

ADDRESSING SEXUAL HEALTH AND WELLBEING IN PATIENTS WITH ADVANCED CANCER

Dr. Miriam Colleran
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SHIFTING SANDS ... PALLIATIVE CARE & QOL

-You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die.



'Even if I'm dying, until I actually die, I'm still living.'

PAUL KALANITHI



- QoL - an end point of secondary importance only to survival (ASCO, JCO 1996; 14:671-679).

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SHIFTING SANDS: SEXUAL HEALTH & QOL

Shared personal experiences

'The most difficult thing is the loss of physical contact; not being able to make love to my wife is almost unbelievable'

Christopher Reeve post neck injury. RIP



'Of course she missed her breast... this is, in general, the most difficult and often agonizing problem for a woman with breast cancer. It can devastate her self-image and virtually nullify her sex drive, since she often feels completely "undesirable".'



Research

- 27,500 people in 29 countries, 82% of men and 76% of women agreed that **"satisfactory sex is essential to maintain a relationship"** (Nicolosi et al. Global Study of Sexual Attitudes and Behaviors, Urology 2004)

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• But what is sexuality?

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SEXUALITY WHO WORKING DEFINITION 2006A

" a central aspect of being human encompasses sex, gender identities and roles, sexual orientation

..... expressed in thoughts, fantasies practices, roles and relationships....

... biological, psychological political and religious and spiritual factors."



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LUCY KALANITHI, EPILOGUE IN WHEN BREATH BECOMES AIR, P212

"I thought of our cozy bed empty at home, remembered falling in love in New haven twelve years earlier, surprised right away by how well our bodies and limbs fit together, and thought how ever since, we'd both slept best when entwined."



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RESEARCH IN PATIENTS ON CANCER AND SEXUALITY

- Body image
- Early
- Mixed stages
- Survivorship
- Advanced cancer - very limited at the time of onset of study. Audit



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LEMIEUX L, KAISER S, PEREIRA J, MEADOWS LM. PALLIATIVE MEDICINE 2004

- Emotional connection
- Validation
- More emphasis on verbal / non-intercourse forms of intimacy
- Progressive disease-↓ frequency of sexual intercourse

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NOVAN & MORAG 2003 PROSTATE CANCER



'I'm trying to forget all the sexual pleasures I used to have. Whenever these thoughts cross my mind, it only adds to the grief, so I simply try to get rid of them. I would convince myself that, even without hormonal treatment, at my age there would anyway have been a drop in my sexual capacity. It happens with many older men who haven't undergone that treatment.'

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OBJECTIVE:

- To assess the impact of advanced cancer on the sexual health of patients with advanced cancer & the coping methods used.

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METHOD:

- A purposeful, random sample of patients with advanced cancer admitted throughout a specialist palliative care service were invited to participate
- November 2006 to April 2007
- Interviews were digitally recorded and transcribed verbatim
- Recruitment stopped when data saturation was reached
- Data was analysed using Grounded Theory to identify the codes, categories & themes
- Triangulation. Copies of interview offered to participants
- Consent to use quotations in writing & recordings.

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THE STANDARDIZED OPEN-ENDED INTERVIEW:

- How old are you?
- What type of cancer do you have?
- When was it diagnosed?
- Have you had any treatments for it?
- When did you last have treatment for your cancer?
- Used you work outside the home?
- Are you still working outside the home?
- How long are you with your partner?
- Do you have any children?
- Do you think that your cancer has affected you physically?
- Do you think that your cancer has affected you emotionally?

