Sexual issues

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What we do know

➢ Research emphasis on cancer and treatment effects:
  ▪ Altered sense of sexual self
  ▪ Reduction in sexual interest
  ▪ Increase in sexual problems
    ▪ Not always associated in a decrease in relationship satisfaction

➢ The views of partners tend to be overlooked
Sternberg’s Theory of Love (1986)

- Components are defined uniquely by individuals
- Good quality relationships usually have a close match between partners’ patterns
- Partners need to be able to match each other’s interpretation of love if their needs are to be met
- Interpretations need to be translated into action
- Illness can re-shape components to the couple’s benefit or detriment
Sternberg’s Theory of Love (1986)

- Passion
- Intimacy
- Commitment
Sternberg’s Theory of Love (1986)
Commitment vs intimacy ... and passion?

“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.”

(Toombs 2008)
Organisational issues

- Canadian study - hospice
- 10 patients with cancer
- All had partners

“While I was in that group of four or five patients ... I did not show my intimacy. We still held hands, but I would not try to grab her and kiss her and cuddle... But once we got our private room, things changed. She was sitting on the bed, we were holding, kissing, hugging... I could be more open, I could let my feelings go (crying)... in the private room, you can open up and be more yourself.”
What are the experiences of patients and partners of patients with a life-limiting illness in relation to sexuality and intimacy?

**Supervised by:** Prof Mary Boulton and Dr Jane Appleton
Methodology and Method

- Heideggerian hermeneutic phenomenology
- Purposive sample of patients and partners
- Motor neurone disease and terminal cancer
- Unstructured conversational interviews
  - Two interviews per person
  - Couples interviewed separately
## Sample

<table>
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<tr>
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<th>Patients</th>
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<th>Partners</th>
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<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
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<td>Female</td>
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<tr>
<td>MND</td>
<td>8</td>
<td>5</td>
<td>5</td>
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<tr>
<td>Cancer</td>
<td>5</td>
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Two cases

Jim (82) and Betty (70)
• Jim – MND 4 years
• Wheelchair dependent
• Only movement was in one finger
• Totally reliant on QDS package of care

Ray (50) and Julie (45)
• Ray – MND 4 years
• Wheelchair dependent
• Only movement was in one shoulder and wrist
• Totally reliant on Julie for all care
• Needed repositioning at night +++
• Non-invasive ventilation at night
Being-towards-death-of-the-couple

Connecting

Disconnecting

Re-connecting
Re-connecting

“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.”
Our role?

“I think it would be nice to be given the choice”

“It brings things to the surface ... things that have been rumbling around in the back of your mind”

“An opportunity to talk if you want to”
Bring up the topic in an appropriate way

• ‘People sometimes have concerns about how their intimate relationship has been affected. Is this something you might find helpful talking about?’

• ‘Some people taking this type of medication / having this treatment find that it has reduced their interest in sex / sexual feelings / the ability to make love. Is this something that concerns you or your partner?’
**BLISSS**

- Bring up the topic in an appropriate way
- Listen actively to the Individual experience
- Support the individual
- Stimulate communication between partners
- Supply personalised advice and information (if necessary, refer to a specialist)

(de Vocht 2011:99)

to ‘review’ (Taylor and Davis, 2007)
We need to…

- Challenge our assumptions and prejudices
- Overcome our reticence at broaching this subject
- Recognise and overcome our need to ‘fix’ things
- Be comfortable with not being the ‘expert’
- Recognise the experience / expertise within the individual / couple
- Be alongside the individual / couple in distress, creating safety and support in the spirit of boundaried exploration
Practical suggestions

• How is love and affection expressed within your relationship?

• Create a wish-list of things you would like to change within your relationship:
  – What feels manageable / achievable?

• Intimate communication
  – What I like is ... /
  – When you ... I feel ...

• Do they know how you feel / what you have just told me?
  – Would it help to write to your partner?
  – A facilitated conversation?
Organisational considerations

- Challenge assumptions and stereotypes
- Education
- Environment:
  - Who manages the ‘do not disturb’ notices?
  - Locks on the inside of doors?
  - Equitable access to all facilities?
- Sensitivity and confidentiality in written records
  - “Impact on personal relationship discussed”
- Who to refer to?
- Policy development
Treating the whole person

“Don’t just focus on my body, but help with the relationship”

(Matzo and Hijjazi 2009: 279)

“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.”

(Taylor, 2014a: 444)
Communication

Emotional intimacy

Physical affection

Sexual intimacy

‘Sex’
The next step?
Useful resources

- Sexual advice Association
- MND Association
- National Association of People Abused in Childhood
References


Matzo M, Hijjazi K (2009) If you don’t ask me ... don’t expect me to tell. *Journal of Hospice and Palliative Nursing* 11(5) 271-281.


Further Reading

Marie Curie (2016) *Hiding who I am*

University of Nottingham (2015) *The Last Outing*
Nottingham: University of Nottingham.
https://www.nottingham.ac.uk/research/groups/srcc/documents/projects/srcc-project-report-last-outing.pdf
Further reading


