

Impact case study (REF3)

Institution: Staffordshire University		
Unit of Assessment: 32 Art and Design: History, Theory and Practice		
Title of case study: Sex, Cancer and Art Textile Activism: Empowering Patients and Challenging Health Professionals		
Period when the underpinning research was undertaken: 2012-2018		
Details of staff conducting the underpinning research from the submitting unit:		
Name: Colette Dobson	Role: Senior Lecturer	Period employed by submitting HEI: September 2003 - January 2021
Period when the claimed impact occurred: February 2014 – December 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

Since 2012, Colette Dobson has undertaken collaborative research seeking to improve communication between patients and health care professionals about the sexual consequences of treatments for cancer. As well as significant benefits (in terms of creativity, confidence, and wellbeing) for 6 breast cancer patients who joined the collaboration group, the impact has expanded to include:

- Approximately 1,000 health professionals took part in experiential workshops and study days using the research methodology and artistic outputs. They benefitted from new tools to support professional development and reflective practice, leading to improved knowledge, understanding, and ability to talk about sex with patients.
- The development of a new resource (visual aid) which is used in three nurse-led cancer clinics at Christie Hospital, Manchester (the largest single site cancer centre in Europe). This has led to better outcomes for patients experiencing sexual and relationship problems following cancer treatment.
- The research has also benefitted 75 other patients/survivors and 270 health professionals through a programme of public engagement.

2. Underpinning research

Sexual and relationship problems are common following cancer treatments. Considering our research and the wider evidence base, patients express feelings of guilt and disempowerment and are unable to raise the subject. It is often seen as a taboo and less important in the context of the wider treatment programme. Health professionals report feeling anxious and inadequately skilled to handle questions on sexuality and relationships. For both groups, this leads to poor assessment and treatment, impacting on patients' broader long-term wellbeing. Dobson developed a novel approach of using design activism to allow these marginalised issues to be discussed and addressed.

Since 2000, Dobson has worked on the restricted communication of women resulting from conformity to religious and social expectation. Her research engages new modes of art textile activism. This took on a new dimension in 2012, with her role as Lead Artistic Researcher in a collaborative NHS project, *Sexuality and Cancer* (with psychosexual consultant Dr Josie Butcher, Cheshire Wirral Partnership (CWP) NHS Trust, as Principal Investigator). *Sexuality and Cancer* uses design activism to explore questions around sexuality and relationships following cancer treatment. It engages directly with both patients and health professionals to understand their perspectives and ensure their diverse needs are met. This novel and highly collaborative approach empowers patients to use art and new forms of artistic expression as an alternative language to express and communicate feelings of emotional and physical trauma using visual metaphors. It focuses on the concepts of damage and repair, asking 'at what stage does change become damage and what is the nature of repair?' For health professionals, this challenging approach confronts them with a form of communication that is unfamiliar and hard to understand. It purposefully replicates a sense of the patient's perspective in dealing with medical issues.

The findings of two experiential workshops with health professionals (in 2011 and 2014) were evaluated and published [3.1; 3.2]. Using art textile as a metaphor for the patient's voice within a communication skills workshop offered attendees a new pathway of learning. The success of the

initial workshop led to the research developing in two main directions: sexuality and prostate cancer, and sexuality and breast cancer (from 2016/17). In both cases, the development of the artwork was underpinned by findings from focus groups with patients, which captured the personal stories of the treatment journey and its aftermath, as well as idealised understandings of gender and sexuality. Dobson worked directly with patients' first-hand experiences, creating visual work in response to their verbal expressions of perceived unmet emotional and sexual needs. Patients experienced loss across all aspects. Breast cancer patients were often unaware and unprepared for the damage that is often caused to the vagina and vulva during breast cancer treatment, and the sexual difficulties that this damage can lead to.

