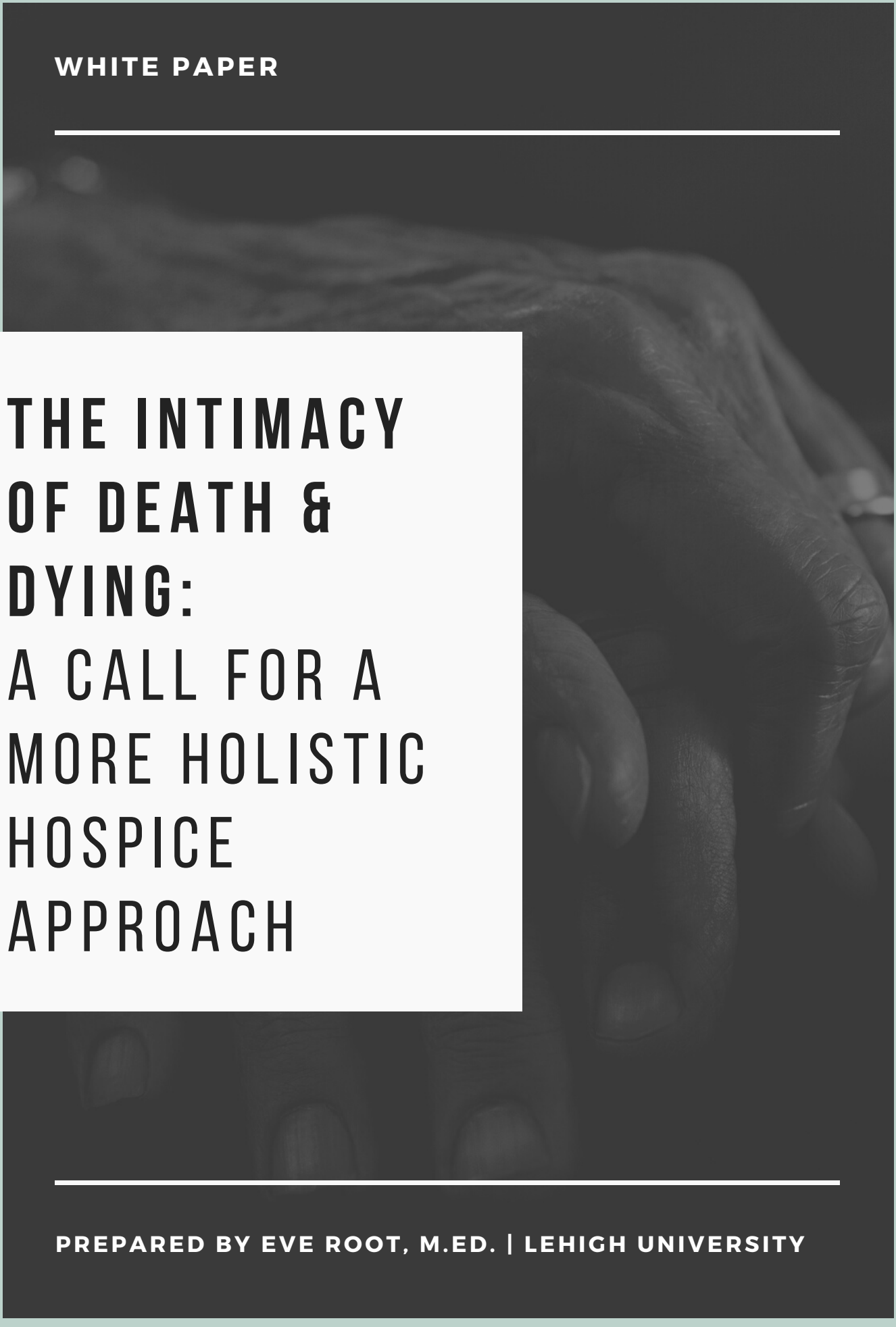
WHITE PAPER



THE INTIMACY OF DEATH & DYING:
A CALL FOR A MORE HOLISTIC HOSPICE APPROACH

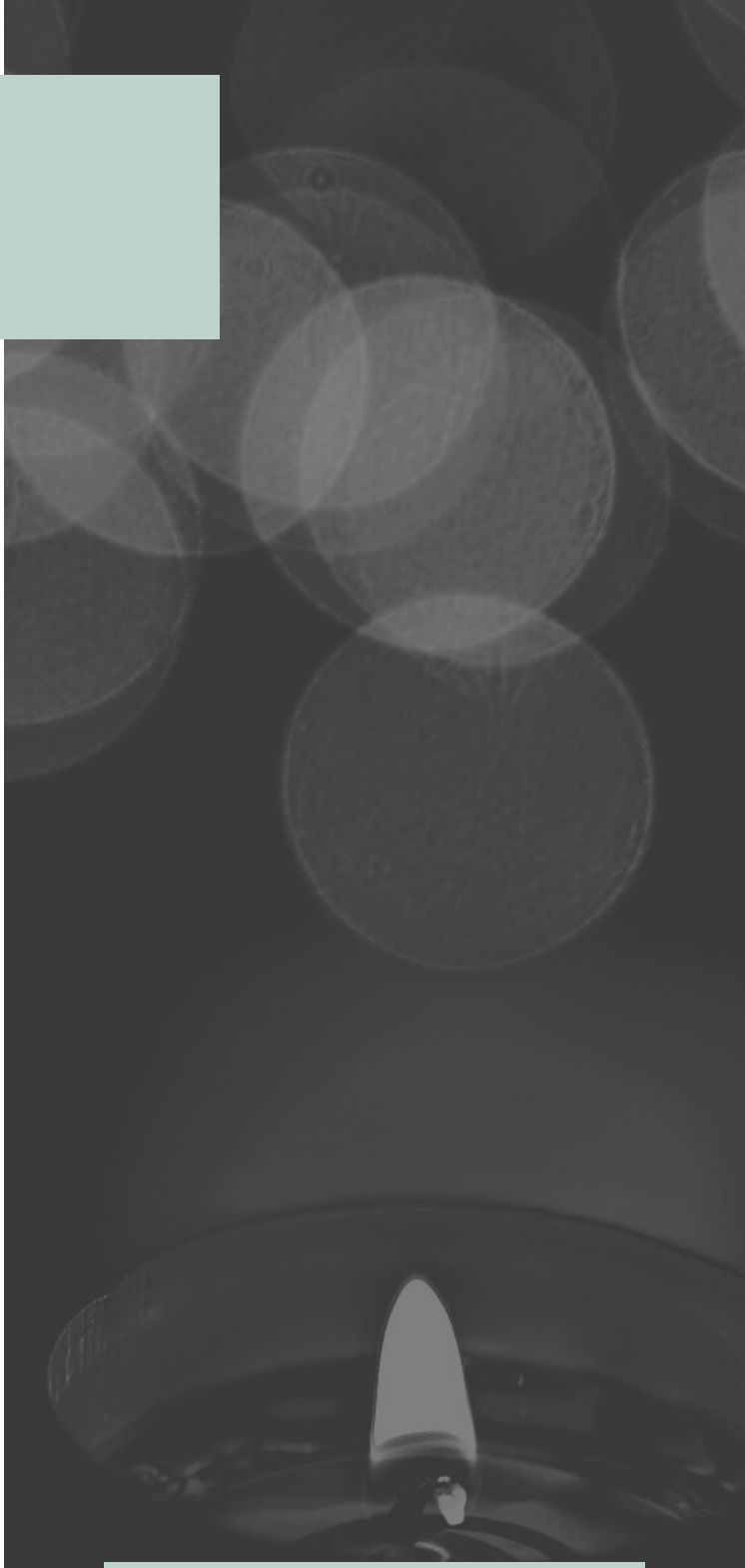
PREPARED BY EVE ROOT, M.ED. | LEHIGH UNIVERSITY

INTRODUCTION

Sex and death are both innately human experiences, so why is it so taboo to talk about them?

