Intimacy: the last taboo?

Princess Alice Hospice

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Background

People approaching the end of life experience a succession of changes and losses, such as changes to their physical appearance, reduction in motor ability and sensory loss. As well as people's own physical limitations, specialist equipment and the increasing presence of professionals and paid carers often reduce privacy and inhibit intimacy (Lernieux et al, 2004). Intimacy in this context includes not only overt sexual activity but also many other forms of intimate contact such as hugging, kissing, sitting close together watching TV, shared bathing, informal massage and sleeping together in the same bed.

This can lead to a loss of emotional connection, leaving both patients and the people that are important to them, with a burden of emotional pain that often remains unspoken and therefore unaddressed. To ensure we were supporting hospice staff to be confident enough to explore this vital aspect of patients and their partners lives we developed an education intervention to not only increase knowledge but ensure hospice staff felt competent and confident to explore these themes openly.

Aim

To educate and support the multi-disciplinary team (MPT) to increase confidence in communicating with patients and their partners on sexuality and intimacy.

"I can now consider equipment when addressing adaptations/hospital bed to help consider how this may restrict their *intimacy*".

"Increased *confidence* in being able to start a discussion"

Method

A baseline audit was undertaken looking at the patient notes of 20 patients across the In Patient Unit (IPU) and Community team to establish if any conversations of this nature had been recorded. It was found that only 10% of MPT members were recording conversations with patients about their sexuality and intimacy needs.

A working group of MPT members was formed and agreed on the following strategies to ensure sexuality and intimacy was part of our holistic assessment:

- We undertook face to face consultation with patients and their families and this allowed us to identify what was needed for improved communication on this issue.
- A Schwartz© Round was held focusing on sexuality and intimacy aimed to encourage discussion around this subject.

Education sessions were delivered to the MPT staff including communication skills and how to note cues from patients and those important to them. The format of these sessions included:

- discussing sexuality and intimacy in the context of palliative and end of life care
- explaining what people with a life-limiting illness might want from professional carers
- discussing why it might be difficult to discuss patient concerns about sexuality and intimacy
- explore communication skills in initiating conversations about sexuality and intimacy.

Findings

The evaluation identified that there was initial reticence in opening up the conversation, feeling uncomfortable with the subject. After attending the awareness session's the professionals recognised increased confidence in their practice. Equipment and practices were updated and explored to increase opportunities for private time and facilitate intimacy.

A leaflet was designed and evaluated by a service user focus group and was named "Remaining Close". This was then distributed to patients and their partners both on the in-patient unit and in the community to promote a conversation and for staff to use as a tool to initiate discussion.

There has been a 70% increase in recorded conversations with patients and their partners around sexuality and intimacy. Anecdotally we have seen more open conversations on the IPU and in the community around supporting people to explore their sexuality and to promote intimacy and privacy when we can.

Case Study 1

A 65 year old man with cancer was admitted to the hospice. The nurse walked into the patients room and interrupted the patient and his wife being intimate but as they had been on awareness training they were able to respond appropriately by being open and facilitate the couple to have undisturbed private time.

Case Study 2

A couple had been married for 60 years and enjoyed ballroom dancing together. When he was dying the staff lowered his hospital bed so that it was the same level as his wifes bed so she could hold her husband in her arms as he died.

Conclusion

Issues around intimacy can exacerbate the overall negative impact of illness, such as loss of self-esteem and sense of isolation. This can lead to poor mental health and overall reduction in quality of life for both patients and their loved ones. By empowering the MPT to feel confident in this area it gives a signal to those we support that they can talk openly and be valued fully as a person in every facet of their identity. An ongoing working group for the IPU considers the layout of patient rooms, equipment/ hospital beds / screens for privacy, signage on door to alert staff and continued awareness raising for all new staff.

Reference: Lemieux L, Kaiser S, Pereira J, Meadows LM.Sexuality in palliative care: patient perspectives Palliative Medicine 2004; 18:630 637

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