

Sexual Expression in Persons Living with Dementia and Impact on Person-centred Nursing in a Care Home Setting: A Phenomenological Inquiry



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AIMS OF THIS PRESENTATION



- To provide an overview on my PhD research.
- Discuss the key findings from this research.
- Present a new conceptual framework , the Sensuous Framework.
- Describe the relationship between sexual expression and the Sensuous Framework.
- Highlight the implications for practice, research and education.

WHAT DOES THE LITERATURE SAY?

- Older persons including persons living with dementia generally see intimate and sexual relationships as an important part of their life.
- A recent survey of a nationally representative sample of people aged 50-90+ (Lee and Tetley, 2017) found that men and women remain sexually active and sexually intimate into their 70s, 80s and 90s.
- More evidence and better person-centred caring experiences are needed to work out person-centred responses to sexual expression.
- Most of the literature regarding dementia and sexual expression is from long-term care settings and positions sexual expression as a behavioural and psychological symptom of dementia (BPSD).



RESEARCH QUESTION & AIMS

The research question guiding this study was:

“What is the meaning of sexual expression in persons living with dementia who live in a nursing home setting and how is sexual expression understood by the nurses providing care?”

The aims of this study were:

- To gain knowledge on the manifestation and meaning of sexual expression in people living with dementia in nursing home settings.
- To explore how sexual expression in persons living with dementia is understood by nurses working in the nursing home.
- To explore the relationship between sensuousness and sexual expression.

PHILOSOPHICAL UNDERPINNINGS

Being

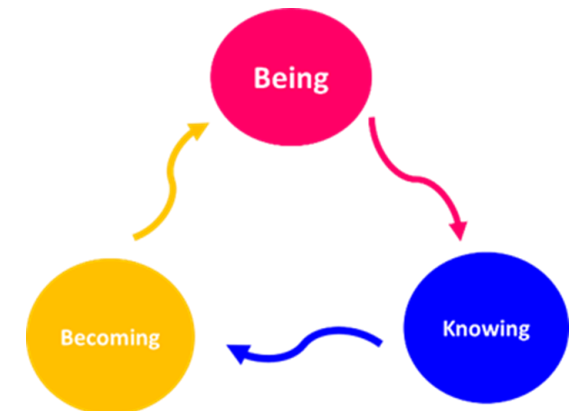
- The body is fundamental in our existence; the body is a subject – not an object.
- Persons are embodied beings within the world.
- Our perception, emotions, senses and desires are crucial to our human existence.

Knowing

- Knowledge is gained through our bodies and our interactions with the world and others in the world.
- Emotions, senses and desires are fundamental to gaining meaning.
- There is no single truth and person's life experiences, and perceptions are highly valued.

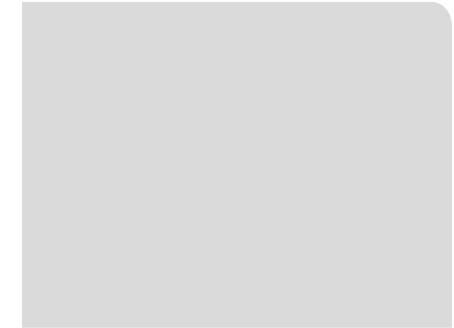
Becoming

- Persons are in a constant mode of becoming.
- Learning, intention and action originate from our emotions, senses and desires as they provide us with feelings, sensations and pleasures respectively.