As professionals providing end-of-life care, many of us have started to challenge our own stigmas around death and dying, but sex and intimacy are too often forgotten as part of our practice.

As care providers, our shared goal is to improve the quality of life for our patients. Research shows that sex and intimacy can have a profound impact on the quality of life for individuals at all stages, including end-of-life. Unfortunately, many professionals assume our patients are not interested in engaging in intimate or sexual experiences on hospice or other facilities providing end-of-life care. This paper is here to challenge that assumption, help us begin a conversation about sexuality and intimacy as it relates to our care, and provide resources to inform our practice.



CREATED FOR PROFESSIONALS PROVIDING END-OF-LIFE CARE.

(E.G., NURSES, PSYCHOLOGISTS, CHAPLAINS, PHYSICIANS, SOCIAL WORKERS)

HOW TO USE THIS RESOURCE

If you're reading this, you're likely a professional working on a hospice unit or another long-term care facility where you help patients with life-threatening illness live and die with dignity. You might be a nurse, a chaplain, a psychologist, a social worker, a physician, or another wonderful employee dedicated to improving the quality of life for your patients. **This resource is for you!**

This resource is set up through an interdisciplinary lens because sex and intimacy impact a variety of aspects of our patient's well-being including their physical, psychological, and spiritual health.

Although we may not name it as intimacy, we see intimacy used in our care on a daily basis. Intimacy can be a hand on the shoulder during rounds by a physician, a nurse's gentle touch when providing care, or a chaplain holding hands while meeting spiritual needs. But we still might be missing a larger piece of the puzzle, particularly that of intimacy as it relates to sexual expression and desire.

This process includes **expanding** what we mean when we say intimacy and quality of life. Challenging us and our patients to consider what sexual expression is and what it can look like for diverse patients who we care for.

PSST...BEFORE YOU GO ON

Reading this might feel uncomfortable, and that's ok (and very *normal*!) Our own feelings around sex and intimacy can impact our care, so it's important to consider what might be coming up for you as you continue through this paper. This discomfort might include your own ideas of sex & sexuality, or perhaps uncover some cultural stigma and *myths* you may have internalized like "sex is only for young and healthy people". The first step is considering these factors and how they make you feel. Next try to consider how this might impact your work with patients. If you made it this far into the resource, *you've already started!*

QUESTIONS TO CONSIDER TO INCREASE EMPATHY

- IS SEX AND INTIMACY IMPORTANT TO YOU TODAY?
- HOW DOES CULTURE IMPACT YOUR OWN RELATIONSHIP TO SEX AND INTIMACY?
- DO YOU THINK YOU MIGHT STILL FIND THIS IMPORTANT AS YOU AGE OR FACE ILLNESS?

DEFINE IN ORDER TO PROVIDE

BEFORE WE GO ON DISCUSSING HOW TO IMPLEMENT A MORE HOLISTIC APPROACH TO CARE THAT INCLUDES SEX, SEXUALITY, AND INTIMACY, LET'S TAKE A MOMENT AND DEFINE SOME TERMS YOU MIGHT SEE THROUGHOUT THE RESOURCE.

DEFINITIONS MAY VARY BASED ON PROFESSION OR RESOURCE. BELOW THESE TERMS WERE DEFINED USING APA (2021) DICTIONARY OF PSYCHOLOGY

INTIMACY

Interpersonal state of extreme emotional closeness. Intimacy characterizes close, familiar, and usually affectionate or loving personal relationships and requires the parties to have a detailed knowledge or deep understanding of each other.

