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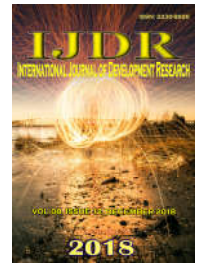
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QUALITY OF LIFE, PAIN, AND DISABILITY POST-SURGICAL MANAGEMENT OF BREAST CANCER

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ABSTRACT

Introduction: Breast cancer is ranked as the 4th on the list of the deadliest cancers in 2017 worldwide. While in the Arab world, Breast cancer is the most common among women ⁽¹⁾ ⁽²⁾. In Palestine, breast cancer is number one most common cancer with a percentage of 17.8% of all the reported cancer cases in Palestine, in 2016 and in 2015 it was as high as 33.7% ⁽³⁾. Surgery is the best management for breast cancer with expected complication pain and functional impairments (Cheville and Tchou, 2007). The aim of this study is to investigate the physical dysfunction and the quality of life for patients' post-surgical intervention for breast cancer in Palestine. **Methods:** A Quantitative cross-sectional study was carried out using: a personal data collection sheet, the SF-36 (The Quality of life Questionnaire – Short form) and the Shoulder Disability questionnaire. 20 patients who underwent surgical-intervention for breast cancer were included in the study. **Results:** The quality of life for the patients ranged from poor to excellent but the worst scores were seen in the emotional wellbeing and energy domains (45, 44) respectively. The most common complications among the participants were the Frozen shoulder and lymphedema (30%, 25%) respectively. There was a statistically significant difference between the type of surgery and the social functioning score of the patients ($X^2 = 9.284, P=0.026$.) Shoulder disability was associated with the General Health domain of the SF-36 ($R=.569, P=0.04$), Spouse support (was associated with the physical score, Extent of religious belief was associated with better social functioning score ($R=.420, P=0.048$), Knowledge from medical staff was correlated with better physical score ($R=.374, P=0.05$). **Conclusion:** Palestinian Postsurgical breast cancer survivors suffers from pain, disability and quality of life challenges, rehabilitation services is missing, and medical staff is not investing enough time in patient's empowerment after surgery.

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INTRODUCTION

Cancer is known as group of diseases in which cancerous cells spread through the body and starts making changes until it becomes out of control (Haddou Rahou *et al.*, 2016). There are 4 types for breast cancer surgery: *Mastectomy*: is removal of the entire breast tissue only; no lymph nodes or muscles are removed. *Lumpectomy*: is removal of the cancer (lump/mass) and a rim of surrounding normal tissue. *Radical mastectomy*: is removal of the entire breast, the underlying muscles of the chest wall, most of the lymph node chains that drain the breast and the skin over the breast. *Axillary Lymph Node Dissection*:

which is the removal of the lymph nodes under the armpit either for testing for the extent of spread in cancer cells in the lymphatic system or as part of the radical mastectomy procedure (Friese *et al.*, 2017). Breast cancer survivors who went through surgical treatment or breast cancer suffer from pain and functional compromises specifically post mastectomy (Cheville and Tchou, 2007). It Compromises of: Myofascial dysfunction, frozen shoulder, axillary web syndrome, post-mastectomy syndrome, lymphostasis, donor site morbidity post breast reconstruction (Cheville and Tchou, 2007; Ebaugh *et al.*, 2011). The aim of the study is to investigate the outcomes for breast cancer survivor's post-surgical intervention, the side effects of the procedure, the quality of life, most common complications and to assess the status of rehabilitation for those patients in Palestine.

