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Experiences of sexuality and intimacy in terminal illness: A phenomenological study

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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

Cancer, couple, Heidegger, motor neuron disease, palliative care, partner, phenomenology, sexuality, terminal illness, terminally ill

What is already known about the topic?

- Existing research largely overlooks sexuality and intimacy in terminal illness.
- Some patients with cancer and motor neuron disease have unmet sexual needs.
- Health-care professionals often do not address sexuality and intimacy with patients and their partners.

What this paper adds?

- Sexuality and intimacy exist in the context of relationships and do not necessarily involve sexual activity.
- Patients and partners of patients living with a terminal illness experience connecting and disconnecting within their coupled relationship.
- This study provides evidence that patients and their partners would value the opportunity to discuss any concerns they might have about their coupled relationship.

Implications for practice, theory or policy

- Palliative care professionals have a role in providing patients and their partners with opportunities to discuss their coupled relationship.
- Further research is needed to understand whether, and how, palliative care professionals can facilitate connecting and re-connecting between partners.

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Background

The words of Cicely Saunders[1] were pivotal in establishing the ethos of the hospice movement and have been adopted by organisations around the world:

> You matter because you are you … we will do all we can, not only to help you die peacefully, but also to live until you die.

If sexuality is integral to the uniqueness of each person,[2] then it should be acknowledged and addressed in palliative care. However, there is a paucity of research considering sexuality and intimacy in people with terminal illnesses. An earlier study in the United Kingdom explored sexual function and satisfaction in patients with different stages of cancer.[3] Both oncology and palliative care patients reported sexual difficulties and wanted the opportunity to discuss their concerns with a professional.[3]

Unmet needs regarding sexuality and intimacy have also been found in studies in the Netherlands,[4] Australia[5,6] and Italy.[7] However, because these studies recruited patients from 'cancer and palliative care' services,[5,6] 'cancer support and rehabilitation groups'[4] and 'palliative care and acute pain' services,[7] it remains unclear whether an altered sense of sexual self concerns people nearing end of life.

American research found that hospice patients expressed sexual health concerns, yet none reported having been asked about their sexual or intimacy needs since admission.[8] Hospice nurses did not consider sexual health a priority, and assumptions about patients being 'too old' or 'too sick' were prevalent.[8]

Of the limited existing research, most studies considered patients with cancer.[4–7,9] Research on motor neuron disease (MND) shows that sexual activity is rarely discussed by doctors,[10] though remains important, even for those who are ventilated.[11] Despite increased sexual problems, this is not always associated with reduced relationship satisfaction.[10] This study was undertaken to address a gap in research on MND and cancer.

Research question

How do patients and partners of patients living with a life-limiting illness make sense of their experiences of sexuality and intimacy?

Method

A Heideggerian hermeneutic methodology was chosen. This is an interpretive phenomenological approach that seeks to uncover shared meanings; the intention is not to draw comparisons. Recruitment from outpatient, community and hospice inpatient units took place between 2008 and 2010. Doctors and specialist nurses were initially asked to offer a letter of invitation to everyone who was eligible (Figure 1). To ensure as broad a range of participants as possible, a purposive strategy was used to target under-represented groups.

Conversational interviews are consistent with this methodology.[12] I asked participants

- their reasons for taking part,
- how their (or their partner's) illness affected them in their day-to-day life,
- whether this had affected intimacy or sexuality,
- whether health-care professionals had spoken with them about these matters.

A structured interview schedule was not used so that experiences that were meaningful to participants could freely emerge. I used prompts to encourage elaboration and explore experiences in more depth. Couples were interviewed separately so participants could describe their experiences without concern for their partner's reaction. Interviews were held in a location of participants' choice (usually their own home) and averaged 66 minutes. They were audio-recorded and transcribed verbatim. A total of 34 participants consented to a second interview 2–6 weeks later to elaborate on themes discussed in their first interview. Four patients and two partners withdrew before the second interview because of illness. One patient did not respond to the follow-up request.

- Adult patients or partners of a patient with MND or life-limiting cancer
- Aware that their condition was life-limiting
- Able to consent
- Able to speak English (because the sensitive subject matter precluded the use of an interpreter).

Figure 1. Inclusion criteria.