SEXUALITY

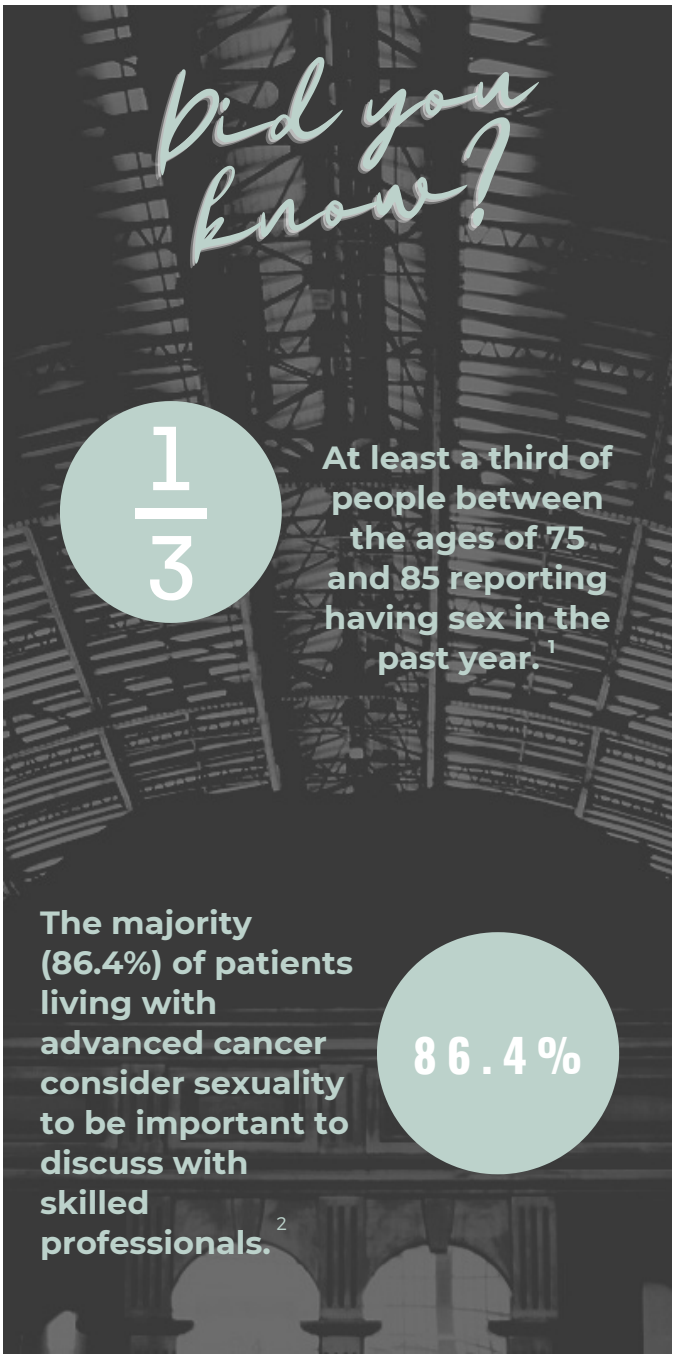
1. Capacity to derive pleasure from various forms of sexual activity and behavior, particularly from sexual intercourse. 2. All aspects of sexual behavior, including gender identity, orientation, attitudes, and activity.

