

Breast Cancer Rehabilitation Services in South Africa and Survivor Experience of These Services in Two Dedicated Cancer Units

Portia M. Motsoeneng

University of Cape Town

Anita Beutel

University of Cape Town

Theresa L. Burgess

University of Cape Town

Niri Naidoo

University of Cape Town

Annemie Stewart

University of Cape Town

Delva Shamley (✉ delva.shamley@uct.ac.za)

University of Cape Town Faculty of Health Sciences <https://orcid.org/0000-0003-2355-6629>

Research Article

Keywords: Survivor, Rehabilitation, Pathway, Education, Health Services

Posted Date: April 8th, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-1320162/v1>

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Abstract

Purpose Integrated rehabilitation health care pathways are implemented to meet both physical and clinical needs of breast cancer survivors as they transition from medical treatment to long term survivorship. The aim of this study was to assess current South African upper limb rehabilitation service provision, and perspectives of these from health professionals and breast cancer survivors.

Methods A sequential explanatory mixed-methods design informed this study. Service provision was evaluated via an online survey questionnaire completed by health practitioners working in public and private breast cancer units. Focus groups were conducted with both public health practitioners providing the services and breast cancer survivors accessing the services.

Results This study has revealed a dearth of rehabilitation services for breast cancer survivors in the public health sector of South Africa. Data reveal an overstretched, understaffed and poorly trained public health sector, unable to deliver adequate upper limb services to breast cancer survivors. Focus group data suggests that this is due to financial austerity rather than poor recognition of the need. Limited patient education is driving poor upper limb outcomes and barriers to change in exercise behaviour.

Conclusion Current South African upper limb rehabilitation services do not cater for the needs of breast cancer survivors, leading to poor health outcomes.

Introduction

Breast Cancer (BC) accounts for approximately 12% of worldwide cancer cases in women, with higher breast cancer-related deaths reported in economically developing countries, compared to developed countries [1]. The 1-year relative survival rate for women diagnosed with breast cancer in SA is 78% compared to 50% survival rate 3 decades ago [2–4]. This significant increase in the number of cancer survivor population can be accredited to the advancements in treatment modalities [5, 6]. However, despite these advances, treatment often results in well-known upper limb sequelae. This is more relevant to LMICs where the vast majority of patients present at late stages and require more radical approaches [4–6].

Our data show that 1–6 years post treatment breast cancer survivors in a South African population experience severe pain (14%), moderate pain (14%), mild pain (46%), while 63% experience some level of upper limb disability [7]. These findings are similar to the global picture, resulting in the Institute of Medicine (IOM) recommending the implementation of Survivorship Care Plans (SCP). The intention of these plans is to deliver evidence-based cancer survivorship care that addresses known side effects of treatment. A key aim is to assist patients to transition between the levels of care [8–11]. Indeed, breast cancer survivors are the biggest recipients of the SCP[12] and women with a SCP report higher levels of overall care satisfaction when compared to those without [13–15]. However, policies rely on evidence-based data, which do not necessarily translate into real world health services, contributing to the failure of these plans to improve survivor quality of life[16]. On the other hand, patient generated health data

(PGHD) provides meaningful treatment-related health outcomes which should support contextually relevant planning decisions [17].

South Africa does not have a breast cancer survivorship care plan that addresses the later phases of survivor's care, including post treatment sequelae. In addition, no data exists on current service provision of the rehabilitation component of care for breast cancer survivors in South Africa.

The aim of this study was to obtain data on current upper limb rehabilitation services in South Africa, and to explore the experience of these services by health professionals and breast cancer survivors, in two dedicated oncology units.

Methods

This study utilised a sequential explanatory mixed methods approach. Responses from an online quantitative survey informed the development of open-ended questions for focus groups held with Health Care Professionals (HCP) and Breast Cancer Survivors (BCS). Ethical approval to conduct this research was obtained from the UCT, Faculty of Health Sciences Human Research Ethics Committee (HREC REF: 284/2019 and HREC REF: 509/2019). EQUATOR reporting guidelines for qualitative research (COREQ) were implemented for quality assurance.

Data Collection Instruments

National Online Survey

A national convenience sample of HCP was obtained through the Director of Women's Health at the National Department of Health, Chief Executive Officers or Hospital Managers of public breast cancer units, Physiotherapy and Occupational Specialist Interest groups. An Online Survey was distributed via *RED Cap 9.5.13 - © 2020 Vanderbilt University*. The survey questionnaire consisted of three domains (Part 1: General questions about breast cancer rehabilitation service delivery in their facility; Part 2: Assessment and Management of Breast Cancer Related Lymphoedema (BCRL); Part 3: Assessment and management of upper limb pain and dysfunction) and 25 items. Eight breast cancer units (8 Provinces), and 50 health professionals received the survey. Return of the completed survey was considered consent. Repeat emails were sent to ensure provincial representation in the sample.

