

Breast Cancer Survivor Experience Of Rehabilitation Services In South Africa: Towards A Cancer Survivorship Plan

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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 treatment to survivorship. The aim of this study was to assess the current South African upper limb rehabilitation service, provision, and perspectives of these from the health professionals and the end users breast cancer survivor with upper limb disorder.

Methods

A sequential 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. Poor patient education is driving poor upper limb outcomes and barriers to exercise behaviour.

Conclusion

The current South African upper limb rehabilitation services does not cater for the unmet needs of a breast cancer survivor leading to poor health outcomes.

Introduction

Breast Cancer (BC) accounts for 11% of worldwide cancer cases in women, with more breast cancer-related deaths reported in economically developing countries, compared to developed countries [1]. Recent data indicate an improvement in the relative survival rate among women diagnosed with BC in developing countries like South Africa (SA). The 3-year relative survival rate for women diagnosed with breast cancer in SA is 84% [2, 3]. This significant increase in the number of cancer survivor population can be accredited, but not limited, to the advancements in treatment modalities [3, 4]. Never the less, treatment for breast cancer patients remains a challenge in SA with many going undiagnosed and untreated for years [4–6]. As a result, treatment often includes more radical approaches leading to well-known upper limb sequelae.

Our data show that 74% of breast cancer survivors in a South African population, experience some degree of upper limb pain (either mild, moderate or severe) post treatment, while 63% experience some level of upper limb disability [7].

The Institute of Medicine (IOM) recommends the implementation of Survivorship Care Plans (SCP) to best deliver cancer survivorship care. The aim of these survivorship care plans 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 with those without [13–15].

However, 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 rehabilitation service provision and the health professionals and breast cancer survivors experience of these services. Findings will inform the breast cancer SCP for South Africa.

Methods

This study used a sequential mixed method approach. The status of current rehabilitation services in SA was obtained via an online quantitative survey questionnaire. Data from the responses informed the development of open-ended questions for focus groups held with health care professionals (HCP) and breast cancer survivors.

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).

National Online Survey

A convenience sample 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.

Two repeat emails were sent and return of the completed survey was considered consent.

Focus Group discussions

HCP focus groups aimed to explore the survey responses (underlying reasons for absent or fragmented services and level of support for an integrated care pathway inclusive of rehabilitation) and the level of knowledge of treatment related long-term side effects. Survivor 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 service pathway.

Focus group discussions 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 [16] and were conducted until data saturation was reached [17].

EQUATOR reporting guidelines for qualitative research (COREQ) were implemented for quality assurance.

Participants

HCP were invited to volunteer via an email sent to the head of the respective departments (Physiotherapy, Occupational Therapy, Radiation Oncology). BC survivors were invited via adverts on advocacy group media and posters and information leaflets placed in waiting areas of the oncology outpatient clinics.

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.

A maximum of 6 participants were included in each FG. Recordings were independently transcribed, and transcriptions subjected to forward- and back translation into English where necessary. Validation of transcriptions was achieved through member checking [18].

Data management and analyses

Survey data was descriptively analysed and reported.

Qualitative analyses of the FG transcripts were conducted using open coding and thematic analysis, whereby data were organized into categories, sub-categories, and themes [19]. Responses to questions in the FG discussion guide were grouped and the content of these categories and themes were validated independently by three authors without discrepancy. Sites themes were developed into propositions and modeled in an Interrelationship Diagram (ID) to determine driver and effect variables [20].

Results

National Survey

Eight breast cancer units (8 Provinces) were contacted, and 50 health professionals received the survey. Seventeen (34%) HCPs responded to the survey (Table 1& supplementary file 1). It is notable that 7(41%) were from public and 10(59%) from private institutions. Physiotherapists 5 (50%) formed the largest group of responders in the private sector compared to the public where doctors 5 (71%) were the main responders. Of the 8 provinces only 3 are represented in the survey data.

