

**Sexuality – One
of the remaining
taboos?**

A painting of a couple sitting together in a dimly lit room, reading a book. The man is on the left, wearing a red jacket, and the woman is on the right, wearing a red top. They are both looking at the book. The room is dark, with a small table in the foreground holding a bowl of fruit and a vase of purple flowers. The overall mood is intimate and quiet.

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Overview



- My professional experience
- Definition of Sexuality
- Sexuality and the literature
- My research experience
- Reflections for the way forward

Professional Experience



Professional Experience



Professional Experience



- 48yr old lady, Metastatic Breast Cancer

Professional Experience



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 - Cachexia, Ascites, Bilateral Mastectomy scars

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Professional Experience



- 48yr old lady, Metastatic Breast Cancer
 - Cachexia, Ascites, Bilateral Mastectomy scars“Should I show my husband?”

- 76yr old widow, Vulval Cancer,
 - Fungating wound, total pain“I don’t feel like a woman anymore”

What is Sexuality?



- “a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction” WHO Draft Definition (2002)
- Sex is something we do, sexuality is something we are! Girts (1990)

Sexuality and Age



- Sexual desire and activity persist into old age

Gregoire 1999, Nicolosi et al 2004

- Presence of sexual partner more important than age in determining sexual activity

Nishimoto 1995

- Sexual dysfunction tends to increase with age, especially in men

Nicolosi 2004

Sexuality and Cancer



- Many studies in cancer survivors
- Focus on physical problems resulting from disease process or treatments
- Cancer patients are more likely to abandon sexual activity before they are emotionally ready to do so

Anderson and van der Does (1994)

Initiating Discussions..



- Few medical professionals engage in discussion about sexuality after cancer treatment

Watkins et al (1998), Bergmak et al (1999), Stead et al (2002)

- Sexuality is not really a medical concern

Butler et al (1998), Burbie et al(1992), Rogers et al (2002)

- Evidence of unmet information needs relating to sexual issues

Stead et al (2002) Butler et al (1998), Lemieux (2004)

- Easier for highly reflexive patients to ask?

Horden A, Street A. 2007

Sexuality and Palliative Care



- Rarely explored in a palliative care setting

Wells, P. 2002, EJPC, 9;3: 119-122

Yaniv, H. 1995, EJPC, 2;2: 72

- Difficult for both patients and staff to discuss

“I am so shy to ask them and maybe the same with them..”

“Never saw a doctor change to so many different colours of red in all your life”

Lemieux et al. 2004.
Palliative Medicine, 18;7:



- *“a holistic approach to palliative care would include opportunities to discuss the impact of their illness on their sexuality”*

In an Irish Context...



- What would you want to be talking to dying people about sex for?!

My research



- To explore the experience of health professionals in dealing with patients' sexuality issues.
- To explore the perceptions of health professionals regarding the importance of sexuality for Irish Palliative Care patients.
- To develop a patient questionnaire to establish whether concerns relating to sexuality are important to Irish Palliative Care patients

Methodology



- Phase 1: Focus group study with health care professionals working palliative care
- Phase 2: Postal questionnaire to home care and day care patients, Our Lady's Hospice, Harold's Cross

Focus Group Study



- 3 focus groups with health professionals
- Exploring the perceptions of Health Professionals (HPs) of the importance of sexuality to Irish Palliative Care patients
- Analysis of data
 - Thematic content analysis (Burnard 1991)
 - Coding of data with “emergence” of categories from the data
 - Initial codes → Final codes → Categories → Themes
 - Validity check

Questionnaire Study



- Questionnaire developed using themes from the focus group study
- 17 questions developed, including two free-text boxes and the General Health Questionnaire (GHQ-12)

Questionnaire Content



- Aspects of sexuality, changes in these and their importance
- Existing concerns relating to sexuality and role of health professional
- Unspoken need
- Experience of loss
- Sense of wellbeing (GHQ-12)
- Demographic data

