Let's talk about it

Putting sexuality and intimacy on the agenda in a palliative care ward

Neringah Hospital

Let's Talk about it: Research study at Neringah

- Neringah is a 19 bedded palliative care ward.
- We conducted a survey from staff to ask them how they thought we could put sexuality onto the agenda in the ward.
- Results of the survey done at Neringah will be presented.
- The education given to the staff will be presented.
- The strategies we implemented will also be discussed.

Background

- Research has shown that patients in palliative care have unmet sexual needs.
- It has also shown that the patients would like staff to initiate the conversation.

Background

- Sexuality is part of the holistic care of our patients.
- Sexuality is linked to the "wholeness" of a person, which is threatened by life-limiting illness.
- It is important to normalise sexuality and intimacy.

- Staff may feel uncomfortable about the whole issue and need education.

- This emphasises the need to determine who should be responsible for initiating the conversation and the importance of providing training to health personnel involved in this care.

Sexuality and Intimacy

What does this mean?

Sexuality and intimacy

- Sexuality is an intrinsic part of being human, and can be an intimate form of communication that relieves suffering.
- There is an assumption that sexuality means sexual intercourse and function.
- Patients in palliative care have described it as “emotional closeness”, but assert that “physical expressions remain important”.
- Sexuality is “whatever the patient says it is.”

Sexuality and intimacy

- Often, intimacy and sexuality are used interchangeably.
- Arguably, intimacy is just a euphemism for sexuality.
- Intimacy is about communication, identity, mutual acceptance, closeness.

(Hordern & Currow,2003).

What is sexuality and intimacy?

Staff's quotes from survey

- Sexuality/ intimacy means the closeness between two consenting people, including hugging, kissing and sexual intercourse"
- Sexuality – expression of sexual needs/ requirements/ desires. Intimacy – can include sexual needs but also romantic/ emotional needs, need for closeness/ affection
- Closest and intimate relationships allowing an expression of love, often physical. Giving and receiving of such expressions. Self-worth and appreciation within a couple/ for one another

Health professionals have a tendency to assume that people with life-limiting diseases are “too sick” or “too old” to continue to be sexual beings.

Staff’s quotes from survey

“It’s very difficult because most of our patients are old & too sick to discuss things related to sexuality & intimacy.”

“I think palliative care patients in Neringah are too sick to think about sexuality. So, we don’t need to improve sexuality and intimacy conservation.”

OK, so why is sexuality and intimacy important in palliative care?

- Sometimes, there is a deep regret in the bereaved person, that they were unable to provide the intimacy that they knew their partner wanted.

- "We all remember the first time we made love, but it would be nice to remember the last time".

- Patients whose sexual needs remain unidentified and unacknowledged, assume that their sexual concerns are irrelevant.

- Research overwhelmingly shows that patients value sexuality and want opportunities to discuss it.

- There is imposed abstinence, reduced displays of affection and emotional disengagement.

- **A holistic approach to palliative care includes a professional discussion of sexuality, which is as important as physical symptoms.**

Myths about sexuality in palliative care

- Have to be young to be sexual
- Have to be beautiful and desirable (media defined)
- Have to have a (heterosexual) partner to have sex.
- If your partner dies, it's the end of your sex life.

More myths about sexuality……..

- Older people should be looking after their grandchildren, not being sexual!
- Derogatory terms about older people prevalent.
- Myths of aging – tend to be negative
- You can't have sexual needs if you are sick.
- Dying individuals and their loved ones are viewed as asexual.

(Gaunt et al,2009)

What are the perceived barriers to sexuality and intimacy in palliative care?

- *Staff barriers*
- *Patient barriers*
- *Systemic barriers*

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What are the perceived barriers to sexuality and intimacy in palliative care?

- *Staff barriers*

Embarrassment.

Vulnerability.

There is safety in a medicalised approach.

Negative sexual experiences by the health care professional.

Expectation that patients focus on the physical symptoms of their disease and "are too sick" to think about intimacy and sexuality.

" How can I bring up sex . . . I have far more important things to address with them! "

Holdern et al, 2007

What are the perceived barriers to sexuality and intimacy in palliative care?

