How Breast Cancer Patients Use People and Resources to Receive Social and Moral Support Throughout Treatment

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ABSTRACT

Breast cancer patients experience pain and distress unlike many others. The research question for this literature review is: “How do breast cancer patients use people and resources to receive social and moral support throughout treatment and what are it’s impacts after treatment?” Cancer can take a very active and healthy patient and knock them down completely. This literature review seeks to cover the mental and physical experiences of patients and how support can benefit patients before, during, and after treatment. The findings from this review show that breast cancer patients seek support in many ways such as social and moral support, physical support, and support from their healthcare providers. This support in turn helps patients to cope, helps them recover more efficiently, maintain a normal life once treatment is over. This research is divided into three primary sections and two sub-sections. First the literature review will cover why patients need support, followed by the technology that is currently being used and created, and finally, the impact of the support on patients’ mental health, physical health, and their family members. Through social and moral support breast cancer patients will experience better quality of life and physical well-being.

KEYWORDS

Coping, Family Life, Emotional Support, Instrumental Support, Quality of Life

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1 Introduction

One in eight women will be diagnosed with breast cancer in their lifetime (Susan G. Komen, 2021). From the initial diagnosis all the way to the end of treatment, breast cancer patients experience a plethora of changes both physically and mentally. This literature review examines how support can help improve the mental and physical symptoms that come along with breast cancer to give patients with better quality of life.

The research in this paper is viewed through a worldwide lens. Studies are based in the United States, China, Australia, Ghana, the UK, and Kashmir, providing a wide range of data to be interpreted. When interpreting data, the location of the patients around the world was taken into consideration because of cultural differences. Due to the common age groups of patients, they have similar experiences. Breast cancer patients are frequently mothers, wives and employees, and have a lifelong foundation of friends and family that go through similar experiences. These similar experiences provide a strong push towards support and the many challenges that come with it.

This paper is divided into three main sections, each including sub-sections of their own. First, the paper lays a foundation for what patients experience and why they have a need for support. The second section highlights findings on how support increases overall quality of life in both physical and mental health. This section also discusses the effects on the mental health of family members and includes the concerns of mothers. Finally, the third section covers how patients use technology for social and informational support. The findings about technology influence the needs patients have when reaching out to their social networks.

2 Mental and Emotional Experiences

Breast cancer patients need support from the moment they start diagnosis, to post operation and treatment. Because they experience so many unknown and abnormal emotions, physical changes, and lifestyle changes, they need to have supporters help them through the process. This process involves making personal treatment decisions, helping patients clear brain fog, keeping patients healthy and active, and maintaining positive body image. All these studies display the short-term needs for breast cancer support and how they benefit the patient long-term.

Women want to make their own decisions but often do not always get the support from friends and family that allows them to do so (Schmid-Büchi et al., 2008). Women feel a sense of control when they make their own decisions about the desired results that they want to have after treatment (Schmid-Büchi et al., 2008). Treatment decisions usually involve the decision between a mastectomy and a lumpectomy (World Health Organization, 2021); this means that the patient has the choice between removing the breast all together or just the tumor. Patients also want to decide whether they receive radiation therapy to lower the chances of reoccurrence and potentially remove lymph nodes (World Health Organization, 2021). These are all treatment decisions that patients want to make on their own or with the informational and moral support from others. Not only can support be given from family members but support can also come from medical professionals. The more support patients receive about the treatment decisions that they make, the more in-control they will feel.

Cochran, (2019) argues the idea that breast cancer support should be part of a built-in treatment plan. She explained that when her treatment concluded, she thought life would return to normal and it did not. She was physically unable to complete ordinary tasks and experienced ‘brain fog’ that followed treatment. This ‘brain fog’ is really called cognitive disfunction and can make women feel confused and incapable of completing tasks that were once normal and easy to them (Cochran, 2019). Younger breast cancer patients are also more likely to experience cognitive disfunction than their elders (Helena et al., 2021). According to Helena et al. (2021), breast cancer survivors are more likely to experience anxiety and depression and the mood of survivors can alter unless otherwise helped by others. If patients are to receive support after treatment, they can have less anxiety, depression, and be able to return to good cognitive health at a faster rate.

2.1 Physical Experiences

At diagnosis patients typically appear to be healthy other than physical symptoms related to breast cancer. It is not until later that those treatments begin to take a toll on the body, body image, and sexuality. Lam et al. (2012) revealed that in the first year after diagnosis, patients experience, “deteriorating body image and sexuality (p.964).” This study also determined that the response from patients to the initial breast cancer diagnosis is an indicator of the long-term outcomes that they may experience (Lam et al., 2012). After treatment, patients experience a great deal of fatigue along with emotional distress (Schmid-Büchi et al., 2008). With this being said, when patients are feeling this fatigue, they may have a greater need for help and support.

