

Supporting Sexual Intimacy in Palliative Care

Isabel White

Email:

isabel.white@rmh.nhs.uk

Bridget Taylor

Email:

bmtaylor@brookes.ac.uk

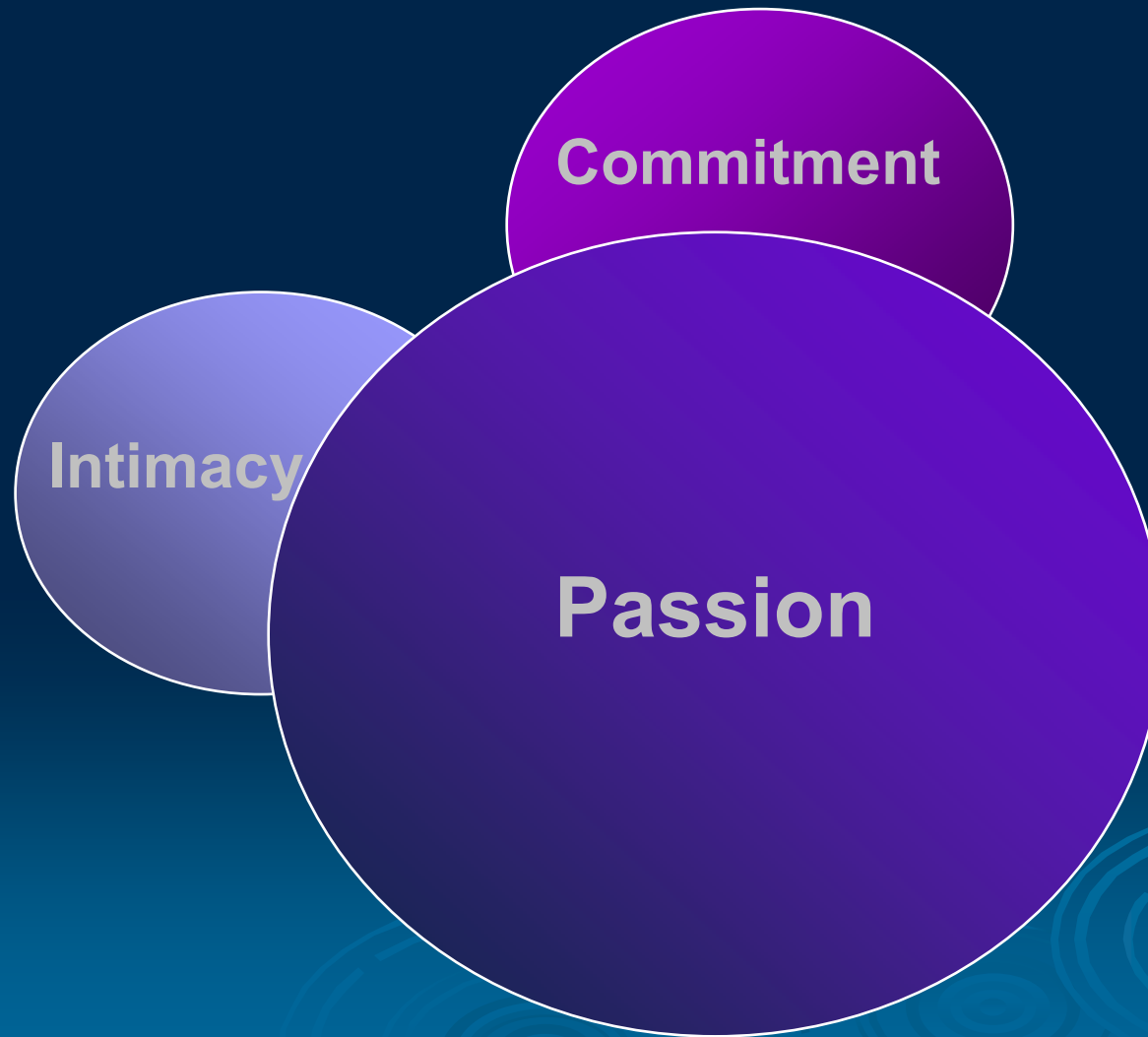
Sternberg's Theory of Love (1986)



Sternberg's Theory of Love (1986)

- Components defined uniquely by individuals
- Good quality relationships usually have a close match between partners' patterns
- Partners need to be able to match our interpretation of love if our needs are to be met
- Interpretations need to be translated into action
- Illness-related circumstances and roles may reshape components to the couple's benefit or detriment

Sternberg's Theory of Love (1986)



Sternberg's Theory of Love (1986)



Commitment vs intimacy

“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)