Reasons staff struggle to open the conversation are lack of training (84.8%), concern patients are embarrassed because of their age/culture (75.8%), lack of time (63.6%) and feels it's too intrusive (51.5%)

There have been incidences where staff have been embarrassed by intimacy.

Patient barriers

Body image and self-concept:
Advanced illness affects a person's appearance and therefore, his/her sense of "being sexy".
Surgery, cachexia, odour of tumours, pain: all contribute.
Grooming and appearance are important aspects of sexuality.

Changes in sexual desire and functioning:
Limitations of their illness, e.g mastectomy, prostatectomy.
Not feeling sexy.

Social concerns:

"The staff may think I'm just a dirty old man."
Shyness of patients to initiate the conversation.
"I don't want to make the staff feel embarrassed."
"I was searching for the right person who would understand what I was feeling".

(Hordern et al, 2007)

Systemic barriers

Lack of privacy

Sharing a room with other patients,

Constant interruptions, and single beds.

Embarrassment by the health personnel if the patient should mention the topic.

Obstacles that prevent patients expressing their sexuality: They are too sick to think about it (93.9%), embarrassment (84.8%) and no privacy (84.8%)

Discrimination

Staff need to have neutral gender language: partner, not husband/wife.

Diffusion of responsibility

Whose role is it to do this?

Staff to raise the issue with patients are doctors (79.4%), social worker (73.5%) and nurses (70.6%). Most thought it's an MDT approach

How can we help?

Normalise sexuality

Educate staff.

Provide resources to facilitate sexuality.

Aromatherapy.

Encourage communication between patients and their partners.

Give them time alone together.

Help with washing and make-up application, etc.

The good news

- Physiological changes not to be confused with the capacity for love and intimacy.
- We may be satiable when it comes to sex but insatiable when it comes to being loved
- Adult psychological health is associated with sexual compatibility and connectedness
- No fixed biological limit to a satisfactory sex life during old age
- Older people's sexual activity level is correlated to their sexual activity and enjoyment before, during and after their middle years .

(Gaunt et al,2009)

How can we put sexuality and intimacy on the agenda in Neringah?

Staff suggestions from survey:

- Training
- Champions
- Ways to ensure patients have privacy.
- Pamphlets, include it in the admission form, consent form

So what did we do at Neringah?

Team approach: Stepped Skills model

(De Vocht et al 2011)

Step 1

- Teams discuss that “a sexuality and intimacy attitude” needs to be developed.
- Teams acknowledge that sexuality and intimacy are basic and enduring aspects of being human.
- A schedule of education was given to all staff, including medical, nursing and Allied Health.

Step 2

- **Allocation of roles.**
- Not every team member needs to discuss these private issues. Everyone has their own strengths and weaknesses.
- Each team member has roles, which are clear and complementary
- **NB. We need to make sure that we aren't all saying the same thing to the patient. Documentation would be important.**

Two roles

- **Spotters:**
  - the staff in direct contact with the patient and partner.
  - Look for “cues” that patients need sexuality and intimacy discussion.
  - Use conversation openers (see previous)
  - Refer to Champions

Two roles

- **Champions:**

- Have extra training.
  - Role and personal preference.
  - Currently, we have allocated two people for this role: social worker and staff specialist.

Training

The PLISSIT method of communication

- P: Permission
- LI: Limited Information
- SS: Specific Suggestions.
- IT: Intensive Therapy

- This is a "stepped approach" with fewer people needing increased care
- Most people only need Permission and Limited Information.

Important to understand that you can stop at any time during this method.

If you feel uncomfortable with these conversations, refer them to a "Champion" at any time.

The *P*LISSIT method of communication

- **Permission**

Having a willingness to discuss sexually related topics.

It involves **asking** permission to talk about sexual topics.

It also involves **giving them** permission to be a sexual being.

Followed by an open ended invitation to have this conversation.

EXAMPLE: *" It is normal for people/couples in your situation to have concerns regarding sexuality and intimacy. What concerns are you having?"*

The *P*LISSIT method of communication

- **Permission**

Part of this is about being able to **interpret cues** from patients or their partners.