Results

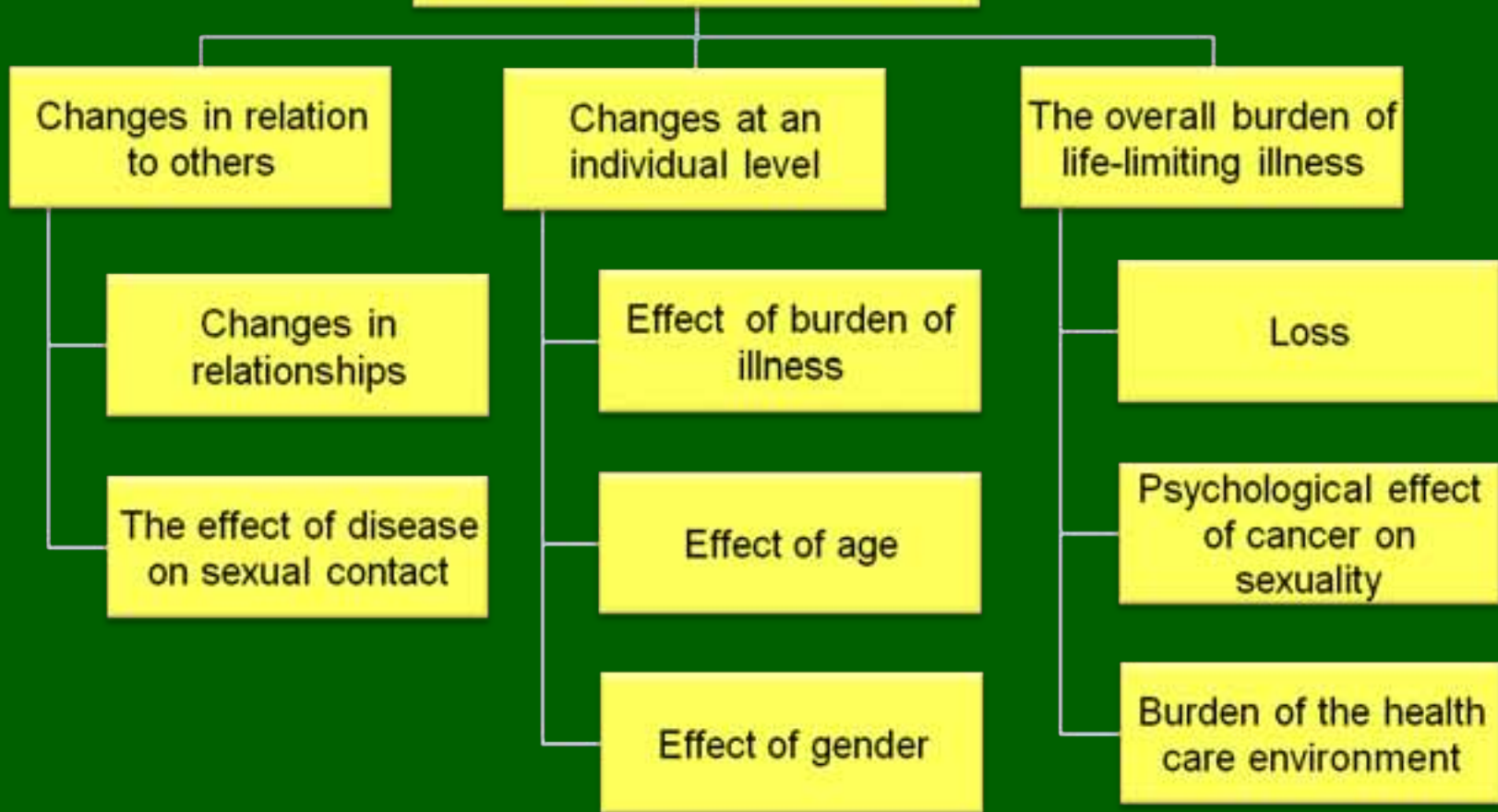


Focus Group Study

Theme 1



The impact of loss and change on sexuality



Nurse

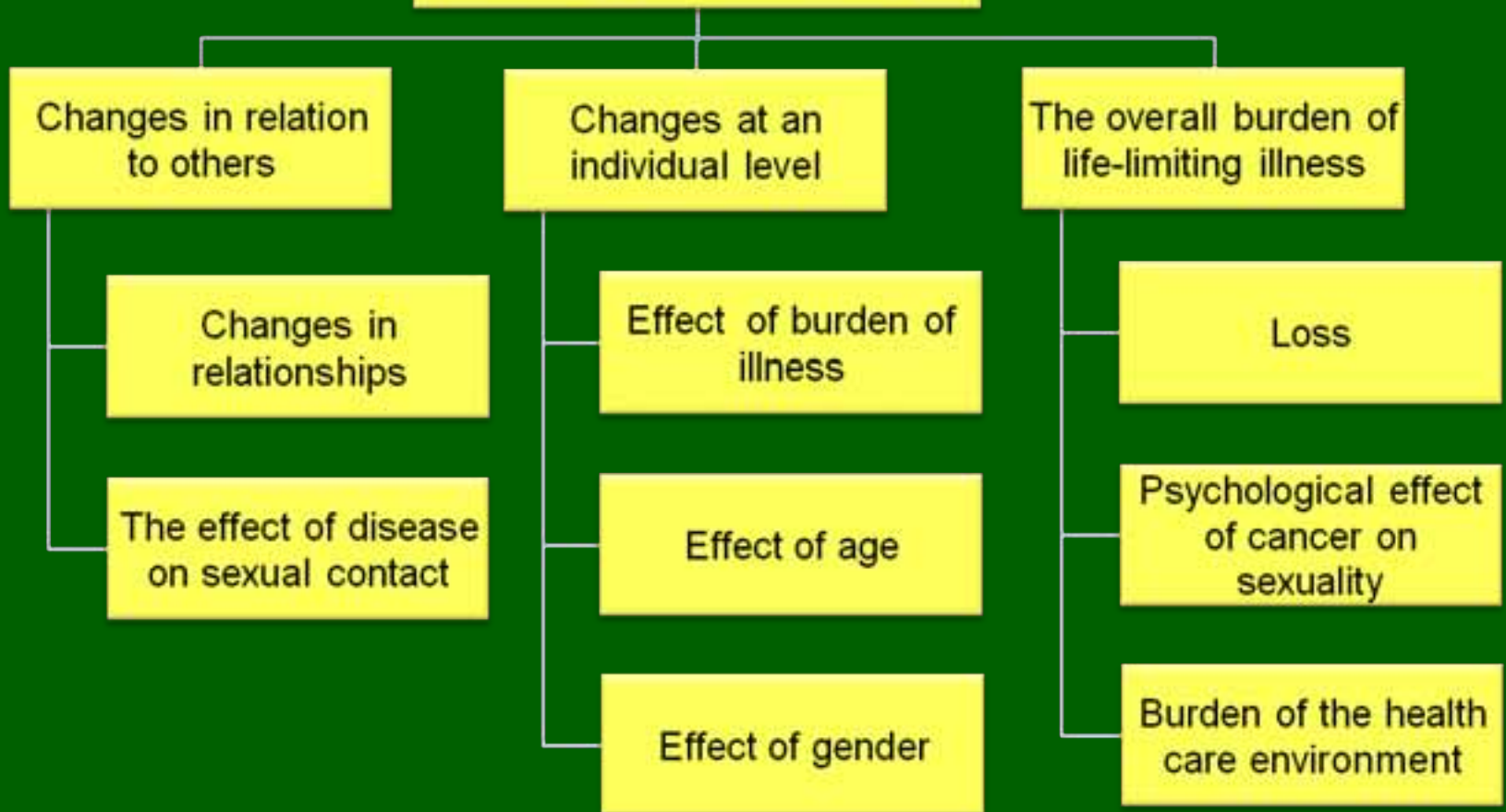


- *“Whether it is spoken or unspoken there must be some wondering about are you still attractive as a person because you have this physical problem - a weeping leg or a colostomy bag...”*