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MATERIALS AND METHODS

The approval to conduct this study was granted by Bethlehem University and Al-Hussien Governmental Hospital. Convenient sampling method was used due to the time limitation. All survivors of breast cancer surgery were included in this study, those who had other musculoskeletal problems previous to the surgery were excluded, 20 participants were recruited from west bank (Palestine), 2 refused and others were excluded as they did not fit in the inclusion criteria. The study was conducted in Bethlehem and Hebron. The majority of the patients have had their surgery in Al-Hussein Government Hospital. Quantitative cross-sectional study design was used in this study, Tools of data collection were: the data collection sheet that included (Personal variables, like age, medical history, time since surgery, what stage of cancer, site of surgery, type of surgery. Socio-demographic variable like, extent of religious belief, marital status, place of living. Rehabilitation variables we recaptured in terms of physiotherapy frequency, intensity and patient's self-involvement in the treatment. The Optimal Performance Physiotherapy Disability Questionnaire was used to assess the extent of shoulder dysfunction post-surgical intervention for breast cancer and it consists of 16 items. The higher the score out of 100 the higher the disability. It's both valid and reliable (Van der Windt *et al.*, 1998). Quality of life Short Form 36 health Survey (SF-36) was used to measure the quality of life. It has 8 domains that are measured with 36 items. (Physical functioning, Body pain, Role limitation due to physical health, Role limitation due to emotional problems, Emotional well-being, Social functioning, Energy/fatigue, and General Health perceptions. The SF-36 is both valid and reliable (Brazier *et al.*, 1992).

RESULTS

The age ranged between 32-78 years old (M=54, SD=11). The Weight between 51-94 kilograms (M=70, SD=20). The height ranged between 154-170 cm (M=163, SD=4) Body Mass Index (M=29.4, SD=6.6). 90% were married and 10% are either single or widows. No single participant of our sample had any type post-surgical rehabilitation services, Main types of surgeries were Radical mastectomy was (30%), Axillary Lymph Node Dissection (10%), Radical mastectomy and axillary lymph node dissection (55%), and Lumpectomy (5%). The most common complications post-surgical intervention for breast cancer were Frozen shoulder 30%, Lymphedema 25% (Figure 1), Post Mastectomy Pain Syndrome 20%, Axillary Web Syndrome 15%.



Figure 1. One of the breast surgery survivors without post-surgical rehabilitation (Patient consent was attained to use for scientific use)

In terms of shoulder disability, Table (1) shows the descriptive statistics of the (SDQ) Shoulder Disability Questionnaire and pain among post-surgical intervention for breast cancer patients, where it shows moderate pain reported by the participants with a prevalent shoulder disability still post the surgical intervention after a period of median 10.5 months post-surgery there was a positive statistically significant correlation between Shoulder Disability Questionnaire score and body mass index ($R=.602$, $P=.015$). Also, there was a statistically significant correlation between Shoulder Disability Questionnaire score and the General Health Domain of the SF-36 ($R=.569$, $P=.004$). In terms of quality of life (SF-36) As shown in Figure 2 which describes the domains of SF-36, it ranged between poor and excellent: Physical (M=78, SD=34), General Health (M=54, SD=26), Social Functioning (M=51, SD=24), Pain (M=49, SD=34), Energy (M=45, SD=26), Emotional Wellbeing (M=44, SD=27).