- ***Balanced integration*** requires congruence between the methodology and the method
- ***Openness*** requires consideration of the researcher's pre-suppositions
- ***Concreteness*** refers to the relevance of the findings for everyday life and their applicability to practice
- ***Resonance*** involves the emotional effect of the findings upon the reader. The concepts presented should be surprising, yet obvious
- ***Actualisation*** refers to the potential for resonance in the future. If, by reading this paper, the reader is encouraged to 'think on'[17], further affirmation of the interpretations is achieved.

Figure 2. Five expressions of rigour for hermeneutic phenomenology.[18]

Analysis

Consistent with Heidegger's[13] hermeneutic circle of interpretation, analysis involved an iterative process of reading, rereading and interpreting the transcripts to identify emergent themes. Contrary to Consolidated Criteria for Reporting Qualitative Research (COREQ) recommendations,[14] findings were not returned to participants for confirmation; this was for both ethical and methodological reasons. Because of patient participants' declining health, I was concerned about compromising confidentiality and the potential for causing distress. In addition, participants' perspectives on sexuality and intimacy were likely to have altered since data collection due to changing circumstances; this would have resulted in them interpreting their prior experiences from a new position.[15] Emergent themes were, however, tested at the second interview.

In contrast to other qualitative research that requires an audit trail and independent verification of themes, this methodology uses different criteria as expressions of rigour (Figure 2). Heidegger[13] recognised that understanding is always 'on the way'; there is always the potential for new findings to emerge from data. Findings are merely interpretations[16] that present 'a calling, an invitation to others to come and look and think'[17] (p. 1393).

Ethical considerations

Ethical approval was granted by Milton Keynes National Health Service (NHS) Ethics Committee (reference 08/H0603/3); participating organisations' ethical requirements were met. Because I was a nurse in one of the recruiting hospices, people in a dependent relationship were not invited to participate to avoid coercion. Those invited were made aware of my gender, role and place of work to inform their decision-making.

I obtained written consent before each interview and informed participants of their right to withdraw without giving a reason. Using 'process consent',[19] I re-established participants' willingness to continue when they appeared tired, unwell or distressed. Only one participant chose to end the interview when they became upset.

Table 1. Participants.

	Patients		Partners		Total
	Male	Female	Male	Female	
MND	8	5	5	5	23
Cancer	5	9	1	3	18
Total	13	14	6	8	41

MND: motor neuron disease.

At the end of each interview, participants had time to debrief and were offered details of support services. All interview transcripts were anonymised; names used here are pseudonyms.

Participants

A total of 27 patients and 14 partners participated (aged 32–83 years) (Table 1). Two patients were single, one was separated, four were divorced and the remainder were married or in a partnered relationship. Two partners were bereaved (2.5 and 3 months previously). One patient identified as lesbian and one as bisexual; the remainder were heterosexual. All except one self-identified as White British.

Findings

When someone has a life-limiting illness, their coupled relationship is also dying. In their being-towards-death-of-the-couple, patients and partners of patients with MND and terminal cancer experienced connecting, disconnecting and, for some, re-connecting (Figure 3).

Connecting

From the narratives these participants shared, the essence of sexuality and intimacy was described as 'connecting'. Even those who were not in a partnered relationship emphasised the relational quality of sexuality. In particular, their descriptions reflected a sense of no longer being eligible for partnered relationships:

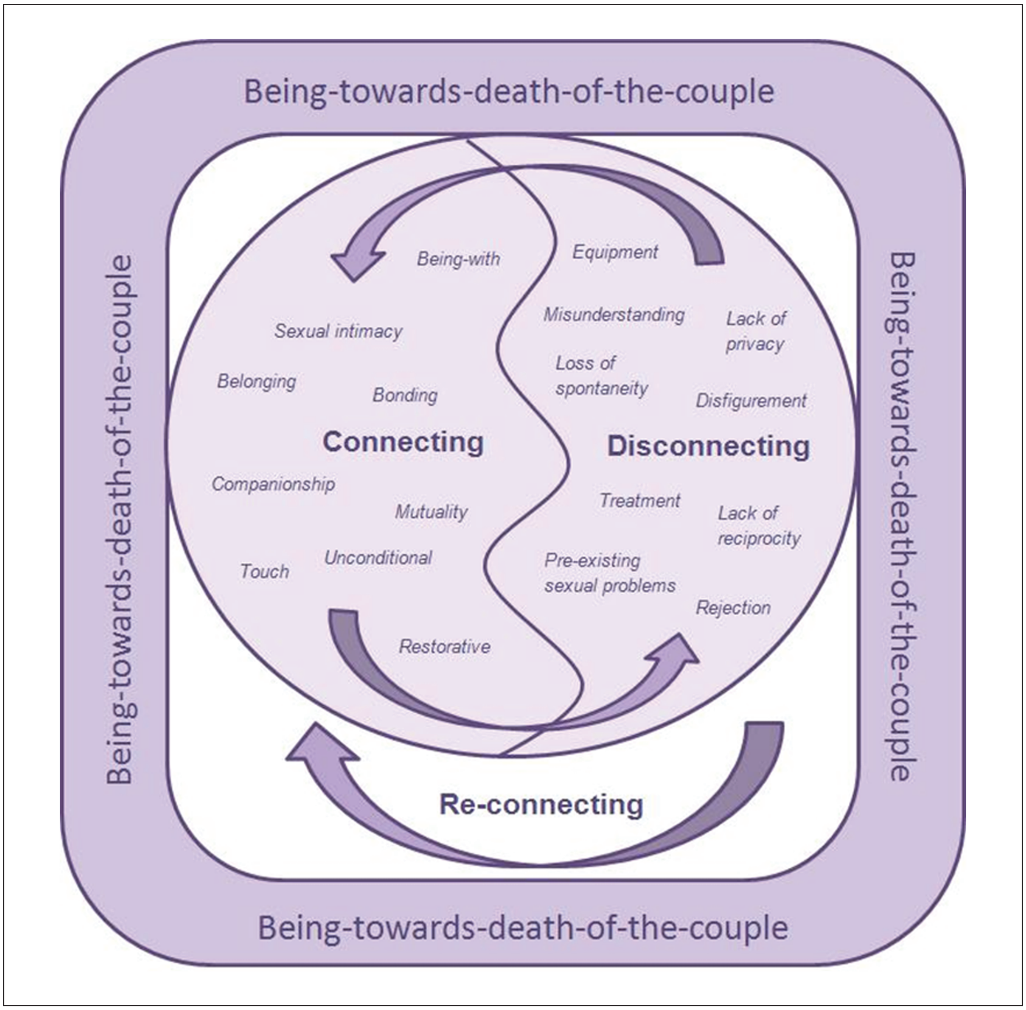

Figure 3. Being-towards-death-of-the-couple.
Source: Adapted from Taylor[21] (p. 88).

> It is difficult to go out there and get into a new relationship, especially now. I'm quite lucky 'cause I've got a long prognosis, I think. How does a bloke, why would he want to get into a relationship with a single woman who has got a life-limiting illness? You're not going to be a really good catch are you? (Kim)

Connecting was experienced as a quality of relatedness that was freely given; it conveyed support and a sense of belonging, and did not require anything in return:

> I just love the fact that Liz cuddles into me … it's like coming home, it's like being away for years and years and years, away the other side of the world and going back to the place you were born in, that's what it's like with Liz. She makes me feel comfortable, she makes me feel safe … She holds me and she, I can't explain it, she loves me for me … She just loves me for me, she doesn't want anything from me. (Jane)

Participants who were in a sexual relationship differentiated between 'sex' as a means of achieving sexual satisfaction and 'making love', which involved connecting:

> Making love is about two people, it's not about one … We share in each other's emotions. (Tom)

> It's the intimacy and the closeness that I hanker for rather than just the sex, because I could go anywhere and get sex. You know, you can go and pay for it down the road. (Sean)

As well as being freely given, connecting sexually involved reciprocity:

> It's mutual. I suppose that encapsulates it most. It's a mutual thing, it's giving two ways. (Jim)

> It's feeling wonderful with the person you love and enjoying making each other satisfied. (Julie)

Connecting was also experienced through non-sexual touch:

> When I go to bed at night, to actually remove your bedclothes and to be close and intimate, to me that's something altogether different. It's just something warm and tender and I just love

> that feeling. It's just nice when the two of you are together, whether you're caressing each other or just close to each other, I think that's absolutely brilliant and you don't even necessarily have to go through the full act of making love, it's a real connection, it's a real bonding isn't it, it's a real bringing together. (Tom)

'Being in someone else's arms and being together and being able to discuss things' were experienced by Tom as 'a real connection'. This involved the freedom of touch without the expectation of intercourse.

