

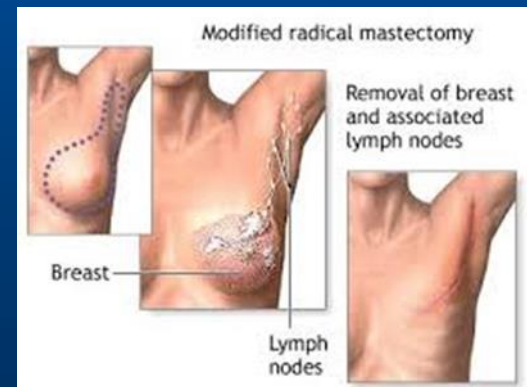
Experiences of women in transition to survivorship following mastectomy in the Cape Metropole

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INTRODUCTION

- Female breast cancer is one of the most diagnosed cancers and cause of cancer death among women in developed and economically developing countries (Jemal *et al.*, 2011:69).
- Prevalence and distribution of breast cancer in the Western Cape:
 - 46.9% in the mixed ancestry group
 - 42.9% in the white Afrikaner
 - 10.2% in the African Xhosa population (Schoeman *et al.*, 2013:529,532).
- Surgical treatment for breast cancer, mastectomy, is recommended with or without axillary clearance (Elder *et al.*, 2005:202).



RESEARCH PROBLEM STATEMENT

- **Research Problem**

Healthcare workers may not comprehend the challenges women experience following mastectomy.

The researchers, assisting with breast surgery, identified a need to explore and describe these experiences in order to understand the challenges patients face.

- **Significance**

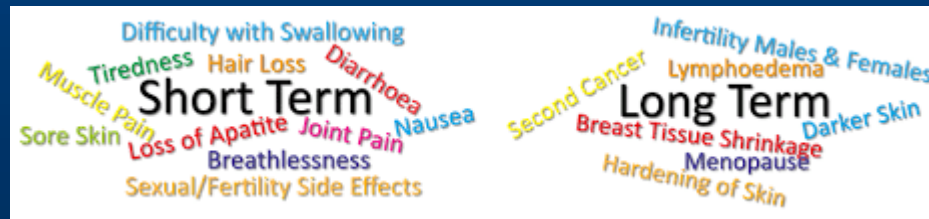
New knowledge for health care workers in order to enhance support structures for patients, families and caregivers

RESEARCH QUESTION

What are the lived experiences of women as they transition to survivorship following mastectomy in the Cape Metropole ?

Research aim and objectives

Explore and describe the lived experiences of women in the Cape Metropole as they transition to survivorship following mastectomy.



ETHICAL CONSIDERATIONS

Ethical Considerations

- Ethical approval gained from Health Research Ethics Committee at Stellenbosch University (Reference S14/11/266)
- Informed consent gained from participants
- Anonymity, confidentiality
- Protection from harm
- Emotional support

RESEARCH METHODOLOGY

- **Research Design**

Qualitative research design with a descriptive phenomenological approach.

- **Philosophical underpinning**

Husserlian phenomenology – describe lived experiences.

Reality is a creation of the individuals involved in the research and is therefore subjective (Nieuwenhuis, 2011:65).

RESEARCH METHODOLOGY cont.

- **Population**

Women residing in the Cape Metropole who have had a mastectomy.

- **Inclusion Criteria**

English speaking women residing in the Cape Metropole who have had a mastectomy for breast cancer with adjuvant or neo adjuvant therapy.

- **Sampling**

Snowball / network sampling method from a non-governmental support agency in Cape Town and colleagues.

RESEARCH METHODOLOGY cont.

- **Sample Size:** according to depth and credibility of information required until data saturation achieved
(Grove *et al.*, 2013:371; De Vos *et al.*, 2013:391).

However, authors argue that each life is unique and data will therefore never be truly saturated since new data always emerges (Wray *et al.*, cited in O' Reilly & Parker, 2012:194).

RESEARCH METHODOLOGY cont.