Table 1. Descriptive statistics of SDQ and Pain

	Min	Max	Mean	STD	Median
SDQ	0	100	65	31.5	70
Pain	1	5	3.0	1.2	3

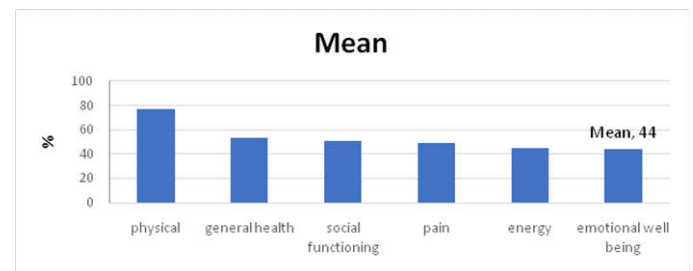


Figure 2. Domains of the SF-36 among post-surgical breast cancer survivors

The physical domain in the SF-36 had a significant correlation with the General Health score ($R=-.800$, $P=.000$), Pain score ($R=.648$, $P=.001$), Social Functioning Score ($R=.512$, $P=.010$), Energy score ($R=-.583$, $P=.004$), Emotional Wellbeing score ($R=.646$, $P=.001$), body mass index ($R=-.485$, $P=.047$). A statistically significant correlation was found between the general health domain and Body Mass Index ($R=.470$, $P=0.05$), Energy Score ($R=.597$, $P=0.00$), Pain Score ($R=-.747$, $P=0.00$), Social Functioning Score ($R=-.675$, $P=0.00$), and emotional Wellbeing Score ($R=-.679$, $P=0.00$). The social functioning domain showed a significant correlation with age ($R=-.435$, $P=0.03$), General Health score ($R=-.675$, $P=0.00$), pain score ($R=.861$, $P=0.00$), energy score ($R=-.589$, $P=0.00$), and physical score ($R=.512$, $P=0.01$). The pain domain has a significantly correlated with general health score ($R=-.747$, $P=0.00$), social functioning ($R=.861$, $P=0.00$), energy ($R=-.589$, $P=0.00$), emotional wellbeing ($R=.403$, $P=0.04$) and the physical score ($R=.648$, $P=0.00$). The energy domain had a significant correlation with body mass index ($R=.533$, $P=0.03$), general health score ($R=.597$, $P=0.00$), pain ($R=-.589$, $P=0.00$), social functioning ($R=-.589$, $P=0.00$), emotional wellbeing ($R=-.669$, $P=0.00$) and the physical score ($R=-.583$, $P=0.00$). The effect of the emotional wellbeing score was significantly correlated with age ($R=.379$, $P=0.05$), body mass index ($R=-.702$, $P=0.00$), general health ($R=-.679$, $P=0.00$), pain ($R=.403$, $P=0.04$), energy ($R=-.669$, $P=0.00$) and the physical score ($R=.646$, $P=0.00$). Perception of quality of sexual life was reported with an average of: 3.1 (SD=1.07) on a Likert scale of 1-5 with 5 meaning strongly agree, sexual life after the surgery

has a significantly inversely correlation with pain score ($R=-.428$, $P=.030$), the social functioning score ($R=-.383$, $P=.048$), and the energy score ($R=.480$, $P=.016$). Perception of whether family support helped patients to cope with the disease scored an average of 3.75 ($SD=1.118$). The spouse support effect was significant on all the domains in the table. The time that has passed since surgery ($R=-.400$, $P=.040$), body mass index ($R=-.506$, $P=.039$) and the physical score ($R=.500$, $P=.012$). The help from the medical staff to explain the foreseen challenges and how to deal with it had a significant effect on the physical score ($R=.374$, $P=0.05$). Perception of whether religion helped patients cope with the disease scored an average of 4.3500 ($SD=.812$). there was a significant association between religion and the domain of social functioning score, where the more the patient felt that religion would help her cope, the higher her social functioning score would be. ($R=.420$, $P=.048$). In terms of the difference between different types of surgery in relation to social functioning, A Kruskal Wallis test was performed, which showed that there was a statistically significant difference between the different types of surgery in relation to social functioning score $X^2(2) = 9.284$, $P=0.026$, with better social functioning among lumpectomy as compared to other types of surgery

DISCUSSION

Our age group ranged between 32-78 this is because we included all breast cancer survivor's post-surgical intervention due to the time limit. The majority of our patients were Muslims which is expected since the majority of Palestinians are Muslims with only 1% Christian population (The Diyar Consortium, 2007). As shown in the results section, the average age was 55 which is considered older than the average age reported in the studies of Bahgat, 2016 (21-60) and Sabino Neto, 2012 (18-60) (Sabino Neto *et al.*, 2012; Bahgat *et al.*, 2016). This shows that the Palestinian cancer victims may be affected at an older age than the international population. This could be due to many factors, like type of diet, genetic predisposition, and other environmental factors. This also shows the importance of health promotion and campaigns to raise awareness about this issue. This however, gives a motivation for further research to investigate the average age of breast cancer patients among the breast cancer cohort in Palestine. On the other hand, there could be many younger patients with undetected cancer due to lack of early screening which could decrease the age mean since many of mastectomy survivors were subjected to the surgery based on very early stage changes within the breast that were detected through public organized screening campaigns. The type of surgery that each of the participants had undergone was different and the majority had undergone both radical mastectomy and axillary lymph node dissection as its well known that this is the most common procedure based on medical necessity. From a prophylactic point of view from surgeons, but they don't have any preventive measures against complications associated with mastectomy. Which means that they're also negligent about the complications which was obvious in the behaviour of the medical staff before and after the surgery. This was shown in how the post-surgical breast cancer survivors answered the question of whether they received any instructions or not from the medical staff. The need for better advice and precautions for the patient by the health care provider puts emphasis the importance of helping the patient get prepared in a better way and add factors that would promote better physical function and wellbeing post-surgery. And this comes in consensus with

