence that can be incorporated into educational programmes

sexual behaviours in residents with dementia		recorded and transcribed verbatim -Intercoder reliability of 0.92 -Rigor ensured through four components of trustworthiness (truth value, applicability, consistency, and neutrality)	touch, sexual expression without touching others and sexual talk		
"Staff Attitudes Towards Sexual Relationships Among Institutionalized People with Dementia: Does an Extreme Cautionary Stance Predominate?". Villar, Celdran, Faba & Serrat (2014) Study Objective(s): 	-Spain -Staff members of residential aged care facilities. -n=53	-Qualitative -Vignette methodology -Random sampling and purposive non-probability sampling technique -Semi-structured interviews -Data recorded and transcribed verbatim -Content analysis used to identify main themes -Nvivo 2.0 analysis	-Staff members perceived sexual relations between a cognitively well resident and a resident with dementia as abuse (54.7%) or possible abuse (35.8%) -Staff members perceived sexual relations between two residents	Strengths: -Ethical approval obtained Limitations: -Potential for order related bias due to interview format	-Findings of this study provide valuable information on the attitudes of staff members in relation to expression of sexuality in residents with dementia and the need for change in attitude

- Exploration of staff member's perceptions and reactions to sexual situations involving residents with dementia in residential care homes		software used - Trustworthiness maintained through independent double checks by two researchers	with dementia as possibly abusive (39.6% or non-abusive (37.7%)		
"Intimacy between care home residents with dementia: Findings from a literature review". Wiskerke, & Manthorpe (2016) Study Objective(s): -Investigate the views of family members and care providers in relation to the forming of new relationships or sexual	-Final inclusion n=9 Inclusion criteria: -Focus on sexuality, intimacy and relationship between residents with dementia -Focus on views of family members and care providers Exclusion criteria: -Not written in English or Dutch. -Non-dementia care	-Systematic literature review -Research published between 1946-2014	-Emerging themes included sexuality in old age, dementia and sexuality, hyper-sexuality, views regarding sexuality, relationships and communication, and new relationships -Forming of new relationships found to be emotionally painful for family members	Strengths -No conflict of interest declared Limitations -Search included articles over several decades. -Included peer reviewed literature in English only - Potential for bias due to methodological challenges associated with combining various study designs	-Findings provide valuable information into the views of family members in the forming of new relationships between residents with dementia

intimacy between residents with dementia	nursing homes		and challenging for care facilities		
"Public Attitudes Toward Sexual Expression in Long-Term Care: Does Context Matter?". Yelland & Hosier (2015) Study Objective(s): - Examination of the influence of age and sex on public attitudes towards sexuality and long term care. -To gain an understanding of the of the influence of long term care on perceptions of sexuality as a basic	-Southern state in USA. -325 respondents (Response rate of 34%)	-Qualitative -Factorial Vignette methodology - Telephone interviews electronically recorded -Probability sampling used in recruitment of respondents -Measures taken to reduce sampling bias -Independent variables analyzed using a logistic regression model -Open ended questions typed verbatim and coded -Inter-rater reliability assured through second coder	-No statistically significant relationship between attitude and age or sex -A statistically significant relationship was found between education, parenthood status and religion and a positive attitude toward sexual relations in long term care -19 percent of respondents did not feel resident should be allowed to have a sexual relationshi	Strengths: -Verbal consent was obtained Limitations: -Not specified if ethical approval was obtained	-Findings provide valuable information on public attitudes towards sexuality in older adults residing in long term care facilities

human need in older adults			p with their spouse within the long term care facility. 60 percent of these respondents were over the age of 55		

Appendix B

Consultation Report

Sexuality and Dementia in Long Term Care Facilities: An Educational Resource Manual for Healthcare Providers

Consultation Report

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On a national level, little has been done in long term care [LTC] facilities to create environments conductive to or supportive of expression of sexuality in residents living with dementia (Tarzia, Fetherstonhaugh, & Bauer, 2012). Nursing staff, upon encounter of sexual expression between residents, are continuously reporting experiencing difficulties, distress, and confusion in relation to how they should respond (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). Currently, Eastern Health has no generic policy in place on responding to expressions of sexuality in residents with dementia. The Agnes Pratt Home [APH], a LTC facility within Eastern Health recently developed their own written protocol to be used by nursing staff at the home as a guideline in responding to expressions of sexuality in this population (Delaney-Martin, 2016).

Following implementation of this protocol, I felt that although beneficial in guiding nursing staff's responses, the protocol was short and task oriented. It held little meaning for nursing staff as they lacked understanding of the rationalization behind the recommended responses. Furthermore, it was evident that many nursing staff working in the home had only a vague understanding of sexuality and dementia and the need for expression of sexuality in these residents.

Research further supports the need for increased education for nursing staff in relation to identifying and responding to the sexuality needs of residents. A review of the literature revealed four main areas requiring increased nursing education in relation to sexuality and dementia: attitudes, beliefs, and misconceptions, appropriate versus inappropriate behaviours, consent and capacity and forming of new relationships/pre-

existing relationships. In majority of studies education was identified as the most effective strategy in enhancing the knowledge of nursing staff. The proposed project of an educational resource manual to compliment the currently existing protocol implemented by the APH, would not only provide meaningful rationale to support recommended responses outlined in the protocol but would also enhance the knowledge of nursing staff in relation to sexuality and dementia and the need for expression of sexuality in this population.

The main purpose of conducting consultations with key members of the healthcare team was to determine if an educational resource manual would be beneficial to nursing staff working on the dementia care units at the APH. For nursing staff who feel an educational resource manual would be beneficial, consultations would further allow for the exploration of their learning needs and input on material they would like included in the manual.

The key objectives guiding consultations were as follows:

1. To identify existing educational resources and training sessions on sexuality and dementia.
2. To evaluate the need for a learning resource manual on sexuality and dementia for nurses working in LTC facilities.
3. To identify the topics nursing staff and management feel should be included in a learning resource manual.

Participants

Consultations were conducted with two Registered Nurses [RNs], two Licensed

Practical Nurses [LPN], and two Personal Care Attendants [PCAs]. The Resident Care Manager [RCM] on the two dementia care units was also consulted with.

Nursing staff were selected via purposive sampling. Inclusion criteria included:

1. Permanent full time employees only
2. One-year experience working on one of the two dementia care units

Data Collection

Data was collected in person at the APH using semi-structured interviews (see Appendix A for interview guide template for LPNs, PCAs, and RNs, and resident care manager). Interviews were conducted during working hours in a private area and took approximately 20 to 30 minutes.

A face-to-face semi-structured interview was chosen as the method of data collection. Face-to-face interviews allowed for control of clarity and depth of questioning through methods such as probing which helped to enhance the quality of data. Quality of data was further assured by verbally stating responses back to the participants during the interview process (Polit & Beck, 2012).

Data Management and Analysis

Data from face-to-face interviews was transcribed verbatim into a word document and stored on a password protected laptop. All guiding questions for the interview were open ended. Content analysis was used in the summarization of data and emerging themes and patterns were identified and grouped into categories.

Results

The main themes that emerged from the consultations included: views of nursing staff, need for more education and resources, and priority learning needs. Discussion of each of these will take place below.

The first theme was the views of nursing staff. All participants agreed that sexuality is a basic human need that begins at birth and continues throughout the lifespan and does not diminish with old age or cognitive status. Half of participants felt that LTC facilities should promote environments where the sexuality needs of residents with dementia can be met. The other fifty percent although they disagreed with promoting such an environment, felt that sexual expression should not be condoned or shamed when it does occur. Forms of sexual expression that participants felt were appropriate included holding hands, kissing, hugging, and cuddling. Forms of inappropriate sexual expressions included sexual intercourse, fondling of another resident, masturbating in public, and disrobing. All participants stated that sexual relations between residents were not wrong. However, several experienced staff voiced that some of the typical responses of their co-workers upon encounter of sexual expression in residents was negative and included shock, panic, disgust, and turning a blind eye. Despite these negative responses all participants felt that male and female residents with dementia should not be segregated onto separate units unless there is a safety issue which puts the residents or other residents at risk. Participants in support of co-ed dementia care units felt that social interaction between male and female residents is beneficial and sexual behaviours will still occur on segregated units.

The second theme was the need for more education and resources. All participants stated that there is a need for more education on sexuality and dementia in their workplace setting. Fifty percent of participants stated they were aware of a guideline that was recently implemented on their unit by their resident care manager on responding to sexual expression. The other half of participants however stated that they were not aware of any policies, guidelines, educational resources or training on sexuality and dementia in their workplace. Participants voiced that majority of their skills in responding to sexual expression on dementia care units have come from their experience working with this population. Experienced nursing staff stated that some of the common concerns and questions that they have been faced with in relation to sexual expression in residents with dementia included 'Is this allowed to happen? What do I do?, Do I separate them?, Is this legal?, 'What do I tell families', 'Is the resident competent to engage in such behaviour?' All participants agreed that there is a need for more educational resources, in-services, and policies on responding to sexual expression in this population and felt that it should be included in orientation to LTC including cooperate and site orientation. It was further suggested that how to respond to sexual aggression should be incorporated into the gentle persuasive approach training for managing aggressive behaviours in residents with dementia.