Connecting was experienced as a way of renewing affectional bonds and an escape from the reality of illness and impending death:

> It's a beautiful feeling [cuddling my wife] … It feels as if the worries have all been washed away. And yet I know they haven't. (Stanley)

Disconnecting

A dominant theme from 17 patients in partnered relationships ($n = 20$) and 12 partners ($n = 14$) was one of disconnecting. This was experienced in a variety of ways and for a variety of reasons.

Disconnecting due to cancer treatment. For some, disconnecting began prior to the life-limiting diagnosis, as a consequence of cancer treatment:

> When I was on chemo, my wife turned round and said, she says I don't want that bloody thing inside me with all that shit in you … I just turned over and cuddled into her, started playing with her and she just turned over onto her belly and I thought, well that's it. And ever since I haven't touched her. Oh, we've had kisses and that sort of thing, but I haven't touched her … I'm ashamed to say … it upsets me sometimes because I feel that I'm letting her down. (Stanley)

Stanley was in his 70s and described feelings of guilt, rejection and jealousy.

Disconnecting through disfigurement. Disconnecting was experienced through changes in body image:

> [In the past] If I didn't have my nightie on, I would sit up and I knew that he found it quite attractive to be able to look up at my breasts. But that's a thing I never do now … He doesn't tend to touch the breast form … he tends to only touch the left breast. It makes me feel if I ever have to have that removed, what then? Then there'd be nothing left and how would he feel about that? And how would I feel about that? (Angela)

Angela's sexual relationship had lost its playfulness. Sleeping side-by-side brought the future into the present, reminding her of what might yet come. Her inability to speak with her husband about these matters reinforced the disconnecting she experienced.

Disconnecting brought about by medical equipment. Participants who used equipment that was provided to enable described how it restricted connecting:[20]

> I always sort of kiss him goodnight when he's in bed, but just a light kiss. It's quite a difficult act to kiss properly when someone's, you know, always at a distance, in an armchair or something, you can't actually physically manage it very easily. (Betty)

> I do miss the hugs and all that. We used to sleep sort of wrapped up. And I can't do that now because he's got a mask and everything and it is very restrictive. (Claire)

The introduction of a hospital bed heralded the end of sexual relationships[20] and impeded closeness and physical touch.

Disconnecting through diminishing touch. Kathleen's sexual relationship with her husband had ceased completely since her cancer diagnosis 4 months previously. Her sadness was compounded by diminishing physical touch:

> The close relationship you get just to kiss and cuddle and in the end it's, the cuddling and the kissing's gone. You know, he'll come and give me a little peck on the cheek and he tells me he loves me, and I know he loves me dearly but … We're slowly dying a sort of death really.

Kathleen died 2 weeks after this interview.

Disconnecting through immobility, pain and loss of spontaneity. Experiences of disconnecting occurred through immobility and pain:

> Sometimes I put his arm round me when he's sitting in his chair, but that's painful for him. I miss that contact. (Betty)

Others described a loss of spontaneity in their sexual relationship that arose due to immobility:

> I just miss the intimacy and the spontaneity and the not having to plan … but you've just got to adapt to it. (Claire)

Although Claire adapted to the changes imposed by her husband's immobility, becoming the active partner sexually, others experienced disconnecting through loss of spontaneity. Bert experienced erectile dysfunction following surgery:

> The main thing, I think, the fact that we had always done it on a spontaneity basis and that spontaneity was no longer available … Neither of us liked the idea of [me] having injections [to create an erection] but I think it was the lack of spontaneity which was the main thing.

Once the spontaneity had gone, all sexual contact between Bert and his wife stopped. Jacky still needed to connect with him through non-sexual touch:

> [He]'s never been a terribly demonstrative sort of person, so I think I've always, I've always felt that that's been a bit lacking really, you know, he's not the sort of person who'll come up and suddenly give you cuddle or a kiss or something like that, he just isn't that sort of person. I've almost had 40 years of it, really, but it's just the level has changed, if you like (pause). I think they have become more important now. I mean if he was a bit more demonstrative now, it would be lovely, and I try to be but it's very difficult when he doesn't really take to it if I suddenly come up and give him a cuddle.