Data Collection instrument

- Semi structured interview guide : open-ended questions
- Refined with guidance from organisers of the non-governmental support agency
- Refined during the process of data collection (Grove *et al.*, 2013:274).
- Field notes

● Pilot Interview

Gain insight into the interviewing process

RESEARCH METHODOLOGY cont.

- **Data Collection**

Data collection (March 2015 – August 2015) included seven electronically recorded interviews at a venue of the participants choice, mostly their homes. Recordings were transcribed verbatim.

- **Data Analysis**

Thematic analysis according to Terre Blanche, Durrheim and Kelly's (2012:322) data analysis strategy for qualitative research.

Transcribed data - data reduction – by coding, attach meaning to data - themes identified from codes – presented as findings - Interpretation - placed findings in larger context.

RESEARCH METHODOLOGY cont.

- **Trustworthiness** influenced by:

Researcher: Bracketing: laying aside what is known about the phenomenon, in order to hear the voice of the participant.
(Grove *et al.*, 2013:687).

Reflexivity: Awareness of personal feelings, experiences and worldview that may influence data collection and analysis.
(Grove *et al.*, 2013:707).

RESEARCH METHODOLOGY cont.

- Credibility, dependability, conformability and transferability (Lincoln & Guba, 1985:316-323)

Credibility : authenticity of data

Verification of data by participants and supervisor.

Field notes.

Dependability: Auditable and logical research process (Schurink, Fouche & De Vos, 2013:420).

Interviews transcribed verbatim with field notes attached.

RESEARCH METHODOLOGY cont.



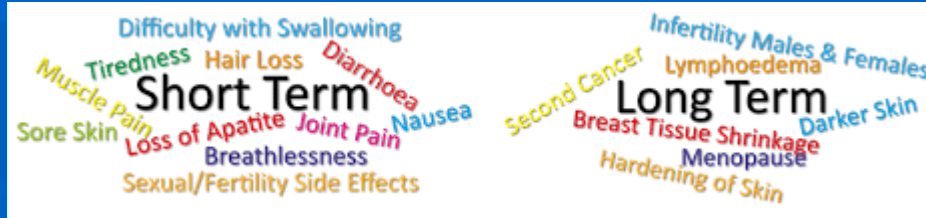
Conformability and Transferability were ensured by:

- Quality of data was ensured:

A meticulously detailed and systematic audit trail of recordings, transcriptions and field notes are available providing accuracy with which the phenomenon was captured and interpreted (Ritchie & Lewis, 2003:269).

- Cross checking or member-checking of coding and themes in analysis was done with each participant (Wahyuni, 2012:77) that enhanced the rich description of the phenomenon (Wahyuni, 2012:77).

FINDINGS



Themes	Sub themes
Psychological experiences	Emotional distress Concern for family and children Coping strategies: Acceptance Positivity Information avoidance
Physical experiences	Psychological impact of changes in appearance
Social experiences	Making changes Cultural impact of breast cancer
Support needs in transition to survivorship	Psychological support from family and friends Physical support needs Support needs of affected family Support groups

FINDINGS

Experiences were based on each individual journey associated with the breast cancer diagnosis, the surgery and the cancer related treatments.



Theme: Psychological Experiences: emotional distress and shock.

On breast cancer diagnosis, P2 expressed that she felt:

'shell shocked, it feels as if someone has actually kicked you',



while another felt an urgency for the cancer *'to be taken away from me'* P3.

Theme: psychological experiences

- Concern for family and children.

A participant with two daughters shared: *'I step by step prepared them'* P7.

A participant expressed her sense of guilt and helplessness toward her 16-year-old daughter:

'Oh, that was terrible because especially with the chemotherapy, I was just useless. I sort of felt guilty because I couldn't do anything for my daughter. ... I neglected her...Not that I wanted to but I couldn't because I really couldn't...help myself. I was tired all the time' P1.

Theme: Psychological experiences: Coping strategies:
Acceptance, Information avoidance and positivity.

A participant voiced:

‘What I’ve noticed about me, I didn’t want someone to tell me about cancer, what are they experiencing something like that, I wanted to, to be for me to be a first time experience. Because I just say to myself I don’t want to say...yo...the chemo, I’m going to get sick and stuff like that ... P6.