One cue might be if you ask a patient if they want a companion bed, and they say yes.

Another might be if a patient says: "I feel ugly and unloved." Your answer may be: "You have been through so much since your diagnosis. This may have affected how you see yourself as a woman/man." AND THEN?

If a patient does not continue this conversation, it may be time to stop.

The *PLISSIT* method of communication

- **Limited Information**

This may be a discussion of how their sexuality has been affected by their condition.

Depending on their response would be a guide as to whether the conversation should continue.

The PLISSIT method of communication

- **Specific information**

Concrete suggestions on how to cope.

Encourage couple conversations.

Offer them private time, massage oils, companion beds.

The PLISS*IT* method of communication

- **Intensive therapy**

Refer to a sex therapist.

Refer to an OT for equipment they may need.

Research has shown that not many patients reach this stage.

Phrases on how to start the conversation and cues

- "Some people who are going through an illness like yours have been concerned about their sexuality."
- Ask a patient and partner if they want a companion bed, and if they say yes, say that they can have private time together if they would like.
- "Do you have any intimacy needs that we could help you and your partner with?"
- A patient wants to dress up for a visitor and asks for help. "Is this person someone special?"
- "Would you like some private time with this person?"
- It can be hard for people at this stage in your illness to express physical love and sexual needs. How can I facilitate these needs for you?
- You have been through so much since your diagnosis. This may affect the way you see yourself as a woman/man.
- You must be wondering how all of this will affect you sexually or intimately. Let's talk about that.
- Sometimes tiredness like this can make it hard to feel good about yourself after all that you have been through. How has this impacted on your relationship and other intimate areas of your life?

Reaction from the patients

- In the study done by de Vocht et al, patients did not take offense if the issue of sexuality and intimacy were brought up.
- EVEN THOUGH some of them were definite that they did **not** feel a need to talk about it.
- Patients didn't mind the gender or age of the professional, as long as they were genuine.
- A person-oriented approach is wanted, rather than a "medical" or "sickness" approach.
- A medicalised, questionnaire based approach is not conducive to discussion about sexuality/intimacy.

Providing patients with the opportunity to have sexual/intimate time together with their partners

A companion bed offered to all couples.

If they said "yes" this was seen as a cue.

Called "private couple time"

A sign was created and education to all staff about what this sign means.

This sign was given to these patients and their partners.