Jacky was able to hold Bert when he was in pain but, with the knowledge that his life was limited, kisses and hugs had become 'more important'. She needed him to be more demonstrative than he had been in the past, and experienced disconnecting through diminishing touch:

> I don't know quite how to say it really … (sighing) it's almost got to the stage where we don't even cuddle as much because, we are just sort of living our lives alongside one another without very much intimacy at all … I'm getting used to it but it's taking a long time … and I'm not really sure I feel totally okay about it, but I realise this is the best we've got.

Jacky and Bert had not spoken to each other about their loss, which further compounded the disconnecting they experienced.

Disconnecting due to altered feelings. Some participants described changes in the way they perceived their partner:

> I felt like I was kissing a stranger … I knew he wasn't cleaning his teeth a lot, so I was just put off. But if I did, I'd be, it sounds really awful, but I'd hold my breath and it was just a quick peck and quick get-away. Which sounds awful. It wasn't Jake … I don't know what else to say, it just wasn't Jake … If I was single, I wouldn't go out and fancy him, like how I used to … as he is now, I wouldn't go out and think, ooh look he's a nice bloke, he just wasn't my type. And unfortunately, I know he's my husband, but the feelings have changed. (Katy)

Jake's changed behaviour (due to a brain tumour) might have accounted for some of Katy's altered feelings.

Disconnecting through misunderstanding. The silence surrounding sex within coupled relationships provided room for misunderstandings to flourish:

> I think what helped me enormously was that … he had been put on tablets … and I hadn't realised until about a year afterwards, or more, that they had side effects of decreasing your libido. And that actually was a help to me to know that … rather than maybe just my body falling to pieces, you know, and that gave me a little bit more confidence. Rather than feeling it's just difficult for him to cope with my physical appearance … And I think I was blaming myself for perhaps a year and a half to two years, maybe, thinking that it was me …

Rita's interpretation of the changes in their sexual relationship fed self-doubts and feelings of insecurity. It was only when they spoke about this (prompted by her husband reading the information leaflet with the medication he had been taking for many months) that Rita was able to reinterpret his reduced sexual interest:

> Thinking that it was me, and I don't think maybe that's quite the case … it wasn't all my fault that he was less interested. That if these drugs were doing that, then that was part of it, and that has made it much easier for me to accept, he doesn't feel like it either so that's great. It's not just me … it wasn't just me turning him off.

One bereaved woman was troubled by the arguments she and her partner had because he wanted to maintain a sexual relationship until 2 weeks before he died. Although Michelle willingly gave oral sex and masturbated him, she felt unable to have intercourse:

> I didn't have the words to say what I meant but I think he thought that I just didn't fancy him anymore and, you know, why don't you want to do this, why don't you … you know, you can still get on it and please yourself. I think he still wanted to think that he could please me, whereas for me it wasn't like that, I didn't need to have sex to feel loved or needed by him and I guess I wasn't really explaining myself … I used to try and shrug it off, the conversation, I wouldn't really address it because we'd never talked … you know, no-one had ever talked to me about it … The feeling that having sex brought me was just a *constant reminder* that I was going to lose [him] soon … obviously I didn't want to upset him by saying that because it was like reminding him, you know, *you're dying*.

Michelle felt they needed a mediator to resolve these arguments, but no one had ever given her the opportunity to discuss these matters and she did not feel able to ask. Her partner died before this was resolved, and Michelle described a deep sense of remorse and guilt.

Re-connecting

Although disconnecting was a dominant theme, four participants also described experiences of re-connecting with their partner. Two patients described this as an increased intensity in their sexual relationship immediately after diagnosis:

Susie	It was an intensity of you've only got one life, live it. Stop worrying about being tired, stop worrying about the children. Just concentrate on how much you love this man.
BT	Uh-uh (pause). Connecting emotionally?

> Susie Absolutely, because I'd been connecting at maybe 50%, because the 50% was thinking about [the children] … But it was weird that our intensity, um, really did go a bit mad. We just needed to hold each other really, really close. But it's not that surprising.
>
> BT What triggered that do you think?
>
> Susie This was a very big, this was a big thing that was happening. And that maybe we wouldn't be, have a chance to be intimate for a while and that we needed to just remind each other how much we meant to each other. It was our way of expressing how much we meant to each other.