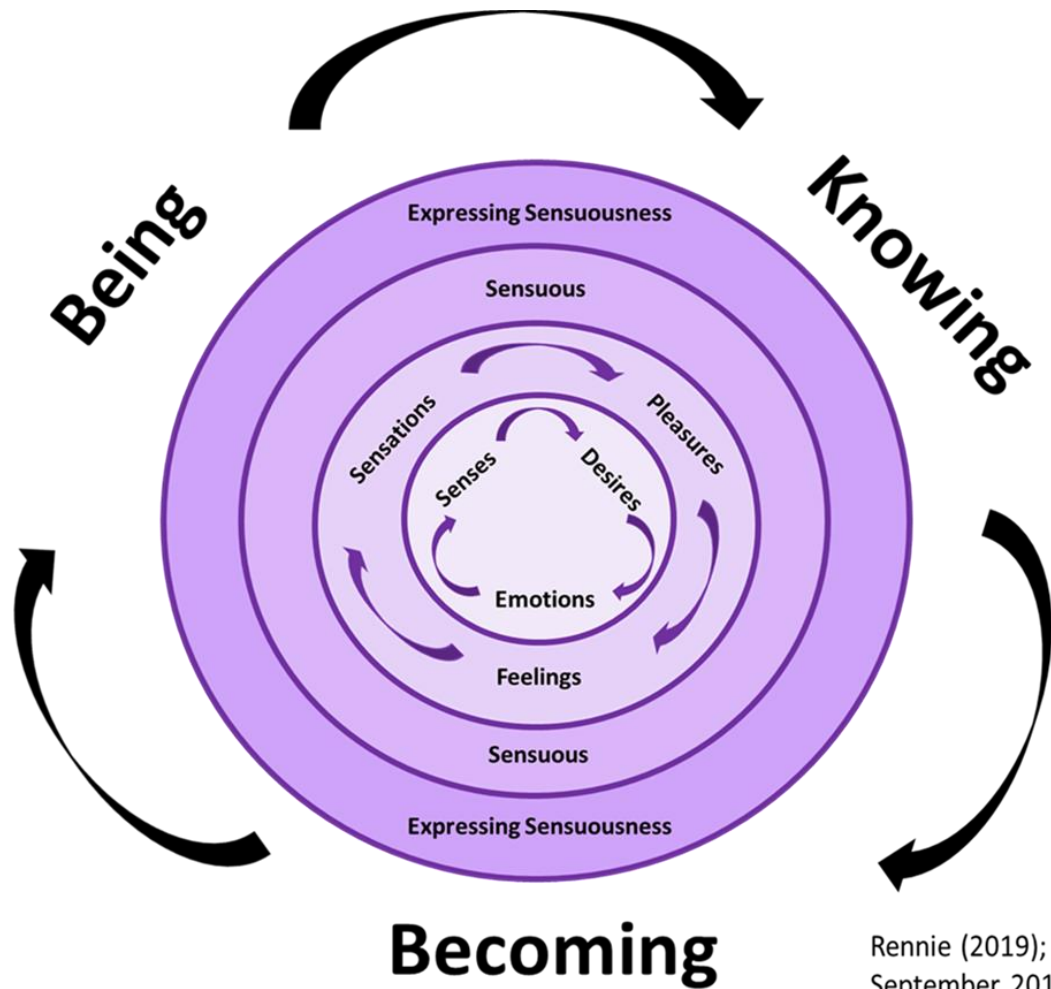


BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA MODEL

“BPSD are an integral part of the disease process and present severe problems to patients, their families and caregivers, and society at large” and “BPSD are treatable and generally respond better to therapy than other symptoms or syndromes of dementia”
(IPA 2015)



THEORETICAL FRAMEWORK



Sensuousness is our expression of our sensuous capabilities. The way I am defining 'sensuous' is:

"Our ability to bodily experience, our emotions, senses and/or desires through our feelings, sensations and/or pleasures respectively."

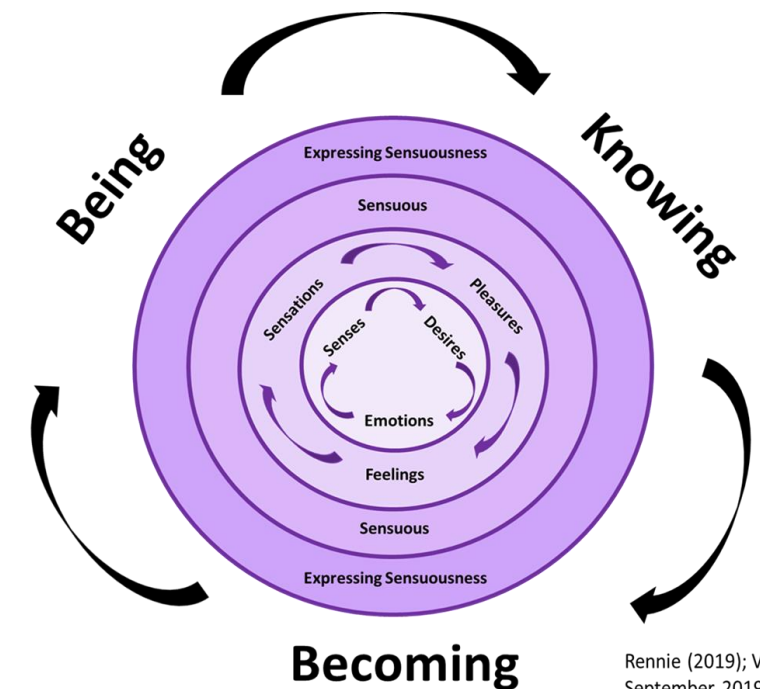
The way I am defining 'sensuousness' is:

"The gratification and/or expression of our emotions, senses and/or desires"

Rennie (2019); Version :
September 2019

SENSUOUSNESS

- What this definition of sensuousness achieves is that it incorporates all emotions, senses and desires and how our body reacts to those feelings, sensations and pleasures.
- In addition, reframing of sexual expression to sensuousness will encourage development of a new framework to be constructed in which bodily expressions is viewed as a form of general communication and a way of expressing emotions and feelings, and enable the focus to be more on understanding what the communication is about and how to best respond to it.
- By viewing sexual expression through the lens of sensuousness, is to highlight that one gesture, movement or act can have multiple meanings and is very context-bound.



A SENSUOUS METHODOLOGY

- The researcher – participant is subjective, interactive and interdependent. (Person-centred and participatory)
- Participants will be included in the research as far as possible and will be given free choice (Person-centred and participatory)
- The four existentials (corporeality, relationality, spatiality and temporality) will be used as guides for discovery and reflecting on human experience (existential phenomenology)
- Embodiment and emotions will be highly valued throughout the research (existential phenomenology/Sensuousness).
- Researcher is aware and explicit in particular how own views (prejudices) can influence the research process and interpretations of text, but will not attempt to bracket them. Rather the researcher will engage in reflectivity and reflexivity throughout in order to bring together the perspectives of others and self (Person-centred and participatory/Existential Phenomenology).
- The researcher will pay close attention to senses, emotions and desires throughout this research (Sensuousness).
- Researcher uses own knowledge, senses, emotions, intuitions and imagination to understand nuances embedded in text (Existential phenomenology/Sensuousness).



SETTING & PARTICIPANTS

- **Setting:** A Nursing Home in Scotland
- **Participants:**
 - Eleven members of the Nursing Team: Valerie, Katie, Susan, Helen, David, Catherine, Emily, Liz, Mark and Erin.
 - Four Persons Living with Dementia: Frank, Steve, Ella & Archie

RECRUITMENT, CONSENT & RELATIONSHIPS

- Participants were included in the research as far as possible and given free choice.
- Process consent methods was used for persons living with dementia.
- Researcher was an honorary staff member and 'worked' in the home throughout the duration of the relationships.
- Time was spent with every participant prior to data collection.
- A research plan was created with the residents living with dementia prior to recorded conversations.

SENSUOUS KNOWING: CAPTURING EXPERIENCES OF SEXUAL EXPRESSION & INTERACTING WITH THE DATA

- Conversational interviews with both persons living with dementia and the nursing team participants.
- Participant observation with the nursing team.
- Radical reflection and reflexivity.
- Existential Analysis and Writing in the dark to discover essences and hidden meanings.