Focus Group Discussions- Public Oncology Centres

HCP focus groups aimed to explore the survey responses (underlying reasons for absent or fragmented services, the level of support for an integrated care pathway inclusive of rehabilitation), and the level of knowledge of treatment related long-term side effects. BCS focus groups aimed to explore the experience of long-term physical side effects of BC treatment and their experience of rehabilitation services to identify rehabilitation needs for a future rehabilitation pathway.

Focus groups were run at two public tertiary hospitals servicing populations from low-income households and representing active oncology units. Focus Group discussion guides were deductively developed from survey data and previous research [18] and were conducted until data saturation was reached [19]. Groups had a maximum of 6 participants as recommended by Kruegar & Casey et al 2000 [19].

Participant identification and selection

HCPs received an email invitation from the head of the respective departments (Physiotherapy, Occupational Therapy, Radiation Oncology, Surgery). All HCP volunteers were included in the focus groups.

BCS were invited via adverts on advocacy group media, posters and information leaflets placed in waiting areas of oncology outpatient clinics. BCS were only excluded from the study if they were under 18 years of age.

Study Procedure

Participants signed informed consent, completed a socio-demographic questionnaire and signed a confidentiality agreement before participating in the FG discussion. The measurement instruments included the respective researchers (PM at site 1 and AB at site 2), FG discussion guides containing open-ended, semi-structured questions and a digital recorder. Trained FG facilitators took field notes during the FGs to ensure that contextual factors were considered.

Recordings were independently transcribed, and transcriptions subjected to forward- and back translation into English where necessary. Validation of transcriptions was achieved through member checking [20].

Data management and analyses

Survey data was independently analysed and is presented as descriptive statistics. Qualitative analyses of the FG transcripts were conducted using open coding and thematic analysis, whereby data were organized into categories, sub-categories, and themes [21](Supplementary data). Categories and themes were independently validated by three authors and discrepancies resolved. Triangulation of survey data, and themes from HCP focus group and BCS focus group was carried out to deduce common themes (add fielding refs).

Common themes were developed into propositions and modeled in an Interrelationship Diagraph (ID) to determine driver and effect variables [22]. Interrelationship Diagraphs are an efficient approach for identifying key variables for future interventions, while propositions represent hypotheses related to the effect of the changed variable.

Results

National Survey

Thirty-three (66%) HCPs responded to the survey (Table 1& supplementary file 1). Respondents from private and public institutions were equally represented. Physiotherapists (50%) formed the largest group of responders in the private sector compared to the public sector where doctors (47%) were the main responders followed by physiotherapist (41%). Of the 8 provinces, 5 are represented in the survey data.

Upper limb assessment in public and private sectors is largely carried out by Physiotherapists. Only 31% of respondents were formally trained to assess and manage BCRL in public sector versus 100% in private. The private sector offers upper limb services at every point in the care pathway as opposed to the public sector which is focused at post-surgery and post-radiotherapy.

Table 1 Summary of survey data.

	private n (%)	public n (%)	total n (%)
Total Respondents	16 (48)	17 (52)	33 (100)
Profession of respondents			
Doctor	0 (0)	8 (47)	8 (24)
Physiotherapist	8 (50)	7 (41)	15 (46)
BC nurse	3 (19)	2 (12)	5 (15)
Other	5 (31)	0 (0)	5 (15)
Rehab service delivery			
Are there official guidelines/ protocols for the assessment and management of:			
Upper limb functioning (yes) *missing 2	10 (67)	8 (50)	18 (58)
BCRL (yes) *missing 2	12 (80)	4 (25)	16 (52)
Which health practitioner/s conduct/s the assessment and management of upper limb pain and dysfunction among breast cancer patients? *missing 1			
Physiotherapist	9 (60)	8 (50)	17 (55)
Medical Oncologist	2 (13)	3 (18)	5 (16)
Management of BCRL			
Have you ever received clinical skill training for assessment and management of BCRL?			
Yes	16 (100)	5 (31)	21 (66)
How many breast cancer patients with BCRL do you see per month? *missing 14			
None	1 (7)	1 (25)	2 (11)
1-4	7 (47)	3 (75)	10 (53)
5-10	4 (27)	0 (0)	4 (21)
10-20	2 (13)	0 (0)	2 (11)
>20	1 (7)	0 (0)	1 (5)
Do you assess the breast cancer patients for BCRL? *missing 1			
Yes	16 (100)	8 (50)	24 (75)
Why do you not assess the patients for BCRL? *missing 1			
Not trained	-	3 (18)	