Theme 1



The impact of loss and change on sexuality



Social Worker



Social Worker



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Social Worker



Social Worker

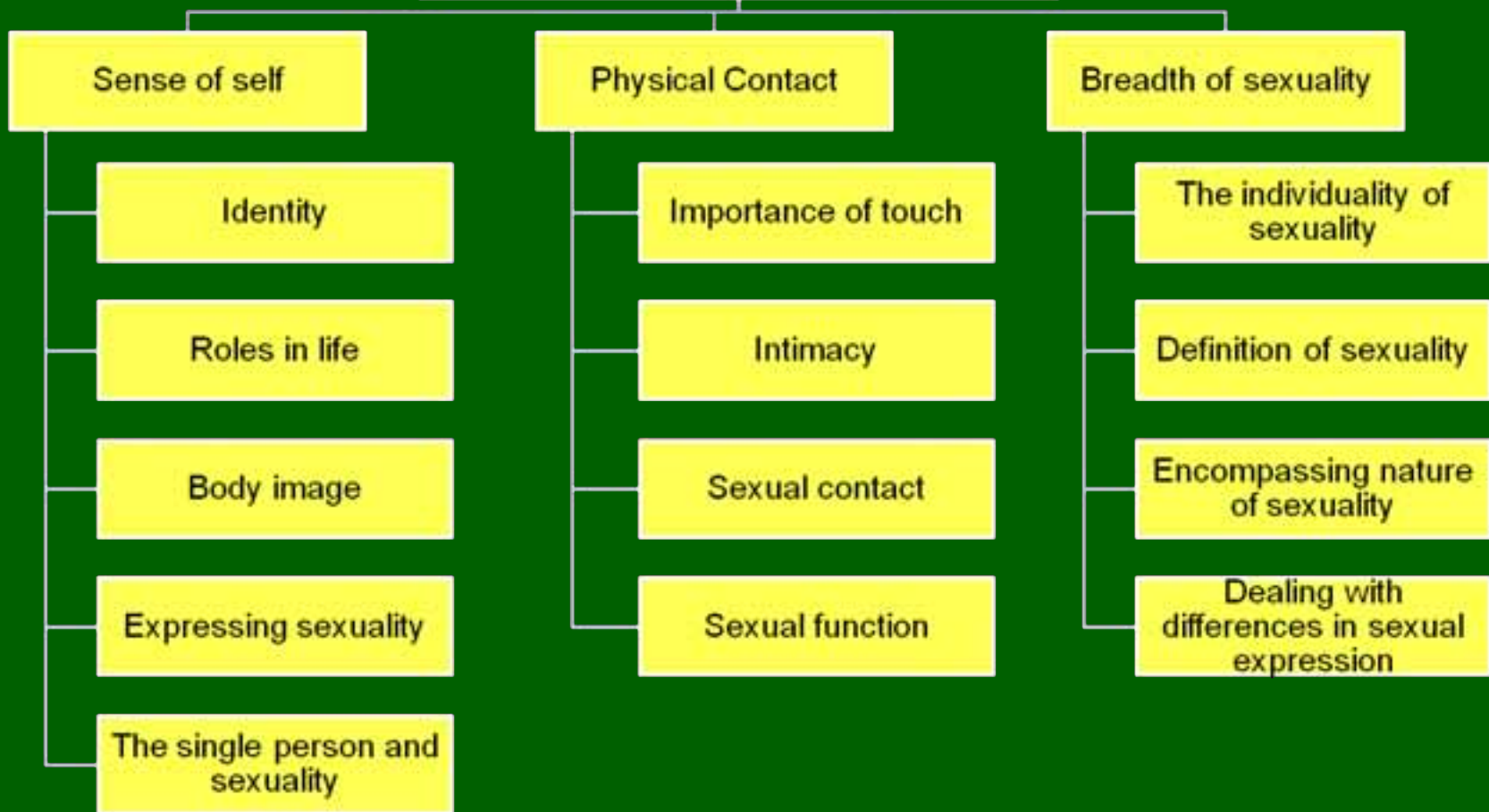


- *“They had been trying to have children hadn’t managed to conceive and now this was the final insult and this was a really strong statement.”*

Theme 2



The diversity of sexuality



Nurses..



Nurses..



Nurses..



- *“I think it can’t be defined it’s a very broad area everyone’s sexuality is individual to them so if you are addressing the issue of sexuality first you have to identify what it is for someone.”*

Nurses..