2.2 Need For Support

Ginter and Braun (2019) provide very interesting findings about patients who do not have partners. This article reveals that patients are very hesitant to tell their parents and seek support from their mothers because often mothers are either too involved or completely remove themselves from the supportive processes (Ginter & Braun, 2019). Patients tend to gravitate towards siblings because they can pick up the slack of their parents when they are not available (Ginter & Braun, 2019). This is not to say that parents are not a good form of support, but sometimes patients need support that goes beyond parents and family. Sometimes the best support can come from friends and strangers, especially in the circumstances of not having a partner (Ginter & Braun, 2019). Ginter and Braun also found that women without partners also seek support from friends but friends frequently change from diagnosis to the end of treatment. This indicates that women without partners may have a more difficult time finding proper support which will impact their quality of life. Additionally, family and friends unintentionally say things that can come off as insensitive (Ginter & Braun, 2019). Cochron, (2019) also mentioned in her TED Talk that people make unfiltered comments to patients based on their own biases against cancer. These biases against cancer and insensitive comments are a reason in a shift toward other likeminded patients, family, and friends for support. Patients need support that is sensitive to their issues and supportive of their specific needs.

The American Psychological Association (2011) reported that patients need various types of psychological support, including individual care to change the way patients think about and view treatments or group therapy. Although certain therapies work differently per individual, each of these types of treatment will be beneficial because patients will be able to receive emotional support from those who are knowledgeable about the subject and share similar experiences (American Psychological Association, 2011). Allowing patients to find specific help will improve their psychological well-being and overall quality of life. Coworkers can also be a great source for support because they truly want to help but patients also struggle with wanting to disclose information on their own terms (Ginter & Braun, 2019). Wang et al. (1999) finds that many women need counseling and support regarding financial concerns, work concerns, and a need to take care of and support family members as well. Although family members are not a primary audience of this study, family members are important to be taken care of as well especially when the patient is not able to fulfill contributions.

When looking at all these patient needs, it is easy to tell that support is a major component to ensuring the well-being of patients, upon diagnosis, throughout treatments, and as they step back into the real world. This life-threatening disease takes a toll on all aspects of life mentally, physically, emotionally, and socially. Support can provide a foundation for decreasing the stigma behind breast cancer and getting patients one step closer to a normal life.

3 Mental Health and Coping

Some long-term implications of support for breast cancer patients include, the bettering of the treatment process, higher quality of life, care for family, and physical benefits such as being able to recover at a faster rate. Support can be given in many ways but the primary ways that patients receive support is through meal preparation, childcare, help around the house, or even arriving to treatments with a friend. These different means of support can be given improve the quality of life for patients by reducing anxiety and depression, helping patients find purpose again, and directly impacting the pain levels.

If patients have a better treatment process, they could experience improved quality of life and mental health. When patients receive social support there are positive impacts on the treatment process (Adam & Koranteng., 2020). On the other hand, when patients do not receive support, they are more likely to struggle mentally and have a more difficult treatment process. Another impact on the quality of life is the stigma behind breast cancer. Patients tend to hide their treatments, diagnosis, and the problems associated with breast cancer because of the stigma that surrounds it. If they receive support, they may be less likely to hide their experiences (Daniel et al., 2021). This is not the case for all women; some women want to share their experiences to further discuss the topic and stop the stigma and help others get back to better health. Patient to patient support is necessary to help women to realize that they are not alone (Daniel et al., 2021). Helping stop the stigma will improve quality of life for women both mentally and physically. Many women go into self-isolation due to distress from treatments (Daniel et al., 2021). Support is necessary to moderate this distress and help women adapt to their changing situation.

Those who undergo chemotherapy are shown to receive more emotional support and those who have a mastectomy receive more instrumental support, meaning assistance with basic tasks such as walking, personal hygiene, or driving a car (Bloom et al., 2001). Patients who receive instrumental support are typically in need because they are not capable of completing certain tasks. Instrumental support is seen to have a negative impact on patients because it can make them feel hopeless and weaker than they may be (Bloom et al., 2001). This is not to say that care takers should not provide instrumental support, but rather care takers should be sure to take into consideration the extent of which the patient may desire the instrumental support.

Patients look to family, friends, and neighbors for support. Support can come in all forms but the most impactful social support often comes in the form of physical acts such as taking care of children, providing rides, cooking meals, and cleaning (Hamid & Khan., 2021). Hamid and Khan also show that patients who receive physical support can be positively impacted and have a higher quality of life than those who do not. This study implies that physical support is beneficial to completing basic tasks and helping a patient return to normal. However, similarly to the previous study, too much physical support, can be overwhelming for some patients, making them feel useless (Bloom et al., 2001). It is important to keep in mind the limits to patients' personal needs for support.