	private n (%)	public n (%)	total n (%)
Don't see follow-up patients	-	1 (6)	
Do you provide the treatment for breast cancer patients with BCRL?			
Yes	15 (94)	10 (59)	25 (76)
At what phase/s of the breast cancer treatment process are the breast cancer patients when you treat them for BCRL?			
At diagnosis	2 (12.5)	0 (0)	2 (6)
Post-surgery	10 (63)	5 (29)	15 (46)
During RT	9 (56)	2 (12)	11 (33)
Post RT	10 (63)	6 (35)	16 (49)
During Chemotherapy	9 (56)	2 (12)	11 (33)
Post Chemotherapy	10 (63)	2 (12)	12 (36)
Palliative	9 (56)	3 (18)	12 (36)
Prior adjuvant therapy	4 (25)	1 (6)	5 (15)
During adjuvant therapy	7 (44)	1 (6)	8 (24)
Post-adjuvant therapy	6 (38)	2 (12)	8 (24)
Post-treatment (Completed treatment but accessing facility for BCRL symptoms)	11 (69)	6 (35)	17 (52)
UL pain and dysfunction			
Have you ever received clinical skill training for assessment and management of upper limb pain and dysfunction (decreased range of movement, e.g.)? *missing 6			
Yes	14 (88)	5 (39)	19 (66)
How many breast cancer patients with upper limb pain and dysfunction do you see per month? *missing 4			
None	1 (7)	3 (25)	4 (15)
1-4	10 (67)	7 (58)	17 (63)
5-10	2 (13)	2 (17)	4 (15)
10-20	2 (13)	0 (0)	2 (7)
Do you assess the upper limb pain and dysfunction of breast cancer patients'? (E.g. can the pt. move the affected arm above the head?) *missing 4			
Yes	16 (100)	10 (77)	26 (90)

	private n (%)	public n (%)	total n (%)
Who in your unit does assess the breast cancer patients for upper limb pain and dysfunction?			
Medical Officers	0 (0)	2 (12)	2 (6)
Do you provide treatment for breast cancer patients with upper limb pain and dysfunction? *missing 4			
Yes	13 (81)	7 (54)	20 (69)
At which phase/s of the breast cancer treatment process are the breast cancer patients when you treat them for upper limb pain and dysfunction?			
At diagnosis	3 (19)	1 (6)	4 (12)
Post-surgery	10 (63)	7 (41)	17 (52)
During RT	7 (44)	3 (18)	10 (30)
Post RT	10 (63)	1 (6)	11 (33)
During Chemotherapy	8 (50)	1 (6)	9 (27)
Post Chemotherapy	8 (50)	2 (12)	10 (30)
Palliative	8 (50)	1 (6)	9 (27)
Prior adjuvant therapy	4 (25)	1 (6)	5 (15)
During adjuvant therapy	6 (38)	1 (6)	7 (21)
Post-adjuvant therapy	6 (38)	1 (6)	7 (21)
Post-treatment (Completed treatment but accessing facility for UL pain and dysfunction)	10 (63)	3 (18)	13 (39)

Focus groups.

HCP group participants included (Doctor, breast care Nurse, Surgeon, Occupational Therapist, Orthotist, Radiation Oncologist, Counselor).

A total of 34 BCS (11 at site 1 and 23 at site 2) and 13 health care professionals (HCP) participated in the FGDs. The median age for BCS was 55 years, and the youngest was 38 years. Only 41% of the survivors had formal employment with most doing manual work. Of those employed, or with some form of income, 56% had a household income of R5000.00 (258.58€ or 326.28\$) or less per month. 74% of the cancer survivors reported that they experience some form of shoulder morbidity and 65% had developed lymphoedema post cancer treatment.

Four common themes and 1 additional theme from the BCS data, were deduced during triangulation. The additional theme emerging from BCS data was that of family support. This came out strongly and is therefore included as a variable in inductive analyses and the development of the ID model (Figure 1).

Modelling common themes into an Interrelationship Diagraph demonstrates a strong relationship between education as a driver of all other variables (Out=4). Fragmented services were deemed to be a barrier to exercise and driving the development of upper limb morbidity. Indeed, upper limb morbidity emerges as the variable most affected by all other variables (In= 4). Not surprisingly, this is followed by exercise barriers (In=3).

The following six design propositions were developed, within themes, to inform future the development of a rehabilitation care pathway.

1. Education

Proposition 1: Poor education and knowledge is disempowering survivors thereby limiting their ability to self-manage upper limb problems.