Lauridsen, 2005 (Lauridsen *et al.*, 2005). The quality of life of the participants ranged from poor to excellent. The worst domain was the emotional wellbeing. This shows that despite the fact that such a thing couldn't be easily measured and sometimes left unnoticed from health care providers, it's an important aspect that should be taken into consideration. Health care providers must be health promoters before being service givers and help in guiding the patient toward counselling services and help support them psychologically and help their families understand this too, which was recommended by: Mustafa, 2009 and McCallin. As WHO defines Quality of Life its main issue about this definition is that it's the patient's personal perception about her own life which varies across culture, religions, socio-economic status and this perception is strongly associated with the emotional aspects after the surgery which means that this particular aspect of the mastectomy post-surgical complications should be well appreciated and managed.

The most common complications that the participants are suffering from are frozen shoulder, lymphedema, post mastectomy pain syndrome and axillary web syndrome respectively. The majority of the studies agree that these are the most common complications (Palestinian Ministry of Health, 2015; Ebaugh *et al.*, 2011). This shows the extent to how many patients suffer from those complications silently. This could be due to the lack of knowledge among the health care providers and the patients about the surgery. For as long as those complications are going to be ignored, the worst the patient's quality of life is going to be and the only way to help improve this is by raising awareness about what the physiotherapy role is in post-surgery rehabilitation to both the health care providers and patients who are about to or have undergone surgical intervention for breast cancer. This leads us to the main finding of this study that none of the survivors have received physiotherapy rehabilitation or any other rehabilitation services post-surgery. It shows the lack of understanding of rehabilitation services importance for those complications among both health care providers and patients. It also indicates that there was no investment from the medical staff side in empowering and educating patient after the surgery.

The majority of the literature strongly advises of a comprehensive and holistic rehabilitation approach that focuses on both the physical and the psychological aspects to ensure the patient's maximum level of physical function and emotional wellbeing (Testa *et al.*, 2013; Na *et al.*, 1999; Bahgat *et al.*, 2016; Mostafa *et al.*, 2009). McCallin in 2005 put more emphasis on the importance of paying attention to the psychological changes along with the physiotherapy rehabilitation (McCallin *et al.*, 2004). This shows the urgent need to come with a holistic comprehensive rehabilitation approach which could not just improve the survivors' quality of life, but also reduce the cost of treating the complications after they become severe instead of using conservative and preventive measure like physiotherapy which supports the findings of Kark 2005 (Stout *et al.*, 2012; Kärki *et al.*, 2005). Even the only centre in Palestine that is dedicated to manage post-surgical complications of breast cancer survivors doesn't include physiotherapy among its personnel and it's situated in Nablus and Ramallah which is challenging from accessibility point of view for patients from North and South of the West Bank. Religion and family support had a huge impact on the patient's way of coping with the disease and this goes well

with what Donnelly and colleagues concluded in a literature review in 2013 (Donnelly *et al.*, 2013). This is because believing in a bigger force that could help ease the consequence of the surgery helps many patients deal with it or sometimes accept things as they are which makes them feel content about what they have. This doesn't necessarily mean that religion really helps, but among religious societies like the Palestinian society it does have an effect on the patient's quality of life and sometimes even pain or their perception of it. Specially that from religious point of view pain and disease are considered as things that god would reward the victims for after their patience and acceptance of what they have been going through. Which goes well with the acceptance of their current status which in term is considered a developed stage in bargaining on the Kubler-Ross Grief Cycle. Quality of Life as mentioned above is about one's perception of their life. Spouse support in terms of late Maslow in his hierarchy of human needs is about safety and love and belonging needs in the second and third level respectively.

Which means that his perception would affect her sense of safety and belonging and therefore affect her quality of life due to the judgmental perception of her by her spouse whether it was true or false it still determines a lot about her perceived quality of life. In the results section, we could see that the support from the spouse was very low and that along with the time that passes after the surgery it decreases. It also showed a connection with the body mass index which shows how the woman's image affects how much of a help her spouse would be. It didn't just stop there, it also showed that the better her physical score would be, the more of a helpful the spouse would be, which in our opinion shows disastrous results because the worse those factors get the less the support from the spouse would be seen. Since in the Palestinian society females are considered to be the main care givers in the house, the amount of help the survivor receives from others could influence on how she perceives herself. Pain and shoulder dysfunction is associated with the patient's quality of life to a great extent in both the physical and psychological aspects.