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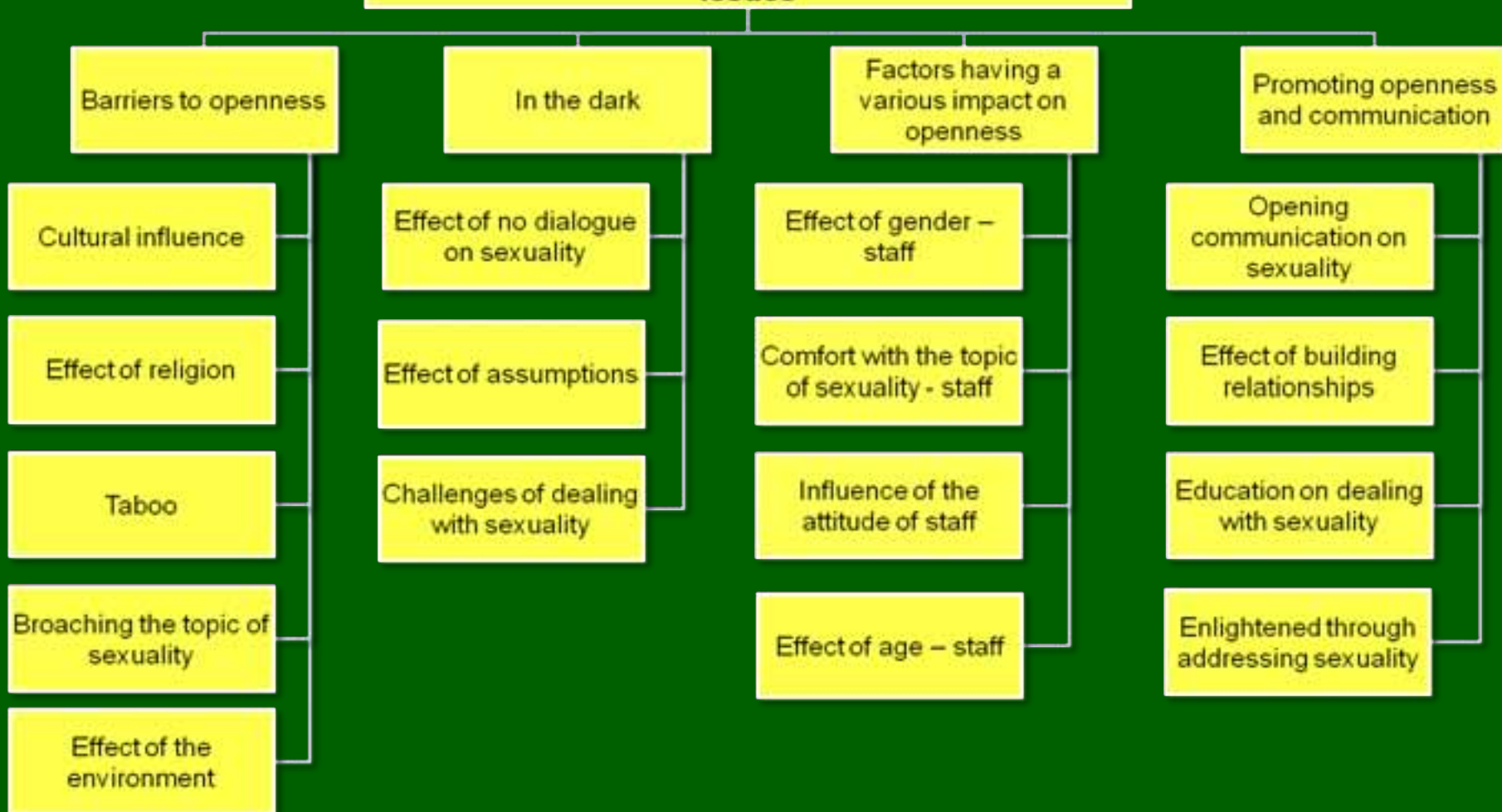


- *“I think it can’t be defined it’s a very broad area everyone’s sexuality is individual to them so if you are addressing the issue of sexuality first you have to identify what it is for someone.”*
- *“... as someone said to me one day ... ‘at least I know I’m still alive in some way or that somebody still loves me’.”*

Theme 3



Coming out of the dark – shedding light on sexual issues



Nurses



Nurses



Nurses



- *“I didn’t know how to answer her, and I just gave her some answer that was up in the air - it wasn’t an answer...but I think it was the Irish upbringing – it was just something you didn’t talk about.”*