SEXUAL DESIRE

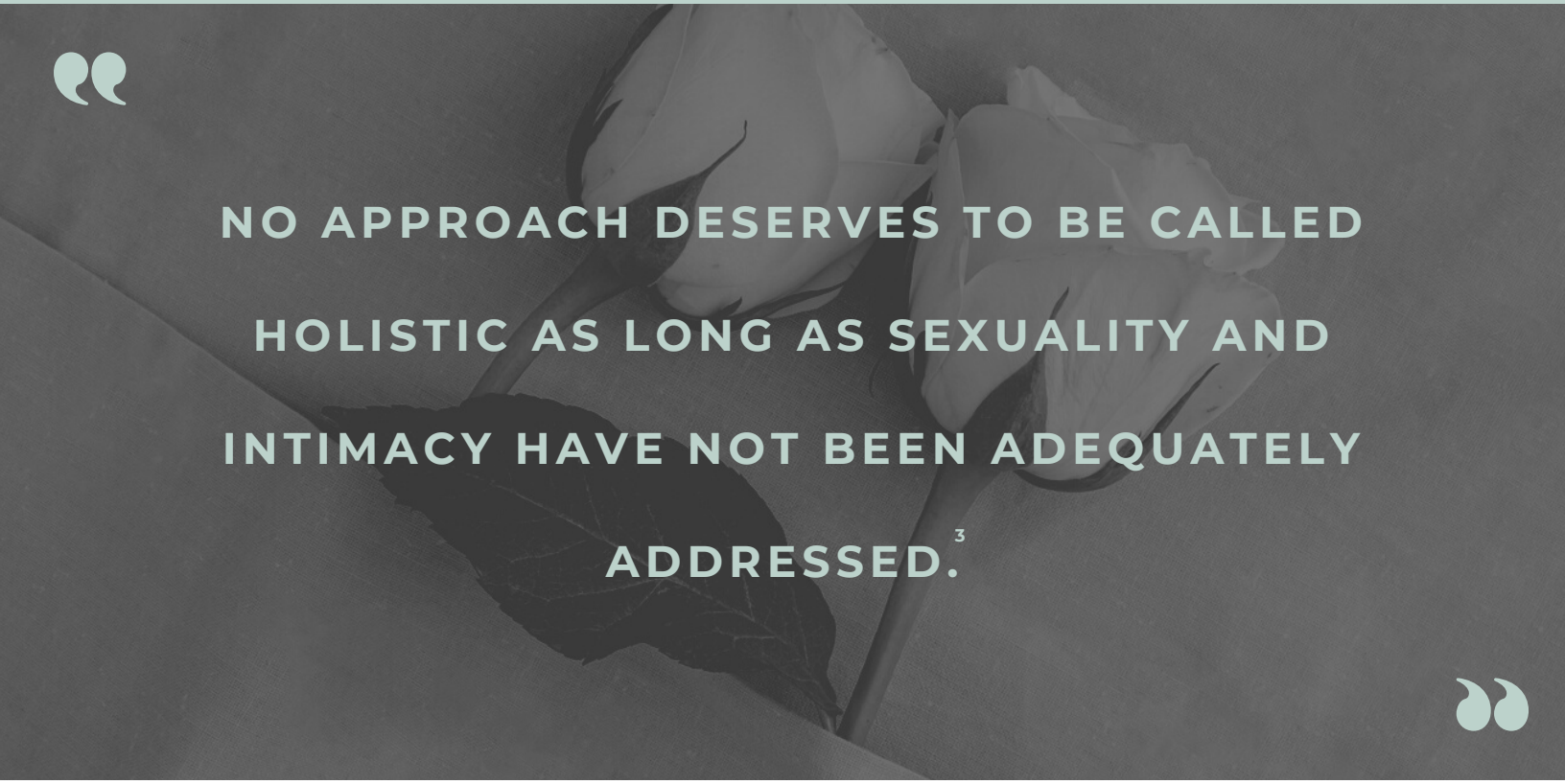
Subjective awareness of desire for sexual satisfaction, irrespective of sexual activity

SEXUAL ORIENTATION

Component of identity that includes a person's sexual and emotional attraction to another person and the behavior and/or social affiliation that may result from this attraction. Individuals may identify as lesbian, gay, heterosexual, bisexual, queer, pansexual, or asexual, among others.



WHY IS THIS IMPORTANT?



> NO APPROACH DESERVES TO BE CALLED HOLISTIC AS LONG AS SEXUALITY AND INTIMACY HAVE NOT BEEN ADEQUATELY ADDRESSED.[3]

BENEFITS OF SEX & INTIMACY IN LATER LIFE

- LESSEN DEPRESSION; IMPROVE MOOD
- SOURCE OF EMOTIONAL EXPRESSION
- DISTRACT/HELP MANAGE PAIN
- RELIEVE STRESS
- DIMINISH MUSCLE TENSION
- FEELING CARED FOR
- INCREASE FEELINGS OF CONNECTIONS & LOVE
- RELEASES OXYTOCIN (IMPACTS MOOD & INFLAMMATION)

BARRIERS THAT MIGHT INTERFERE

IMPACT OF DISEASE & ILLNESS

Disease and illness impact our bodies in a variety of ways, including how it relates to our sexual interest, desire, and expression. As healthcare providers, it's our responsibility to bring this discussion up, normalize this experience, and plan together when relevant on how to address this barrier.