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THE SEMI-STRUCTURED INTERVIEW GUIDE - PATIENTS 13

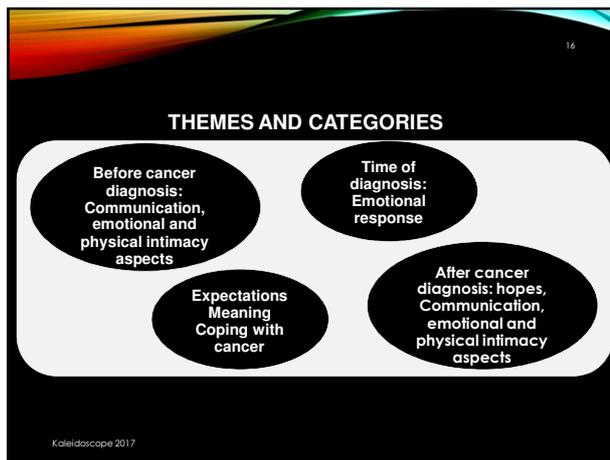
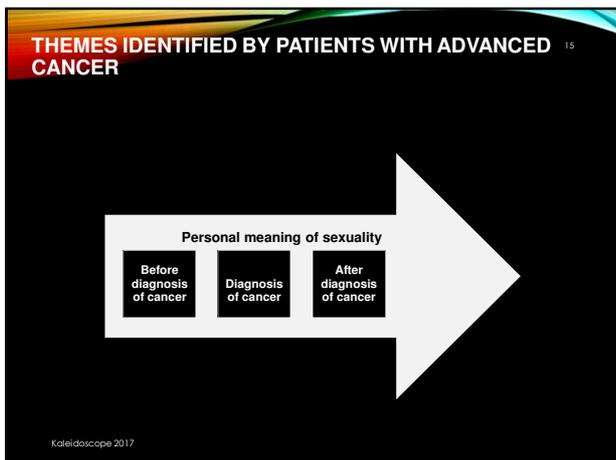
- Body image
- Self esteem
- Issues concerning the participants' emotional relationship with their partner- does the participant perceive that their relationship has changed as their cancer has progressed?
- Does the participant perceive that these changes have been positive or negative?
- Issues concerning the participants' physical relationship with their partner- does the participant perceive that their relationship has changed as their cancer has progressed?
- Does the participant perceive that these changes have been positive or negative?
- The strategies used by the participant in coping with physical, emotional changes both as an individual and in their relationship- including denial, avoidance, open communication, increased emphasis on non-intercourse means of expressing affection such as hugging or kissing

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RESULTS: 14

- 12 patients were included (One interview was excluded due to technical difficulties)
- Themes identified included:
 - individualised meaning and value of sexuality
 - Anticipation of changing intimacy and sexual expression with age, illness, marital status and relationship duration

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THEME: PERSONAL MEANING OF SEXUALITY
CATEGORY: PERSONAL DEFINITIONS

Womanhood:	Patient 3:	"I don't know really, it's, it just means to me that I had two children and I was happy."
Manhood:	Patient 2:	"Well, well obvious, one obvious thing would be of course whether I would get erections."

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THEME: PERSONAL MEANING OF SEXUALITY 18
CATEGORY: EXPECTATIONS OF SEXUALITY WITH AGING

'This question of my age... I am prepared to accept that, eh, sexuality does not play an important part in my life, in my thinking.'
Patient 2, a 77 year old man with prostate cancer

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THEME: PERSONAL MEANING OF SEXUALITY 19

CATEGORY: SHIFTING SANDS IN ATTITUDES TO SEXUAL INTIMACY

"I was married for three weeks before I interfered with my wife. Does that answer your question?"

....

"Before I ... before I molested her or had sex. So ... that answers your question."

Patient 6, a 73 year old married man with lung cancer, discussing consensual sex with his wife. Valued self control & self discipline over sexual activity

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THEME: DIAGNOSIS OF CANCER 20

CATEGORY: EMOTIONAL IMPACT

"Apparently this type of cancer is a death sentence."

Patient 6, a 73 year old married man with lung cancer

"With the brain, I was given six months."

Patient 5, a 33 year old married woman with metastatic breast cancer

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THEME: BEFORE CANCER 21

CATEGORY: COUPLES AND TEAMWORK



"... When it came to, eh, well like her experience with the cancer, I done what I could at that time... helpin' and...I wasn't able to do a great deal but I paid a lot more attention to situations than I wouldn't have normally in that respect ..."

Patient 6, a 73 year old man with non-small cell lung cancer



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THEME: BEFORE CANCER 22

CATEGORY: COMMUNICATION FOR PATIENTS IN RELATIONSHIPS

"... Oh that's always the case. Oh people always say (patient 5) name and (husband) row the whole time but we love each other you know. Like he, he's a, we're just different personalities for a couple who ended up together. We definitely are but that's normal for us ..."

Patient 5, a 33 year married woman with advanced breast cancer.

Patient 1, a 76 year old married man with small cell lung cancer – shared a story of their wedding day

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THEME: BEFORE CANCER 23

CATEGORY: EMOTIONAL INTIMACY

"... He used to think the world of me, I know he did. Yeah and I loved him too. He was a good man but I suppose you have to be grateful to God for what you get, don't you? We had a lovely life ..." Patient 4, 74 year old woman with breast cancer

Single:

"... She (daughter) is the only, em, female companion ... For quite a number of years..." Patient 2, separated man with prostate cancer

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THEME: BEFORE CANCER 24

CATEGORY: PHYSICAL INTIMACY

"...We were in the one room but in separate beds and with the... we had no problem with that. Em, I'm a light sleeper and during the night if she had to get up and attend to business, she'd wake me and that easily mean an hour before I'd get back to sleep. Now she'd have only hit the bed and you'd hear her snoring. Now I often wish I could do that. (laughs) But to solve that problem, my attitude was move into the other small room ..." Patient 6, a 73 year old married man with lung cancer