Nurses



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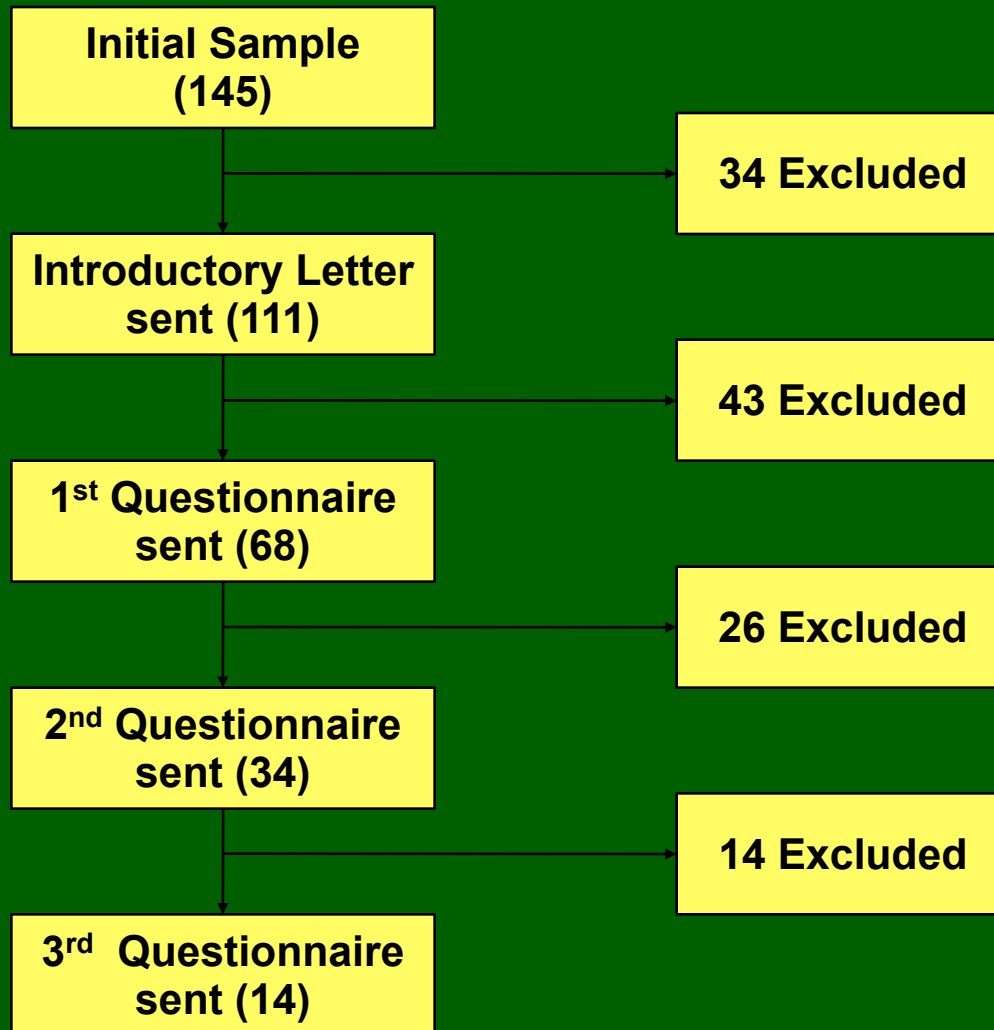


- *“I didn’t know how to answer her, and I just gave her some answer that was up in the air - it wasn’t an answer...but I think it was the Irish upbringing – it was just something you didn’t talk about.”*
- *“But I suppose... maybe we presume that all the sexuality questions might have been dealt with in the acute hospital, when they were going for their treatment?”*

Results



Questionnaire Study



Returned Questionnaires



- 15 returned (13.5% response rate)
- 9 female, 6 male – Average age 62.9
- Diagnosis
 - Breast Cancer 4
 - Colon Cancer 3
 - Prostate 2
 - Stomach, Pancreatic, Unknown, Renal Cell, GB
- Married 8, Single 2, Widowed 4, Same Sex relationship 1

Main Findings



- 4 patients had concerns about their sexuality
- 1 patient had been asked about sexuality by a social worker
- 8 felt it was appropriate for Health professionals to ask about sexuality
- 5 patients did not want any information/discussion around sexuality
- General Health Questionnaire -12: average score 3
- Most significant loss: Independence

Why the Low Response Rate?



- Questionnaire design or administration?
 - Contained questions of a sensitive nature
 - Gave the respondent an option to opt out of the study (Streiner and Norman)
- Unfamiliar with principal investigator?
 - Terry et al. *Int Med J* 36(2006)406-413
 - Importance of health worker-patient relationship Shover et al (1995), Dittemar (1989)
- Need for face to face contact?
 - Ananth et al. *Palliative Medicine* 2003; 17:202-205



- Cultural effect?
 - sexuality is specific to a given culture and hence shaped by the society in which it exists (Foucault 1979; Gagnon & Simon 1973)
 - Unwritten rule... “sick people are not sexual” (Shell 2008)
- Influence of the Catholic Church?
 - “left a generation of Irish women with poor sexual literacy” (Lavin & Hyde 2006)

Why address sexuality at all?



- *“being treated as an asexual being because of age or illness by health care providers can be a powerful experience for someone whose sexuality is already traumatised and vulnerable”*

MacElveen, McCorkle 1985

Sexuality Vs Personhood



Sexuality Vs Personhood



- Personhood
 - *The state of being an individual or having human characteristics and feelings*
- Sexuality
 - *A broader definition*
 - *Ensures more “aspects” of a person are considered*

Reflections



- Awareness of own views and comfort level
- Importance of establishing relationships
 - Not a “tick the box” exercise
 - “establishing a relationship between the interviewer and the patient to allow for an honest and open discussion of sexuality issues” (Stausmire, 2004)
- Importance of education for health professionals
 - e.g. use of PLISSIT model



Thank you!