The last theme was priority learning needs. All participants supported the development of an educational resource manual on sexuality and dementia. Some of the priority topics that participants voiced they would like to see included in an educational resource manual included: the effects of dementia on sexuality, responding to different

forms of sexual expression, evidence based strategies/interventions in managing sexual expression supported by research and used in other facilities, involving and educating families on sexuality and dementia, and identifying and responding to sexual aggression.

Permissions

The Health Research Ethics Authority (HREA) screening tool was used to determine whether or not ethical approval was needed for the proposed project (see appendix C). Based on this screening tool it was determined that ethical approval was not required. Permission to consult with participants was obtained from the administrator of the APH and consent was obtained from participants through verbal consent. Participants were given the option to withdraw from the interview at any time. Following analysis of data all questionnaires were destroyed to ensure confidentiality of data.

Conclusion

Following consultations with key members of the healthcare team at the APH it was evident that there was a significant need for the development of an educational resource manual on sexuality and dementia. All participants despite their job title and/or years of experience strongly felt they would benefit from more education in this area and all agreed that an educational resource manual would help meet this need.

Consultations with nursing staff were of great value in providing a frontline perspective on the need for an educational resource manual. Consultations allowed for valuable input from nursing staff on material that they felt should be included in the manual. Findings from the consultations were consistent with those identified throughout the literature including the need for more education on: responding to sexual expressions,

appropriate versus inappropriate behaviour, consent and capacity, and communicating and educating family members. Overall, findings generated from consultations provided validation to support the continual development of an educational resource manual on sexuality and dementia.

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Appendix A

Semi-Structured Interview Guideline Questions

LPNs and PCAs

1. Do you feel sexuality is a basic human need that continues throughout the life span? Explain.

2. Do you feel individuals with dementia have a need for love, intimacy and companionship? Explain.

3. Do you feel males and females with dementia should be separated to different nursing floors? Explain.

3. Do you feel nursing homes should promote an environment where the sexuality needs of residents with dementia can be expressed? If you answer yes, what are some ways this can be done without compromising the safety of other residents?

4. Do you feel the Agnes Pratt Nursing Home creates an environment conductive to or supportive of expression of sexuality in residents with dementia? Explain.

5. What forms of sexual expression do you feel are appropriate and not appropriate in residents with dementia?

6. Do you feel sexual relations between residents with dementia is wrong? Explain.

7. Are you aware of any educational resources such as policies, protocols or training sessions in place within the Agnes Pratt Nursing Home to support staff in responding to expressions of sexuality in residents with dementia?

8. Have you received an education/training on sexuality and dementia? If so what type of education/training have you received?

9. Do you feel you have the necessary education and skills to respond to expressions of sexuality in residents with dementia? Explain.

10. Do you feel you would benefit from a learning resource manual on sexuality and dementia? Why or Why not? If yes, what are some important topics you feel should be included?

RNs

1. Do you feel sexuality is a basic human need that continues throughout the life span? Explain.

2. Do you feel individuals with dementia have a need for love, intimacy and companionship? Explain.

3. Do you feel males and females with dementia should be separated to different nursing floors? Explain.

4. Do you feel nursing homes should promote an environment where the sexuality needs of residents with dementia can be expressed? If you answer yes, what are some ways this can be done without compromising the safety of other residents?

5. Do you feel the Agnes Pratt Nursing Home creates an environment conductive to or supportive of expression of sexuality in residents with dementia? Why or Why not?

6. What forms of sexual expression do you feel are appropriate and not appropriate in residents with dementia?

7. Do you feel sexual relations between residents with dementia is wrong? Explain.

8. What are some of the typical reactions and responses of nursing staff (LPN's and PCAs) on your unit in relation to expressions of sexuality in residents with dementia?

9. What are some of the concerns and questions that you hear from nursing staff (LPNs and PCA's) on your unit in relation to sexual expression in residents with dementia?

10. Are you aware of any educational resources such as policies or protocols in place within the Agnes Pratt Nursing Home to support nursing staff in responding to expressions of sexuality in residents with dementia?

11. Do you feel you have the necessary education and skills to respond to expressions of sexuality in residents with dementia? Explain.

12. Do you feel nursing staff (LPN's and PCA's) on your unit have the necessary education and skills to respond to expressions of sexuality in residents with dementia? Why or why not?

13. Do you feel you would benefit from a learning resource manual on sexuality and dementia? Why or Why not? If yes, what are some important topics you feel should be included?

14. Do you feel nursing staff on your unit (LPN's and PCA's) would benefit from a learning resource manual on sexuality and dementia? Why or why not?

Resident Care Manager

1. Do you receive many calls from nursing staff in relation to incidents of sexual expression on your units? What types of questions and concerns do you hear?

2. Do you receive many calls from families regarding incidents of sexual expression in residents with dementia? What types of questions and concerns do you hear?

3. Are nurses given any education or training on sexuality and dementia in their general or site orientation to long term care?

4. Are nursing staff at the Agnes Pratt Nursing Home provided with any education/training on sexuality and dementia? If yes explain.

5. Do you feel nursing staff would benefit from a learning resource manual on sexuality and dementia? Why or Why not? If yes, what are some important topics you feel should be included?

Appendix B

Health Research Ethics Authority Screening Tool

	Question	**Yes**	**No**
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review		**N**
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?		**N**
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. **IF NO** to both questions, continue to complete the checklist.		**N**
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	**Y**	
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	**Y**	
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?		**N**
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?		**N**
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?		**N**
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)		**2**	
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	**Y**	
9.	Is the project intended to define a best practice within your organization or practice?	**Y**	
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	**Y**	
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	**Y**	
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		**N**
LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)		**4**	

	SUMMARY **See Interpretation Below**		

Interpretation:

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.
- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).
- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: http://www.hrea.ca/Ethics-Review-Required.aspx.

Appendix C

Educational Resource Manual

Sexuality in Older Adults with Dementia

(IMAGE (RETRIEVED FROM HTTPS://COMMONS.WIKIMEDIA.ORG/WIKI/CATEGORY:OLD_COUPLES#/ MEDIA/FILE:IT%27S_ ALL_ABOUT_LOVE.JPG)

A resource manual for healthcare providers working in long term care facilities.

Developed by Karla Oates, BNR

Table of Contents

Introduction

Who is this educational resource manual for?

This manual was developed for use by nursing staff working on dementia care units at the Agnes Pratt Nursing Home.

What is the purpose of this manual?

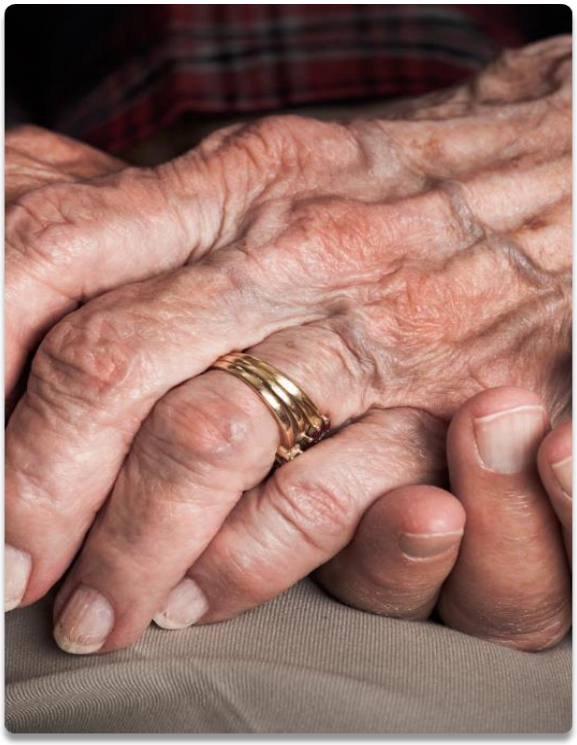
The purpose of this manual is to enhance the knowledge of nursing staff in relation to expression of sexuality in residents with dementia. This manual is intended to help educate nursing staff on how to identify and respond appropriately to expressions of sexuality when working on dementia care units.

How can this manual be used?

This manual can be used by novice nursing staff who are new to dementia care or experienced nursing staff currently working on the dementia care units. Although intended for nursing staff this manual may also be used by other members of the healthcare team who are interested in learning more about expression of sexuality in this population. To complete this education manual, it is recommended you work through each of the five modules at your own pace completing incorporated learning activities for each module as you go.

Reminder
When caring for residents with dementia, you must follow the policies and guidelines of your employing agency.

Module One:
Sexuality and Older Adults



(Image retrieved from www.pixabay.com)

Learning Objectives:

Upon completion of this module you will be able to:

- Define sexuality and intimacy
-Discuss the importance of expression of sexuality in older adults
-Describe the difference between sexual behaviors and intimate behaviors
-Describe the different types of sexuality and gender identities
- Identify common myths and misconceptions associated with sexuality in older adults
- Identify your own personal attitudes related to sexuality in older adults

Understanding Sexuality and Intimacy

Sexuality is a basic human need that begins at birth and continues throughout the lifespan. It is an important component of one's identity and is positively linked to overall physical and psychological well-being (Hajjar & Kamel, 2003; Ogden, 2001). Every individual, regardless of age, has a need for love, intimacy and companionship; this does not change as people grow older and is no different for individuals living with dementia (Hajjar & Kamel). In some situations, expression of sexuality becomes the only way individuals with dementia have left in relation to communicating with others (Wornell, 2014).