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THEME: BEFORE CANCER 25

CATEGORY: SEXUAL ACTIVITY



"I don't know. It just seemed to cool down ... No, no, no, didn't bother any more. ... I didn't miss anything of that 'cos I know I had love for him anyway, you know" Patient 9, 77 year old married man with lung cancer

'I was not very good in performance'

- Patient 2, 77year old man with prostate cancer, separated

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THEME: DIAGNOSIS OF CANCER

CATEGORY: EMOTIONAL IMPACT OF DIAGNOSIS



- 'It was, it was, em...numbing, I suppose...because you're upset but you're not really...you don't really know what it is.' Patient 2, 77year old man with prostate cancer
- 'Nobody wants my emotions on top of them nor do I want to be loading them on to everybody else' Patient 2, 77year old man with prostate cancer

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THEME: AFTER CANCER 27

CATEGORY: IMPACT OF CANCER & TREATMENT

- Fatigue
- Pain
- Impaired mobility
- Dyspnoea
- Hair loss
- Hirsutism
- Loss of height- patient with myeloma
- Colostomy, urinary catheter
- Segmentectomy, radiotherapy

'I've wondered to what extent this hormone treatment has effected me....in the question...of my maleness.' Patient 2, 77year old man with prostate cancer

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THEME: AFTER DIAGNOSIS OF CANCER 28

CATEGORY: BODY IMAGE

- "I went and got electrolysis ... I went in for, oh, I (pause) spent a good fortune on it (laughed)... but I didn't care ... Every, every bit of pain was worth it ..."

Patient 8, a 48 year old single woman with multiple myeloma on steroid-related hirsutism

- Patient 4 a 74 year old widow discussed her mastectomy for breast cancer

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THEME: AFTER DIAGNOSIS OF CANCER 29

CATEGORY: SINGLE PATIENTS WITH ADVANCED CANCER & HOPES OF FUTURE ROMANCE

- "There I was, you know and all of a sudden then, that whole area of life was gone, among a lot of things. But, I just got on with it."

Patient 8, a 49 year old single woman with multiple myeloma



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THEME: AFTER THE DIAGNOSIS OF CANCER 30

CATEGORIES:

- Communication as a couple

"He always put me first, you know, so I'd say that's love to me. I feel I had love up to the end ... you know it didn't show you sex-ways but I had it. I feel I had it." Patient 4, a 74 year old woman widowed after her mastectomy

- Non-intercourse intimate touch
- Shared bed - Patient 5, a 33 year old married mother with metastatic breast cancer

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THEME: AFTER THE DIAGNOSIS OF CANCER 31

CATEGORY: SEXUAL INTIMACY

- Reprioritisation
"Just to be bothered about sex ... there'd be more on the mind than that."
 Patient 6, a 73 year old married man with lung cancer
- *"We still have a sex life, eh, (pause) maybe not exactly as it used to be but (long pause) that's to be understood, you know ... (pause) Your mind is preoccupied with other things."*
 Patient 7, a 57 year old married man with lung cancer



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THEME: AFTER DIAGNOSIS 32

CATEGORY: EMOTIONAL RESPONSE TO ADVANCED CANCER JOURNEY

“... I don't know what it is, but I don't let it, I just keep going and, eh, you know, I don't wallow in things really, I think I have changed with all of this. Well, I knew, I mean I think I'm tougher or something. Nothing makes, makes me cry nearly now” Patient 8, 49 year old single woman with multiple myeloma

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THEME: AFTER DIAGNOSIS 33

CATEGORY: EMOTIONAL RESPONSE TO ADVANCED CANCER JOURNEY

- “Em, I feel, not like a child, but I feel so helpless and, eh, like a burden if you like, to, to not being able to do that...”
 Patient 6, a 73 year old man with lung cancer
- “Well, what can I do, you know? If I wake up tomorrow morning, it's a bonus ... and adopt that frame of mind about it ...” Patient 6

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THEME: AFTER DIAGNOSIS 34

CATEGORY: EMOTIONAL RESPONSE TO ADVANCED CANCER JOURNEY

“... Emotion, I mean I look at my, my three year old son and I just think, I'm sorry for being upset ... He's three, you know I just think it's so unfair that life is like this. ...”
 Patient 5, a 33 year old married woman with breast cancer

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THEME: AFTER DIAGNOSIS 35

CATEGORY: COPING, SHIFTING EMPATHY

“... I'm not going to know if anything happens to me but my family will and he will and he's only three. (voice quivering) So, definitely, I wouldn't say I'm depressed I, most of the time because I want a normality at this time. Whatever happens happens, you never know. But sometimes you do get your moments where you think but it's just for him as a child, it's so unfair. It's so unfair for my husband but he's not my blood relation, he's not my child. You know so that is upsetting definitely, definitely.” Patient 5, a 33 year old married mother with breast cancer, tearful, mild chuckle

