

Institution: University of Surrey
Unit of Assessment: UOA 3 Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: <p style="text-align: center;">Improving the health and wellbeing of cancer survivors</p>
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>Improvements in therapy have increased the 5-year survival rate for a number of cancers, leading to a new focus on promoting the health and wellbeing of cancer survivors. In the UK alone, over 500,000 people have physical or psychological consequences associated with cancer or its treatment.</p> <p>Research at the University of Surrey has led to the development of self-management interventions for cancer survivors, demonstrating that active patient involvement leads to significant health and wellbeing benefits. These studies have driven national and international practice policy in the management of the consequences of cancer and its treatment.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>Successful treatment of male and female cancers occurring within the pelvic region is becoming more commonplace. However, these improved survival rates have increased the need for improved management of the consequences of cancer and its treatment, with over 150,000 people in the UK alone currently living with the physical or psychological consequences associated with the disease or treatment of cancers within the pelvic region. Unmet needs of patients post therapy, such as sexual difficulty, are poorly assessed and management can be poor in the transition to primary care.</p> <p>In research work funded by the Prostate Cancer Charity, Faithfull (Professor of Cancer Nursing Practice) undertook a multi-centre observational study into this area. The resultant publication in 2009 identified major gaps in provision of care, including significant unmet needs in relation to psychological distress, sexuality and urinary function, all of which were related to the nursing care received both during- and post-treatment (1). Specialist staff in the hospitals studied had rapidly growing caseloads as well as varying levels of experience in managing men's care long term (2). The findings of this research were extended in 2013, through a European Oncology Nursing Society-funded project that examined practice across seven European countries, demonstrating a similar lack of equity and access for men living with the consequences of cancer and its treatment (3). This was the first study to demonstrate a direct link between nursing care provided and after care outcomes for men with prostate cancer.</p> <p>Through a national online survey funded by the National Cancer Survivorship Initiative and Macmillan, the Surrey research team examined competencies in managing cancer as a chronic illness (2011). The views of oncology and haematology nurses, plus primary care and allied health professionals, were collated and demonstrated an important skills gap in the continuing professional development of NHS staff with respect to the management of chronic cancer survivorship</p> <p>The identified treatment gap is not limited to the management of the chronic treatment of male-specific pelvic cancers. Further work by Faithfull through a Cancer Research UK-funded study assessed morbidity in females following successful pelvic cancer treatment. Through observation of clinical consultations and interviews with women post pelvic radiotherapy it was possible to</p>

demonstrate poor use of assessment tools, lack of recognition of problem areas, and fear of raising difficult problems that could not be addressed (4).

Having led the identification and characterisation of the issue of post-treatment management in survivors of pelvic cancer radiotherapy, the team of Faithfull examined methodologies that could be developed to mitigate these issues. A Cancer Research UK-funded systematic review resulted in a 2010 publication providing the first comprehensive review of this area, and highlighted important principles of targeting self-management techniques including adherence and methodology for use of these techniques in managing prostate cancer patients with chronic urinary late effects (5).

This work informed a further Cancer Research UK-funded study evaluating the use of cognitive and behaviour programmes in the self-management of lower urinary tract symptoms post prostate cancer treatment. The resulting publication in 2011 demonstrated the feasibility of these techniques in hospital settings, their implementation and links to long-term patient outcomes and quality of life (6).

3. References to the research (indicative maximum of six references)

1. Ream, E., Quennell, A., Fincham, L., Faithfull, S., Khoo, V., Wilson-Barnett, J., and Richardson, A. (2008) *Supportive care needs of men living with prostate cancer in England: a survey*. British Journal of Cancer 98:1903-1909.
DOI:10.1038/sj.bjc.6604406
2. Ream, E., Wilson-Barnett, J., Faithfull, S., Fincham, L., Khoo, V., & Richardson, A. (2009) *Working patterns and perceived contribution of prostate cancer clinical nurse specialists: A mixed method investigation*. International Journal of Nursing Studies. 46:1345-1354.
DOI:10.1016/j.ijnurstu.2009.03.006
3. Cockle-Hearne, J., Charnay-Sonnek, F., Denis L., Fairbanks, H.E., Kelly, D., Kav, S., Leonard, K., van Muilekom, E., Fernandez-Ortega, P., Jensen, B.T and Faithfull, S. (2013) *The impact of supportive nursing care on the needs of men with prostate cancer: a study across seven European countries*. British Journal of Cancer 109:2121-2130.
DOI: 10.1038/bjc.2013.568
4. White, I. D., Allan, H. and Faithfull, S. (2011). *Assessment of treatment-induced female sexual morbidity in oncology: Is this a part of routine medical follow-up after radical pelvic radiotherapy* British Journal of Cancer 105:903-910.
DOI:10.1038/bjc.2011.339
5. Cockle-Hearne, J. and Faithfull, S. (2010) *Self-management for men surviving prostate cancer: a review of behavioural and psychosocial interventions to understand what strategies can work, for whom and in what circumstances*. Psycho-Oncology 19:909-922.
DOI:10.1002/pon.1657.
6. Faithfull, S., Cockle-Hearne, J., & Khoo, V. (2011) *Self-management after prostate cancer treatment: evaluating the feasibility of providing a cognitive and behavioural programme for lower urinary tract symptoms*. BJU International. 107:783-790.
DOI:10.1111/j.1464-410X.2010.09588.x

4. Details of the impact (indicative maximum 750 words)

The work described here on the development of self-management in the treatment of chronic symptoms for survivors of pelvic cancer radiotherapy, has had an important policy impact, leading

to the adoption of this approach by the UK National Health Service. In addition, the impacts at both the societal, and health and wellbeing at the individual level have been made through the dissemination of this information to the general public, and the use of these self-management tools leading to significant improvements in quality of life for cancer survivors.