The World Health Organization [WHO] (2002) defines sexuality as "a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (p 5).

Sexual behavior is overt and in most cases, is directly linked to satisfying sexual desire. When sexual behavior is no longer possible or desirable emotional connectedness with another is often achieved through intimacy (Dementia Training Study Centers, 2013). Understanding that sexuality not only involves sexual intercourse and sexual behaviors but that it also involves intimate behaviors such as wanting to feel close to someone is important in understanding the sexuality needs of residents with dementia (International Longevity Center [ILC], 2011).

Examples of Intimate Behaviors Include:

- Touching, kissing on the cheek, holding hands
- Empathetic understanding and comforting
- Sharing jokes and stories
- Being with friends

Examples of Sexual Behaviors Include:

- Flirtatious behaviors

"I truly feel that there are as many ways of loving as there are people in the world and as there are days in the life of those people"

(Mary Calderone, physician and pioneer in the field of human sexuality)

- Gestures of romance
- Oral sex
- Sexual intercourse
- Watching pornography
- Masturbation

Types of Sexuality and Gender

Expressions of sexuality and intimacy are directly related to what type of sexuality an individual identifies with and their individual needs at that time (Bauer, McAuliffe, & Nay, 2004; Dementia Training Study Centers, 2013). It is important to recognize that not all residents with dementia are heterosexual (ILC, 2011).

Homosexual
A term to describe a person whose primary sexual orientation is to members of the same gender. Most people prefer to not use this label, preferring to use other terms such as gay or lesbian. Older individuals may be more comfortable with this term over gay/lesbian (Steele 2010, p 13).

Bisexual
A word describing a person whose sexual orientation is directed towards men and women although not necessarily at the same time (Steele, 2010, p 13).

Gay A word to describe a person whose primary sexual orientation is to members of the same gender or who identifies as a member of the gay community. This word refers to men and women although many women prefer the term lesbian (Steele, 2010, p 13).

Autosexual
A word describing a person whose significant sexual involvement is with oneself or a person who prefers masturbation over partnered sex (Steele, 2010, p 13).

Intersex
A person who has a mixture of male and female genetic and/or physical sex characteristics. Formerly called "hermaphrodites". Many intersexed people consider themselves to be part of the trans community (Steele, 2010, p 13).

Transgendered
A person whose gender identity is different from his/her biological sex, regardless of the status of the surgical and hormonal gender reassignment processes. Often used as an umbrella term to include transsexuals, transgenderists, transvestites, and two-spirited, intersexed and transgendered people (Steele, 2010, p 13).

Transsexual
A term used for a person who has an intense long-term experience of being the sex opposite to his/her birth-assigned sex and who typically pursues a medical and legal transformation to become the other sex (Steele, 2010, p 13).

Myths and Misconceptions

Sexuality in the elderly is an issue that is seldom spoke about openly and constructively in Western Society. One explanation for this is media's portrayal of older adults as being asexual human beings (Allen, Petro, & Phillips; Benbow & Beeston, 2012; Bouman, Arcelus, & Benbow, 2006).

This ageist stereotype has resulted in many negative public misconceptions including:

- Older adults are unattractive and sexually undesirable
- Sex is for younger individuals
- Older adults are incapable of sex
- Older adults are no longer interested in sex or relationships

Healthcare providers are not immune to these negative misconceptions and attitudes. Attitudes are strongly related to nursing staff's behavior towards residents. It is therefore important that nursing staff take the time to evaluate their own personal attitudes and how they conflict with or support the

resident's rights to sexual expression (Alzheimer's Association, 2015). The following comments are not uncommon to hear amongst healthcare providers working in long term care facilities:

ILC, 2011, p 8

Time to Reflect

Reflect on your own attitudes, beliefs, and values in relation to sexuality and aging. What are they and where do they come from?
(Dementia Training Study Centers, 2013)

True or False

1. Sexuality is a basic human need that begins at birth and continues throughout the lifespan

   True/False

2. Older individuals with dementia are incapable of having sex

   True/False

3. Sharing jokes and stories is an example of an intimate behavior

   True/False

4. Intimate behaviors always lead to sexual intercourse

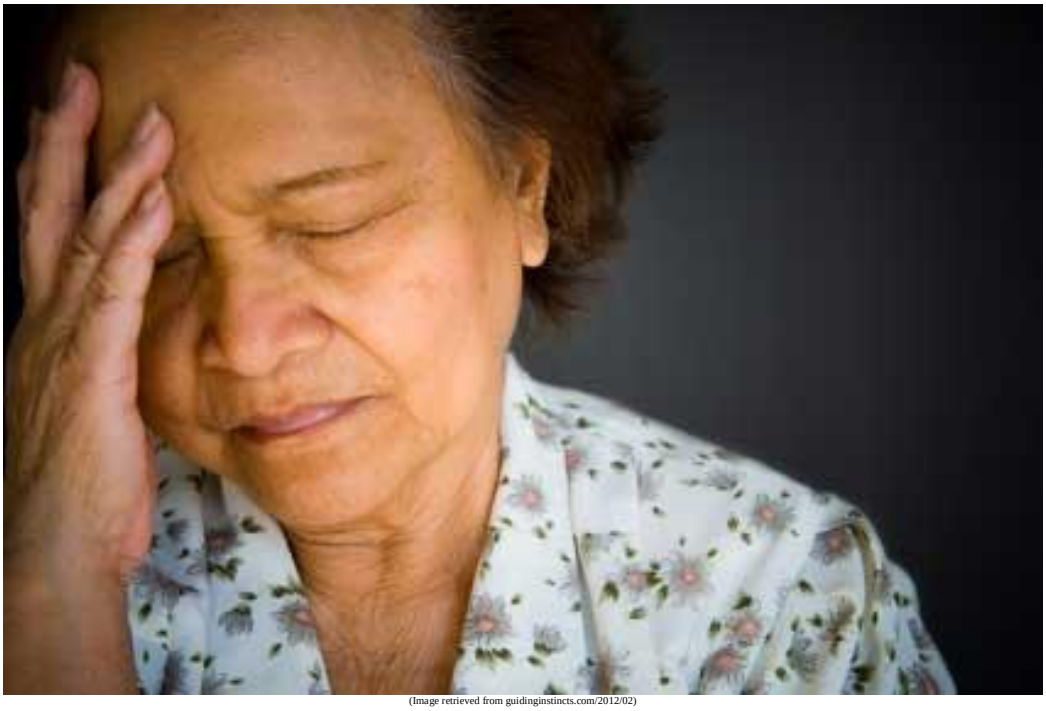
   True/False

5. When sexual behavior is no longer possible or desirable emotional connectedness with another is often achieved through intimacy

   True/False

Answers: **1.** T **2.** F **3.** T **4.** F **5.** T

Module Two:
Impact of Dementia on Sexuality – What Happens to the Brain



(Image retrieved from guidinginstincts.com/2012/02)

Learning Objectives:

Upon completion of this module you will be able to:
-Recognize the effects dementia may have on sexuality
-Identify how different dementia brain lesions impact sexual behaviors

Dementia Facts

- Dementia is a progressive disease that affects the brain and is characterized by a decline in memory and increase in cognitive impairments (ILC, 2011).

- The development of tangles and plaques in the brain associated with dementia lead to the death of brain cells (ILC, 2011).

- An estimated 47.5 million people worldwide are living with dementia. By the year 2030 this number is expected to increase to an estimated 75.6 million (WHO, 2016).

- Although dementia is most common in older adults it can affect individuals of any age (ILC, 2011).

- The most common form of dementia is Alzheimer's disease which contributes to 60-70 percent of all cases of dementia (WHO, 2016).

With the rapid aging of the baby boomers and continuing rise in life expectancy rates the number of individuals living with dementia residing in long term care facilities is only expected to increase. It is therefore essential that attention be placed on understanding the sexuality needs of this population.

Types of Dementia

Types of Dementia	Description
Alzheimer's disease	Most common type of dementia. It accounts for 60 – 80 per cent of cases. Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgement,

	disorientation, confusion, behavior changes, trouble speaking, swallowing and walking.
Vascular dementia	Considered the second most common type of dementia. Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed dementia	Characterized by the presence of the hallmark abnormalities of Alzheimer's disease and another type of dementia, most commonly vascular dementia, but also other types, such as dementia with Lewy bodies.
Dementia with Lewy body	Shares characteristics with both Alzheimer's and Parkinson's diseases. It accounts for around four per cent of all cases of dementia in older people. The symptoms that indicate this specific type of dementia are mental decline, recurrent visual hallucinations or depression, increasing problems handling the tasks of daily living, repeated falls and sleep disturbances and fluctuations in autonomic processes.
Dementia in Parkinson's disease	Many people who have Parkinson's disease develop dementia in the later stages of the disease.
Frontotemporal dementia	Involves damage to brain cells, especially in the front and side regions of the brain. Typical symptoms include changes in personality and behavior and difficulty with language.