This may affect their quality of life because it would stop them from taking part in many activities. Like sports or social gathering because they don't want to show people their pain and suffering and many of the patients have problems with accepting their body changes so they prefer to stay at home and avoid social gatherings. Many studies agree with that because it doesn't only affect their function and energy but it prevents them from doing many physical activities which respectively affect their emotional wellbeing (Cheville and Tchou, 2007; Stevens *et al.*, 1995; Ververs *et al.*, 2001; Ganz *et al.*, 1998; Jassim and Whitford, 2013). In addition, empathy and sympathy are two different things and sometimes exaggerating sympathy presentations puts the survivor in a low social status specially when they connect the issue to death and ask direct questions about their private life. False comparisons with outcomes of other survivors' that don't represent the patient's situation could affect them in a negatively. Then, connecting the patient's health status (cancer) with death could threaten her level of acceptance and coping mechanism. Therefore, encouraging the patient to interact socially could be a double-edged sword because of its devastating consequences due to the contradictions between scientific facts and societal myths about the disease and the lack of awareness about the patient's social environment elements. Regardless of Freud's overrated importance of the sexual aspect in the life of

humans, but that doesn't make this aspect any less important for the survivors' quality of life. One of the domains of the Quality of Life Questionnaire is the social domain and the sexual aspect is one of the most intimate aspects of social interactions that's affected by the survivor's perception of her self-image from the other's point of view. Our results showed that there's no actual sexual satisfaction among mastectomy survivors. This may affect their self-perception which will influence their social participation. Sexual satisfaction is based on how the patient perceives her self-image and how her spouse perceives it too since her perception is mostly a reflection of his perception of her. Like we mentioned earlier, this would affect her quality of life on so many aspects. The complications after the surgery plays a huge role in how a woman would perceive herself after experiencing the extent of those complications. Then, the worse those complications are, the worse her sexual life would be, this agrees with Jassim and Whitford in 2013. Addressing those issues in the first place is very essential in improving the quality of life for those women according to Fobair and colleagues, 2006 (Fobair *et al.*, 2006).

There's a lack of knowledge among patients in terms of education that they should've received from health care providers in order to understand more about the surgery and its complications. Not knowing what to expect s going to leave the patient unaware and less prepared for the potential complications that she's going to face which will lead to late detection and later more sever complications. "*One of the patients told us that she had no idea what to do with the stitches and others reported never having received instructions on how to deal with the pain.*" This again brings attention to the importance of post-surgical capacity building of both the patient and their families to face this escalating multidimensional deconditioning of post-surgical breast cancer survivors. Finally, the results proved that there's a relationship between the type of surgery and the quality of life for the patients. This puts more emphasis on why it's very important for doctors to be more careful with the type of surgery and only perform the surgery that's needed. This as well shows the importance of educating women about the types of surgeries and what to expect afterwards. The authors strongly recommend a future interventional study that investigates the effect of a holistic post-operative protocol that is based on awareness empowerment and direct contact with mastectomy survivors. To compare the surgery outcomes of those future researches with the outcome of current practices where rehabilitation isn't part of the management plan of breast cancer survivor's post-surgical intervention.

Conclusion

We concluded that postsurgical rehabilitation for breast cancer survivors in Palestine is missing, and medical staff is not taking care of patient's empowerment after surgery. Patients in Palestine are exhibiting a evident post-surgical complications represented in residual pain, shoulder disability, and decreased quality of life even after several months from the surgery.

Recommendation: The Authors emphasize the importance of a doctors and medical staff-oriented awareness campaigns, and to incorporate physiotherapy in the management protocol of our breast cancer post-surgical management plan. Starting an initiative for support groups for those patients and for physiotherapists to understand through campaigns more about what the patient can do after the surgery and how can a

physiotherapist help as well. This as well should be taught to other health care providers to avoid the devastating situation for those survivors when they seek help from professionals who are not equipped with the proper knowledge about the potential physical and psychological complications after the surgery.

Limitation: The time limit, not obtaining the permit to go to AlHussien Hospital easily, and not receiving the expected help from doctors and health care provider.

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