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THEME: AFTER DIAGNOSIS OF CANCER 36

CATEGORY: IMPACT ON LIFESTYLE & QOL

‘So one could say on the one hand, my quality of life has been pretty, pretty good but I...how do you measure that?...what quality of life should I be expecting?’
 □ Patient 2, 77year old man with prostate cancer

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THEME: AFTER CANCER 37

CATEGORY: SHIFTING SANDS OF BODY IMAGE

- Breast surgery
- 'That didn't worry me greatly, eh, the notion of actually losing my hair.' Patient 2, 77 y.o. man with prostate cancer
- 'I'm not a mirror man... I like to look alright when I'm going out with (wife's name), of course' Patient 1, 76 y.o. man with small cell lung ca.

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THEME: AFTER DIAGNOSIS 38

CATEGORY: SHIFTING SANDS & COPING WITH CANCER

- Endogenous Coping
 - Humour
 - Re-prioritisation
 - Belief systems including religiosity
- Exogenous supports
 - Spouse
 - Family and friends
 - Healthcare professionals

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THEME: AFTER CANCER DIAGNOSIS 39

CATEGORY: SINGLE PATIENTS WITH ADVANCED CANCER

“ ... You know well from the time when somebody might give you the odd glance. (interviewer: 'the eye,' yeah) 'the eye,' I mean I know that's gone, but I don't care, accept it. But, em, it all happened, you see, in one bang for me. It was weird, I often think, you know, there I was, you know and all of a sudden then, that whole area of life was gone, among a lot of things. But, I just got on with it ...” Patient 8, a 49 year old single woman with multiple myeloma.

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THEME: AFTER THE DIAGNOSIS OF CANCER 40

CATEGORY: IMPACT ON EMOTIONAL ASPECT OF RELATIONSHIP

• 'Strengthened it mainly.' Patient 1, 76 year old married man with small cell lung cancer



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THEME: AFTER DIAGNOSIS OF CANCER 41

CATEGORY: INTIMACY - PHYSICAL

- Non-intercourse intimate touch
- Shared bed
- Sexual intercourse “And anyhow I don't think even had I been that way inclined prior to last May when I found out all this information, I think that would have put an end to that. You'd have more concerns or, eh, or you'd have had a wider window to look at. Well... just to be bothered about sex ... there'd be more on the mind than that I would think... well as I say I can only speak for myself.” Patient 6, a 73 year old married man with lung cancer

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THEME: AFTER DIAGNOSIS OF CANCER 42

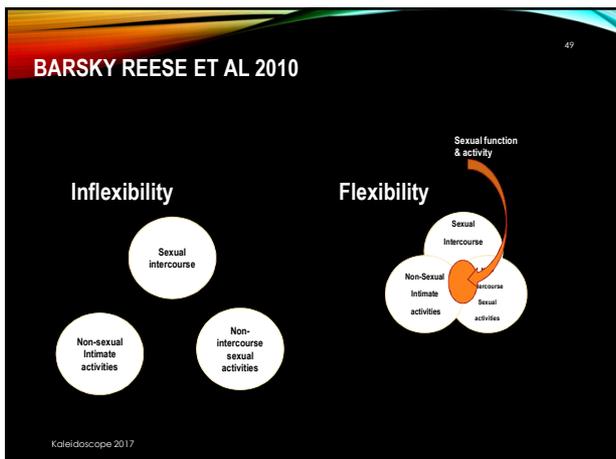
CATEGORY: THERAPEUTIC DIALOGUE REGARDING THE IMPACT ON SEXUALITY

“... I suppose, I suppose it wouldn't be any harm to ask them...I don't know...I don't know has it effected my sexuality...I mean I don't feel any less of a man than when I hadn't got the cancer. I just feel a little bit unfortunate that I did get ...” Patient 7, a 57 year old married man with lung cancer

If they could talk to one of them, suggest that they talk to both ... because obviously the partner would feeling it as well.

Patient 12, a separated 49 year old woman with advanced bowel cancer

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- CONCLUSIONS:**
- ▶ Life before and after the diagnosis of cancer
 - ▶ Personal definitions of sexuality
 - ▶ Holistic nature of sexuality
 - ▶ Impact is individualised and variable
 - ▶ Influencing factors
 - ▶ Shifting sands in expectations of sexuality over time & with age & illness
 - ▶ Sexuality is an aspect of quality of life for patients
 - ▶ Patients want to discuss the impact of advanced cancer on their sexuality
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