(Dementia and the Eight Types of Dementia, Bob De Marco, 2011. Adapted from ILC, 2011 http://www.ilcuk.org.uk/files/pdf_pdf_184.pdf)

The Impact of Dementia on Sexual Behaviors

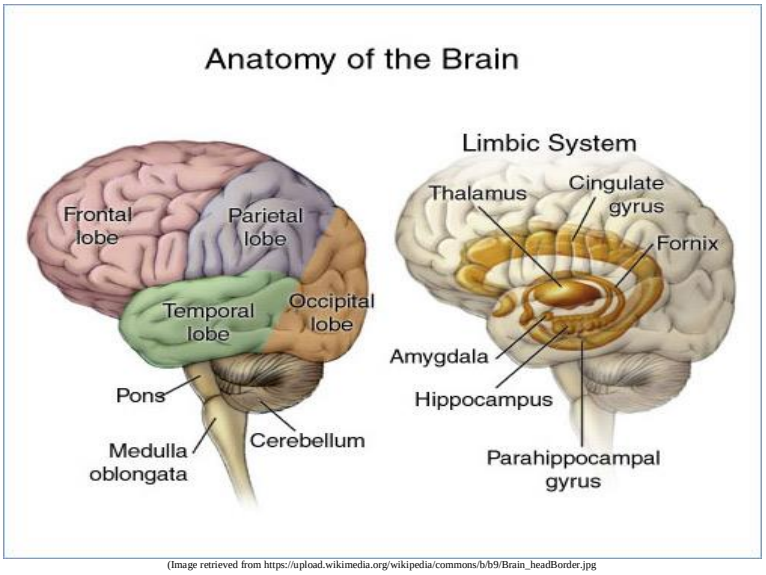
Understanding how dementia effects sexuality can help make dealing with unexpected expressions of sexuality easier. The neurobiological changes related to dementia during the early and middle stages of the disease can have various effects on sexuality.

During these stages relationships and social functioning remain heavily intact and in some situations, sexual desire remains but with issues such as:

- Touching, kissing, hugging or flirting with others without their consent
- Misinterpretation of behaviors and body language as being sexual
- Increased interest in sexual activity
- Loss of ability to appropriately act in public settings such as exposing and touching genitals
- Making inappropriate sexual comments towards others
- Making inappropriate sexual advances towards others
- Change in sexual orientation or preference

(Alzheimers Association, 2015; Dementia Training Study Centres, 2013; Wonell, 2014)

The Brain



(Image retrieved from https://upload.wikimedia.org/wikipedia/commons/b/b9/Brain_headBorder.jpg

The frontal and temporal lobes are located in the outer cortex of the brain. These lobes are commonly affected in individuals with dementia and are responsible for transforming memories which result in ability to rationally act and consciously recognize things. Dopamine also referred to as the pleasure chemical is linked to sexual pleasure and desire. Dopamine is found in the frontal lobe of the brain and is highly responsible for conscious decision making including ability to override urges to engage in inappropriate sexual behaviors and sexual aggression (Wornell, 2014).

Brain Lesions Associated with Different Types of Dementia and Effects on Sexuality

Alzheimer's Disease	Lesion – toxic protein deposition with secondary inflammatory response Area Affected – cortex, gray matter, particular focus on temporal lobes/hippocampus Effect on Sexuality – frontal lobe disinhibition, limbic system dysfunction, including possible Kluver-Bucy syndrome
Vascular Dementia	Lesion - strokes Area Affected – grey or white matter, specific or global Effect on Sexuality – frontal lobe disinhibition from frontal lobe annihilation, leading to inappropriate behaviors, specific lesions to limbic system, striatum, or hypothalamus; seizures may lead to mania and hypersexuality
Lewy Body Dementia	Lesion – toxic Lewy body (a type of protein) Area Affected – grey matter, cortex with special focus on temporal lobes and striatum Effect on Sexuality – frontal lobe disinhibition leading to inappropriate

	behaviors, limbic system destruction/Kluver-Bucy syndrome
Parkinson's Disease Dementia	Lesion – toxic Lewy body Area Affected – subcortex specific to striatum Effect on Sexuality – hypersexuality from excessive dopamine replacement therapy
Frontotemporal Dementia	Lesion – a type of protein that stabilizes a transport system between neurons is destroyed Area Affected – cortex, gray matter specific to frontal lobes, temporal lobe later Effect on Sexuality – disinhibition leading to personality changes and inappropriate sexual behaviors
Traumatic Brain Injury	Lesion – caused by trauma Area Affected – anywhere to any degree Effect on Sexuality – traumatic lesions in frontal lobes cause disinhibition and small lesions in striatum, leading to inappropriate behaviors; hypothalamus or limbic system lead to inappropriate or bizarre sexual behaviors; secondary seizures may lead to manic hypersexuality.
Aids Dementia Complex	Lesion – HIV virus causes area of destructive inflammation Area Affected – white matter, subcortex Effect on Sexuality – disinhibition leading to inappropriate behavior; specific opportunistic infections may lead to abnormal sexual behavior
Alcohol Dementia	Lesion – toxic effects of ethanol Area Affected - global Effect on Sexuality – disinhibition leading to inappropriate behaviors yet with verbal intelligence preserved, allowing for engagement in social activities
Huntington's Disease	Lesion – genetic disorder marked by abnormal protein accumulation in cells Area Affected – striatum initially; eventually affecting the entire brain

	through the mutation of an important interactive protein Effect on Sexuality – compulsive sexual behavior from striatal destruction
Wilson's Disease	Lesion – genetic disorder marked by abnormal copper deposits in brain tissues Area Affected – frontal cortex and striatum Effect on Sexuality – disinhibition leading to inappropriate behaviors and compulsive sex from striatal lesions
Creutzfeldt-Jakob Disease (Mad Cow Disease)	Lesion – transmissible protein called a prion destroys tissue, causing spongiform holes in the brain Area Affected - global Effect on Sexuality – disinhibition leading to inappropriate behavior, possibly transmitted sexually to others

(Adapted from Wornell, 2014)

Module Three:
Dementia and Sexual Behaviors

(Image retrieved from blogs.cdc.gov)

Learning Objectives:

Upon completion of this module you will be able to:
-Distinguish between different types of sexual behavior
- Distinguish between inappropriate versus appropriate sexual behavior

Categorizing Sexual Behavior

Verbal

- Sexual comments towards staff, visitors or other residents
- Can include swearing

Physical linked to self

- Masturbating
- Disrobing/Exposure of genitals
- Touching

Physical linked to others

- Kissing and hugging exceeding normal affection
- Touching/grabbing/fondling of staff, visitors or other residents
- Attempted oral sex or intercourse with staff, visitors or other residents

(ILC, 2011)

Appropriate versus Inappropriate Sexual Behavior

Sexually inappropriate behaviors, although a fairly uncommon occurrence within long term care facilities, have been found to be most common amongst cognitively impaired residents (Kamel & Hajjar, 2003). Distinguishing inappropriate sexual behavior from appropriate sexual behavior can be a very challenging and complex process (Kamel & Hajjar).

Sexual behaviors often become labelled problematic when residents express their sexual desires or feelings in inappropriate places and inappropriate ways (Burke, Yaari, Tariot, Fleisher, Hall, & Brand, 2013; ILC, 2011). Just because a behavior is inappropriate does not mean that it is necessarily abnormal. Sometimes behavior which is interpreted by nursing staff as abnormal in nature, may hold a completely different meaning to the resident with dementia (Kamel, & Hajjar, 2003).

For example:

- Engaging in behavior such as masturbation in public places due to an unawareness of surroundings
- Mistaking another resident or staff member for a significant other and as a result try to engage in relations similar to that of a married couple
- Two residents lying together in the same bed. The intention may not necessarily be sexual in nature it may stem from the need for intimacy and reassurance created by fear of loneliness
- Activities such as undressing a resident prior to showering in their bedroom may be misinterpreted by the resident as being sexual in nature
- A resident who disrobes in a public area may be overheated or in pain
- A resident who unzips his pants in public may need to use the washroom

(Dementia Training Study Centers, 2013; Ehrenfeld et al, 1999; Kamel, & Hajjar, 2003; Kuhn, 1998).

Sexually Inappropriate behaviors may also be linked to:

- Disease factors
- Social factors
- Psychological factors
- Medications
- Illicit drugs or alcohol

(Stimson, 2011)

Case Study

During a movie night being held on the unit in the center lounge for the residents, Albert, a 73-year-old man with frontotemporal dementia, unzipped his pants and began masturbating during a romantic scene involving a couple holding hands. The other residents were shocked. One nurse snickered and called the resident a ‘dirty old man’ while another nurse told him his behavior was disgusting and to zip back up his pants. Albert as a result felt embarrassed and began to cry.

1. What do you think could be happening here?
2. How would you as a staff member respond in this situation?

Answers to Case Study:

1. The sexual behavior Albert is expressing in this scenario (removing his clothing and masturbating) is appropriate. Albert, was doing what felt good to him. It is the setting and context (center lounge) that is inappropriate.
2. Nursing staff should respond in a calm and non-judgmental manner and re-direct Albert by for example taking him to a private area such as his room.

Module Four:
Dementia and Relationships

(Image retrieved from www.pixabay.com)

Learning Objectives:

Upon completion of this module you will be able to:
-Describe the impact of dementia on pre-existing relationships
-Identify ways to support existing partners of residents and their families

Impact on Pre-Existing Relationships

> ***"Young love is about wanting to be happy. Old love is about wanting someone else to be happy."***
>
> **(Mary Pipher, psychologist)**

Changes in the brain associated with Dementia, may have a significant impact on the expression, form, and nature of sexual relationships between pre-existing couples. Some common problems include:

- Lack of regard of feelings for healthy partner
- Decreased sexual interest
- Increased sexual interest
- Inability to recognize healthy partner
- Awkward and inappropriate sexual demands

(ILC, 2011)

It's important to keep in mind that each relationship will be different. In some situations, individuals may have entered the nursing home as a couple in which one or both partner(s) may have dementia. In most situations however the partner with dementia resides in the nursing home while the partner without dementia remains home (ILC, 2011).