SIDE EFFECTS OF MEDICATION

As we know, medication can have a range of side effects. Since end-of-life care takes a more holistic and palliative approach to treatment, consider the patient's values as it relates to sex and intimacy when managing their medication. Try inviting the patient's voice and autonomy into the room when making these decisions when possible.

CHANGES IN SENSE OF IDENTITY

Aging and living with terminal disease not only changes our bodies, but it also changes our relationship to our bodies. Introducing this topic with our patients should also include discussions around our patient's own internalized stigmas, myths, and/or sense of self. A strength-based approach to sex and intimacy across the life span is recommended.

INSTITUTIONAL BARRIERS

In addition to the societal cultural stigmas, institutional/facility culture may impact this type of work! Notice how your team speaks about these issues. The policies of your facilities might also act as barriers. Advocacy is vital and might include encouraging the team to knock before entering rooms or even making privacy signs!

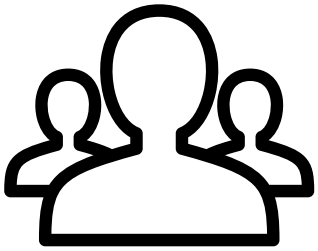
CHRONIC PAIN

Chronic pain may interfere with one's expression of sexuality because of the pain itself or other factors associated with chronic pain such as mood, decreased drive or desire, medication to manage pain, or stress. Normalizing this with our patients and bringing up creative solutions (e.g., new positions) can help reduce this barrier.

STIGMA

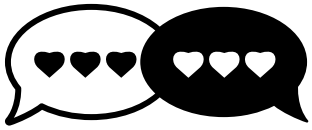
Aging and death are both culturally charged topics, let alone the intersection with sex. Therefore, cultural ideas of a "*good death*" for each patient are likely embedded in other identities such as religion, nationality, or family background, which might (not always) be associated with other stigma or challenging relationships to sex and intimacy in later life.

HOW TO HAVE THE **HARD** CONVERSATION...



Who Should have the conversation?

As many of us know from working on an interdisciplinary team, all of us have different expertise and skills that we use to help our clients and families work towards what we refer to as a “good death”. There’s no one “right” person or profession to begin this conversation, but trust and non-judgement should be prioritized when approaching this topic.



Don't forget...

Many patients’ **caregivers** are also their partners or spouses. The transition from romantic relationships to caregiving relationships can be particularly challenging. This conversation can and should be had with both the patient and the loved ones. Similar tips and questions can be asked!

What does it look like?

This conversation might look and sound different depending on you, the patient, and your setting. The goal is to let your patient and patient's loved ones know sex and intimacy can be discussed with their care team. Example questions to begin this conversation might include:

"WHAT DID SEX AND INTIMACY MEAN TO YOU BEFORE ARRIVING ON THIS UNIT AND WHAT DOES IT MEAN TO YOU NOW?"

"WHAT IS YOUR RELATIONSHIP TO PHYSICAL TOUCH HOW WOULD YOU LIKE US TO MODIFY OUR CARE WITH THAT IN MIND?"

"DO YOU HAVE ANY WORRIES OR CONCERNS REGARDING SEX OR INTIMACY AS IT RELATES TO YOUR ILLNESS?"

WHAT CAN I DO TO MAKE YOU FEEL MORE COMFORTABLE SPEAKING TO ME ABOUT TOPICS OF INTIMACY?

HELPFUL TIPS/REMINDERS

CAPACITY

Capacity is defined as the the maximum ability of an individual to receive or retain information and knowledge or to function in mental or physical tasks (APA, 2021); therefore, it is important to consider the patient's capacity to make decisions related to sexual expression and intimacy. However, this should be properly assessed, and just because one's capacity to engage in a behavior may be limited, their rights to have space to discuss these topics may still be relevant and necessary to care.