Upper limb assessment in the public sector is carried out by Physiotherapists and Medical Oncologist. Only 33% of respondents were formally trained to assess and manage BCRL in public sector versus 67% in private. The private sector offers upper limb services at every point in the care pathway as opposed to the public sector which is limited to post-surgery and post-radiotherapy. A notable disparity is seen between numbers of survivors seen monthly in private vs public.

Table 1
Summary of survey data.

	private n (%)	public n (%)	total n (%)
Total Respondents	10 (59)	7 (41)	17 (100)
Profession of respondents			
Doctor	0 (0)	5 (71)	5 (29)
Physiotherapist	5 (50)	2 (29)	7 (41)
BC nurse	1 (10)	0 (0)	1 (6)
Other	4 (40)	0 (0)	4 (24)
Rehab service delivery			
Are there official guidelines/ protocols for the assessment and management of:			
Upper limb functioning (yes) *missing 1	5 (56)	4 (57)	9 (56)
BCRL (yes) *missing 1	7 (78)		
Which health practitioner/s conduct/s the assessment and management of upper limb pain and dysfunction among breast cancer patients? *missing 1			
Physiotherapist	6 (67)	3 (43)	9 (56)
Medical Oncologist	1 (11)	3 (43)	4 (25)
Management of BCRL			
Have you ever received clinical skill training for assessment and management of BCRL?			
Yes	10 (100)	2 (33)	12 (75)
How many breast cancer patients with BCRL do you see per month? *missing 6			
None	1 (11)	1 (50)	2 (18)
1-4	3 (33)	1 (50)	4 (36)
5-10	3 (33)	0 (0)	3 (27)

	private n (%)	public n (%)	total n (%)
10–20	1 (11)	0 (0)	1 (9)
>20	1 (11)	0 (0)	1 (9)
Do you assess the breast cancer patients for BCRL?			
Yes	10 (100)	4 (57)	14 (82)
Why do you not assess the patients for BCRL? *missing 1			
Not trained	-	2 (29)	
Don't see follow-up patients	-	1 (14)	
Do you provide the treatment for breast cancer patients with BCRL?			
Yes	9 (90)	4 (57)	13 (77)
At what phase/s of the breast cancer treatment process are the breast cancer patients when you treat them for BCRL?			
At diagnosis	2 (20)	0 (0)	2 (12)
Post-surgery	6 (60)	2 (29)	8 (47)
During RT	6 (60)	0 (0)	6 (35)
Post RT	7 (70)	3 (43)	10 (59)
During Chemotherapy	6 (60)	0 (0)	6 (35)
Post Chemotherapy	7 (70)	0 (0)	7 (41)
Palliative	5 (50)	1 (14)	6 (35)
Prior adjuvant therapy	3 (30)	0 (0)	3 (18)
During adjuvant therapy	4 (40)	0 (0)	4 (24)
Post-adjuvant therapy	4 (40)	1 (14)	5 (29)
Post-treatment (Completed treatment but accessing facility for BCRL symptoms)	7 (70)	1 (14)	8 (47)

	private n (%)	public n (%)	total n (%)
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.)?			
Yes	9 (90)	2 (40)	11 (73)
How many breast cancer patients with upper limb pain and dysfunction do you see per month? *missing 4			
None	1 (11)	2 (50)	3 (23)
1-4	5 (56)	1 (25)	6 (46)
5-10	2 (22)	1 (25)	3 (23)
10-20	1 (11)	0 (0)	1 (8)
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?)			
Yes	10 (100)	4 (80)	14 (93)
Who in your unit does assess the breast cancer patients for upper limb pain and dysfunction?			
Medical Officers	-	1 (14)	-
Do you provide treatment for breast cancer patients with upper limb pain and dysfunction?			
Yes	8 (80)	3 (60)	11 (73)
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	2 (20)	0 (0)	2 (12)
Post-surgery	6 (60)	3 (43)	9 (53)
During RT	5 (50)	1 (14)	6 (35)
Post RT	6 (60)	0 (0)	6 (35)
During Chemotherapy	6 (60)	0 (0)	6 (35)

	private n (%)	public n (%)	total n (%)
Post Chemotherapy	7 (70)	0 (0)	7 (41)
Palliative	6 (60)	0 (0)	6 (35)
Prior adjuvant therapy	4 (40)	0 (0)	4 (24)
During adjuvant therapy	5 (50)	0 (0)	5 (29)
Post-adjuvant therapy	5 (50)	0 (0)	5 (29)
Post-treatment (Completed treatment but accessing facility for BCRL symptoms)	8 (80)	0 (0)	8 (47)

Focus groups.