No matter what the situation there is no one more affected by the loss of what was then the healthy partner (Wornell, 2014). Some couples may wish to maintain a sexual and intimate relationship despite a diagnosis of dementia. Family and friends are often supportive of the continuation of such relationships. It is important that nursing staff also be supportive and acknowledge that the need for intimacy, love, and sexual expression does not go away just because a person has been diagnosed with dementia (ILC, 2011).

Nursing staff can help to support pre-existing relationships by:

- Including the sexual history of residents in care plans
- Allowing regular visits inside and outside the nursing home
- Providing privacy for couples through use of for example 'do not disturb signs'

- Maintaining open communication with the resident's partner and family

(ILC, 2011)

Educating existing partners and their families on the effects of dementia on sexuality will help increase their understanding and help them more readily adapt to the changes associated with the disease (Wornell, 2014).

> ***"Persons with dementia are capable of relationships of deep meaning, and they are humans of great value and purpose despite their cognitive changes"***
> ***(Advanced Gerontological Education, 2014, p 9)***

Forming of New Relationships

Perhaps one of the greatest challenges for families and nursing staff is when residents form new intimate relationships with other residents in the long-term care facility (ILC, 2011). However, just because a resident has dementia does not mean they are incapable of forming new intimate relationships.

The forming of new relationships often becomes problematic when one or both residents already have an existing partner not residing in the long-term care facility (ILC, 2011). The forming of new relationships can be very uncomfortable and emotionally painful for the existing partner and their families. Conflict may arise between family members in relation to the appropriateness and the necessity of the relationship (Kamel & Hajjar, 2003; Wiskerke & Manthorpe).

Things to consider:

- Have the family been informed of the new relationship?
- Does one or both resident(s) have a pre-existing partner residing outside of the long-term care facility?
- What are the family's views on the new relationship?

Integral to the forming of new relationships is the resident's capacity to consent to the relationship. If neither resident is deemed to be at risk physically or mentally as a result of the relationship, then ways to support the relationship should be considered (ILC, 2011). Module Five will discuss how to assess a resident's awareness of actions to determine whether a relationship between two residents should be supported to continue.

Important Note

If the relationship, whether new or pre-existing, involves intimacy of a sexual nature, healthcare workers need to monitor the relationship on an ongoing basis to ensure the resident with dementia has the capacity to consent to such relations (ILC, 2011).

Time to Reflect

Reflect on how past relationships have developed amongst residents on the unit you are currently working.

How did these relationships affect others on the unit?
How did you feel in relation to communicating the development of these relationships to the resident's family members?

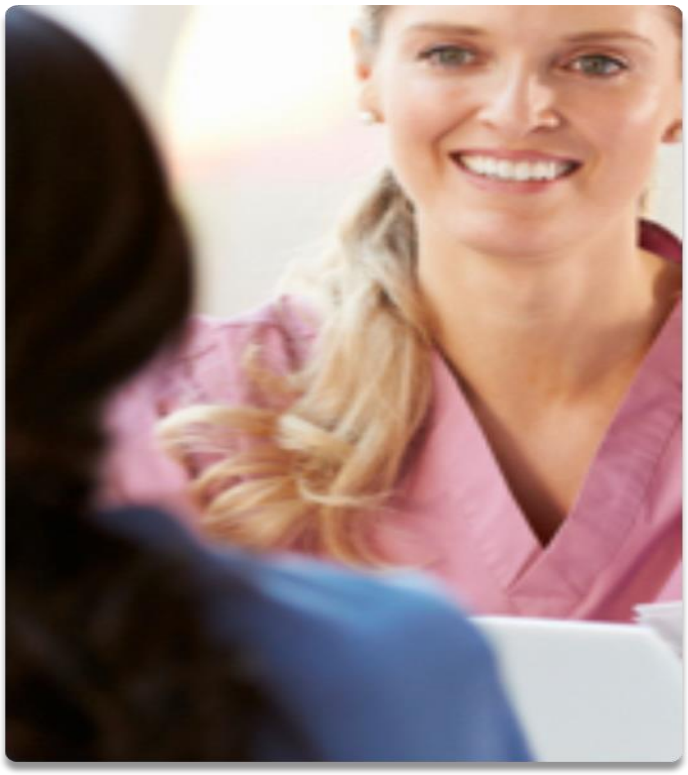
Case Study

John lives in a long-term care facility and was diagnosed with Alzheimer's disease. His wife of 20 years Mary took care of John at home for as long as she could, but the physical demands became too much for her. John and Mary had a very close and intimate relationship prior to John's admission and she visits him on a daily basis. The two enjoy spending quality time together in John's room. A nursing staff member on the unit noticed that during their visits they were unintentionally being disturbed by housekeeping and other members of the healthcare team going in and out of John's room on an ongoing basis.

1. What do you feel the nursing staff member can do to help facilitate and support John and Mary's relationship?

Answer to Case Study: To enhance the couple's quality of time together and provide for undisturbed privacy 'a do not disturb' sign can be given to John and Mary to hang on the door during their visits together. The use of 'do not disturb' signs have been found to be very effective in promoting privacy for couples in many long-term care facilities (ILC, 2011).

Module Five:
Responding to Sexual Behaviors in Residents with Dementia



(Image retrieved from niddk.nih.gov/healthinformation)

Learning Objectives:

Upon completion of this module you will be able to:

-Define person centered approach
-Identify the steps involved in assessing and evaluating sexual behaviors
- Describe interventions and strategies in responding to sexual expressions and sexual advances
-Identify potential sexual risks of vulnerable residents
-Identify signs of sexual abuse

Admission Assessment of Sexuality

Sexuality should be discussed just as commonly as any other aspect of health in residents with dementia. Assessment of sexuality should begin immediately upon admission into a long-term care facility (Hajjar and Kamel, 2003). Several sexuality assessment tools have been developed to help nurses in gathering background information on a resident's social and sexual history (see appendix D for an example of an admission sexual history tool).

Points to remember when asking about sexual history:

- Questions should be asked in a forthright, and dignified manner
- Questions should not be followed by an apology
- Use the word partner to avoid making assumptions about sexual orientation
- Respect reluctance of residents/families to disclose information
- Avoid being intrusive or asking questions that are unnecessary

(Hajjar and Kamel, 2003; Stimson, 2011)

Assessment of Sexual Behaviors

The first step in assessing sexual behaviors is determining whether the behavior is concerning. If the behavior is deemed to be of concern due to serious risk to self or others an immediate response is warranted (Dementia Training Study Centers, 2013).

In such a situation nursing staff, should respond by:

- Remaining calm. Refraining from showing signs of shock or embarrassment
- Being non-judgmental and try to maintain the resident's dignity. Do not reprimand or scold the resident.
- Providing reassurance to any family or other residents who are present
- Distracting and redirecting the resident to an alternate area if taking place in a public area

(Dementia Training Study Centers, 2013; ILC, 2011)

Following the incident an evaluation of the resident's sexual behavior should be conducted to determine the necessary or appropriate interventions that need to be put in place.

The evaluation should include:

1. An adequate description of the sexual behavior. Observations of individual(s), including resident(s), partner, family and/or staff, who witnessed the behavior should be confirmed and validated. The verbal and physical actions of the resident(s) should be documented along with any negative effects to the resident(s) and interventions completed by nursing staff (see appendix A for Sexual Behavior Assessment Part One and Two).
2. The degree of risk (see appendix B for Protocol for Responding to Sexual Behaviors between Residents with Dementia at the Agnes Pratt Home).
3. An assessment of awareness of actions of the resident(s) involved (see appendix C for Assessment of Awareness of Actions).
4. Gathering of information from family or sexual admission history if completed upon arrival to the facility that may help provide a better understanding of the resident(s) behavior. (see appendix D for Admission Sexual History tool).
5. A team meeting or care conference

(Lichtenburg, 1997; Lichtenburg & Strezpak, 1990; Steele, 2010)

Important Point
There is not an all or nothing approach, each resident is different and each situation is unique therefore assessment and evaluation should be individualized for each resident (Stimson, 2011).

Management of Sexually Inappropriate Behaviors

There is no drug currently licensed to treat problematic sexual behavior in residents with dementia (ILC, 2011). The recommended approach in the management of this type of behavior is non-pharmacological consisting of a person-centered behavior management approach (Alagiakrishnan et al, 2005;

ILC). A person-centered approach involves treating residents as "individuals regardless of their age and health status, adopting the point of view of the person with dementia and considering his/her unique needs and feelings (including sexuality and dementia) as the basis on which to provide as personalized care as possible" (Villar, Celdran, Faba & Serrat, 2013, p 404).