The systematic review undertaken at the University of Surrey (led by Faithfull) underpinned the development of Health Policy to include self-management as a key strategy for managing cancer patient's long term. Through active engagement and representation on relevant Department of Health committees, the work of Faithfull helped develop the publication of a White Paper (**Ref 1**) providing guidance to cancer services with regard to targeting interventions and contributed to the National Cancer Survivorship agenda (**Ref 2**). In addition to driving general policy on cancer survivorship, this work has led to specific symptom management strategies for people who have received pelvic radiotherapy (STEP). Specifically, this relates to the development of NICE/NHS national guidance on lower urinary tract symptoms following cancer treatment (**Ref 3**).

The impact of this work on developing policy has been followed by a significant public communication plan, leading to a societal impact through the better understanding of self-management of symptoms for cancer survivors. For example, the review provided the definition for self-management for the Health Foundation guidance on chronic illness self-management "helping people help themselves". Tailored support is instrumental in the NCSI Department of Health Vision for NHS improvement with "top 10 tips" for self-management and work by the author quoted in developing cancer support services (**Ref 4**).

The importance of dealing with the issues of cancer survivorship is highlighted in the Macmillan Cancer Support report on the impact of cancer survivorship (**Ref 5**), and has led to the development of patient information leaflets for both men and women (**Ref 6**). In addition to printed medium, a short film (Getting Down to Coping) has been developed in collaboration with Dimpleby Cancer Care, to convey the findings of this research. This societal impact of this work is evidenced by the national recognition gained for this film, and it's utilisation by patient groups to give positive coping messages for men undergoing prostate cancer treatment (**Ref 7**).

In addition to having a positive impact at the national level, the findings of this research are being absorbed into European Policy, through the action of patient lobby and nursing groups at EU level (**Ref 8**) and through an appointed EU task force on survivorship as a fellow of the academy of cancer scientists (ECCO; **Ref 9**).

5. Sources to corroborate the impact (indicative maximum of 10 references)

- Ref 1.** DOH Report: An intelligent Framework for cancer (2011)
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_132385.pdf
- Ref 2.** NHS National Cancer Survivorship Initiative Vision (2010)
<http://www.ncsi.org.uk/>
- Ref 3.** NHS national guidance on lower urinary tract symptoms following cancer treatment
<http://www.nice.org.uk/nicemedia/live/12984/48557/48557.pdf> (2010)
<http://www.evidence.nhs.uk/documents/lower-urinary-tract-symptoms-evidence-update-march-2012.pdf> (2012)
- Ref 4.** Cancer Consequences and Treatment (CCaT) Top 10 tips for survivors
<http://www.cancerconsequences.org/10-tips-for-survivors.html>

- Ref 5.** Macmillan Cancer Support Advice: Pelvic radiotherapy in men: possible late effects (2012)
<http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Radiotherapy/Pelvicradiotherapyinmen/Pelvicradiotherapyinmen.aspx>
Macmillan Cancer Support Advice: Pelvic radiotherapy in women: possible late effects (2012)
<http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Radiotherapy/Pelvicradiotherapyinwomen/Pelvicradiotherapyinwomen.aspx>
- Ref 6.** Macmillan Cancer Report on “Throwing Light on the Consequences of Cancer and its Treatment”
http://www.ncsi.org.uk/wp-content/uploads/MAC14312_CoT_Throwing-light_report_FINAL.pdf
- Ref 7.** ‘Getting Down to Coping’ with Prostate Cancer Film, supported by Dimbleby Cancer Care (2012)
<http://www.dimblebycancer.org/news/getting-down-to-coping-with-prostate-cancer>
http://www.surrey.ac.uk/mediacentre/press/2012/76405_new_video_launched_to_help_prostate_cancer_patients.htm
- Ref 8.** Impact on European Policy through Lobby Group Representation (2010)
http://www.cancerworld.org/Articles/Issues_39/Cover_Story/Sara_Faithfull%3A_unleashing_the_potential_of_cancer_nursing.htm
- Ref 9.** Fellow of the academy of cancer scientists tasked with leading survivorship research within Europe <http://www.europeancanceracademy.eu/Fellows/Directory.aspx>
Cavalli, F. *An appeal to world leaders: stop cancer now*. The Lancet. (2013) **381**: 425-426.
DOI:10.1016/S0140-6736(13)60059-8