



Experiences,
Coping and
Holistic Needs
Assessment in
UK Breast
Cancer
Survivors

B Y
L Y D I A B R I G G S



Background: Breast Cancer

Breast cancer affects 1 in 8 women worldwide, with there currently being 691,000 individuals living with or beyond the disease in the UK (Cancer Research UK, 2014), and 1.7 million cases were diagnosed globally in 2012 alone (IARC, 2012).

Breast cancer represents 25% of all cancer diagnosed worldwide (IARC, 2012).

Survival rates are on the increase, with 86% currently living five years beyond their diagnosis in the UK (Cancer Research UK, 2014).



Background: Unmet Needs

What are the implications of this rising population?

According to Macmillan Cancer Support, the average person living with or beyond cancer reports five 'unmet needs' [Rowe, Young and Rowlands, 2014].

Research indicates that there are a myriad of physical, psychological and social concerns which can affect people's lives long after their treatment [NCSI, 2013].





Background: Common Concerns



PHYSICAL

- Pain
 - Exhaustion
 - Lymphoedema
 - Hot flushes
 - Aches and Pains
 - Reduced mobility
 - Loss of sensation
 - Skin changes
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EMOTIONAL

- Depression
 - Anxiety
 - Isolation
 - Abandonment
 - Loss of confidence
 - Mood changes
 - Anger
 - Hopelessness
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SOCIAL

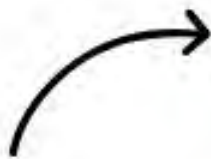
- Family issues
 - Housing issues
 - Financial issues
 - Returning to work
 - Relationship strain
 - Worry about children
 - Poor social support
-



Background: The Recovery Package

The cancer strategy for England and collaborative work of the National Cancer Survivorship Initiative have recognised the importance of encouraging self-management and a better quality of life for those living with and beyond cancer (Independent Cancer Taskforce, 2015; NCSI, 2013), which led to the creation of 'The Recovery Package'; a series of interventions which should be offered to every individual diagnosed with cancer (NCSI, 2013):

Holistic Needs Assessment and Care Planning,
Treatment Summaries, Cancer Care Review and
Health and Wellbeing Event



Macmillan's Electronic Holistic Needs Assessment (eHNA)



Identifies...

- physical, emotional, social, practical and spiritual concerns

- The care plan is shared with the patient and other care providers



Holistic Needs Assessment & Care Planning



Actions...

- are put into place with the patient to address the concerns such as signposting and referrals



- A corresponding care plan is created by the healthcare professional to discuss these



- Allows the patient to rate these from 0-10 based on severity

The Study:

Aims

The study aimed to understand the experiences of having and coping with breast cancer

A further aim was to discuss and gain an understanding of participants' experiences of completing Macmillan's eHNA as part of their routine aftercare.

Recruitment

15 UK Breast Cancer Survivors aged 46 to 81 with a diagnosis of non-metastatic invasive breast cancer who had been treated surgically were recruited for the study.

These were recruited through an NHS clinic and full NHS ethical approval was granted for the study.

Letters of invitation were sent by the usual care provider



Data Collection

Semi-structured interviews were undertaken ranging in length from 25 minutes to 1 hour 10 minutes.

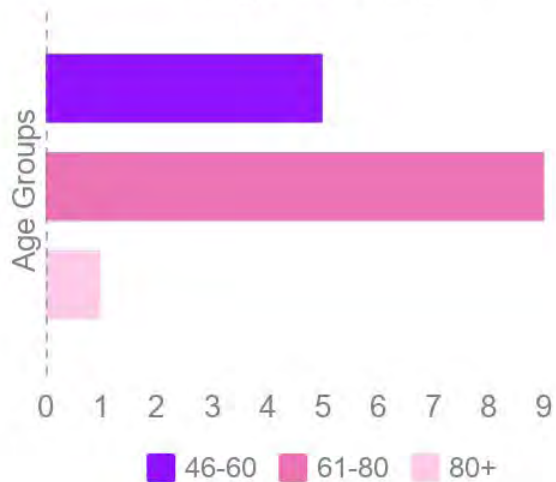
Participants were offered the option to be interviewed either at home or in the hospital (54% home, 46% hospital).

Data Analysis

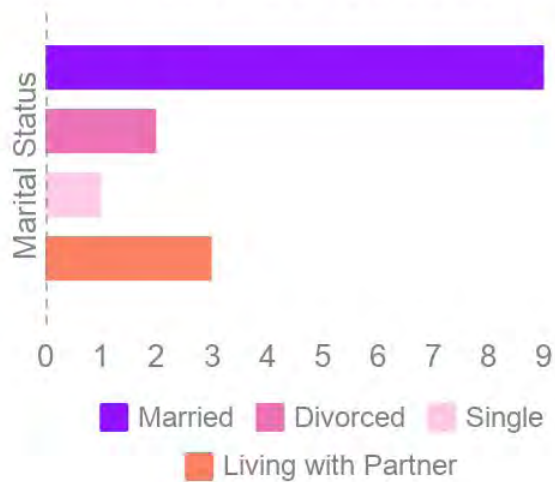
Interviews were transcribed manually and coded through NVivo 11. The principles of thematic analysis were utilised to generate 4 themes and 11 subthemes.