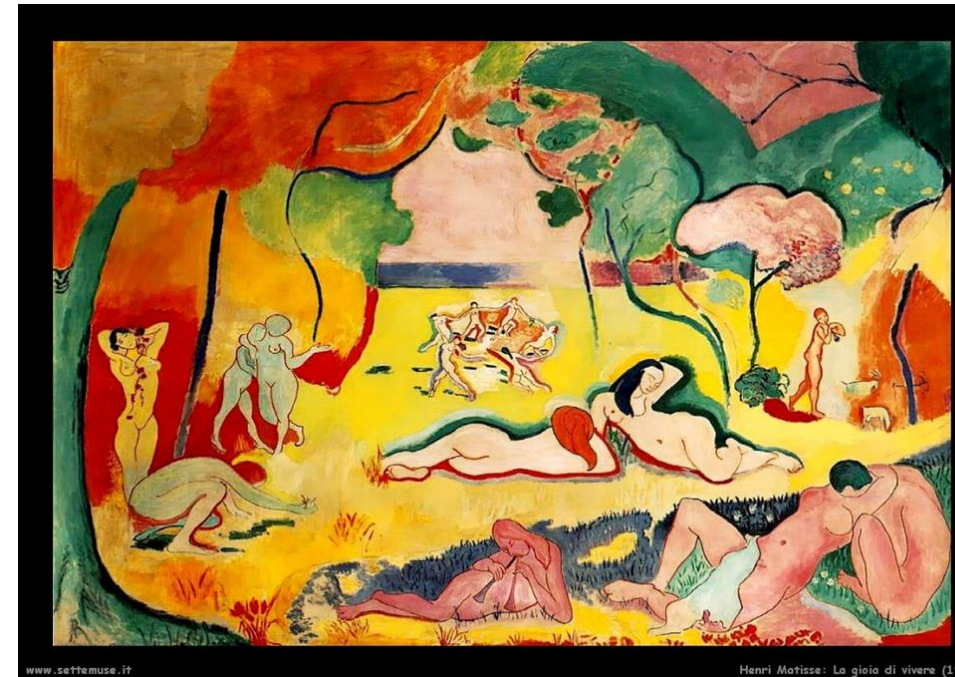


Summary of Implications

Practice	Research	Education
<ul style="list-style-type: none"> • A need to embrace a new understanding of sexual expression in persons living with dementia that embraces emotions, desires and senses. • Acceptance and acknowledgment that older people with dementia have a need for intimacy, love and sexual expression. • A need to include more persons living with dementia in discussions around sexual expression and intimate relationships. • A need to support and mentor nursing and care staff in becoming confident practitioners regarding sexual expression and intimacy needs. • Practice development methods to develop person-centred care practices regarding sexual expression for nursing homes. • Promoting a culture of acceptance, dignity and privacy for all residents is important for supporting sexual expression. 	<ul style="list-style-type: none"> • A need for more research on sexual expression which is inclusive of persons living with dementia. • Further use of the Sensuous methodology which has explores the lived experiences of sexual expression in a person-centred way and considers the sensuous knowledge of all participants and the researcher. • A need for further research using rigorous and person-centred methods to explore with is regarded as sensitive topics with persons living with dementia who have an Adults with Incapacity (AWI) certificate. • An exploration of sexual expression in acute care settings and how nurses experience this phenomenon in hospital. • Future research exploring sexual expression and diversity, e.g. how sexual expression is perceived in various ethnic cultures and LGBTQ+ communities. 	<ul style="list-style-type: none"> • Education and awareness-raising for nurses and care workers in nursing homes on sexual expression for persons living with dementia. • Increased educational discussions and material about older age sexuality in general. • More attention paid to sexuality and wellbeing in undergraduate and post-graduate nursing programmes.

CONCLUDING REMARKS

- Sexual expression is an embodied manifestation in which a person living with dementia expresses their desire for sexual intimacy, meaningful human relationships, and their femininity or masculinity.
- Sexual expression is connected with feelings of love, closeness and intimacy.
- Nurses experience discomfort and uncertainty with sexual expression.
- There is need for new embodied understandings when it comes to sexual expression in persons living with dementia.
- More research and practice development work is needed to ensure older persons living with dementia can express their sexuality when residing in a nursing/care home.



THE ESSENCE OF SEXUAL EXPRESSION AS EXPERIENCED BY THE NURSING TEAM

- A challenging aspect of dementia care giving which evokes feelings of embarrassment, uncomfortableness and/or shock.
- Uncertainty on how to be person-centred and what is the right thing to do.
- A dynamic spectrum of various expressions, with some being acceptable and others unacceptable.
- Considered as a private aspect of a person's life.
- A human desire which is not associated with older persons living with dementia.
- A quality of life which is forgotten about or not considered important.
- Easier to ignore, use distraction techniques or approach with humour.
- Desexualisation of the aging body.
- Unsure of any meaning behind the expression and how the person is feeling.
- Anxiety around the perspectives and opinions of families/legal representatives.

THE ESSENCE OF SEXUAL EXPRESSION FOR PERSONS LIVING WITH DEMENTIA

- A desire to be physically close to another and for sexual touch.
- A need for intimacy and human connection.
- Experiencing pleasurable sensations through a more sensitive aging body.
- A deep sense of feeling loved, special and experiencing happiness.
- Reminiscing about meaningful relationships, both past and present.
- An element of a person's femininity or masculinity.
- Insufficient time, space, and privacy in a nursing home environment.
- An enjoyable topic to speak about and rekindle memories.
- Using humour as a way of making a serious subject light-hearted.

Persons Living with Dementia

The **phenomenon of sexual expression in persons living with dementia:**

An embodied manifestation in which a person living with dementia expresses their desire for sexual intimacy, meaningful human relationships, and their femininity or masculinity.

The Nursing Team

The **phenomenon of sexual expression in persons living with dementia as experienced by nurses:**

A dynamic spectrum of various acceptable and unacceptable expressions, the meaning of which is unknown, and includes perceiving the ageing body as desexualised.