Examples of non-pharmacological approaches which can help in the management of inappropriate sexual behaviors include:

- Music Therapy
- Bringing for walks off the unit and outdoors
- Art Therapy
- Assigning manual tasks for example folding face cloths
- Providing residents with opportunities to stroke or touch by offering pet therapy or providing them with soft stuffed animals and fake fur
- Having beauty and cosmetic services available
- Encouraging hugging and kissing during family visitation
- Providing 'do not disturb' signs when spouses visit to allow for privacy
- Allowing for home visits

(Alagiakrishnan et al, 2005; Kamel & Hajjar, 2003; Stimson, 2011)

The most important way to manage inappropriate sexual behaviors is to be able to recognize and anticipate the behavior before it becomes problematic. For example, being able to identify antecedents or what triggers the behavior can allow for early intervention (The National Alzheimer Center of The Hebrew Home for the Aged at Riverdale, 2002).

Important Point

There are many ways in which sexually inappropriate behaviors can be managed; attention should be placed on the person not the behavior (Dementia Training Study Centre, 2013).

Assessment of New Relationships

One of the biggest ethical challenges pertaining to sexuality and dementia has to do with capacity and consent (Tarzia, Fetherstonhaugh, & Bauer, 2012). Due to impairments associated with dementia such as communication, understanding and reasoning, consent to engage in a relationship is often difficult to obtain and in some situations, cannot be assured (Villar, et al., 2013). Just because a resident has been deemed incompetent to make medical decisions does not mean that all task specific competency is diminished (Kuhn, 2002).

> ***"A resident may perform poorly on a mental status test but his or her preference for a special friend of lover may be quite evident." (Kuhn, 2002)***

How staff respond to the forming of new relationships between two residents is often influenced by the nature of the relationship. Holding hands or cuddling for example does not generally provoke a response. However, when the relationship appears to be sexual or becomes sexual in nature the risk and cognitive capacity of the resident(s) to engage in sexual behavior must be assessed (Dementia Training Study Centers, 2013) (see appendix C for example of Assessment of Awareness of Actions Tool).

In assessing a resident(s) awareness of actions and determining whether a relationship between two resident(s) should be supported to continue the following questions should be asked:

- Resident's Awareness of the Relationship
    1. Is the resident aware of who is initiating sexual contact?
    2. Does the resident believe that the other person is a spouse or partner?
    3. Are they aware of the others identity and intent?

4. Can the resident state what level of intimacy they would be comfortable with?

- Residents Ability to Avoid Exploitation
    1. Is the behavior consistent with formerly held beliefs/values?
    2. Does the resident have the capacity to say no (verbally or non-verbally) to any uninvited sexual contact?
- Resident's Awareness of Potential Risks
    1. Does the resident realize the relationship may be time limited?
    2. Can the resident describe how they will react when the relationship ends?

(Lichtenburg, 1997; Lichtenburg & Strezpak, 1990; Steele, 2007)

Sexual Abuse

Nursing staff have an obligation to maintain the dignity of residents while at the same time ensuring the protection of residents from neglect and abuse (Wornell, 2014).

Physical symptoms of sexual abuse

- Unexplained bruising or bleeding of the genital area, breasts, buttocks, or lower abdomen or thighs
- Genital trauma, trouble walking, and pain when sitting

Behavioral symptoms of sexual abuse

- Sudden onset of agitation when being changed
- Sudden onset of refusal to undress or be bathed
- Sudden onset of talking about sexual acts

(Dementia Training Study Centres, 2013; PEAK Centre on Aging, 2003; White, 2011)

If sexual abuse is suspected action should be taken immediately by nursing staff:

- Remove and protect resident from risk
- Support resident
- Notify management immediately and follow employing agency's protocol on suspected sexual abuse (see Appendix B for Protocol for

Responding to Sexual Behaviors between Residents with Dementia at the Agnes Pratt Home).

- Report to police if necessary

(Stimson, 2011).

Looking After Yourself

If you have witnessed or been subjected to inappropriate or aggressive sexual behavior you may feel upset, angry or emotional. It is important to seek reassurance and support from your coworkers and management team and openly discuss any feelings you may be experiencing. Make sure all inappropriate sexual behavior is reported and documented at all times (Dementia Training Study centers, 2014; Series & Degano, 2005).

Short Answer Questions

1. List five non-pharmacological approaches in managing inappropriate sexual behaviors.
2. When determining whether a relationship should be supported to continue, what three things should the nurse include in her assessment?
3. What are some of the behavioral and physical signs of sexual abuse?

Case Study One

During a recreation event in the center lounge with musical entertainment, John and Margaret who are off in the corner by themselves begin kissing and John begins fondling her breasts. Some of the other residents become upset. The staff member scolds John and Margaret for their behavior. As a result, John becomes angry and starts yelling disrupting the event and other residents.

1. Do you feel that the staff member responded appropriately to this situation?
2. How could the staff member have responded differently?
3. What do you feel could have triggered this resident's behavior?

Case Study Two

As nurse Anna is doing her 8pm routine surveillance check she finds Norah, a female resident with dementia lying on her bed naked with male resident, Billy, who also has dementia and is naked on the bed. Norah appears frightened and unaware of what is happening as Billy appears to be attempting to have sexual intercourse with her. Nurse Anna responds by screaming out for help and running into the room trying to separate the two residents. As a result, both residents become agitated. Norah bites nurse Anna on the hand and Billy picks up a chair and throws it at the wall.

1. Do you feel the staff member responded appropriately to this situation?
2. How could the staff member have responded differently?

3. What are the steps that should be followed when sexual abuse is suspected?

Answers to Short Answer Questions:

1.Music Therapy, bringing for walks off the unit and outdoors, art therapy, assigning manual tasks for example folding face cloths, providing residents with opportunities to stroke or touch by offering pet therapy or providing them with soft stuffed animals and fake fur, having beauty and cosmetic services available, encouraging hugging and kissing during family visitation, providing 'do not disturb' signs when spouses visit to allow for privacy, allowing for home visits.

2. Resident's Awareness of the Relationship, Residents Ability to Avoid Exploitation, Resident's Awareness of Potential Risks.

3. Physical symptoms of sexual abuse

- Unexplained bruising or bleeding of the genital area, breasts, buttocks, or lower abdomen or thighs
- Genital trauma, trouble walking, and pain when sitting

Behavioral symptoms of sexual abuse

- Sudden onset of agitation when being changed
- Sudden onset of refusal to undress or be bathed
- Sudden onset of talking about sexual acts

Answers to Case Study one:

1. The staff member should not have responded by scolding and criticizing John and Margaret for their behavior.

2.A. Remaining calm. Refraining from showing signs of shock or embarrassment, B. Being non-judgement and try to maintain the resident's dignity. Do not reprimand or scold the resident, C. Providing reassurance to any family or other residents who are present, and D. Distracting and redirecting the resident to an alternate area if taking place in a public area.

3.A possible trigger could have been the residents being off to themselves in the corner. Noticing this could have helped to prevent the behavior from occurring. Recognizing that dementia residents are more likely to become anxious and engage in inappropriate behavior due to lack of structure is important in preventing behaviors such as this from developing (The National Alzheimer Center of The Hebrew Home for the Aged At Riverdale, 2002). Paying attention to the resident's behavior could have alerted the staff

member to include John and Margaret in the activity preventing such behavior from occurring.

Answers to Case Study two:

1.The staff member should not have responded by screaming out and running into the room. This resulted in both residents becoming agitated and aggressive.

2. A. Remaining calm. Refraining from showing signs of shock or embarrassment, B. Being non-judgement and try to maintain the resident's dignity. Do not reprimand or scold the resident, C. Providing reassurance to any family or other residents who are present, and D. Distracting and redirecting the resident to an alternate area if taking place in a public area.

3. If sexual abuse is suspected action should be taken immediately by nursing staff:

- Remove and protect resident from risk
- Support resident
- Notify management immediately and follow employing agency's protocol on suspected sexual abuse (see appendix B for Protocol for Responding to Sexual Behaviors between Residents with Dementia at the Agnes Pratt Home).
- Report to police if necessary

If staff suspect that a resident had engaged in an unwelcomed sexual act, the following is a guideline developed by the APH on how to respond:

- Charge RN to be notified upon discovery of suspected incident and preliminary physical exam to be completed by RN immediately. LPN can be designated by RN to perform assessment if necessary.
- Assessment to be done for: presence/absence of semen/ bodily fluid / genital trauma / an erection, psychological state of all residents involved.
- Charge RN to notify RCM/CC as soon as possible. If no Manager available, RN to decide if can wait until following day to notify Manager, depending on severity and level of harm.
- The RN may decide to contact MD without consent from SDM if assessment indicates that further examination or treatment is required. If in doubt, determination to be made after discussion with SDM if MD should be consulted for further medical examination. Goal is to not make incident any more traumatic to resident(s) involved.

- SDM to be notified of suspected incident as soon as possible post examination. If alleged incident occurs during the night, Charge RN to determine if feasible to wait until following day to notify SDM, depending on level of risk and harm. When in doubt, notify family immediately.
- SW to complete a report in accordance with the Adult Protection Act.

Watch enclosed video – Freedom of sexual expression: Dementia and resident rights in long-term care facilities (2002).

Important Points

- Every individual, regardless of age, has a need for love, intimacy and companionship; this does not change as people grow older and is no different for individuals living with dementia (Hajjar & Kamel, 2003).

- Expression of sexuality is an important component of one's identity and is positively linked to overall physical, psychological and social well-being (Hajjar & Kamel, 2003; Ogden, 2001).