Survivors have general dissatisfaction of information received at public facilities; health practitioners do not provide survivors with information about the risk of developing upper limb disorders or how to manage the long-term side effects. BCS6: *"I receive absolutely no information from health practitioners, I should've known from my past experience, surgeons don't give information, but he also had no nurse to give information, nobody assisted me, that's what I'm so upset about."* BCS27: *"They don't tell you the nitty gritty stuff that you really need to know."* BCS18: *"No, no one told me, I didn't know that all these things are going to happen to me."* This limited availability of information from the health facilities has left many of the cancer survivors with no option but to self-educate, to understand their new reality. BCS10: *"I discovered quite a lot of my own, I had to find a specialist, nobody ever gave me that information. what I do know about lymph is through the additional studying I have done. So, I've learnt a lot. I've learnt that you must self-diagnose"*. One of the evident risks of patients not receiving formal upper limb disorder education is the conflicting advice survivors receive from family members and HCP with no knowledge of upper limb disorder, or fellow survivors on how to manage the disorder and this may delay patients' rehabilitation. BCS17: *"My sister told me that if I don't exercise my arm it will stay like this."* BCS2: *"I remember coming home from surgery and my sister-in-law and my husband going, no, no, no don't even wash just rest."* BCS6: *"And I went to my doctor and she then said she could not see what was wrong, oh, the swelling of your arm will go down, just walk up the wall with your fingers"*. The main form of information offered to patients are take-home pamphlets, however, not all survivors receive the information or remember getting the pamphlet. BCS4: *I am sure, definitely not they never gave me one (pamphlets)*. The concern on the limited information shared at the facilities raised by survivors during FG discussions was further confirmed by the health providers during focus group discussions, HCP1: *"From our side in terms of oncology, that is a point where it's very weak in terms of our knowledge and how to advise patients for lymphoedema care. We leave it to the nursing sisters and the physios and then the lymphoedema clinic."*

2. Experience of Upper Limb Morbidity.

Proposition 2: South African breast cancer survivors experience well known emotional, physical and functional side effects of treatment which impact on QoL.

Participants reported a deterioration in quality of life due to upper limb disorders, finding it difficult to perform daily tasks with the affected arm e.g., simple tasks like combing hair or doing housework. BCS20: *I can't really lift the arm. I do not have power in my arms anymore. I used to be able to lift heavy things. I can't do that anymore.* BCS9: *"My husband sometimes wants me to lift this, to help him to carry this and this, then I said, you know what, I really can't do it."* Survivors living with upper limb disorders also experienced psychological distress, due to continuous concern about body image, the constant body changes and low self-esteem. BCS12: *"I felt too embarrassed to go back aquarobics for my lymphoedema."* BCS23: *"I had no issues and I just got depressed; I was in a bad, bad place."* BCS15: *"For me the continuous body changes can change the tone for the day you know"*. Respondents also reported on living in discomfort, due to the arm swelling, chronic fatigue and pain on the affected arm. BCS26: *"It pains terribly, you just get a sudden stabbing pain."*

3. Fragmented Rehabilitation Services

Proposition 3: Current care pathways do not provide long term surveillance and management for the development of latent upper limb side effects.

Proposition 4: BCRL care services are fragmented and lead to high personal cost for the survivor.

Survivors described rehabilitation services as fragmented and non-existent, with overcrowded facilities and long waiting periods leaving many patients feeling neglected by the health sector. BCS17: *"I had my surgery. then I was discharged then... nothing." there was nobody to direct me"* BCS29: *"I rehabilitated myself, we have had no rehabilitation."* Respondents also feel that the staff were always rushed, making it difficult to engage the health providers on any changes happening to their body. BCS7: *"I understand there's a lot of people that perhaps didn't have time to do massages (BCRL care). I just found that she was really rushed and on occasions, I thought that we should have had more time.* BCS8: *I just felt she just wanted to get away."* To date, upper limb rehabilitation services are mostly offered in the private health sector which comes at a great personal cost for survivors without medical insurance; BCS15: *"As the average person you've just got to fork out a lot, and it's this constant thing"*. HCPs confirmed fragmented health services, overcrowded and understaffed facilities and limited time spent with patients. HCP3: *"the day hospitals, there's too many patients, you know, the problem with our system is everything is flooded. Especially now, we're discharging a lot of patients from our clinic very early because we can't keep up with the numbers. Outcomes and what happen to our patients we do not know, we have so much clinical work."*

4. Future Rehabilitation Services

Proposition 5: Rehabilitation services should be personalized, delivered at different points of care, and in different formats, within the public health sector.

Proposition 6: Group exercise programs delivered in communities would engender a shared support mechanism.