Persons Living with Dementia

The lived experience of sexual expression in persons living with dementia:

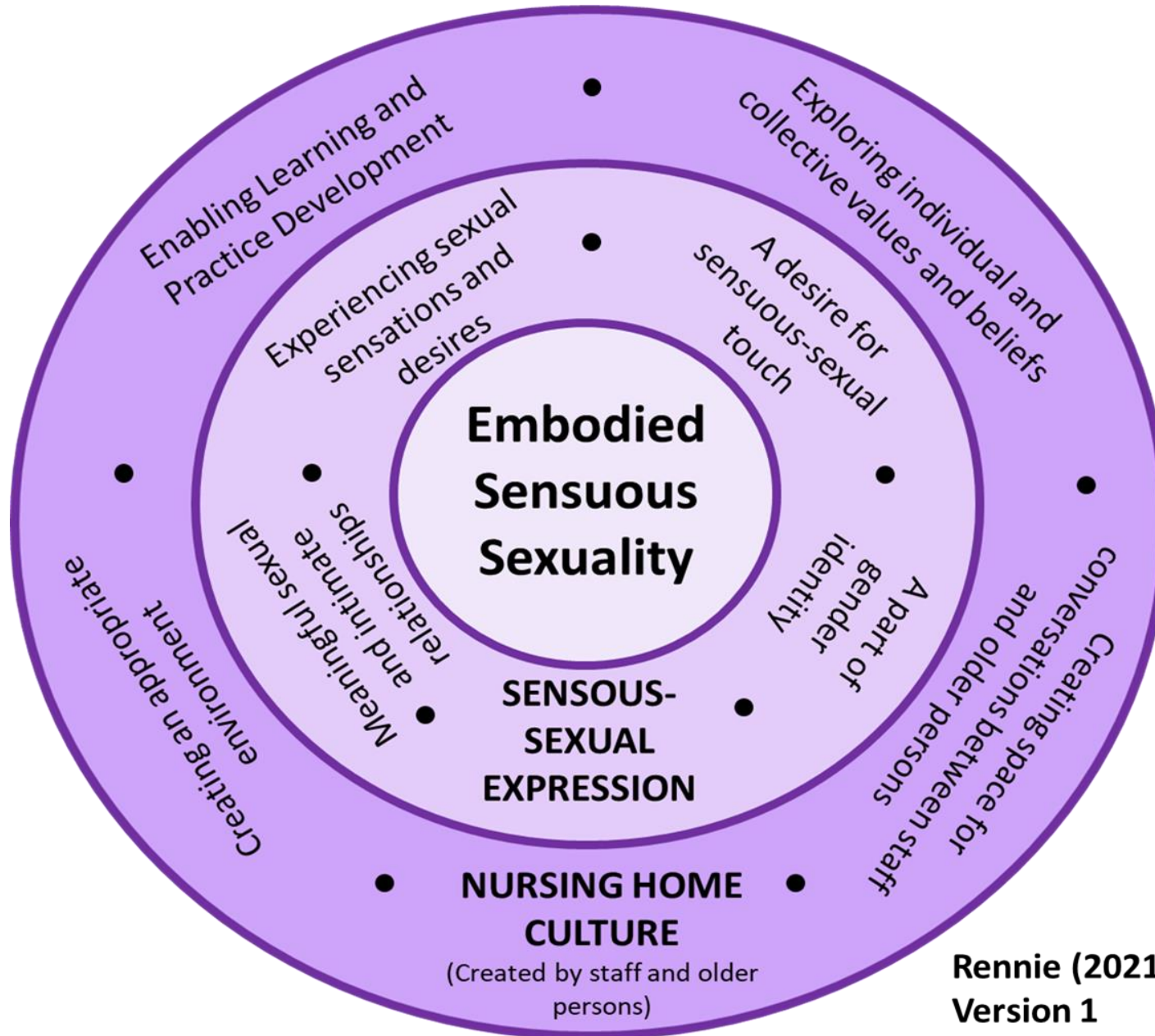
A pleasurable part of life with feelings of being loved, reminiscing about and/or grieving for previous and present sexual relationships, but difficult to express within the context of a nursing home.

The Nursing Team

The lived experience of sexual expression in persons living with dementia as experienced by nurses:

A challenging and uncertain element of dementia care, which is often forgotten about, evokes feelings of discomfort and anxiety, and is easier to ignore or respond using distraction or humour.

The Sensuous-Sexual Expression Framework



**Rennie (2021);
Version 1**

A woman with blonde hair is sitting on a sofa, smiling and holding a small dog. She is wearing a light-colored, patterned top. To her left is a lamp with a white shade and a dark base. On the wall behind her is a framed picture. The scene is dimly lit, suggesting an evening or indoor setting with artificial light.

THANK YOU

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