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## Nurses' perceptions of providing psychosexual care for women experiencing gynaecological cancer



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#### ABSTRACT

*Purpose*: To gain insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment and how this aligns with nurses globally. *Methods*: A qualitative descriptive design was chosen to facilitate insight into nurses' perspectives of their reality. Seventeen nurses working at a tertiary women's hospital in Western Australia participated in one-on-one interviews and were asked to describe their perceptions and identify factors that facilitate or challenge psychosexual care provision.

Results: Data analysis revealed five themes affecting the provision of psychosexual care: (1) Nurses use strategies to aid the conversation (subthemes: supporting the woman, facilitating engagement); (2) Women have unique psychosexual needs (subthemes: diversity, receptiveness); (3) Nurses are influenced by personal and professional experience and values (subthemes: confidence, values, making assumptions); (4) Systems within the health service affect care (subthemes: being supported by the system, working as a team); and (5) Society influences attitudes around sexuality. Nurses' views differed around whether these factors had a positive or negative impact on the conversation required to provide this care.

Conclusions: Factors influencing nurses' provision of psychosexual care are multifaceted and differ amongst nurses. Recommended strategies to improve service provision include guidelines and documentation to integrate assessment of psychosexual issues as standard care, encouraging shared responsibility of psychosexual care amongst the multidisciplinary team and implementing education programs focussed on improving nurses' confidence and communication skills.

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#### 1. Background

It is estimated over 6000 Australian women will be diagnosed with gynaecological cancer in 2017 (Cancer Australia, 2017). Recent incidence figures show similarities between Australia and major European countries. In 2013, 40 Australian women per 100,000 were diagnosed, compared with 2012 European statistics stating 44, 37 and 34 per 100,000 women were diagnosed in the United Kingdom (UK), Germany and France respectively (International Agency for Research on Cancer, 2012). Due to the nature of the disease and treatment effects, gynaecological cancer can present

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significant challenges to a woman's sexuality.

Sexuality is complex and affects individuals in a unique way. It is a central aspect to being human and encompasses not only sexual function but a variety of dimensions core to a woman's sexual identity (World Health Organisation, 2006). In gynaecological cancer, the organs affected are those which a woman typically identifies as central to her sense of being female (Wilmoth and Spinelli, 2000). Gynaecological cancer is also known to have physical effects on sexual function, fertility and reproduction, hormonal changes, fatigue and bladder and bowel disturbances (Abbott-Anderson and Kwekkeboom, 2012; Gilbert et al., 2011; Grimm et al., 2015; Hopkins et al., 2015; Lee et al., 2015; Wilmoth and Spinelli, 2000).

A systematic review reported the sexual concerns of gynaecological cancer survivors spanning physical, psychological and social domains (Abbott-Anderson and Kwekkeboom, 2012). Many physical concerns related to dyspareunia, including decreased sexual

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activity and satisfaction, difficulties with arousal and orgasm, and vaginal issues. The physical domain also included menopausal symptoms, post-coital bleeding, fatigue and continence issues. Within the psychological domain were decreased interest or enjoyment of sexual activity, poor body image and fear. Social concerns highlighted the significant effect gynaecological cancer can have on relationships. Communication difficulties, perceived changes around interest in sexual activity and maintaining previous roles and expectations were identified.

The extent to which sexuality is affected by gynaecological cancer is inconsistent within international literature (Gilbert et al., 2011). Some studies report low numbers of women affected (Barlow et al., 2014; Kim et al., 2015; Weijmar Schultz et al., 1990), some found around half of women were affected (Grimm et al., 2015; Hopkins et al., 2015; McCallum et al., 2014; Wilmoth et al., 2011), whereas others suggested most or all women report psychosexual issues as a result of their cancer (Cleary et al., 2011; Lara et al., 2012).

Inconsistencies may be attributed in part to how the term sexuality is defined with some studies focussing specifically on sexual functioning and others adopting a more holistic approach. Other contributing factors included the study's methodology, the societal context in which the study was conducted as well as the specific type of gynaecological cancer investigated. The breadth of concerns and diversity of who is affected demonstrates that the type and significance of psychosexual effects differs between women. It is therefore essential that health care professionals assess and provide individualised care based on each woman's unique circumstances and priorities.