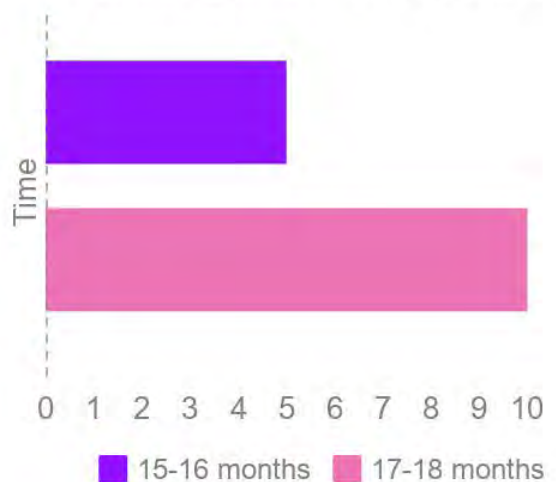
Age Group



Marital Status



Time Since Treatment

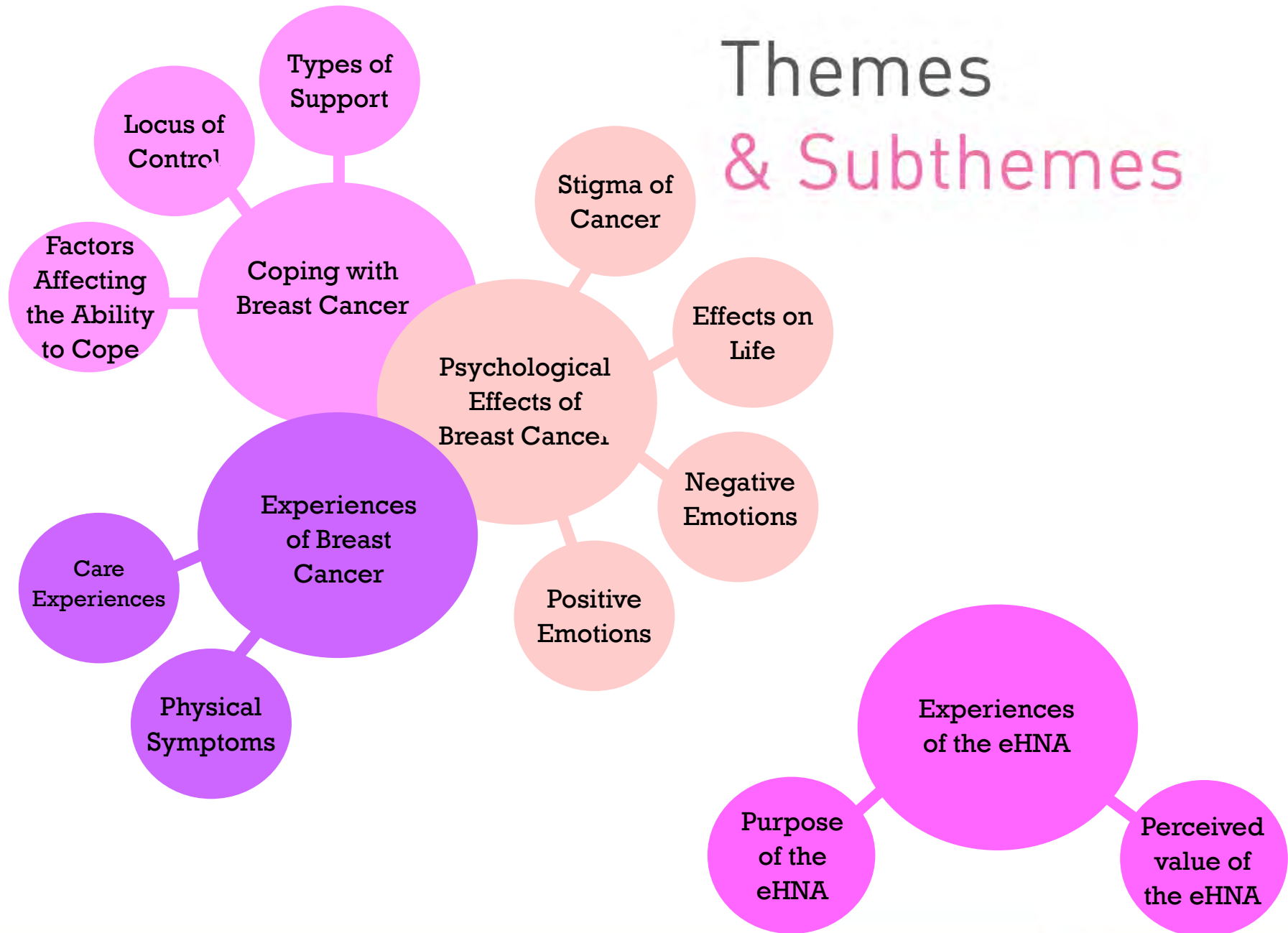


Surgery Type



Participant Demographics

Themes & Subthemes



Locus of Control

“It's the guilt yeah, because you just think well I'm lucky, there are people who are gonna be there who aren't, let them have the time”