A participant believed in staying positive.

‘...but to me it was important that I coped well in order that my family coped well, you know if I had fallen apart, then I think everything else falls apart ‘P4.

Theme: Physical Experiences: altered physical appearance.



On hair loss, due to chemotherapy:

‘almost becoming uglier by the day... you know you appear to be an alien’ P7.

A participant shared the following regarding her scar:

‘But as the time goes I think now, it started sinking in, you know, because, um, I couldn’t look at my scar. I don’t know why... I didn’t, I didn’t, something just, I just felt like not looking at it’ P1.

Major themes: social experiences and support needs in transition to survivorship

● Theme: Social Experiences: Making changes

A participant opted for a bilateral mastectomy. She felt she needed to appear “balanced”.
‘I mean I, my biggest thing is that because I work with people all the time, you don’t want (sigh) anything about the way you look to be a barrier between you and engaging with them, so for example...with the students’ P4.

In an attempt to look normal in society, a participant voiced:

‘I say ok, I mustn’t panic, I went to buy my wiggy, I buy all my, um, the eyebrow pencils, everything, then I just draw, nobody even noticed that. Nobody knows that I didn’t have the hair all this time I was like visiting them with wigs’ P6.

Theme: social experiences of breast cancer perceptions and myths in the African Xhosa community

- . Stigmatization of cancer as an incurable disease.

‘...I think because, they’ve got that thing of saying there is no cure’ P1.

A sense of cultural shame of their incomplete bodies.

‘...again people they don’t want to remove because they rather...because they want to go to the grave fully, not with a part missing,’ P1.

A perception that cancer might be contagious.

‘...she doesn’t want to play with her grandchildren, because she’s like afraid that she’s going to infect them ‘ P6.



One participant shared the following experience whilst washing with other women.

Their response to her follows:

‘...you say to us you don’t have a breast what we are seeing that there is a breast...ye ye ...why did you have to lie to us, and stuff like that.

She replied: I say you know what, what you are doing is so rude, so rude, you were supposed to ask me to show you my breast.... they don’t even understand what is that ‘P6.

Theme: Support needs in transition to survivorship :

Psychological support from family: Physical support needs; Support needs of affected family

Family were identified as the primary care giver and they had great need for support and information.

A participant shared:

I think a family in this situation actually feels helpless, they don't know how to assist you ... I think it's quite important for someone who has had a mastectomy for you to be able to actually say to your family: this is how I would like to be supported, I think it's quite important for you to be able to say that to your family...and without...you not sounding selfish 'P2.

IT'S A FAMILY THING.
(CANCER) AFFECTS
EVERYONE AROUND
THAT INDIVIDUAL.

Support groups were met with conflicting feelings

‘...um, she’s encouraged me on two occasions to join them and I actually chose not to, and made up an excuse ...I didn’t, because it’s like a rehashing of the same thing and they talk about it over and over again... but I’d rather be in a positive space with positive people from time to time than rehashing the same experience and all those dark experiences’ P7.

Another participant had a positive experience from attending her therapy group:

‘It’s like a family thing ...because you meet everybody, same time, if you go today, three weeks later you get that same people ...you see...chemo... Yes, and you keep in touch... we make friends like that’ P3.

RECOMMENDATIONS FOR FUTURE RESEARCH

The experience of hearing the participants words was extraordinarily life changing for us. We are able to empathize with our patients peri-operatively in an informed way and educate other members of the healthcare team.

Since this study consisted of a small sample, we recommend that a national study could occur across cultures and languages, in order to deeply investigate the psychosocial needs of patients, care givers and employers.

Furthermore, research could focus on the needs of the family as primary care givers after hospitalisation.

The development of an education and support program for all African language speaking women with breast cancer in their mother tongue is recommended to increase understanding of the disease and treatments

ACKNOWLEDGEMENT

- *We acknowledge the fortitude of the seven women who generously gave their time to share their experiences with us in the name of improving healthcare for breast cancer survivors.*



THANK YOU



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