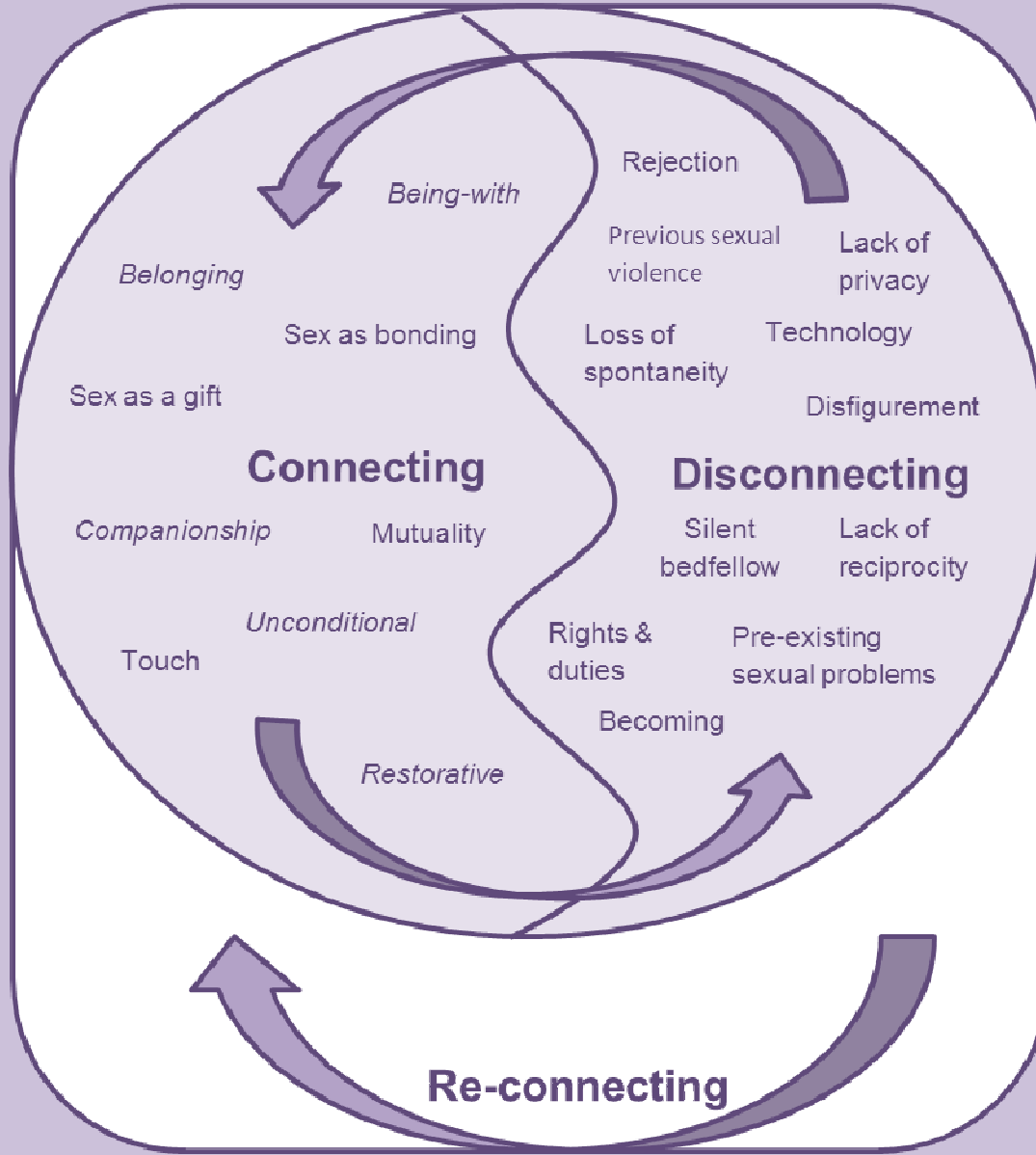




Being-towards-death-of-the-couple

Being-towards-death-of-the-couple

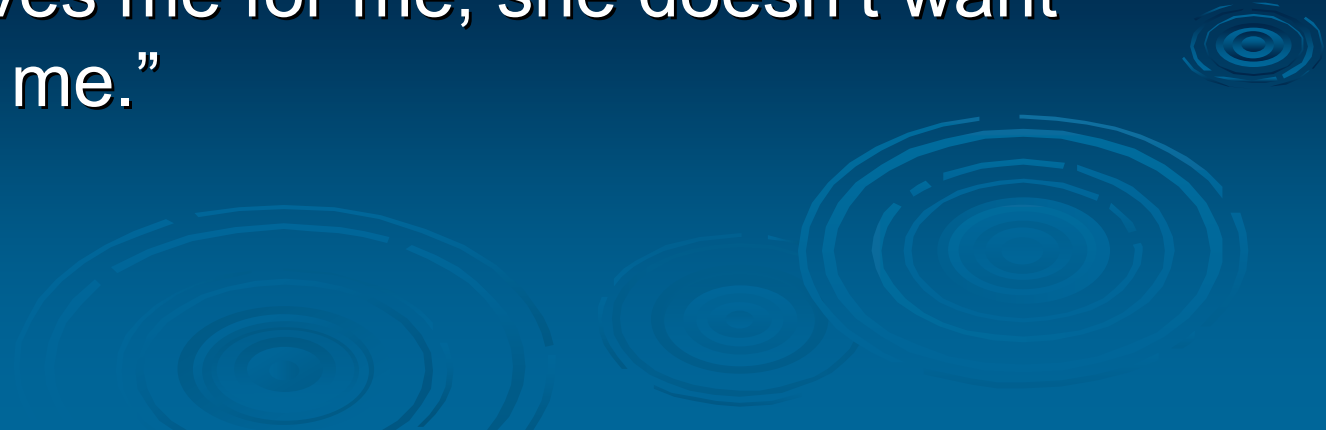
Being-towards-death-of-the-couple



(Taylor 2014)

Connecting

“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.”



Disconnecting

“I felt like I was kissing a stranger. I just felt, um... 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 getaway, which sounds awful. It wasn't Jake... I don't know what else to say, it just wasn't Jake...”



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.”





Permission-giving

- ‘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 comment that it has reduced their interest in sex / sexual feelings / ability to make love. Is that something that is of concern to you / your partner?’


Addressing patients' sexuality requires:

“The humility to be able to listen without needing to know, to take the risk of hearing without the certainty of answers”

(Clifford 1998, p.44)




Permission-giving


- Recognise and overcome our need to 'fix' things
 - Being comfortable with not being the 'expert'
 - Recognise the experience / expertise within the individual / couple
 - Be alongside the individual / couple in distress creating safety & 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 ...
 - Would it help to write to your partner?
- 

Modified Sensate Focus as a vehicle for communication

- Use of touch & feedback to each other about thoughts, sensations & emotions
 - Compassionate communication, acceptance, mutual respect, boundaries
 - Communicate affection & sensuality
 - Create emotional & sexual intimacy
 - Non-coital sexual expression
- 



Organisational Considerations

- Challenging assumptions & stereotypes
- Environment
 - Creating opportunities for privacy
 - Who manages the 'do not disturb' notices?
 - Locks on the inside of doors?
- Sensitivity & confidentiality in written records