(Participant 6)

“Sometimes I think did I sort of cheat something... is something gonna come along?” (Participant 11)



Theme 1: Coping with Breast Cancer

Factors affecting the ability to cope



“I remember thinking how am I gonna get through all of this, and then I thought well it's a bit like how do you eat an elephant... a bit at a time.” (Participant 3)

“I really didn't want to talk about it... I really didn't... I think I probably kept it fairly well contained.” (Participant 2)

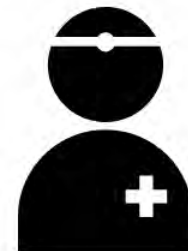
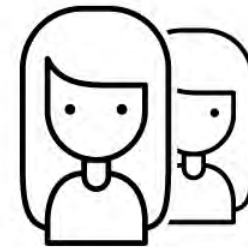
Theme 1: Coping with Breast Cancer



Types of Support

“Everything I wanted to know was there and I know that nurse I could ask anytime, I could ring her, that special nurse I had.” (Participant 12)

“You’re not ever gonna see them again... and you can confide, because you know that they will completely perhaps understand what you’re saying cause you’re going through it, whereas friends and relatives that haven’t been through that perhaps don’t understand your emotions and your thinking.” (Participant 16)





Theme 2: Experiences of Breast Cancer



Care Experiences

“I just wanted somebody to look at me as a person and listen to me.” (Participant 14)

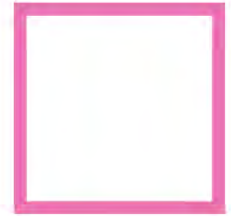
“Somebody just to sit down with you and just explain and just be nice about it, they're just so cold.” (Participant 10)

Physical Symptoms

Hot Flushes
Breast Pain
Sleep Disturbances
Exhaustion
General Aches and Pains

Theme 3:

Psychological Effects of Breast Cancer



Stigma of Cancer

“I think you notice more, how many people are dying with cancer, everything seems to be people dying with cancer.” (Participant 3)

“I don't know whether it's because he was frightened of the word cancer as well.” (Participant 14)



Theme 3:

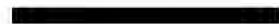
Psychological Effects of Breast Cancer



Effects on Life

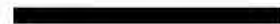
“Well I think having breast cancer changes your outlook on life, totally... or I suppose any sort of cancer.”

(Participant 5)



“I think you realise that so many years you've been saying, oh I can't wait for the kids to grow up, can't wait to retire, can't wait for this, can't wait for that... and you have to enjoy every minute that you get because... you don't know when that's gonna stop.”

(Participant 6)



“I mean apart from going to bed early... I wouldn't... I wouldn't say much had changed.” (Participant 2)



Theme 3:

Psychological Effects of Breast Cancer



Negative Emotions

“It feels like you've gone through a war and you're left with the battle scars, and you're just stood in that field and you're the only one alive, and you're stood there, and you feel like isolated and lonely, you don't know where to go.” (Participant 7)

Positive Emotions

“I wasn't struggling or anything, I'm always quite a positive person and I look forward rather than back.” (Participant 4)

“Yeah, I think it's just a matter of telling yourself to get through it somehow whatever way you can.” (Participant 1)





Theme 4: Experiences of the eHNA

Purpose of the eHNA

“It was never portrayed to me
to be a tool to help me.”
(Participant 4)



“I thought it was for
research... I didn't think it
was for me particularly.”
(Participant 12)



Theme 4: Experiences of the eHNA



Perceived value of the eHNA

“So I suppose maybe it just felt like an add on... it's just something you need to do... so whether or how meaningful it was I don't know.” (Participant 11)

“In my case I thought it was a waste of time.” (Participant 13)

“I didn't find it helpful at all to be honest.” (Participant 3)



Continued...

“Because I think you just think, well I'm just being silly... haven't got any worries, haven't have I, I'm alive.” (Participant 6)

“Because I think psychologically... you know and then maybe a part of you also is almost like... well if I put all of this, then... will they call me back in?” (Participant 11)

“I think it's... you can cope... with sadness and loneliness, but you can't cope with pain if there's something there, I think that's why I put the pain down, because I knew it was there.” (Participant 14)



Conclusions



Issues faced by women treated for breast cancer last long after treatment.

Significant individual differences exist.

A more tailored and personalised approach to care is required.

There is also a need for greater communication and further research around implementation of the eHNA.

Implications For Future Research



Next Steps...



Future research should focus on how the eHNA can be used to provide a more tailored approach to support each individual living with and beyond breast cancer. This should include a focus on:

Barriers to raising psychological concerns

How the eHNA is implemented

Variations in care when delivering the eHNA

Staff perspectives

Thank You

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Reference List



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