Survivors strongly recommended an individually tailored rehabilitation plan to meet the recovery needs of the survivor. BCS19: *"Each of us is an individual and each of us has separate problems and it needs to be handled separately."* Information on the possibility of developing lymphoedema and upper limb disorders should be given to patients at the point of diagnosis, with refresher education post treatment. BCS2: *"for me there should be much more information before the operation or at the start of a treatment. It should be one of the first things that they discuss."* BCS22: *"A person forgets quickly; post treatment education would have helped."*

To improve educational access and reduce information overload on the first hospital visit, upper limb management education can be shared on different platforms which patients can easily access at a later stage when mentally ready. For example, cellphone Apps, brochures, booklets, information talks and short video clips. Video clips should be used to demonstrate how to do the exercise. BCS9: *Most people have smart phones so little videos (WhatsApp video) are useful. Yes, seeing how the exercise is done is much more useful than reading about it (all participants nod in agreement). Information talks and discussions will also be useful."* BCS8: *"Pamphlets/ brochures/ booklets, it's permanent, it's there forever."*

Survivors supported the use of trained community health workers and other survivors to deliver upper limb services at the hospitals and communities. BCS6: *"You know the community health can be taught the basics, add into their kit of teaching lymphoedema management, pre-post-op exercises."* BCS26: *"I would say it needs to be a trained person and a survivor. I mean, maybe the trained person doesn't have time today for that one, then the survivor is there to take us further."*

Appropriate exercise should be used as an intervention to manage and prevent the development of upper limb disorders. BCS11: *"Pre and post-surgery exercise is important anybody can learn that, you don't have to have a specialist to... the swimming exercises, the door exercises, getting outside and getting lots of walk in there, so get your circulation moving. Those things could be so helpful to people and as a prevention rather than waiting, because it's shocking to see how bad your arm gets"*. Health practitioners also supported the development of a new treatment pathway for upper limb disorders like lymphoedema. Health practitioners stressed the importance of relevant, early interventions, which will meet the needs of the patients. HCP4: *We need to adapt them (care pathway) because all those things are copied and pasted from the internet, which is not always relevant to our patients. With the intervention you need to catch them(survivors) early on to change their lifestyle.*

Discussion

This study has revealed a dearth of rehabilitation services for breast cancer survivors in the public health sector of South Africa. The results from the national survey showed an overstretched, understaffed and poorly trained public health sector, unable to deliver adequate upper limb services to breast cancer survivors.

Focus group data suggests that this is due to financial austerity rather than poor recognition of the need. However, FG discussions with health care professionals and survey responses, revealed poor knowledge of the long-term effects of treatment, the epidemiology of these effects and effective management strategies. Survey findings corroborate this finding as rehabilitation input is only provided at points of treatment believed to be responsible for the Physiotherapists and Occupational Therapists demonstrate greater knowledge awareness but again are limited by financial constraints and clinical overload. This barrier to rehabilitation services is however not limited to SA[23–26]. Management of a high clinical case load is currently achieved by providing pamphlets or a session with the physiotherapist or nurse at discharge. Despite evidence of this service, survivors frequently denied receiving either intervention. On further exploration, the timing of these interventions was considered inappropriate by survivors due to information overload. Similarly, Ridner et al 2006 and Maclean et al 2005 found that breast cancer survivors may have trouble in recalling if they received any BCRL information due to distress and information overload from the initial visits at the health facilities [27, 28].

Survivors face barriers including lack of knowledge and understanding of their condition, limited access to rehabilitation services and poor communication with the health care team post medical treatment. These findings are consistent with others and remain unresolved in many countries [29, 30].

Our study supports the need for a structured programme that educates patients about the risk, management, and prevention of upper limb disorders. The use of appropriate targeted upper limb exercise as an intervention, to rehabilitate upper limb pain and dysfunction is well documented[31–34]. Yet there remains a need for structured and integrated services in South Africa.

Development of a rehabilitation service should ideally be shaped around the health needs of individual patients supported by the survivor's comments in this study[35]. However, in resource constraint countries this is unlikely to be sustainable. Addressing the education need will have an immediate effect on upper limb awareness and morbidity through increased uptake of exercise. this is further supported by Lu et al[34] who showed that early patient education followed by exercise can reduce the risk of BCRL. Therefore, service development must focus on pairing points of delivery with appropriate modes of delivery. For example, many public health care institutions have a waiting list for surgery, presenting an ideal teaching moment, delivered on site. This could be followed by less resource intensive approaches such as an Early Warning System via a software application (APP), and survivor led exercise groups in easy to access community centres[36]. These approaches would address two key principles of service delivery, i.e. planning for accessible and sustainable services [35]

A final principle for health service planning is that of culturally appropriate services. The data from this study arises from principles of inequity and inequality in our public health sector. Overcoming these

hurdles will only be possible when planning is inclusive of local service enablers and users. A resounding outcome from enablers and users was unanimous support for a rehabilitation pathway. Where they deviate, is that survivors recommend more staff and enablers know this is not feasible.

