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The re-construction of women's sexual lives after pelvic radiotherapy: A critique of social constructionist and biomedical perspectives on the study of female sexuality after cancer treatment

I.D. White [a,b,*], S. Faithfull [c], H. Allan [c]

[a] King's College, London, UK
[b] The Royal Marsden NHS Foundation Trust, London, UK
[c] School of Health & Social Care, Faculty of Health & Medical Sciences, University of Surrey, Stag Hill, Guildford, GU2 7TE, UK

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ABSTRACT

Pelvic radiotherapy creates physical effects and psychological responses that negatively affect the sexual health of women and couples, yet these sexual consequences are not frequently researched or clinically assessed. This focused ethnographic study explored factors that influence the clinical assessment of treatment-induced female sexual difficulties after pelvic radiotherapy within routine medical follow-up.

Participant observation of follow-up clinics ($n = 69$) and in-depth interviews with 24 women, 5 partners and 20 health professionals were undertaken at two cancer centres in the South East of England from 2005 to 2006. Thematic analysis of interview transcripts resulted in five emergent themes, two of which are explored in detail within this paper.

A social constructionist approach to human sexuality was used to explore representations of female sexuality in oncology follow-up constructed by clinicians, women and their partners. Yet neither social constructionist nor biomedical (the predominant model in medical follow-up) perspectives on human sexuality provided an adequate interpretation of these study findings. This paper argues that the comprehensive study and practice of sexual rehabilitation in oncology requires a synthesis of both biomedical and social constructionist perspectives in order to capture the complex, subjective and embodied nature of the female sexual response in both health and illness.

Introduction

Research commissioned by Macmillan Cancer Support (Macmillan, 2008) has estimated that in the UK the number of people living with cancer currently stands at two million. The National Cancer Survivorship Initiative (DH, 2010) and Improving Outcomes Strategy for Cancer (DH, 2011) specifically acknowledge that insufficient policy, research and clinical attention has been paid to the longer term consequences of cancer and its treatment for a substantial number of people now surviving this disease. As increased numbers of people live with cancer as a long-term condition, their post-treatment quality of life becomes an increasingly important measure of effective treatment and care (Foster, Wright, Hopkinson, & Roffe, 2009). Yet most clinicians still focus on the assessment and management of acute side-effects and may be either unaware or reluctant to recognise the late consequences of cancer treatment (DH, 2010, 2011; Murphy, 2009). As there is no national system for recording significant treatment consequences, estimates of the prevalence of long-term sequelae, including treatment induced sexual difficulties, lacks precision (Maher & Makin, 2007).

More recent quality of life (QOL) and radiotherapy morbidity studies suggest that women receiving pelvic radiotherapy experience greater and more prolonged disruption to their sexual well-being (Bergmark, Avall-Lundqvist, Dickman, Henningsohn, & Steineck, 1999; Davidson, Burns, Routledge, & Swindell, 2003; Donovan et al., 2007; Jensen et al., 2003) than women after surgery alone (Juraskova et al., 2003; Leake, Gurrin, & Hammond, 2001). QOL studies also highlight the multifactorial and complex nature of female sexuality during recovery from cancer (Juraskova et al., 2003; Leake et al., 2001; Tabano, Condosta, & Coons, 2002).

The paucity of accurate clinical prevalence data of specific sexual difficulties among women after pelvic radiotherapy is further complicated by the presence of both transient and persistent sexual difficulties in the UK adult population as a whole, as reflected in

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* Corresponding author. Florence Nightingale School of Nursing & Midwifery, James Clerk Maxwell Building, King's College, London, 57 Waterloo Road, London SE1 8WA, UK. Tel.: +44 (0)2078483038.
E-mail address: isabella.white@kcl.ac.uk (I.D. White).

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findings from the NATSAL 2000 [National Survey of Sexual Attitudes and Lifestyles] survey (Mercer et al., 2003, 2005). A stratified probability sample of 11, 161 adult men and women aged between 16 and 44 years of age (65.4% response) revealed that 15.6% of women had experienced a "persistent" sexual difficulty lasting over 6 months in the year prior to the survey. This compares to estimated prevalence rates of female sexual difficulties associated with gynaecological cancer treatment of between 50 and 80% (Crowther, Corney, & Shepherd, 1994; Flay & Mathews, 1995).

One immediate difficulty faced in making a meaningful comparison of prevalence rates for specific sexual difficulties between this UK population sample and most patient groups within oncology is that a large percentage of people affected by cancer and their partners are over 44 years of age at the time of diagnosis. Hence the "true" prevalence of different types of female sexual dysfunction (FSD) remains a contentious issue with prevalence rates markedly affected by a range of factors including the populations sampled, research instruments selected and measurement parameters set such as duration of FSD, inclusion of sexual distress as a defining characteristic, and the time frame over which women are asked to recall the presence of their sexual difficulty (Hayes, Dennerstein, Bennett, & Fairley, 2008).

