Sexuality and Intimacy in Palliative Care:
Anna Catania
From lover to carer?

‘You know my wife used to kiss me on the lips, then she kissed me on the forehead, then she patted my shoulder, and this morning when she left, she wiggled my toes...’

(Hospice patient: Toombs, 2008)
What is Sexuality?

‘A central aspect of being human throughout life...

- Sex
- Gender identities and roles
- Sexual orientation
- Eroticism, pleasure, intimacy
- Reproduction

(WHO, 2010)
Sexuality is experienced and expressed...

- Thoughts, fantasies
- Desires, beliefs, attitudes, values
- Behaviours, practices
- Roles and relationships

(WHO, 2010)
Intimacy and terminal illness...

Intimate expression can be vital at the end of life, when relationships with loved ones are time-limited.

(Reisman & Gianotten, 2017; Morrissey Stahl et al., 2018)
Experiences of sexuality and intimacy in terminal illness: A phenomenological study

Bridget Taylor

Abstract
Background: There is a paucity of research considering sexuality and intimacy in palliative care. It is therefore unclear whether palliative care professionals have a role in addressing these issues with patients and their partners.

Aim: To understand people's experiences of sexuality and intimacy when living with a terminal illness.

Design: A Heideggerian hermeneutic (interpretive) phenomenological study was undertaken. Data were collected using one-to-one conversational interviews. An iterative approach to analysing the narratives was used to reveal shared meanings.

Setting/participants: A total of 27 patients and 14 partners of patients with either cancer or motor neuron disease were recruited from outpatient, community and hospice inpatient units. All participants were aware that the illness was life-limiting.

Findings: When someone is living with a life-limiting illness, their coupled relationship is also dying. In their being-towards-death-of-the-couple, patients and partners of patients with motor neuron disease and terminal cancer experienced connecting and disconnecting within their coupled relationship. Becoming-apart-as-a-couple was experienced as loss of spontaneity, as lack of reciprocity and as rejection. This was influenced by a range of factors including medical treatments, disfigurement and the disabling effects of equipment. Some participants experienced re-connecting through becoming-closer-as-a-couple, although this was not always sustained.

Conclusions: This study sheds new light on people's experiences of sexuality and intimacy when living with a terminal illness. The ethos of holistic care requires palliative care professionals to provide opportunities for patients and their partners to discuss any concerns they might have about their coupled relationship and to understand the meanings symptoms have for them.

Keywords
Communication About Sexuality in Advanced Illness Aligns With a Palliative Care Approach to Patient-Centered Care

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Abstract Treatment-related sexual complications are common in cancer patients although rarely discussed in the palliative care setting. Sexuality is an important survivorship issue and remains relevant even in the terminal setting. There are multiple barriers in dialogueing about intimacy and sexual functioning from the patient and provider perspectives. Palliative care providers, while not expected to be sexual health experts, can provide comprehensive patient-centered care by including sexual health as part of their evaluation. They can explore how sexual dysfunction can impact coping, and utilize an interdisciplinary approach to manage symptoms.

Introduction

Two topics most health-care providers often tend to avoid discussing with their patients and families, let alone discussing the intersection of the two, include sexuality and death. Advanced illness such as cancer and the complications of treatment can create significant disruptions in sexual functioning on all levels including the biological, psychological, and social [1]. Despite the well-documented prevalence of treatment-related sexual complications such as decreased libido, vaginal atrophy, dyspareunia, and erectile dysfunction [2],
Double taboo!?

How comfortable are we to discuss: Death and Sex?

(Leung, Goldfarb & Dizon, 2016; Cagle & Bolte, 2009)
Our level of comfort...

Attitudes

Beliefs

Knowledge

(Katz, 2017; Benoot et al., 2018)
Ageism...

Assume that old people do not have sex or do not need any form of intimate touch (Gullette, 2011)
Narrow definition of sexual expression...

Focusing on intercourse and sexual performance

(Nyatanga, 2012)
Failure to address sexual issues...