- It is important to recognize that not all residents with dementia are heterosexual (ILC, 2011).

- Healthcare providers are not immune to negative misconceptions and attitudes in relation to sexuality and dementia. It is therefore important that nursing staff take the time to evaluate their own personal attitudes and how they conflict or support with the resident's rights to sexual expression (Alzheimer's Association, 2015).

- Sexuality should be discussed just as commonly as any other aspect of health in residents with dementia. Assessment of sexuality should begin immediately upon admission into a long-term care facility (Hajjar and Kamel, 2003).

- Educating existing partners and their families on the effects of dementia on sexuality will help increase their understanding and help them more readily adapt to the changes associated with the disease (Wornell, 2014).

- Just because a behavior is inappropriate does not mean that it is necessarily abnormal. Sometimes behavior interpreted by nursing staff as abnormal in nature, may to the resident with dementia, hold a completely different meaning (Kamel, & Hajjar, 2003).

- There is not an all or nothing approach, each resident is different and each situation is unique therefore assessment and evaluation should be individualized for each resident (Stimson, 2011).

Additional Resources

Videos

A thousand tomorrows: intimacy, sexuality and Alzheimer's (1994). Chicago, IL: Terra Nova Films.

More than a thousand tomorrows. (2003). Chicago, IL: Terra Nova Films.

Educational Tools

Dementia Training Study Centres. (2013). Sexualities and Dementia: Education Resource for Health Professionals. Available at: http://web.dtsc.com.au/sexualities-dementia-resource/.

International Longevity Center. (2011). The last taboo: A guide to dementia, sexuality, intimacy and sexual behavior in care homes. Available at www.ilcuk.org.uk.

Steele, D. (1997). A best practice approach to intimacy and sexuality: A guide to practice and resource tools for assessment and documentation. PRC: Lanark, Leeds and Grenville Long Term Care Working Group.

Books

Wornell, D. (2014). Sexuality and Dementia: Compassionate and practical strategies for dealing with unexpected or inappropriate behaviors. New York, NY:.Demos Health.

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Appendix A

Sexual Assessment: Part One

Sexual Behaviourial Assessment: Part One

1. A description of the observed behaviour should be obtained, confirmed and validated with persons involved (resident(s), spouse/partner,...) if possible, and with cognizant witnesses: POAPC, family, visitors &/or staff witnessing the event. Objective documentation to include verbal and physical actions of resident(s), antecedents (possible triggers) to behaviour and consequences including evidence of injury, and interventions by staff. Apply the P.I.E.C.E.S. Assessment franmework:

Is this a change in behaviour?

Consider RISKS:
R: Roaming/Wandering:
I: Imminent Physical Danger: (frailty, falls, fire)
S: Suicidal ideation:
K: Kinship: harm to, or from resident
S: Substance use/misuse, self-neglect, safe driving, STIs:

What is the degree of risk? *See Classifications of Sexual Behaviour: Intimacy & Sexuality Resource Tool*
No anticipated risk_____ Low_____ Moderate_____High_____

Assessment: *(possible causes, antecedents, triggers, evidence of injury?)*
Physical: Disease, Drugs, Discomfort, Delirium, Disability & consider sensory loss, sleep disturbance, elimination, etc.., in addition to evidence of injury. Note bruising may not be evident for 4-24 hrs after incident.

Adapted from: Putting the PIECES Together, 2012

Sexual Behavior Assessment: Part Two

Sexual Behaviour Assessment: Part Two

1. Has an Admission Intimacy History been previously completed?
Yes___ No ___

If an Admission Intimacy History was not previously completed:

- Is there information the resident, spouse/partner, POAPC, or family member(s), could share about the resident's life story that may help staff understand certain behaviours? Siblings usually a better resource than children. e.g. past traumas of sexual nature, passivity

_____
_____
_____
_____
_____

2. What is the awareness of the resident involved? (complete Appendix C before proceeding)

_____
_____
_____

If the resident is mentally capable the POAPC/SDM & family are not to be involved unless at the request or consent of the resident.

3. Is there a POAPC /SDM who should be consulted/contacted about the behaviour/ incident? (See LTCH Act 2007 s23 (1) reg 97)
Person contacted:_____ Date/ time:_____
Response: _____
_____
_____
_____

4. Was a critical incident filed electronically with MoHLTC? Yes___ No___
Completed and sent by:_____
Were any recommendations/ actions received:

_____
_____
_____
Was the Director of MoHLTC contacted directly?_____

5. Do Police Services need to be contacted? Yes____ No____
(LTCH Act, 2007) reg 98 Police notification 98. Every licensee of a long-term care home shall ensure that the appropriate police force is immediately notified of any alleged, suspected or witnessed incident of abuse or neglect of a resident that the licensee suspects may constitute a criminal offence.

Adapted from: Putting the PIECES Together, 2012

Appendix B

Protocol for Responding to Sexual Behaviors between Residents with Dementia at the Agnes Pratt Home

Protocol for Responding to Sexual Behaviors between Residents with Dementia at the Agnes Pratt Home

Written by: Shawna Delaney-Martin, BN RN,
Resident Care Manager

February 2016

Introduction:

Human beings require companionship, affection and intimacy at all ages (Kuhn, 2002). People with dementia are no different in that many still have sexual urges and desires. However, dementia can alter the ways in which sexuality is expressed. This is largely due to the disinhibition and loss of executive cognitive function that often accompanies dementia. These sexual urges are often ignored, denied, and stigmatized (Heath, 2012). Despite the theoretical focus on sexual disinhibition, it is important to note that this affects only a minority of persons with dementia (Higgins et al, 2004; Subramani et al, 2011).
It is often difficult for caregivers, staff and families to remain non-judgmental in such cases. There is often conflict among staff in terms of their need to support a resident's right to sexual expression and their need to protect vulnerable residents. It raises many ethical, legal, and practical challenges and how we respond to it is dependent on many factors as every situation is unique. Staff often look for guidance on how to manage inappropriate sexual behaviors, or ISB. However, it is difficult to develop a comprehensive protocol to deal with all potential situations and there is little literature on the management of ISB and the few existing studies on the subject have limitations. Nonetheless, guidance can be extrapolated from other research on the pharmacological and non-pharmacological management of other behavioral and psychological symptoms of dementia (Joller et al, 2013).

Nursing Response: The Basics:

Essentially, staff must remain compassionate to all residents involved and remember that sexual expression is a normal behavior. It is critical that staff guide their response to the behavior from the perspective that every behavior of a cognitively impaired person is the result of an unmet need and that all human behavior is purposeful (Kitwood, 1997). When a person displays ISB, it is our responsibility as caregivers to find out the meaning behind it. It is also important to remember that not all residents are heterosexual. Staff must respond in a respectful and non-punitive manner and not make the person feel shameful or embarrassed when displaying ISB. Staff must also not breach confidentiality and must ensure that the resident's privacy and dignity are respected. Only team members within the circle of care should be informed of the behavior and the care plan as necessary. All assessments and interventions must be documented as per Eastern Health policy. A Focus note and CSRS to be completed by staff on discovery of suspected incident or unwelcomed sexual activity involved in consultation with Charge RN and/ or Manager (if available) as per Eastern Health Policy.

The following information must be clearly documented:

9. Exact date and time of the incident.
10. Residents involved (in each residents chart only).
11. Factual information of what was observed by staff member including, but not limited to, amount of clothing removed if any, actual physical act observed, psychological state of residents, location of incident, physical description of the residents location/position at time of incident, physical assessment findings.
12. Who was notified (RN / Manager / SDM) and when.
13. Nursing interventions implemented.
14. Strategies to reduce immediate risk.
15. Decision to notify MD or not with rationale.
16. Plan for follow up.

Documentation must be clear, concise and factual. Opinions and assumptions are not appropriate to be included in narrative notes. For example, statements such as "resident was observed crying or screaming 'get away from me'" is preferable to "resident appears fearful and traumatized" or resident "seems not herself today". Be careful of the choice of words. For example, it is not appropriate to write "Resident was a victim of sexual assault" if there is no evidence to support this as it carries with it many legal and inflammatory connotations.

The Nursing Care Plan and Kardex must be updated by the end of shift to include interventions and strategies implemented in response to the incident. These include, but are not limited to, the level of observation required, distraction techniques, and safety plan in place.

Determining Capacity to Consent

When two residents with dementia are mutually attracted to one another and form a new relationship many assume they are not capable of consenting to sexual activity. This may or may not be the case as a resident may perform poorly on a mental status test but their willingness to participate in a relationship may be quite evident. Consent between two residents can be implied and professionally acceptable when neither resident protests, even if cognitively impaired. They may protest verbally by saying "No" or by shouting or crying, or they may protest non-verbally by pushing someone away. Unfortunately, it is often difficult to determine if the persons involved have limited, partial or full capacity to make such decisions. An "all or nothing" approach to determining mental capacity is not useful. (Kuhn, 2002). Residents with dementia can be vulnerable to abuse if they are unable to refuse unwanted sexual advances or communicate their refusal. We as caregivers have a duty to protect those vulnerable residents and ensure their safety. While a resident may have a right to sexual expression, this must be balanced with the potential risks of harm for others.