Medical research, particularly within oncology, has largely adopted an essentialist perspective in the study of sexual dysfunction, resulting in a relative neglect of psychological, relational or social components of both male and female sexual difficulties. Essentialism (also referred to as biological determinism) was the first perspective to emerge in defining sexuality, and remains the most influential in sexology even today (Oderberg, 2008). The challenge to a purely biological perspective in the study of sexuality dates from the mid-1970s, with Foucault's (1990a, 1990b, 1992) broadly social constructionist writing on sexuality and the body (Armstrong, 1997; Lupton, 1997). Foucault's (1990a, 1990b, 1992) treatise on the history of sexuality argued that sexuality is both historically and culturally constructed. Where constructionists differ in opinion, it is the extent to which they acknowledge or deny any pre-existent physiological sexual impulse (Armstrong, 1997; Dudrick, 2005; Lupton, 1997). Interesting interpretations of Foucault from the work of Lupton (1997) and Dudrick (2005) argue that Foucault's writings suggest the potential for a subjective or phenomenological body alongside the physiological body. We believe this offers potential for the complex, subjective and embodied nature of the female sexual response after cancer treatment to be more fully understood.

In addition to his writings on sexuality, Foucault offered an analysis of the ways in which knowledge *orders* social realities. He believed that it is the power relations inherent to societies across history that determine which types of knowledge are elevated to the position of *truths* in constructing our contemporary realities (Foucault, 1973; Porter, 1998, pp. 210–211). In medicine and nursing, power is exerted through professional and patient interaction, and discourse through the clinical gaze and medical surveillance (Foucault, 1973; Porter, 1998). Medical and nursing surveillance constructs a system of social norms through the acceptance of a series of '*normalising judgements*' made by professional *experts* (Foucault, 1973). Thus power is exerted through the use of professional knowledge to define precisely what is normal or abnormal. Expressed another way, the power of professional knowledge defines which patient or illness related concerns are considered legitimate versus those perceived as illegitimate. Through the mechanisms of professional practice and language, medical and nursing staff exert control over which signs or symptoms are perceived as credible and investigated, versus those considered irrelevant and not pursued. As will be argued later in this paper following Lupton (1997) and Allan (1999), it is through such mechanisms that women come to understand whether and when sexual concerns may be raised with their treatment team. Thus the synergy of medical and nursing language and practice, as well as the agency of women who recognise acceptable forms of discourse, shape the legitimacy of women's symptoms for the purpose of both clinical assessment and treatment.

The aim of this study was to explore the factors that influence the clinical assessment of treatment-induced sexual difficulties and to understand assessment of women's sexual difficulties within routine oncology follow-up from the perspectives of women, their partners and clinicians. This paper discusses study findings that explore the biomedical (functional), socially constructed and subjective elements of women's changed sexual lives after cancer treatment.

In adopting social constructionism as the underlying theoretical perspective, we use interpretations of Foucault's ideas by Lupton (1997) and Dudrick (2005) to discuss the complex, subjective and embodied nature of the female sexual response in sexual recovery after cancer, namely the physiological and anatomical realities created by pelvic radiotherapy and their consequences for sexual function. This is important theoretically and clinically where sexual assessment reveals an organic basis for many of the sexual difficulties experienced by women in this study. We also argue that a narrow biomedical gaze excludes exploration of the subjective experience which, our findings show, is central to understanding women's sexual recovery post-treatment. We propose that the comprehensive study of female sexuality in oncology requires an integration of both biomedical and social constructionist perspectives (DeLamater & Shibley Hyde, 1998; Dudrick, 2005; Lupton, 1997) in order to capture the complex and subjective nature of the female sexual response in both health and illness.

Methodology & methods

Focused ethnography is used increasingly in the study of health care services and differs in a number of important ways from the classical ethnography of anthropology or sociology (see Table 1) typically exploring naturally occurring phenomena in a more delineated and time-limited manner (Morse & Field, 1996). This focused ethnographic study (2005–2006) included a 5 month period of participant observation of radiotherapy follow-up consultations ($n = 69$) from 2 National Health Service (NHS) cancer centres and 49 in-depth participant interviews (24 women, 5 partners and 20 health professionals).

Ethical approval from the National Research Ethics Service (NRES) and research governance by the research and development departments of two cancer centres in South East England were obtained.

Analysis of participant observation data (field notes and observation schedules) explored the frequency and range of topics discussed, identified relationships between topic prevalence and

Table 1
Characteristics of the focused ethnography.

- Selection of the research topic before commencement of data collection as opposed to emerging during data collection and analysis
- Participants linked by a common site, but this location may be a clinical setting (such as a follow-up clinic) rather than a place of residence
- Participants may not be connected by the same culture, in its broadest sense, but share behavioural norms and a common language emanating from their shared experience of an illness
- Participant observation is limited to specific activities and time frames
- Interviews are limited to the selected topic and surrounding event(s) (adapted from Mueke, 1994)