Institution: University of Wales Trinity Saint David

Unit of Assessment: 04

Title of case study: Supporting individuals living with secondary breast cancer: improving awareness, conversations and care.

Period when the underpinning research was undertaken: 2014 -19

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Dr Ceri Phelpes	Academic Director; Psychology & Counselling	2008 - current

Period when the claimed impact occurred: 2016-2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

The psychosocial impact of a diagnosis of incurable cancer is pervasive and enduring. Collaborative research undertaken between 2014 and 2019 with women living with secondary breast cancer by Dr Ceri Phelps, Director of Psychology, University of Wales Trinity Saint David and Ann M Baker, a clinical nurse specialist in breast cancer care at South West Wales Cancer Centre, Swansea Bay UHB, has improved our understanding of the unmet information and support needs of women living with secondary breast cancer, helped create Wales' first secondary breast cancer nurse specialist post, facilitated the creation of a patient-led support group, informed two secondary breast cancer conferences and has been instrumental in raising awareness of the impact of living with incurable cancer including a parliamentary reception.

2. Underpinning research

Secondary breast cancer (SBC), also known as metastatic (stage 4) breast cancer (MBC), occurs when primary breast cancer cells spread to other parts of the body, such as bone, liver, brain or lung, due to transmission through the blood or lymphatic system. It is not curable and results in prolonged cancer-related treatment and shortened life span. Recent estimates suggest around 35,000 people in the UK are living with SBC, with around five in every 100 people with breast cancer already having secondaries when their cancer is first diagnosed, and around 35 of every 100 people with primary breast cancer developing SBC within 10 years of their first diagnosis (Breast Cancer Now 2015). With significant advances in the treatment and management of SBC, a diagnosis of SBC now reflects a highly distressing and yet potentially longer-term chronic condition. Our initial research carried out in 2014 (Baker & Phelps. 2019) **[i]** with two groups of secondary breast cancer patients highlighted the psychological challenges of not only receiving the diagnosis itself but in adapting to living with the knowledge that they had incurable cancer. This research is based within a wider programme of work led by Dr Phelps actively involving patient populations exploring the psychosocial impact of living with cancer **[ii, iii].**

Crucially, our analysis identified that much of the psychological distress, confusion and frustration identified in this and other studies appeared to directly stem from the nature of the communication between these patients and a range of oncology professionals (Baker & Phelps. 2019) **[i]**. The women in our study talked about a dramatic change in the relationship between them and their healthcare professionals as a direct result of the shift in label from "primary" to "secondary" breast cancer patient. Specific frustrations surrounded a perceived reluctance upon the part of the oncologist in engaging in difficult but much needed conversations about treatment, life expectancy and death. The emotive dialogue around loss of identity and support articulated by the women in this study identified a) a clear need to improve the psychosocial care and support of women living with secondary breast cancer, and that, b) these issues need to be directly addressed by the clinical team who were perceived as the gatekeepers to appropriate information, advice and support. These conclusions have been recognised by the British Psychological Society's Division of Health Psychology as being an excellent example of real-world applied research (Baker & Phelps, 2015) **[iv]**. The findings support previous research that indicated that access to appropriate psychosocial and information support is an important mechanism for empowering patients with SBC and improving quality of life. Our study specifically highlighted the perceived value of clinical nurse specialists in being a critical linchpin in providing this support; in our study the women clearly regarded access to a specialist nurse as a vital source of knowledge about the disease and treatments and an important advocate of their clinical and psychosocial support needs, thus acting as a crucial link between the women and the multidisciplinary team. Our findings supported a growing call to recognise the importance of regular holistic needs assessments at diagnosis and beyond and the importance of a suitably skilled and experienced person to take on an advocacy role beyond simple signposting.

The challenges experienced by health professionals in "breaking bad news" well to a distressed patient has been widely documented by others. However, through our research we have argued that in the context of living with cancer as an incurable yet chronic condition, the longer-term cancer journey needs to be recognised, focusing on the importance of ongoing and regular communication surrounding living with non-curable cancer rather than focusing purely on the diagnosis itself – a significant shift in focus from breaking bad news to living with bad news. As a consequence of our initial study (Baker & Phelps, 2019) **[i],** in 2019 we successfully obtained further grant funding from Tenovus Cancer Care to build on this research and conduct a participatory action research project across two NHS UHBs in South West Wales **[v]**. Due to start in early 2020 the aim of this research was to co-produce a set of recommendations and potential intervention strategies that will improve psychosocial support mechanisms, conversations and information-giving surrounding both the initial secondary breast cancer diagnosis and ongoing consultations throughout the secondary breast cancer journey. Unfortunately, this grant funding was paused due to COVID-19 and we are now seeking further funding avenues to take this work forward.