3.1 Physical Health

Alfano et al., (2007) found that patients who participated in more physical and vigorous activity prior to diagnosis were shown to have a greater quality of life after treatment (Alfano et al., 2007). Patients have different concerns after treatment; this includes physical appearance, weight gain, and sexual drive. After treatment they are seen to have at least one condition that limits activity (Alfano et al., 2007). Physical activity after treatment also helps patients to improve symptoms (Alfano et al., 2007). Physical activity can help patients have a higher quality of life and have physical health benefits.

Fisher et al., (2021) clarifies that there is a direct link between receiving emotional support and experiencing less pain. This is because higher levels of depression are associated with more pain. Caregivers need to give support in order to improve the physical well-being of the patients. Support can include going for walks with the patients, athletic activities, helping them around, the house, and encouraging them to get back on their feet. All these suggestions can improve the physical quality of life of the breast cancer patients because the more support they are able to receive the less pain they may experience (Fisher et al., 2021). Minimizing physical symptoms can aid to the transition back to a normal life.

3.2 Family Life

Patients who experience family avoidance or negative family communication through treatment are more likely to experience adverse mental health effects on a long-term scale (Mallinger et al., 2006). Patients need the positive support from family to help them have a higher quality of life. One of the most challenging realities that many patients face is a terminal diagnosis. Many of these women are mothers and only have a short period of time with their children (Lundquist et al., 2020). This takes careful planning and consideration, but at the end of the day there is not enough time no matter how long these women have to live. This is one of the main concerns for patients who are mothers because they still deeply care about their children and families even though they need to put themselves first. According to Lundquist et al. (2020) these mothers would pack time in by teaching their children things they may learn later in life or activities like making scrap books. One mother discussed how her children were forced to grow up much faster than their peers and take care of her when she was in need (Lundquist et al., 2020).

Partners of breast cancer patients also need support in order to give support. This is another concern of the patients because a diagnosis can put a large amount of pressure on the partner of the patient financially, emotionally, and at work (Borstelmann et al., 2020). If caretakers can't properly provide support, then the patient will likely have a lower quality of life; therefore, support needs to include partners to indirectly provide better well-being to the patient.

Patients worry about their partners' well-being just as much as they worry about their own. According to Borstelmann et al. (2020), partners who did not adapt well to the diagnosis and treatment were shown to have a great amount of anxiety and depression afterwards. If these partners are struggling and fail to receive social support, they are less likely to be an effective and beneficial caretaker.

Breast cancer patients need support more than they may realize at times. Life without support increases depression, anxiety, and lowers quality of life among patients and survivors. Support directly correlates to increased physical and mental health.

4 Technology Needs and Implications

This section reveals how technology is utilized and needed for support. Studies indicate that technology is a great tool to find support but is not the 'end all be all'. Patients still need to rely heavily on medical professionals for support. Technology is a good way to find additional support for patients, families, and friends. It is also very important when considering technology, to consider the limits and desires of patients to keep some information private. The ability to be selective about information sought out online may provide higher satisfaction with support.

There are currently direct correlations between a patients' social networks and their quality of life due to breast cancer (Hemmati et al., 2014). Hemmati et al. also found that patients with a lower quality of life may turn for more support than those with higher quality of life. Consequently, those who receive more support may see a higher quality to their life than those who do not. Patients are seen to have overall satisfaction from online support especially if it matched the type of support that they seek (Vlahovic et al., 2014). Technology allows for patients to receive additional support on top of the support they receive from people in their close circle. Supportive technology is only just emerging with breast cancer and can be pushed even further to fully accommodate the diverse and complex needs of breast cancer patients.

Patients may not always realize what they need, and there is often confusion between needs and wants. A need is defined as the "lack of something wanted or deemed necessary" (Wang et al., 1999). A want is "worry, solitude, or anxiety" (Wang et al., 1999). When it comes to technology many patients do not feel the need to use it at all but there are plenty of resources that can be provided. Attai et al., (2015) showed how patients, friends, and family use a Twitter based Support Group to share personal experiences related to breast cancer. Patients enjoy seeking support online. However, online support only complements medical advice and provides an emotional outlet for patients.

One particular study worked with breast cancer patients to brainstorm and design an application that could help discover their needs and wants of patients through the design process (Skeels et al., 2010). Patients reported that they preferred to give information to close family and friends, coworkers, and other likeminded patients and survivors (Skeels et al., 2010). Patients like to keep their family and friends informed and receive help when they cannot do things themselves (Skeels et al., 2010). This displays the need for family and friends to be in their close network of supporters. Technology allows patients to easily communicate their needs. Also, another study points out that patients who receive too much support with activities that they are no longer capable of doing, sometimes feel worse about their quality of life (Bloom et al., 2001). Although this does not directly relate to technology, it shows that in making technological resources there is a need to provide a boundary on the applications or websites that suit the individual needs of the patient.