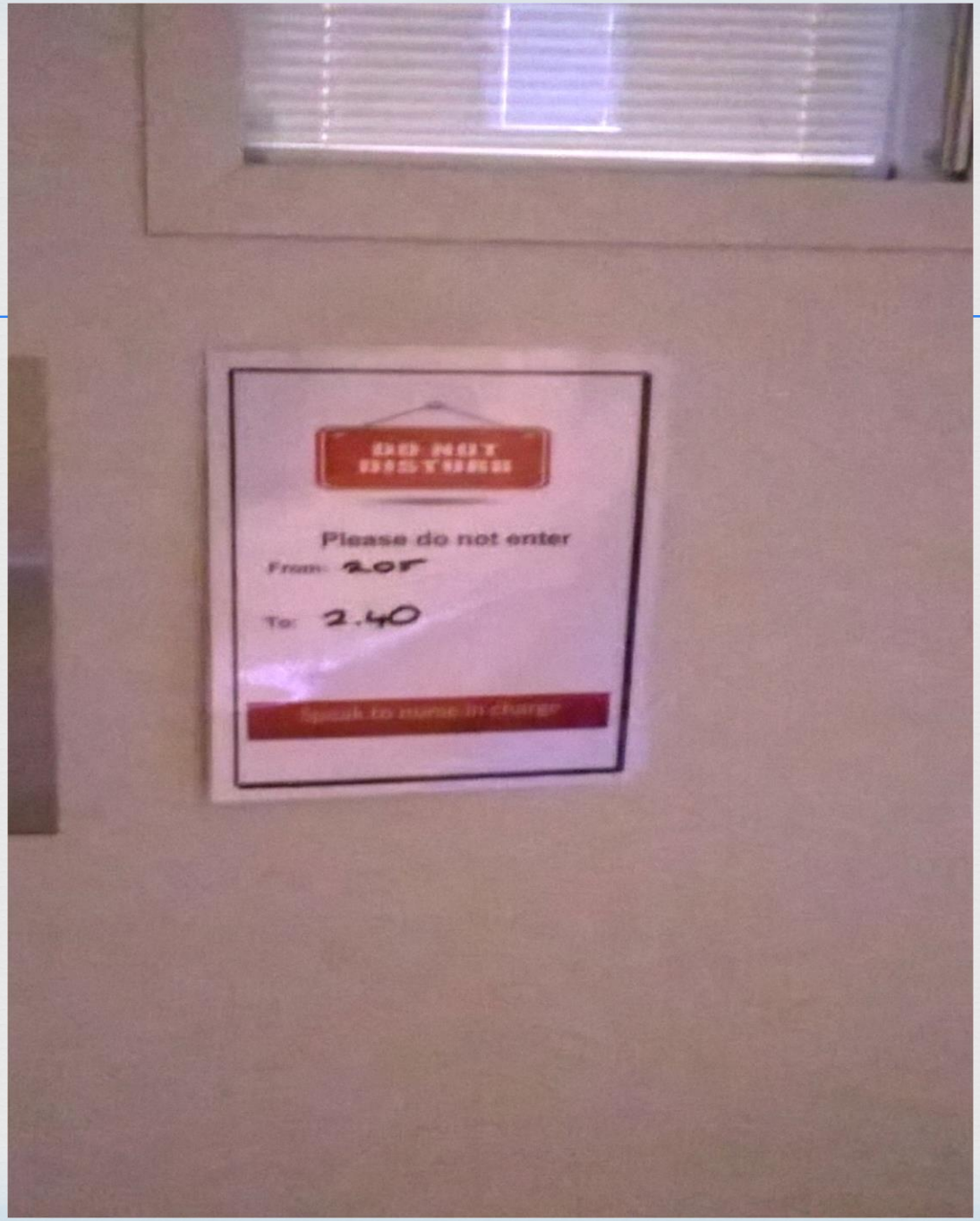
Please do not enter

From:

To:

Speak to nurse in charge

If the sign is up , we DO NOT EVEN KNOCK.
We ABSOLUTELY RESPECT this private time.
ALL staff have been educated about this.


DO NOT DISTURB
Please do not enter
From: 2.05
To: 2.40
Speak to nurse in charge

- **Pamphlets, consent form?**

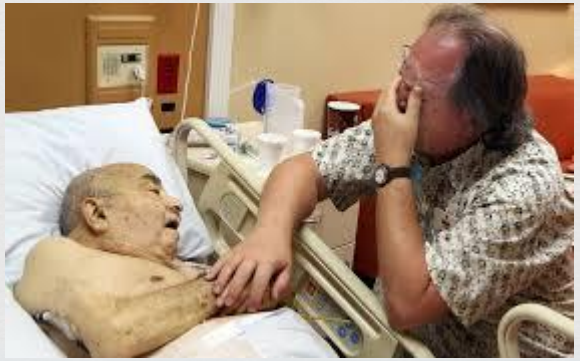
To provide pamphlets to patients as a conversation starter.

Consent form which patients can sign on admission if they are happy to discuss such issues .

- "A medicalised, questionnaire based approach is not conducive to discussion about sexuality/intimacy." (de Vocht, 2011)
- Is this just a cop-out?
- Neringah decided NOT to use this method.

A word about a special group of people: LGBTI

- People in the LGBTI group face additional barriers and stressors in palliative care.
- This includes homophobia, failure of healthcare professionals to recognise their relationships, additional legal and financial burdens.
- They tend to seek medical attention later than the general population



What can we do?

- We need to be aware of their difficulties and ensure they are included.
- We can do this by using gender neutral language,
- Also by picking up cues that a person of the same gender is actually a partner

Limitations of this study

- Neringah is an inpatient unit. Palliative care is not just about end of life care. Most of the patients who benefitted from the signs were receiving end of life care.

- We only interviewed staff and a limited number of patients and carers.

Any questions?

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