3. References to the research

i. Baker, A.M. & Phelps, C. (2019) A changing identity: A focus group study of the experiences of women diagnosed with secondary breast cancer. *Cancer Nursing Practice*

ii. Phelps, C., Butler, C., Cousins, A., & Hughes, C. (2015). Sowing the seeds or failing to blossom? A feasibility study of a simple ecotherapy-based intervention in women affected by breast cancer. *Ecancermedicalscience, 9,* 602. http://doi.org/10.3332/ecancer.2015.602

iii. Phelps, C., Minou, M., Baker, A., Hughes, C., French, H., Hawkins, W., Leeuwenberg, A., Crabtree, R. and Hutchings, P. B. (2017). Necessary but not sufficient? Engaging young people in the development of an avatar-based online intervention designed to provide psychosocial support to young people affected by their own or a family member's cancer diagnosis. *Health Expectations, 20*: 459–470. doi:10.1111/hex.12473

iv. Baker, A.M. & Phelps, C. (2015) "We feel forgotten and feel like we represent the lack of hope. When we are remembered, we are recognized as losing the battle": A focus group study of the experiences of women diagnosed with secondary breast cancer and their psychosocial support needs. *Conference Proceeding; British Psychosocial Oncology Society Conference: End of life care & practitioner development and wellbeing*

Grants

v. Tenovus Cancer Care. £29,841. T Grant Reference, TIG2020-08
*Tackling difficult conversations: A participatory action research project to enhance patient-healthcare professional communication around secondary breast canc*er.
Awarded 2020, revised start date Sept 2020, subsequently on hold due to COVID19

Awards

vi. Baker, A.M. & Phelps, C. (2015) "We feel forgotten and feel like we represent the lack of hope. When we are remembered, we are recognized as losing the battle": A focus group study of the experiences of women diagnosed with secondary breast cancer and their psychosocial support needs. *Conference Proceeding; British Psychological Society: Health Psychology in Action Prize Winning Poster.*

4. Details of the impact

Wales first secondary breast cancer nurse specialist role (March 2016 – present)
Research has demonstrated that the cancer clinical nurse specialist role is valued by patients for the provision of emotional and information support. As such, much recent focus on service provision has been on improving SBC patients' access to a designated nurse specialist or keyworker with appropriate knowledge of the disease, treatments and support needs, who act as an advocate and a link between the patient and the multidisciplinary team (MDT) (Breast Cancer Campaign 2018). However, according to the Breast Cancer Campaign, three-quarters of NHS trusts and health boards across the UK do not have enough specialist nursing care for those with SBC and women with the disease are often not signposted to appropriate support services. In Wales, the situation prior to 2016 was worse, with no dedicated nursing provision. Responding to this shortfall, Baker was able to use the data from the underpinning research **[i, ii, iii],** to present a detailed case for improved nursing support for secondary breast cancer patients. This case was accepted by senior management at her employing UHB (Swansea Bay University Health Board) and in March 2016, Baker was appointed as Wales' first dedicated specialist SBC nurse. This post is based at the South West Wales Cancer Centre, Singleton Hospital, with funding by Swansea Bay University Health Board. This role has enabled patients to access specialist support and nursing care in line with existing recommendations, for example those from the Breast Cancer Campaign (2018).

Improvement in service delivery (2016-present)
Since the creation of this post, and Baker's appointment to the role at Swansea Bay University Health Board, more than 250 patients have been able to access a designated nurse specialist with appropriate knowledge of the disease, treatments and support needs for patients with SBC. Through this post Baker established a nurse-led clinic to facilitate early treatments and regular holistic needs assessments [1]. This specialist support has included access to appropriate psychological and clinical support and information at diagnosis, at progression and when treatment changes, and crucially, an advocate to serve as a link between the patient and the wider multidisciplinary team. Bakers' appointment, for which she received her British Empire Medal (2020), has also clarified key issues around the demands and expectations of this SBC nurse specialist role and the support required by service providers for posts to remain sustainable including: the need for appropriate training in specialist skills and knowledge, recognition of the need to provide appropriate emotional support, whether through training, counselling skills or increased clinical supervision, for those working in SBC care and opportunities to improve communication skills between patients with SBC and other oncology professionals, including consultants. In this regard, a key finding from the research that have informed service delivery was both that **a)** oncology healthcare professionals must be made more aware of effective communication strategies to reduce self-stigma among their patients and with regard to difficult conversations about a diagnosis of SBC and **b)** that the power of the patient voice in driving change and shaping services needs to be better recognised and embedded in the co-design and co-development of future SBC services [2] (Baker & Phelps, 2019).