Susie recognised that she had previously had sex with her husband without fully connecting, but in 'the shadow of impending death'[21] experienced moments of re-connecting and a need to 'hold each other really, really close':

> The children are an incredibly huge distraction … You do want to put your heart and soul into them, and relationships with your other half can really take a back seat. You can feel exhausted and you can still make love with your partner, but not be emotionally connected because you're so tired. And nowadays it's a case of well hang on, let's get on with it when the kids are at school rather than do something else. He's immensely important to me and I'm immensely important to him, so let's celebrate that … and he knows that after nine o'clock you can't get a sentence out of me, I'm so tired.

The re-connecting described by Susie was, for Tom, only momentary:

> We went through that really good period [for a week], through that really horrible period, when I first had this diagnosed. That was probably one of the strongest periods of our sexual relationship because it just seemed to be something that both of us wanted anytime of the night, anytime that it was right. It just seemed to be a relief for the two of us and it worked and it just came, I mean it was really a strengthening of our relationship from that point of view … it was strange; it was something that, it was a one-off.

Existing sexual or relationship difficulties influenced how partners communicated with each other. However, some couples experienced re-connecting through a new way of relating as a couple:

> A few months ago I was lying in bed next to him and this finger came out and actually touched me and that's never happened before, *never ever*, he touched me because he wanted to and … I would've loved to have been touched [eyes filled with tears] … and now occasionally he puts his hand over and just rubs my back. (Frances)

Given her husband's limited prognosis, Frances was not hopeful that there would be time to repair their sexual relationship. Nevertheless, she described this as 'healing time' for them as a couple:

> This time is gifted time, since the operation, since the diagnosis … this is positive time not negative time … I've never had the chance to love him the way I want to love him and he's never let me love him the way I want to love him, he's never let me close before.

Re-connecting brought about by the research interviews. Some participants described conversations with their partner that had been prompted by the first interview. These conversations brought about re-connecting through resolving misunderstandings and reducing feelings of rejection:

> I actually talked to Paul about, we had a conversation about the fact that, about our sex life and he actually admitted for the first time ever, 'yes it never really worked did it'. And that for me is a fantastic thing that he's prepared to actually say that, admit that. That is a very positive result of the interview as it made me talk to him, and that was probably a conversation I would never have had with him if you hadn't come and asked me about it.

A role for health-care professionals?

Even though participants had agreed to take part in a study that would require them to talk about sexuality and intimacy, they were reticent in broaching the subject with health-care professionals. They stressed that health-care professionals should not *require* people to discuss this aspect of their lives, but should create opportunities:

> It would be intrusive of people to just come barging straight in and saying 'what's your sex life like?' I'd say 'mind your own business' … By all means broach it and let people know what is available by way of counselling and all the rest of it, but not to push it too hard … Tell them what's available and let them make their own choice. (Barry)

Sean highlighted the lack of support for couples when the organisational focus is centred upon the individual:

> … when somebody is diagnosed, the relationship just totally changes in every aspect and there doesn't seem to be much support for that. There is support for the carers [from a local hospice], there is support for the patients, but there is not much support for the actual relationship between the two … Some couples come closer together, some it drives them apart, and there doesn't seem to be any sort of help in that area.

Discussion

'An interpretation is never a pre-suppositionless apprehending of something presented to us'[13] (pp. 191–192). I had hitherto believed that sexuality is integral to who we are, and is not reliant upon being in a coupled relationship.

This view is supported by the literature[22] but has been challenged by this study's participants, who understood sexuality and intimacy to be relational experiences; patients who were single, divorced or widowed considered themselves ineligible for partnered relationships.

Previous research in palliative care has largely focussed on sexual behaviour and sexual intimacy,[3–6,8,10] but this study provides new understanding. It has shown that 'connecting' within coupled relationships does include, but is not reliant on sexual intercourse or sexual satisfaction; it is also experienced through non-sexual touch. Connecting is experienced through a sense of belonging and renewing of affectional bonds.

Although research with hospice patients ($n = 10$) found a greater emphasis on emotional attachment and non-sexual touch,[9] this study has shown this is not always the case. Disconnecting occurs when sexual relationships are impeded.

Barriers to intimacy in hospital and hospice settings include lack of privacy and single beds.[9] This study identifies further barriers to both sexual and non-sexual intimacy: regardless of setting, participants experienced disconnecting through immobility, pain, disfigurement, misunderstandings and altered feelings.

Experiences of disconnecting pervaded the narratives. This is further exemplified in a quote from Toombs:[23]

> 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.