- Discomfort/Shame - discussing sexuality and intimacy...

- Fear of embarrassing patients and relatives...
  
  (Saunamaki & Engstrom, 2014)
Over coming barriers...

Non-judgmental attitude (Leung, Goldfarb & Dizon, 2016)

Do not focus on the illness but on the person/couple (Blagbrough, 2010)

Be aware of our own attitudes and beliefs
Assessment sheets

Address sexuality and intimacy?

Heteronormative?

Core competence (NHPCO, 2001)
Assessment of needs:
Biopsychosocial model

Physical hurdles

- Pain
- Scarring
- Decrease mobility
- Shortness of breath
Psychosocial issues:

- Body image/sexual identity
- Cultural/ethnic background
  
  (Cagle&Bolte, 2009)
- Religious beliefs
- Anxiety/Depression
Couple attachment...

• Enormous amount of emotional stress on the couple
  (Tie & Poulsen, 2013)

• Anger, depression, guilt, anxiety

• Distress – criticism, resentment, partner burnout, lack of intimacy

• Romantic relationship dying a death similar to the physical one
  (Taylor, 2014)
• Threat to attachment bond

• Emotional withdrawal

• Partner inaccessible and unresponsive

• Feeling of rejection

• Circular causality

  (Tie & Poulsen, 2013)
PLISSIT Model
(Developed by Jack Annan)

P - Permission
L - Limited Information
S - Specific Suggestions
I - Intensive Therapy
T - More Training Needed

More Complex

www.westland.academy
Open discussion:

• Help to understand what is happening

• Changes in relationship

• Re-connection with partner

• Emotional intimacy/Sense of belonging

(Taylor, 2014)
Sexuality and intimacy...

• Timing of analgesia
  (Leung, Goldfarb & Dizon, 2016)

• Time of day – to combat fatigue

• Using bronchodilator and inhaler (shortness of breath)
Sexuality and intimacy...

- Giving information about alternative positions for sexual activity
- Awareness of barriers (Incontinence/the presence of an indwelling catheter)
- Loss of control and dignity
Affectionate touch...

Re-negotiating sexual/emotional intimacy
(Gilbert, Ussher & Perz, 2010)

Different not worse

Grieve for loss of previous love life
Affectionate touch...

Life-long basic need:
• Family, friends, health care professionals
Therapeutic touch...

Alternative therapies

(Tabatabaee et al. 2016)
Importance of cleanliness...

• Cleanliness: teeth, nails, hair, clothes

• Participate in routine care of patient (Tabatabaee, 2016)

• Helping adapt to changes caused by the disease (De Vocht, 2017)
A Practitioner’s Guide to End-of-Life Intimacy: Suggestions for Conceptualization and Intervention in Palliative Care

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Abstract
Sexuality and intimacy, including contact, tenderness, and love, are important at every life stage. Intimate expression is especially vital at the end of life, when relationships with loved ones are time limited. Unfortunately, care providers often ignore the potential need for sexual expression, especially at the end of life. In this article, we consider current research on sexuality and end-of-life care and situate these two fields in an ecological framework. We explore how end-of-life sexuality and intimacy can be supported by practitioners in multiple nested contexts and provide suggestions for theoretically-driven interventions. We also provide reflexive considerations for practitioners.

Keywords
caregivers/caregiving, hospice, palliative care, intimacy, sexuality, ecological systems theory
Location, location, location...

- Lack of privacy:
- Hospital/Hospice setting
- At home  
  (Katz, 2017)
Importance of privacy...

- Close door
- Do not disturb
- Given permission to lie down near patient (Benoot et al., 2018)
The final goodbye...

- Need to detach and distance oneself...

- Give permission to let go when the loved one is during their final moments

Your Wings Were Ready But My Heart Was Not
‘We were holding hands. Then the nurse came in and said ‘Maybe you better let go of his hands...it might be easier for him to go...but you can’t, can you? Well, we let go of him put his hands by his body and then very soon he passed away...’

(De Vocht et al., 2011)
References:


References:


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