



The impact of equipment on relationships: Lessons for practice

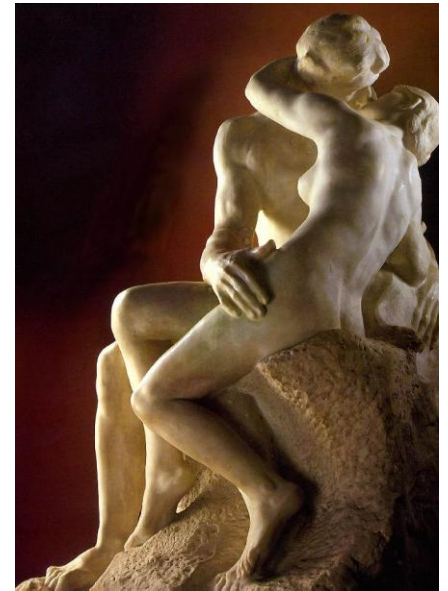
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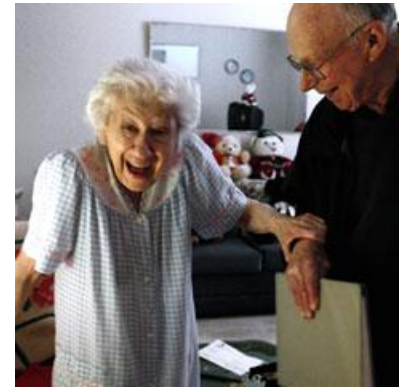
Overview

- Study details
- What do people with MND / ALS and their partners say about equipment?
- Implications for practice



What are the experiences of patients & partners of patients with a life-limiting illness in relation to sexuality and intimacy?

- Heideggerian hermeneutic phenomenology
- 2 interviews
- MND (also terminal cancer)
- 13 Patients: 8 male, 5 female
Aged 46 – 82 years
- 10 partners: 5 male, 5 female
Aged 32 – 76 years



The importance of touch





Equipment's disabling effects



Attempts to overcome the barriers



The impact of light-writers on relationships



The invasiveness of non-invasive ventilation



A role for health care professionals?

“I think it would have to be somebody that you felt empathy with to discuss it. I mean I wouldn't sort of want an OT 'cause I mean they can change so often, popping in and saying, 'now I think I'll fit the loo rail' and then 'how's your sex life?'”

Ex-PLISSIT: The Extended PLISSIT Model

- **P**ermission
- **L**imited **I**nformation
- **S**pecific **S**uggestions
- **I**ntensive **T**herapy
- Reflect
- Review

(Davis & Taylor, 2006)

Just some examples...

Permission-giving

Sometimes people with MND have concerns or questions about how this will affect their sexual relationship. Is there anything you'd like to ask me or talk about?

Limited Information

Having a hospital bed provides many advantages. However, it may also have an impact upon your relationship as a couple

... follow with further permission-giving

Specific Suggestions

- Alternative ways of showing love & affection
- Sign language for 'I love you'

ALS Functional Rating Scale (ALS FRS)

(Haverkamp et al, 1995)

- Speech
- Saliva
- Swallowing
- Handwriting
- Cutting food & handling utensils
- Dressing & hygiene
- Walking
- Climbing stairs
- Breathing
- Turning in bed & adjusting bed clothes

Take home message



- Equipment can impede verbal and physical intimacy
- Addressing sexuality is essential if we are to provide **holistic care**
- We need to reflect on barriers that prevent us from doing this and give people **permission** to talk about this important part of their relationship

References

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