A total of 8 FGs were run, with 34 BC survivors (11 at site 1 and 23 at site 2) and 8 health care providers. The survivors median age was 55 years, the youngest enrolled 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 (281.06€ or 341.23\$) or less per month. 97% of the survivors had formal school education. 25 (74%) of the cancer survivors reported that they experience some form of shoulder morbidity and 22 (65%) had developed lymphoedema post cancer treatment. The recruited health care providers included a consultant doctor, breast cancer nurses, physiotherapists and occupational therapists.

Four overlapping themes were identified from all FG codes and developed into propositions.

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 disorder or how to manage the long-term side effects. Participant 6: *"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."* Participant 27: *"They don't tell you the nitty gritty stuff that you really need to know."* Participant 18: *"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. Participant 10: *"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. Participant 17: *"My sister told me that if I don't exercise my arm it will stay like this."* Participant 2: *"I remember coming home from surgery and my sister-in-law and my husband going, no, no, no don't even wash just rest."* Participant 6: *"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. Participants 4: *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, Participant 1: *"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

SA 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. Participant 20: *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.* Participant 9: *"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. Participant 12: *"I felt too embarrassed to go back aquarobics for my lymphoedema."* Participant 23: *"I had no issues and I just got depressed; I was in a bad, bad place."* Participant 15: *"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. Participants 26: *"It pains terribly, you just get a sudden stabbing pain."*

3. Current 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. Participant 17: *"I had my surgery. then I was discharged then... nothing." there was nobody to direct me* Participant 29: *"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. Participant 7: *"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.* Participant 8: *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; Participant 15: *"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. Participant 3: *"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 could engender a shared support mechanism.

Survivors strongly recommended an individually tailored rehabilitation plan to meet the recovery needs of the survivor. Participant 19: *"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. Participant 2: *"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."* Participant 22: *"A person forgets quickly; post treatment education would have helped."*

To improve educational access and reduce information overload on the first hospital visits, upper limb disorder education can also be shared on different platforms where 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. Participant 9: *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.” Participant 8: “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. Participant 6: *“You know the community health can be taught the basics, add into their kit of teaching lymphoedema management, pre-post-op exercises.”* Participant 26: *“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. Participant 11: *“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. Participant 4: *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.*

Modelling data from the FG themes/sub-themes into an Interrelationship Diagram demonstrates a strong relationship between education as a driver of all other variables (Out = 4). Upper limb morbidity emerges as the variable most affected by other variables (In = 4) followed by exercise barriers (In = 3)

Discussion

This study has revealed a dearth of rehabilitation services for breast cancer survivors in the public health sector of South Africa. Although the survey response from public institutions was poor, provinces with stronger health services were represented. 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 in general revealed poor knowledge of the long-term effects of treatment, the epidemiology of these effects and effective management strategies. 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[21–24]. 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. This concurs with Maclean findings 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 [25]. 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[26–29]. 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[30]. 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. Service development must therefore 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[31]. These approaches would address two key principles of service delivery, i.e. planning for accessible and sustainable services [30]

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 very 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.

Key propositions emerging from the study will be translated into the service design and implementation plan.

Limitation to the study.

Poor survey responses from six provinces limits the generalisability of our findings. Of these only one province is known to have a dedicated cancer centre, thus it may be that the absence of responses represents an absence of structured services.

Declarations

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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.