Summary And Conclusion

Absent and/or fragmented rehabilitation services for upper limb sequelae in breast cancer survivors are leading to poor health outcomes for breast cancer survivors in SA. The true burden of this situation is not fully understood; however, this study has provided initial evidence of the need for an affordable, accessible, and sustainable rehabilitation service. Furthermore, it clearly identified the driver variable for an intervention to induce change.

Findings from this study have informed the development of a rehabilitation care pathway, which is currently undergoing a service development feasibility study.

Limitation To The Study

Three provinces did not respond to the survey. Each province has an oncology unit but no lymphoedema or rehabilitation specialist.

Declarations

Acknowledgements

We would like to thank the cancer survivors and health care professionals who dedicated time for the focus group discussions, And the National Research Fund (NRF) for the PhD scholarship.

Declarations

The authors have nothing to declare.

Funding

This research was funded through The Cancer Association of South Africa (CANSA).

Conflict of Interest

We have read and understood the Journal's policy on disclosing conflicts of interest and declare that we have none.

Ethics approval

Ethical approval to conduct this research was obtained from the UCT Faculty of Health Sciences Human Research Ethics Committee (HREC REF: 284/2019 and HREC REF: 509/2019).

Consent to participate

All participants consented to participate in the study and signed the following statement:

“I declare that: I understand that taking part in this study is voluntary and I have not been forced to take part. And I understand that if I am not comfortable with being in the study I may inform the researcher at any time that I choose to leave the study.”

Consent for publication

Not applicable.

Availability of data and material

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request

Code availability

Not applicable.

Authors' contributions

MP and DS carried out the following at site 1: focus group discussions, data analysis, and validated site 2 focus group data analysis. AB carried out the following at site 2: focus group discussion, focus group data analysis, and validated site1 data analysis. AS designed the national survey and carried out the analysis, DS conceptualised the study and study design, performed triangulation analysis for focus group data at site 1 and 2. The manuscript was written by MP and DS. NN & TB provided guidance and training for focus group facilitators and reviewed draft of manuscript.

References

1. Sung H, Ferlay J, Siegel RL et al (2021) Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA Cancer J Clin* 71:209–249. <https://doi.org/10.3322/caac.21660>
2. Cubasch H, Dickens C, Joffe M et al (2018) Breast cancer survival in Soweto, Johannesburg, South Africa: A receptor-defined cohort of women diagnosed from 2009 to 11. *Cancer Epidemiol* 52:120–127. <https://doi.org/10.1016/j.canep.2017.12.007>
3. Joko-Fru WY, Miranda-Filho A, Soerjomataram I et al (2020) Breast cancer survival in sub-Saharan Africa by age, stage at diagnosis and human development index: A population-based registry study. *Int J Cancer* 146:1208–1218. <https://doi.org/10.1002/ijc.32406>
4. Walker AR, Walker BF, Tshabalala EN et al (1984) Low survival of South African urban black women with breast cancer. *Br J Cancer* 49:241–244. <https://doi.org/10.1038/bjc.1984.37>