The establishment of the Communication Medicine and Art (ComMA) collaboration group in 2017 marked a methodological shift from a more traditional representational approach to an innovative, patient-led, and highly collaborative approach. Six breast cancer focus group participants joined the group, and there were also contributions from three other artists, in addition to Dobson. Dobson's role was pivotal in facilitating textile processes. Patients were introduced to the language of textiles by a dictionary: *The Visual Language of Construction and Reconstruction*. This dictionary was a physical artefact created by Dobson. It uses metaphor to emphasise cloth's intimate relation to the body. The dictionary equates methods of textile construction and reconstruction to surgical procedures of preparation, marking out, shaping, removal of area, seaming, pleating, and padding. This language supported patients' understanding of textile materials and processes. Dobson constructed a range of objects relating to the patients' experiences, including a miniature surgical gown (an article of fear), and a paper wish boat as a symbol of the cancer journey. These objects could be drawn, collaged, and written on by patients, which let them develop their own visual language to communicate with medical practitioners. Whilst patients engaged in debate with artists' work, the artist gained insights into the patients' emotional responses. Research from this symbiotic process has been presented as experiential workshops for health professionals including the 4th International Conference – Sexuality and Breast Cancer, Manchester (2017) [3.3] and 14th International Congress of the European Federation of Sexology, Portugal (2018) [3.4]. Dobson was also invited to speak at the International Symposium on Damage and Repair (2016) at University for the Creative Arts, Farnham [3.5], following a peer review process.

3. References to the research

The five references indicated below are key elements of a multi-component single research output *Empowering Patients and Challenging Health Professionals: Sex, Cancer and Art Textile Activism*: <https://eprints.staffs.ac.uk/lists/31> This research output has been listed in REF2 with a comprehensive PDF of Contextual Information: <http://eprints.staffs.ac.uk/id/eprint/6842>

3.1 Butcher, J. **Dobson, C.** Atkinson, A. et al. (2016) Sex and Cancer: Opening difficult therapeutic conversations and challenging assumptions using Design Activism-language outside the comfort zone. *Sexual and Relationship Therapy*, Vol. 31 No. 4 pp. 493-509 ISSN1468-1994.

<https://eprints.staffs.ac.uk/2103>

3.2 Butcher, J. **Dobson, C.** Atkinson, A. Couzins-Scott, E. and Clayton, A. (2014) *3rd International Conference Living with Sexuality and Cancer - Prostate Cancer*. In: 3rd International Conference Living with Sexuality and Cancer, 28 February 2014, Manchester Conference Centre: <https://eprints.staffs.ac.uk/5202>

3.3 **Dobson, C.** Butcher, J. Clayton, A. Atkinson, A. and Couzins-Scott, E. (2017) *4th International Conference - Sexuality and Cancer Breast Cancer*. In: Sexuality and Breast Cancer, 10 November 2017, Manchester Conference Centre: <https://eprints.staffs.ac.uk/5196>

3.4 Butcher, J. **Dobson, C.**, Atkinson, A. Couzins-Scott, E. and Clayton, A. (2018) *Empowering Patients and Health Professionals through Art*. In: 14th International Congress of the European Federation of Sexology: From Sexology to Sexologies, 11-13 May 2018, Faro Portugal: <https://eprints.staffs.ac.uk/5199>

3.5 **Dobson, C.** (2016) *Repairing Emotional and Sexual Damage Caused by Cancer- International Symposium UCA-University for the Creative Arts*. In: *Damage and Repair - How Can I Make it Better*, February 2016, University of the Creative Arts:

<https://eprints.staffs.ac.uk/5201>

4. Details of the impact

Impact has developed as an integral part of the research process through co-production with 6 **cancer patients/survivors** and experiential workshops with 500 **health professionals**. The reach has been extended to a further 75 cancer patients, 270 health professionals and 200 members of the public through a programme of public engagement activities. In addition, research outputs have been used as an educational resource with approximately 500 more health professionals through a series of study days led by Dr Josie Butcher for Macmillan Cancer Support and Information Service.

Impact on patients

Six breast cancer patients joined the ComMA collaboration group to co-create artwork based on their experiences. For this group, the impacts are deep and profound, with three going on to become patient advocates with ComMA, and taking a leading role at public engagement events to help inform other patients and healthcare professionals about the issues around sex and cancer. The patient advocates co-produced content for the ComMA website [5.1a]. The development of the website was supported by Impact Acceleration Funding provided by Staffordshire University. Website resources include the downloadable booklet 'Your Little Notebook', which is an innovative way of both highlighting the impact of the ComMA collaboration, and signposting others to sources of support [5.1b]. Impacts for members of the ComMA group include:

New ways of thinking visually and creatively: *'...the collaboration with artists [has] enabled and channelled my visual thinking'* [5.2/Stella's Story p.19].

Increased confidence in communicating with/challenging healthcare professionals: *'It gave me the courage to seek help for my sexual problems with my husband. It also made me feel better as I thought my problems were unusual'* [5.2/Patient Focus group Evaluations p.15]. *'My surgical gown filled me with horror every time I had visited my consultant. I asked to remain dressed to speak to my consultant, so I was seen as a person and wear my gown for the examination. The outcome was very positive, and I felt respected'* [5.1b, patient quote].