The Breast of Friends Secondary Breast Cancer Support Group (2014 – present)
Women with secondary breast cancer have unique characteristics and information and support needs that differ from those with early stage breast cancer and which research across the UK has shown are not being consistently met. Participation in Baker and Phelps' research study in 2014 also provided a platform for the participants to establish their own monthly support group. The Breast of Friends Secondary Breast Cancer Support Group was established in 2015 by a number of the women who had attended the initial focus group study and they have continued to meet monthly since that time, illustrating the value of peer support initiatives in providing important support and reducing feelings of isolation and self-stigma. With a poignant often-changing membership due the nature of the diagnosis of around 20 women and with continued support from Ann Baker, the group has provided a platform for patients to be able to engage with a range of experts (e.g. clinicians, palliative care specialists) to educate and inform. This group has also acted as a patient expert advisory panel in recent multidisciplinary research proposals

led by Phelps, Baker and oncology clinicians/consultants and have also been supported by Baker to attend secondary breast cancer conferences (see below). To date we estimate that almost 50 women have benefitted from the support that this group has provided. In 2018 Ann Baker was invited to a Parliamentary Reception in recognition of her work and took three patients from this support group along (only one is still alive) as part of a wider campaign to seek commitment to ensure that everyone with secondary breast cancer in the UK can assess a Secondary Breast Cancer Care package [4].

Education and Awareness Raising: Wales Secondary Breast Cancer Conference, Wales Cancer Network, October 2017 and October 2019

The need for improved awareness of secondary breast cancer and to educate health professionals and support organisations about the complex psychosocial challenges faced by people living with secondary breast cancer emerged clearly from our research, and this research underpinned the successful planning of Wales' first secondary breast cancer conference in October 2017. A follow up conference took place in October 2019 during breast cancer awareness month. Supported and promoted by the Wales Cancer Network, over 200 delegates have attended both of these events, including clinicians, charity representatives, and patients. METUP UK (metupuk.org.uk/) and After Breast Cancer Diagnosis (abcdiagnosis.co.uk) founder Jo Taylor has supported these conferences with a patient advocate talk, with other patient voices being heard alongside cutting edge developments in clinical care from oncology professionals.

These conferences have been unique because they have actively embraced the notion of patient involvement, with members of the Breast of Friends support group and METUP UK being active participants and presenters at both conferences. As such they have facilitated multidisciplinary dialogue and have enabled future projects to be developed. For example,despite greater recognition and resources for secondary breast cancer being made available across a number of UK cancer charities, patient advocacy groups METUP UK and After Breast Cancer Diagnosis continue to promote the need for greater awareness of secondary breast cancer and for greater treatment and clinical support to improve early diagnosis and extend life expectancy. METUP UK is a Metastatic Breast Cancer patient advocacy group working to improve outcomes for those living with secondary breast cancer, with their mission statement seeking to ultimately downgrade secondary breast cancer from an incurable disease to a chronic illness. Key to this mission is encouraging the identification of early "red flag" signs of secondary disease amongst primary breast cancer patients using the Red Flag Infographic development by *abcdiagnosis.* This has been adopted by NHS trusts in England and has been approved for adoption in NHS trusts in Wales. Ann Baker incorporated the use of this infographic into her role prior to this [5].

Jo Taylor of METUP UK and After Breast Cancer Diagnosis [3] states *"As a patient living with secondary breast cancer and an advocate to push change for patients, I have come to know Ann Baker through one particular SBC friend that she was supporting as a patient in her clinic. Ann has always supported the work I do to help SBC patients as it fits in with her role to support them as Clinical Nurse Specialist. She was aware of the infographics I created and made patients aware of them and the work I do. We shared an urgency to make change like for example data collection for SBC patients as across the UK we don't know exactly how many are living with the disease. She has always done everything in her capability to support patients and personally her patients have become friends. So this is additionally hard when patients die. Ann totally embraced the role and glad she pushed to create the only CNS in the whole of Wales! Everyone needs an Ann Baker in their life".*

In 2019, Phelps and Baker successfully obtained funding from Tenovus to take forward the next stage of this research, working in collaboration with two local University Health Boards, oncology consultants, and patient representatives. This project, originally planned to start in September 2020 following an initial delay due to COVID-19 will seek to further improve the experience of those diagnosed and living with secondary breast cancer through identifying strategies to improve difficult conversations around the diagnosis of incurable cancer. We will bring patients and health professionals together to gain an in-depth understanding of these unmet information and support needs and how healthcare professionals feel about communicating with women with secondary breast cancer, resulting in a list of practical recommendations that will be widely disseminated. Unfortunately, this grant funding was paused due to COVID-19 and we are now seeking further funding avenues to take this work forward, whilst continuing to raise wider awareness of this work and its potential relevance to cancer populations during COVID-19 through appropriate social media channels and blogs.

5. Sources to corroborate the impact

Contacts:

1) Secondary breast cancer nurse specialist.
2) Wales Cancer Network Clinical Lead for Breast Cancer.
3) METUP UK and After Breast Cancer Diagnosis

Documents:

4) Breast of Friends Support Group/Patient advocate https://www.uwtsd.ac.uk/news/press-releases/press-2020/dr-ceri-phelps-reflects-on-20-years-of-research-on-world-cancer-day.html .
5) Secondary breast cancer conference & Breast of Friend Support group: https://www.wales.nhs.uk/news/46354