5. Lince-Deroche N, van Rensburg C, Masuku S et al (2017) Breast cancer in South Africa: developing an affordable and achievable plan to improve detection and survival. *South African Heal Rev* 181–188
6. Venter M, Venter C, Botha K (2012) Cancer treatment in South Africa: A narrative literature review. *J Psychol Africa* 22:459–466. <https://doi.org/10.1080/14330237.2012.10820555>
7. Kramer N, Ramjith J, Shamley D (2019) Prevalence of shoulder morbidity after treatment for breast Cancer in South Africa. *Support Care Cancer* 27:2591–2598. <https://doi.org/10.1007/s00520-018-4540-3>
8. Hewitt M, Greenfield S, Stovall E (2005) *From Cancer Patient to Cancer Survivor*
9. Hewitt M, Greenfield S, Stovall E (2006) *The National Academic press-From Cancer Patient to Cancer Survivor: Lost in Transition* (2006)
10. Salz T, Oeffinger KC, McCabe MS et al (2012) Survivorship Care Plans in Research and Practice. *CA Cancer J Clin* 62:101–117. <https://doi.org/10.3322/caac.20142>
11. IOM (2006) *From Cancer Patient to Cancer Survivor: Lost in Transition*. 2006
12. Ganz PA, Hahn EE (2008) Implementing a Survivorship Care Plan for Patients With Breast Cancer. *J Clin Oncol* 26:759–767. <https://doi.org/10.1200/JCO.2007.14.2851>
13. Grunfeld E, Mant D, Vessey MP, Yudkin P (1995) Evaluating primary care follow-up of breast cancer. Methods and preliminary results of three studies
14. Coughlin SS, Caplan L, Stewart JL, Young L (2019) Do Breast Cancer Survivorship Care Plans Improve Health Outcomes?
15. Brennan ME, Gormally JF, Butow P et al (2014) Survivorship care plans in cancer: a systematic review of care plan outcomes. *Br J Cancer* 111. <https://doi.org/10.1038/bjc.2014.505>
16. Grunfeld E, Julian JA, Pond G et al (2011) Evaluating Survivorship Care Plans: Results of a Randomized, Clinical Trial of Patients With Breast Cancer. *J Clin Oncol* 29. <https://doi.org/10.1200/JCO/2011.38.8397>
17. Subramaniam R, Sanjeev R, Kuruvilla S et al (2017) Jargon: A barrier in case history taking? - A cross-sectional survey among dental students and staff. *Dent Res J (Isfahan)* 14:203–208. <https://doi.org/10.4103/1735-3327.208763>
18. Antoinette P, Sander J, Wilson N, Izzo, Stephanie A, Mountford KWH (2012) Factors That Affect Decisions About Physical Activity and Exercise in Survivors of Breast Cancer: A Qualitative Study. *Phys Ther J* 92:525–536. <https://doi.org/10.2522/ptj.20110115>
19. Kruegar R, Casey MA (2000) *Focus Groups. A Practical Guide for Applied Research*
20. Creswell JW, Miller DL (2000) ACE - edtt article by Creswell on validity in quantitative research.pdf. *Theory Pract* 39:124–130
21. Patton MQ *Enhancing the Quality and Credibility of Qualitative Analysis*
22. Brassard M, Ritter D (1994) *The memory jogger: A pocket guide of tools for continuous improvement and effective planning*, first edn. GOAL/QPC, Salem

23. Binkley JM, Harris SR, Levangie PK et al (2012) Patient perspectives on breast cancer treatment side effects and the prospective surveillance model for physical rehabilitation for women with breast cancer. *Cancer* 118:2207–2216. <https://doi.org/10.1002/cncr.27469>
24. Sierla, Robyn Deborah Black, Teresa Sze Mun Lee SK Access to treatment for breast cancer-related lymphoedema in Australia
25. Kantsiper M, Mcdonald EL, Geller G et al (2009) Transitioning to Breast Cancer Survivorship: Perspectives of Patients, Cancer Specialists, and Primary Care Providers. *J Gen Intern Med* 24:459–466. <https://doi.org/10.1007/s11606-009-1000-2>
26. Ganz PA, Har Yip C, Gralow JR et al Supportive care after curative treatment for breast cancer (survivorship care): Resource allocations in low-and middle-income countries. A Breast Health Global Initiative 2013 consensus statement-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/3.0/>). <https://doi.org/10.1016/j.breast.2013.07.049>
27. Thomas-MacLean R, Miedema B, Sue RT (2005) Breast cancer-related lymphedema: women's experiences with an underestimated condition. *Can Fam Physician* 51:246–247
28. Ridner SH (2006) Pretreatment lymphedema education and identified educational resources in breast cancer patients. *Patient Educ Couns* 61:72–79. <https://doi.org/10.1016/j.pec.2005.02.009>
29. Harrison JD, Young JM, Price MA et al (2009) What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer* 17:1117–1128. <https://doi.org/10.1007/s00520-009-0615-5>
30. Demark-Wahnefried W, Clipp EC, Lipkus IM et al (2007) Main outcomes of the FRESH START trial: A sequentially tailored, diet and exercise mailed print intervention among breast and prostate cancer survivors. *J Clin Oncol* 25:2709–2718. <https://doi.org/10.1200/JCO.2007.10.7094>
31. Anderson RT, Kimmick GG, Mccoy TP et al (2012) A randomized trial of exercise on well-being and function following breast cancer surgery: the RESTORE trial. 172–181. <https://doi.org/10.1007/s11764-011-0208-4>
32. Richmond H, Lait C, Srikesavan C et al (2018) Development of an exercise intervention for the prevention of musculoskeletal shoulder problems after breast cancer treatment: The prevention of shoulder problems trial (UK PROSPER). *BMC Health Serv Res* 18:1–12. <https://doi.org/10.1186/s12913-018-3280-x>
33. Chang CJ, Cormier JN (2013) Lymphema interventions: exercise, surgery, and compression devices. <https://doi.org/10.1016/j.soncn.2012.11.005>
34. Kwan ML, Cohn JC, Armer JM et al (2011) Exercise in patients with lymphedema: a systematic review of the contemporary literature. *J Cancer Surviv* 5:320–336. <https://doi.org/10.1007/s11764-011-0203-9>
35. Queensland Health (2015) Guide to Health Service Planning
36. Shamley D, Robb K (2015) An early warning surveillance programme for detecting upper limb deterioration after treatment for breast cancer: A novel technology supported system. *BMC Cancer* 15:1–4. <https://doi.org/10.1186/s12885-015-1636-8>