 - Need to know basis
 - “The impact on personal relationship discussed”
- Who to refer to?
- Policy development

References

- Clifford D (1998) Psycho-sexual awareness in everyday nursing. *Nursing Standard* 12(39) 42-45.
- Sternberg R (1986) A triangular theory of love. *Psychological Review* 93(2), 119-135.
- Taylor B (2014) Experiences of sexuality and intimacy in terminal illness: A phenomenological study. *Palliative Medicine*. Published online before print January 21, 2014, doi:10.1177/0269216313519489.
- Toombs K. *Living at the Boundary: Healing and Incurable Illness*. 2008 Medical Humanities Lecture, Baylor University, USA.
<http://www.baylor.edu/content/services/document.php/74627.pdf>

Further Reading

- **Foley S, Kope S, Sugrue D (2011)** *Sex Matters for Women: A Complete Guide to Taking Care of Your Sexual Self* (2nd edition). London: The Guildford Press.
- **Kaufman M, Silverberg C, Odette F (2007)** *The Ultimate Guide to Sex and Disability*. San Francisco: Cleis Press Inc.
- **Lemieux L, Kaiser S, Pereira J, Meadows L (2004)** Sexuality in palliative care: patient perspectives. *Palliative Medicine* 18(7) 630-637.
- **Markman H, Stanley S, Blumberg S (2010)** *Fighting for Your Marriage*. San Francisco: Jossey-Bass.

Further reading continued...

- **Marsden R, Taylor B (2012)** Leaflet 20A: *Sex and Relationships: for People Living with MND*. Northampton: Motor Neurone Disease Association. Available from: <http://www.mndassociation.org/life-with-mnd/Everyday%20Living/Sex%20and%20relationships>
- **Marsden R, Taylor B (2012)** Leaflet 20B: *Sex and Relationships: for Partners of People Living with MND*. Northampton: Motor Neurone Disease Association. Available from: <http://www.mndassociation.org/life-with-mnd/Everyday%20Living/Sex%20and%20relationships>
- **Taylor B (2011)** The impact of assistive equipment on intimacy and sexual expression. *British Journal of Occupational Therapy* 74(9) 435-442.