Enhanced wellbeing/mental recovery, and improved ability to support other cancer patients: *'Participation in the group has also brought a sense of closure to the trauma which has been beneficial to my relationships with my husband and family. I feel more equipped to communicate with Health Professionals on an equal, informed, and educative level and the experience has enabled me to gain a new perspective and understanding which is useful in supporting others within the oncology community'* [5.2/Stella's Story p.20].

'One of the key benefits of this project for patients (both for the collaboration group and for some of my patients who have seen the artwork), is the recognition that others have similar feelings and difficulties – that the feelings are legitimate and they are not alone' [5.3].

Stella applies insights from the research in her role as Director of a Community Interest Company (a monthly support group for women with a breast cancer diagnosis). Another patient advocate, Kay, set up a new local support group in 2020 (with support and activities being online due to the Covid-19 pandemic in 2020). Kay addressed an audience of 200 people at a Breast Cancer Research event (26/02/20) about the positive impact of participation in ComMA:

'The whole process of being involved in the research has given me the opportunity to express how I felt throughout 'my journey'. I've produced artwork myself that I didn't know I was capable of doing and have always been encouraged by the wonderful artists. I now feel empowered and want to help other women by getting information out there in as many places as possible' [5.2/Kay's Story p.18].

Impact of Public Engagement Events

The reach of the impact has been further extended through a programme of public engagement activities targeted both at health professionals and patients. In 2015, Dobson led a talk and pop-up exhibition to 250 people, students graduating from health care courses (King's College London, Department of Midwifery and Obstetrics), as they transitioned to roles as qualified health professionals. This event drew on research insights about issues of power and

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communication to improve knowledge and understanding of how to build positive relationships, communicate more effectively and ultimately improve the level of care.

With ComMA collaborators, Dobson also led talks and experiential workshops based on the research methodology and findings at a patient day event for Sex and Cancer-Breast Cancer Sex, Sexuality and Femininity 09/03/2018. Attendees included 50 people who were breast cancer patients and 20 people who were health professionals. Patients benefitted through recognising and being able to discuss their problems, with reference to the artwork. They were also signposted to further support. 93% of those who completed an evaluation agreed (completely or very much) that the workshop had helped them to understand the problems a patient may have during the patient journey and how this might affect feelings of femininity, sexuality, sex and relationships [5.2, pp.12-13]. Dobson and two patient advocates presented ComMA work to an audience of 25 people who were cancer patients at Deborah Alfa Hair and Beauty, Brimstage, Wirral (a specialist centre for cancer patients to have hair and wigs cut, styled and given specialist treatments - 04/10/2019). Audience members reported that they benefitted in terms of better knowledge and empowerment [5.2, pp.13-14].

Impact on Health Professionals

'The benefits of the work have extended well beyond CWP, through national and international conferences and also training session for health professionals' [5.4]. Both the prostate cancer work and the breast cancer work have generated impact amongst health professionals because the work *'builds upon existing educational provision for NHS health professionals in terms of communication skills (which is ultimately linked to improved diagnosis)'* [5.4]. Along with the ComMA public engagement events, this has considerably extended the reach of the impact.

i) Impact of Supervision and Study Days

CWP has a Service-Level Agreement with the Christie NHS Foundation Trust Hospital in Manchester. The arts-based outcomes of the breast cancer research have been used since 2017 within the supervision of medical professionals working with patients with sexual difficulties and difficult case management. This is beneficial in reinforcing the key messages from the research findings about the need for more effective communication [5.4].

The co-production methodology and artistic outputs were also introduced into a series of study days for Macmillan Cancer Support and Information Service. These took place across the UK, totalling 20 sessions between 2016 and 2017, with up to 30 people as delegates in each study day, engaging a total of approximately 500 people as delegates. They aimed to enhance understanding of issues faced by cancer patients in order to improve treatment and care. Participants benefitted from learning how to use our communication tools to support their patients: *'It was especially valuable in terms of demonstrating how patients can be empowered, so that they can discuss their problems; access relevant help and support and recognise that they are not on their own'* [5.4].