So how do we determine whether or not a resident has the capacity to consent to sexual activity? Lichtenberg (1997) and Lichtenberg and Strzepek (1990) suggest the following considerations be made to determine capacity:

4. Are they aware of the relationship?
    - To what extent are the residents involved able make their own decisions?
    - Do they recognize the other resident with whom they have the relationship?
5. Are they able to express their wishes either verbally or non-verbally?
    - Can they say no to unwanted sexual contact?
    - Do they know what it means to be sexually active?
    - Are they able to express what level of sexual activity or behavior they are comfortable with?
6. Are they able to avoid exploitation?
    - How will they react if the relationship ends?
    - Are they aware of the potential risks?

An Interdisciplinary Conference including the family should be held to discuss the resident's capacity to consent and what is in their best interests. Not surprisingly, there is often disagreement between parties on their determination of capacity and how to proceed. A care plan must be developed to satisfy all parties yet focused on the best interests of the residents involved. However, if it is determined that the individual(s) lack capacity to consent, the Home has a duty to ensure they are protected from harm.

Assessment:

A thorough and accurate assessment of the behavior is required. This can be done through Dementia Observation Scale (DOS) Charting and discussion with ALL team members within the circle of Care. The following must be considered when assessing the behavior of concern:

8. Is the behavior mainly verbal or physical?
9. What is the meaning behind the behavior? For example….could it be a physical problem? UTI? Med Change? Or is it likely due Loneliness? Boredom? Grieving?
10. How frequently is it happening and when?
11. Is there potential for harm or injury, either physical or emotional?
12. What options are available to meet the resident's needs? (Distraction, therapy, privacy)

13. Are any family members available to consult with?
14. Is the behavior an actual problem? If so, to whom?

A thorough assessment will reveal if the ISB is actually problematic and only then can a determination be made if any intervention is necessary. For assessment purposes, the behavior should then be classified in one of five categories, depending on the level of risk involved.

These Levels are categorized as:

Level 1	Verbal sexual talk, flirting, use of sexually explicit language. Non aggressive, non-physical. Not upsetting to others. No risk of harm.
Level 2	Verbal sexual talk that is upsetting to others, but is easily redirected. Non-physical, Low level of risk.
Level 3	Physical Behaviors of Intimacy/Courtship –like behavior such as kissing, handholding, hugging, hugging, touching of others. It is consentual and there is low risk of harm. Mutual consent is implied by the behavior towards each other.
Level 4	Physical sexual behaviors that are self-directed (Masturbation) or directed at others (exposing oneself to others). May or may not be upsetting to others. Moderate risk of harm.
Level 5	Physical sexual behaviors directed towards others that are unwanted and causes distress. These are aggressive, repetitive sexual behaviors that are unwelcomed and rejected by others. High risk of harm.

Nursing Interventions:

Accordingly, the response to the ISB and the interventions implemented are dependent on the level of risk.

Level 1	• Staff are to respond professionally in a non-punitive manner and not engage in the discussion but rather redirect the discussion to a more socially appropriate context. • Remain calm and respectful.
Level 2	• Use same approach as above but a firmer approach and some additional distraction techniques may be required. • Identify triggers if any. • Goal is to reduce the triggers to reduce the frequency and severity of the behavior and reduce co-residents exposure if upset by the behavior.

Level 3	• Goal is to provide a socially appropriate context for a relationship of companionship. • Redirect socially inappropriate behavior in a non-punitive and respectful manner. • A discussion must be held with family to disclose the behavior and determine if any additional interventions or education is necessary. • Document all behavior and discussions with family and document any changes to the Care Plan.
Level 4	• Staff to observe vigilantly (Close, Cluster or Constant surveillance as per Eastern Health Policy) as per RN's discretion for any signs that the behavior is unwelcomed by others. • Families of all residents are to be notified by RN/Manager as appropriate. • Solutions formulated that allow the person privacy, dignity and opportunity to engage in more socially appropriate interactions. • Documentation is critical to communicate the behavior and solutions, update the Nursing Care Plan by the end of shift. • Dr. and NP should be notified as soon as possible at the discretion of the RN.
Level 5	• The goal is to protect the resident(s) from all unwelcome gestures that are upsetting to them. • Constant surveillance to be initiated until a more long-term solution is found or behavior subsides. • Safety plan/ Nursing Care Plan to be updated by end of shift. • Families are to be notified immediately (RN to use discretion) as per Eastern Health's Disclosure of adverse Events Policy. • Interdisciplinary Team Meeting (including the family) to be held ASAP to discuss treatment options, appropriateness of referral to Psycho-geriatrician, appropriateness of resident for unit. • CSRS report to be completed by end of shift.

If staff suspect that a resident had engaged in an unwelcomed sexual act, the following is a guideline of how to respond:

7. Charge RN to be notified upon discovery of suspected incident and preliminary physical exam to be completed by RN immediately. LPN can be designated by RN to perform assessment if necessary.
8. Assessment to be done for: presence/absence of semen/ bodily fluid / genital trauma / an erection, psychological state of all residents involved.
9. Charge RN to notify RCM/CC as soon as possible. If no Manager available, RN to decide if can wait until following day to notify Manager, depending on severity and level of harm.
10. The RN may decide to contact MD without consent from SDM if assessment indicates that further examination or treatment is required. If in doubt, determination to be made after discussion with SDM if MD should be consulted for further medical examination. Goal is to not make incident any more traumatic to resident(s) involved.
11. SDM to be notified of suspected incident as soon as possible post examination. If alleged incident occurs during the night, Charge RN to determine if feasible to wait until following day to notify SDM, depending on level of risk and harm. When in doubt, notify family immediately.
12. SW to complete a report in accordance with the Adult Protection Act.

It is important to remember that this protocol is only a *guideline* for use at the Agnes Pratt Home and not all recommendations will apply in all situations. A common sense, practical approach is to be used when managing these behaviors as there are no set rules and answers and each situation is unique. And as dementia is progressive, so must the plan of care in response to it. The goal is that this protocol will improve the levels of understanding and education and help nurses make practical decisions to balance the need for resident safety and protection with their need of sexual rights and expression.

Appendix C

Assessment of Awareness of Actions
Assessment of Awareness of Actions (Understanding & Appreciation):

Assessment of Awareness of Actions (Understanding & Appreciation):

Assessment of the sexual behaviour and identification of the terms under which the relationship between the two individuals/residents will be supported should also include a determination of the resident(s) awareness of actions: the ability to understand and appreciate, to participate in a relationship. Lichtenberg (1997) and Lichtenberg and Strzepak (1990) suggest that the following questions be asked to identify the conditions and circumstances to support a finding of capacity.

1. **Resident's Awareness of the Relationship:**
   a) Is the resident aware of who is initiating the sexual contact?
      Yes___ No___
      Comments:_____
   b) Does the resident believe that the other person is a spouse or partner?
      Yes___ No ___ Comments:_____
   c) Are they aware of the other's identity and intent? Yes___ No___
      Comments:_____
      _____
   d) Can the resident state what level of intimacy they would be comfortable with?
      Yes____ No___
      Comments:_____
      _____

2. **Resident's Ability to Avoid Exploitation:**
   a) Is the behaviour consistent with formerly held beliefs/ values?
      Yes___ No___
      Comments:_____
   b) Does the resident have the capacity to say no (verbally or non-verbally) to any uninvited sexual contact? Yes___ No____
      Comments:_____
      _____

3. **Resident's Awareness of Potential Risks:**
   a) Does the resident realize that this relationship may be time limited?
      Yes____ No____
      Comments:_____
   b) Can the resident describe how they will react when the relationship ends?
      Yes____ No____
      Comments:_____
      _____

Is the resident able to respond to questions adequately (verbally or non-verbally)?
_____

Completed by:_____ Date:_____ Time:_____

Adapated from:
Lichtenberg, P.A. (1997). Clinical perspectives on sexual issues in nursing homes. *Top Geriatric Rehabilitation*, 12, 1-10.
Lichtenberg, P., Strezpak, D. (1990). Assessments of institutionalized dementia patient's competencies to participate in intimate relationships. *Gerontologist*, 30(1), 117-120

Appendix D

Admission Sexual History

Admission Intimacy History:_____ _____

Current Marital Status		
Number of marriages or serious relationships:		
Is there current involvement in a relationship?	Yes	No
Do you anticipate your companion will feel comfortable visiting/spending time with you in this place of residence? If not, how could we improve on this?	Yes	No
How do you, the resident identify your sexual orientation: Heterosexual___ Bisexual____ Homosexual___ Lesbian ___ Gay___ Transsexual___ Transgender ___ No comment___		
Are you comfortable with giving/receiving showing affection? i.e. a soothing touch, a hug ...	Yes	No
Are you accustomed to sleeping alone in bed?	Yes	No
Have you noted any changes in behavior in the area of sexual expression or sexual health of which you feel our health care providers should be aware?	Yes	No
Are current behaviors consistent with formerly held beliefs and values?	Yes	No
Would you be comfortable providing a narrative, your life story, to help us know you, the resident better? (refer to LTCH's practice of collecting Life Story)	Yes	No
Any known history of abuse (mistreatment) or trauma: sexual, physical, emotional or verbal?	Yes	No
Any known history of sexually transmitted infections?	Yes	No

Information received from:_____ Date:_____

Completed by:_____

References:(Brown, 2004; Kamel, 2001;Kamel, 2003)

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