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Figures

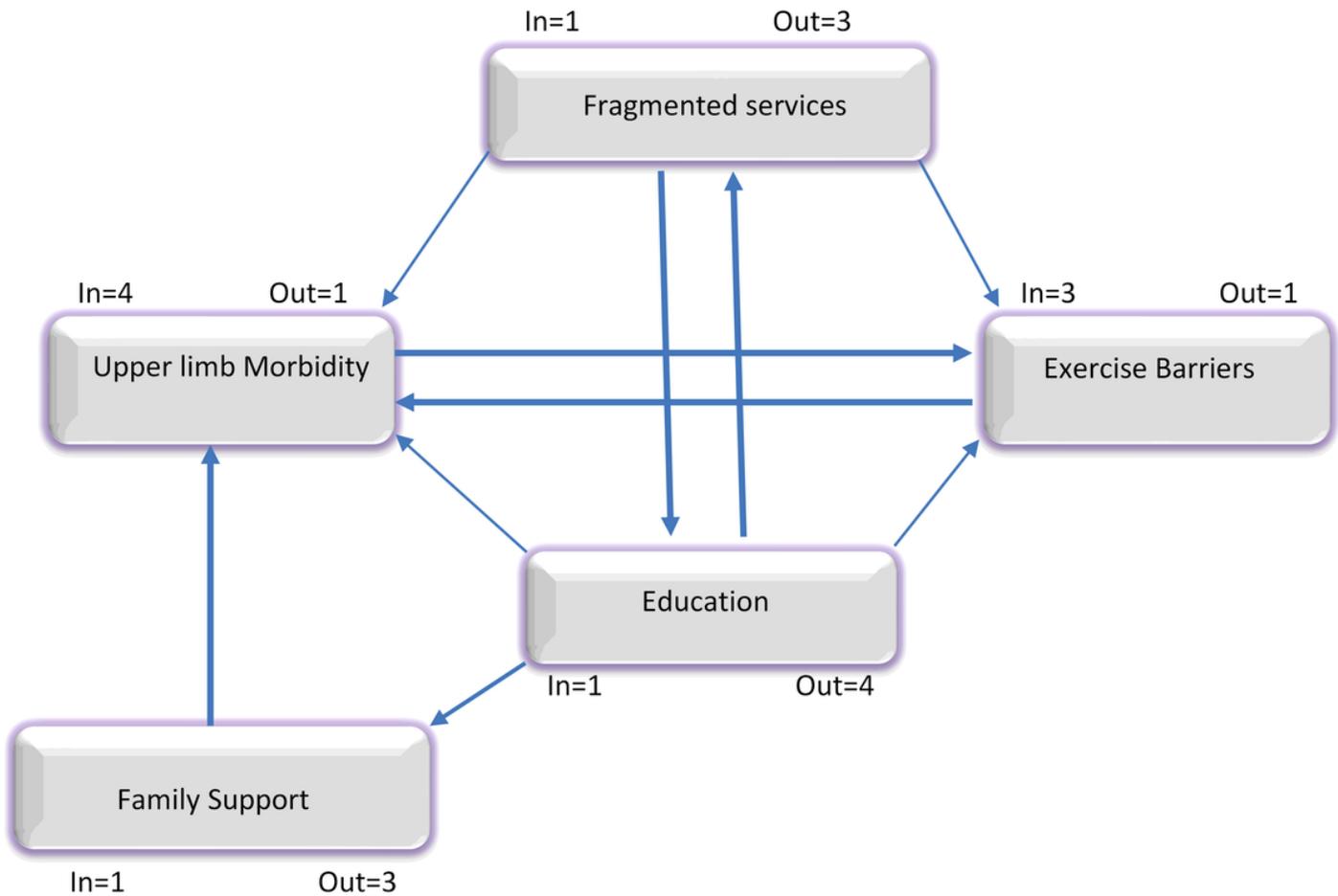


Figure 1

An Interrelationship Diagram showing relationship between driver and effect variables.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [ShamleySupplementaryFile1.docx](#)
- [ShamleySupplementaryfile2.xlsx](#)