As a result of the study days, Christie NHS Trust acquired art objects, namely visualisations of damaged vaginas, informally referred to as 'Doughnuts'. These objects have been used since 2018 in three nurse-led clinics to help patients struggling with sex and relationship issues. As a result, approximately 25 people (patients), per year, benefitted from better outcomes (*i.e.*, discharged without the need for further referral) [5.5]. They are also used with new members of staff to increase their understanding of how treatment can affect patients, which further extends impact.

'The doughnuts help patients to understand why using particular products (e.g. vaginal moisturisers or a lubricant) or using the dilator may be helpful, which I have found makes them more likely to comply with the guidance and helps them to move forwards after treatment... if they have aids to actually see and feel then they (and in some cases their partners too) gain a better understanding. This helps them work together better as a couple and leads to improved relationships' [5.5].

ii) Impact of Experiential Workshops

The research methodology and artistic outputs have helped achieve the learning outcomes of three experiential workshops for a total of 500 people who are health professionals, at

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international conferences (2014, 2017, and 2018), and a national conference in 2019. By engaging with the artwork, health professionals working with oncology patients were challenged to reflect on how they communicate. The challenges considered the need 'to listen to understand' and 'speak to be understood' [3.1]. Evaluation evidence from the prostate cancer conference (2014) demonstrated these sessions impacted on the understanding of these professionals. Of 100 people as participants, 93% indicated that attending had impacted on their thoughts and feelings. Whilst 79% reported they would share information gained in their professional or personal lives, thus extending the reach of the impact [3.1]. The approach was so powerful that at the 4th International Conference Sex and Cancer – Breast Cancer (November 2017), the experiential workshop played a central part in the development of the whole conference. It was pivotal in supporting the key messages of the conference speakers [5.4]. Delegates included GPs, surgeons, neurosurgery, rehabilitation, and palliative care specialists. In addition to quantitative data, the evaluation generated 186 delegate comments that further highlight the impact of the event, in terms of increasing awareness and challenging current practices:

'Very informative and gave me more of an insight into their feelings and emotions' [5.2, p.10].

'I thought the pin boxes helped to illustrate the severity of which intercourse may feel like for patients, this I was very unaware of' [5.2, p.8].

'Made me think more about patient experiences and areas I need to explore within my own work' [5.2, p.10].

'This workshop speaks so much more than any amount of PowerPoint presentations. These images touch the soul, speak more than words, more deeply than 'cognitive' understanding. I found it helpful hearing the stories of the people who were part of the creation of this exhibition. Their experiences added an additional vividness and depth' [5.2, p.11].

A Consultant in Psychological Medicine at Clatterbridge Cancer Centre, Merseyside attended the Sexuality and Breast Cancer experiential workshop and reported that the experience had a lasting impact on her practice:

'Seeing people's experiences communicated through the artwork is powerful, and sometimes shocking, therefore adding a new, deeper perspective to even the most familiar of issues. This has taken my understanding to a new level and deepened my connection with the patient experience, especially in terms of the sense of loss. As a result, I have greater levels of empathy when I am listening to patients communicating the impact of their sadness and loss, whether that is loss of a breast, hair, sexual function, or femininity' [5.3].

The Sexuality and Cancer work was selected as an example of leading innovative practice and included in the CWP Big Book of Best Practice (2016-17) [5.6, p.37] and was shortlisted by CWP for an award recognising Outstanding Contribution to Research Development and Innovation (2018), further demonstrating its value to the Trust [5.7].

5. Sources to corroborate the impact

5.1a ComMA website.

5.1b Your Little Notebook: information booklet co-produced by ComMA group, containing impact evidence from workshop recordings and signposting information. Available on ComMA website.

5.2 Evaluation report: a compilation of evidence, including: 4th International conference – Sexuality and Breast Cancer. Health professionals' evaluations 10/11/2017; Patient Day Event group evaluations – Breast cancer sex sexuality and Femininity 09/03/2018; Me Again event, Brimstage 04/10/2019; Patient focus group evaluations (2018 and 2020); Patient Advocate testimonials 2020.

5.3 Testimonial, Consultant in Psychological Medicine, Clatterbridge Cancer Centre

5.4 Testimonial, Dr Josie Butcher, Psychosexual Consultant, Cheshire Wirral Partnership NHS Health Trust.

5.5 Testimonial, Clinical Nurse, Specialist gynaecology and vulva care, Christie NHS Trust

5.6 Cheshire & Wirral Partnership NHS Foundation Trust Big Book of Best Practice (2016-17)

5.7 Evidence of shortlisting for CWP award