Figures

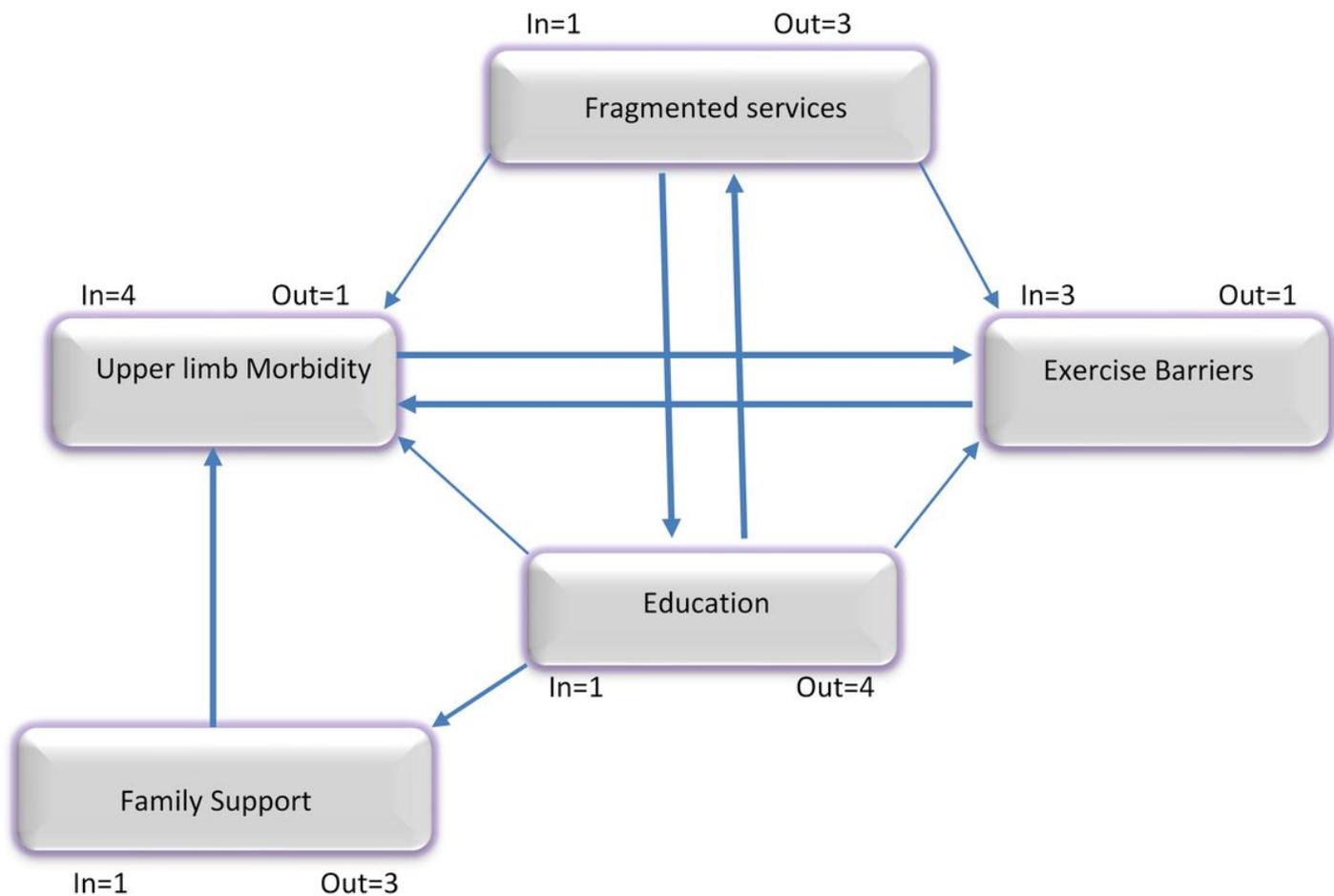


Figure 1

An Interrelationship Diagram showing relationship between driver and effect variables.

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