Women have expressed a desire for health professionals to provide information, support and care relating to psychosexual issues (Ekwall et al., 2003; Park et al., 2009; Rasmusson and Thomé, 2008; Stead et al., 2003; Vermeer, Bakker, Kenter, Stiggelbout, & Ter Kuile, 2016; Wilmoth et al., 2011). Psychosexual care is the assessment and provision of information, advice and treatment around any issue that psychologically, physically or socially impacts the affected woman's body image or sexual function. This includes, but is not limited to, sexual intercourse (Kotronoulas et al., 2009; Magnan and Reynolds, 2006). Nurses provide a supportive and therapeutic role for cancer patients from pre-diagnosis, through diagnosis, treatment and survivorship and are shown to be wellplaced to provide this care (Ayaz, 2013; Booth et al., 2005). There is agreement that the assessment of psychosexual issues is essential for holistic care (Ayaz, 2013; Kotronoulas et al., 2009; Magnan and Norris, 2008) and that assessing and providing this care throughout the continuum of a person's experience of cancer can significantly increase quality of life during the survivorship phase (McCallum et al., 2014). Despite this consensus, the provision of psychosexual care is reportedly underprovided, or poorly addressed by health professionals (Ayaz, 2013; Ferreira et al., 2015).

International studies have investigated the reasons for this gap in care. Quantitative research in the United States (Julien et al., 2010; Magnan and Reynolds, 2006), Taiwan (Tsai, 2004) and China (Zeng et al., 2012) surveyed attitudes and practices of nurses around psychosexual assessment. The Chinese study specifically investigated nurses working with women with gynaecological cancer and identified facilitators to psychosexual care as having a good nurse-patient relationship, good communication skills and access to privacy. Barriers included the perception that women had more important things to be concerned about than having sex, being embarrassed to discuss issues and the belief that sexuality care is a low priority (Zeng et al., 2012). Inadequate knowledge and training relating to sexuality was also identified as a barrier. One US study identified the key barrier as the nurses' perception that patients do not expect nurses to address their sexuality concerns

(Magnan and Reynolds, 2006). A second US study agreed and revealed nurses often defer the discussion of sexuality issues to the physician (Julien et al., 2010). Taiwanese nurses felt patients were embarrassed and did not know how to answer the nurses' questions (Tsai, 2004).

These international quantitative studies may be limited by using surveys which can bias participants with predetermined responses. Oualitative research from Australia (Hordern and Street, 2007a). Canada (Fitch et al., 2013), The Netherlands (Vermeer et al., 2015) and Sweden (Olsson et al., 2012), explored the attitudes of a range of health professionals working in cancer care around communicating about psychosexual issues. Australian findings revealed mismatched expectations of sexuality communication between cancer patients and health professionals including doctors, nurses and allied health professionals, resulting in unmet needs (Hordern and Street, 2007a). Canadian oncology physicians, nurses, social workers and radiation therapists revealed they usually waited for patients to initiate the discussion and acknowledged that patients rarely did (Fitch et al., 2013). When conversations did occur, they mostly focussed on side effects and rarely covered the emotional and personal impact of sexuality issues (Fitch et al., 2013). Dutch oncologists and nurses identified that embarrassment and lack of time hindered their ability to provide psychosexual support to gynaecological cancer survivors (Vermeer et al., 2015). In Sweden, nurses described that psychosexual care was the responsibility of someone else, made assumptions around the patients' need for care based on where they were in their treatment regimen and the belief that patients would place a low priority on sexuality (Olsson et al., 2012). Swedish nurses were also concerned about offending or embarrassing the patient and felt they lacked the knowledge and skills to provide psychosexual support.

Two qualitative studies explored the perceptions of nurses working with women with gynaecological cancer. United Kingdom nurses identified barriers to discussing sexual concerns with women with ovarian cancer suggesting it was not their responsibility, they were embarrassed and lacked the knowledge, experience and resources to provide psychosexual support (Stead et al., 2003). Brazilian nurses described similar sentiments, in that care was focussed on cure and failed to prioritise holistic needs (Ferreira et al., 2015). These nurses revealed the influence cultural values have on the discussion of sexuality as a topic considered private

Cancer Australia (2010) acknowledged these gaps in health professional knowledge by the development of an online professional education resource, "The Psychosexual Care of Women Affected by Gynaecological Cancers". The learning outcomes of this resource are presented in Table 1. Following a comprehensive national implementation phase involving Australian gynaecological cancer leaders and educators, no further evaluation of the resource has been published. The effectiveness of this educational strategy to influence clinical care and patient outcomes is therefore still unknown.

To date, no literature is available on the attitudes and perceptions of Australian health professionals providing psychosexual care to women with gynaecological cancer. Sexuality is a unique and individual construct influenced by a wide variety of factors including the social cultural context within which people live. The study of psychosexual concepts should be within a patient's unique sociocultural environment and results of studies from other sociocultural contexts may not translate internationally (Lee et al., 2015). In order to address this gap, the study aim was to gain insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment and how this aligns with nurses globally.

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