For more information read: Chapter 6: Sexual Consent

INCLUSIVE LANGUAGE

The words we use can significantly shape the comfort and safety our patients and their families experience with us. For example, steer clear of assumptions. If you're unsure about their relationship status, use inclusive words like "partner" or "spouse" rather than assuming the gender of their loved one. Also remember, we do this work to open a door, which our patients may want to close. Normalize if patients are not interested in sex or intimacy while on the unit. Also consider this might be related to other identities (e.g., asexuality) or experiences (e.g., survivor of sexual trauma). **See resource page for further reading.**

1. Bring it up **early and revisit** the conversation after rapport is built. It should be ongoing!
2. Have the conversation in a **private space** (e.g., if a patient has a roommate consider addressing this conversation when the patient is alone)
3. Asking patients their **touch preference** and how this relates to their care.
4. **Normalize** the discomfort of discussing this topic.
5. Remember the **cultural saliency** around sex and intimacy, specifically in the context of a good death. Approach with humility and curiosity, Be aware of your own bias and any assumptions you might enter the conversation holding.
6. **Listen to your patients:** Many times, if we're listening well enough, our patients will tell us themselves. A part of integrating this type of work into our practice is about validating the importance, which might mean challenging some of our own biases or preconceived notions about sex and intimacy at end-of-life and hearing what we often ignore.
7. Give **concrete examples of options** for the patient. For example, carving out time for sexual intimacy doesn't need to include sexual acts. It could mean having a private visit with their loved one where they might be able to cuddle (maybe naked), solo sex/masturbation, or even reminiscing about their previous sex life together privately.

RESOURCES

JUST CLICK ON EACH FOR A LINK!

1. TED TALK: "*IS IT OK FOR GRANDMA TO HAVE SEX? LESSONS FROM AN AGING SEXUALITY EDUCATOR*" PRESENTED BY JANE FLEISHMAN, PH.D

2. FREE WEBCAST (2CE CREDITS): *INTIMACY AND SEXUALITY DURING ILLNESS AND LOSS WEBINAR* PRESENTED BY THE HOSPICE FOUNDATION

1. GRAYER RAINBOWS: COMING OUT LGBT+ LATER IN LIFE

2. SEX OVER 50: OUR BETTER HALF

1. INTIMACY AND SEXUALITY DURING ILLNESS AND LOSS BOOK (DOKA & TUCCI, 2020)

2. SEX IN THE NURSING HOME ARTCLE IN AARP (SCOTT, 2015)

3. LGBTQ-INCLUSIVE HOSPICE AND PALLIATIVE CARE: A PRACTICAL GUIDE TO TRANSFORMING PROFESSIONAL PRACTICE (ACQUAVIVA, 2017)

4. ADDRESSING SEXUALITY IN LONG-TERM CARE: A PERSON-CENTERED APPROACH TO INTIMACY AND DEMENTIA (BOREN, 2018)

5. SEXUAL DESIRE AND PLEASURE (BROTTO & SMITH, 2014)

6. SEXUALITY AND AGING: CLINICAL PERSPECTIVES (HILLMAN, 2012)

***Remember**, this is not a comprehensive resource. The needs, desires, and wants of our patients are unique and vastly different for every one we encounter. This resource is meant to be a steppingstone and provide an argument for individuals and systems providing care to individuals at end-of-life to consider the impact of integrating intimacy and sexuality as essential parts of our care.*

THANK YOU!

KEEP THE DISCUSSION GOING

I ENCOURAGE YOU TO SHARE THIS WITH YOUR COLLEAGUES. PLEASE ALSO FEEL FREE TO REACH OUT TO ME DIRECTLY IF YOU WOULD LIKE TO CONTINUE THIS CONVERSATION OR HAVE ANY QUESTIONS.

EMAIL: EVR218@LEHIGH.EDU

1. Lindau et al., 2007 ; 2. Vitrano et al. 2011; 3. Resiman & Gianotten, 2017, PP. 13