Little by little, this dying man's wife withdrew from him. The disconnecting that he experienced as her touch became less intimate suggests that their coupled relationship was dying.[21] Further evidence of this was described by participants in this study as 'living alongside one another' or 'we're slowly dying a sort of death'.

According to Heidegger,[13] death opens up new possibilities for being. When death becomes part of life, it creates new possibilities for meaning as people re-evaluate their lives.[21] Life can gain a quality it didn't have before[24] as recognition of our own mortality creates new possibilities for 'living today'.[25] For some participants, this was experienced through re-connecting as a couple, although this was not always sustainable.

Because these interviews were held at a snapshot in people's lives, it is unclear whether more couples experienced re-connecting over the subsequent months. Or, indeed, whether the disconnecting that had already been experienced was further compounded. Longitudinal research would provide further insights.

Implications for practice

International research has shown that sexuality and intimacy are often not addressed in clinical practice.[3–10] This study's participants emphasised the need to be given opportunities to discuss these matters. Although the re-connecting some described was prompted by the research interview, a similar conversation could have arisen between couples if a professional had enquired about their intimate relationship.

The Extended PLISSIT Model (Permission, Limited Information, Specific Suggestions and Intensive Therapy) emphasises the importance of *explicit* permission-giving.[26] For example,

> People sometimes have concerns about how their intimate relationship has been affected and how they relate to each other as a couple, is this something you might find helpful talking about?

Permission-giving validates the importance of intimate relationships. It also gives people permission *not* to talk about these issues. However, if, when individuals are first given permission, they decline, this should not be interpreted as a wish never to speak about it; further permission is needed on a subsequent occasion.[27]

If palliative care professionals enable couples to communicate with each other, there is potential for re-connecting if misunderstandings are resolved. However, we must recognise any desire we have to 'fix' things. It is important to recognise that not all relationships can be repaired; it is just as important to validate feelings of remorse, anger and loss, enabling people to make sense of their experiences.

This study raises a number of questions for research that would further inform professional practice:

- What makes it possible for some couples to maintain connecting, where others do not achieve this?
- How can palliative care professionals facilitate connecting between partners?
- How do experiences of connecting, disconnecting and re-connecting influence partners' experiences in bereavement?

Strengths and limitations

This study provides useful insight into an aspect of people's lives that has received scant attention. The findings reported here pertain to a small number of individuals in the United Kingdom, but their experiences might be shared by others in similar situations. My aim is to encourage readers to consider the issues presented here in the context of their own practice, and to consider whether people they care for might have similar experiences.

This study is limited by its homogeneity; further research is needed to understand the experiences of people who are gay, lesbian and bisexual, as well as those of from different ethnic backgrounds. Others who were under-represented are those in the last year of life. For ethical reasons, the inclusion criteria specified that patients should only be invited to participate if the recruiting professional considered them well enough; this possibly encouraged gate-keeping. Further research is needed to understand the experiences of patients and partners in the last weeks of life.

It is feasible that people who agreed to take part in this study valued this aspect of their lives more than others. However, most participants described their reason for taking part in terms of benefitting others, not because of the subject itself:

> If in just one small little way it did help, then you feel you've done your bit. (Sally)

The proportion of individuals who declined participation is unclear. People with MND were invited to participate when both partners were present in an outpatient clinic. In contrast, professionals recruiting those with cancer tended to discuss the study with the patient and ask them to give information to their partner. This form of indirect recruitment proved far less successful. Future studies should consider more effective methods for recruiting partners of people with cancer.

Conclusion

The existing health-care literature has largely overlooked sexuality and intimacy in those who are dying. This study has shown that for these participants, connecting with their partner continued to be important, regardless of age or gender. In their being-towards-death-of-the-couple, participants experienced disconnecting from their partner. Four participants described re-connecting as they experienced becoming-closer-as-a-couple.

If palliative care professionals are to provide holistic care, supporting coupled relationships is essential. This requires us to challenge our beliefs about what is important to people, and any assumptions we might have about age, gender or infirmity.

Ironside et al.[28] ask us to consider how we 'attend to the meaning symptoms have for clients'. Unless we offer patients and partners the opportunity to talk about their coupled relationship, the silence surrounding sexuality will persist and these meanings will remain hidden. How then will we be able to provide care that is truly holistic and enables people to 'live until they die'?

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Declaration of conflicting interests

The author declares that there is no conflict of interest.

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