This section supports the argument that technology has a positive influence on social and moral support and provide insights for how technology can move forward. The limitations include a need for boundaries within a professional setting. If creators can design platforms to suit the needs and limitations of patients, their families, and friends, then patients will be able to have a greater quality of life.

4 Conclusion

After looking at various worldwide sources, it is indisputable that breast cancer patients need and desire social and moral support from the beginning of diagnosis onward. Whether they find support in technology, through friends and family, or professionals, this paper provides insight to how to provide the best support. Patients who receive proper support will have increasingly positive outcomes in all areas. The more support patients receive, the more likely they will be able to get on with life as normal and increase their overall quality of life.

There are many unique situations such as terminal breast cancer, single women, and unsupportive family members. Each of these situations has negative effects on patients; therefore, these patients typically seek support from others. Patients get most of their support from friends and family. These supportive factors allow for others to provide when patients are unable to provide for themselves. Moving forward, this research allows more room to build and improve technological platforms and research to provide the best support for breast cancer patients.

REFERENCES

Adam, A., & Koranteng, F. (2020). Availability, accessibility, and impact of social support on breast cancer treatment among breast cancer patients inKumasi, Ghana: A qualitative study. *PLOS ONE, 15(4).* https://doi.org/10.1371/journal.pone.0231691

Alfano, C. M., Smith, A. W., Irwin, M. L., Bowen, D. J., Sorensen, B., Reeve, B. B., Meeske, K. A., Bernstein, L., Baumgartner, K. B., Ballard-barbash, R., Malone, K. E., & Mctiernan, A. (2007). Physical activity, long-term symptoms, and physical health-related quality of life among breast cancer survivors: a prospective analysis. *Journal of Cancer Survivorship, 1(2),* 116–28. https://doi.org/10.1007/s11764-007-0014-1

American Psychological Association. (2011, October 1). Breast cancer: How your mind can help your body. http://www.apa.org/topics/behavioral-health/breast-cancer

Attai, D. J. Cowher, M. S., AlHamadani, M., Schoger, J. M., Staley, A. C., & Landercasper, J. (2015, July 30). Twitter social media is an effective tool for breast cancer patient education and support: patient-reported outcomes by survey. *JMIR Publications.* 17(7), 188. https://doi.org/10.2196/jmir.4721

Bloom, J. R., Stewart, S. L., Johnston, M., Banks, P., & Fobair, P. (2001). Sources of support and the physical and mental well-being of young women with breast cancer. *Social Science & Medicine, 53(11), 1513–1524.* https://doi.org/10.1016/s0277-9536(00)00440-8

Borstelmann, N. A., Rosenberg, S., Gelber, S., Zheng, Y., Meyer, M., Ruddy, K. J., Schapira, L., Come, S., Borges, V., Cadet, T., Maramaldi, P., & Partridge, A. H. (2020). Partners of young breast cancer survivors: a cross-sectional evaluation of psychosocial concerns, coping, and mental health. *Journal of Psychosocial Oncology, 38(6),* 670–686. https://doi.org/10.1080/07347332.2020.1823546

Cochran, J. (2019.). Unspoken truths of a breast cancer journey. TED. Retrieved September 24, 2021, from https://www.ted.com/talks/jennifer_cochran_unspoken_truths_of_a_breast_cancer_journey?utm_campaign=tedspread&utm_medium=referral&utm_source=tedcomshare.

Daniel, S., Venkateswaran, C., Hutchinson, A., & Johnson, M. J. (2021). 'I don't talk about my distress to others; I feel that I have to suffer my problems...' voices of Indian women with breast cancer: a qualitative interview study. *Supportive Care in Cancer, 29(5).* 2591-2600. https://doi.org/10.1007/s00520-020-05756-8

Fisher, H. M., Winger, J. G., Miller, S. N., Wright, A. N., Plumb Vilardaga, J. C., Majestic, C., Kelleher, S. A., & Somers, T. J. (2021). Relationship between social support, physical symptoms, and depression in women with breast cancer and pain. *Supportive Care in Cancer, 29(9).* 5513-5521. https://doi.org/10.1007/s00520-021-06136-6

Ginter, A. C., & Braun, B. (2019). Social support needs of breast cancer patients without partners. *Journal of Social and Personal Relationships, 36(1),* 43–62. https://doi.org/10.1177/0265407517718390

Hamid, W., & Khan, T. A. (2021). Experiences of social support among Kashmiri women with breast cancer. *Health, Risk & Society, 23(1-2),* 52–72. https://doi.org/10.1080/13698575.2021.1901858

Helena, C., Rachael, W., Garth, F., Susannah, S., & Krishnan, B. (2021). Associations between breast cancer survivorship and adverse mental health outcomes: a matched population-based cohort study in the United Kingdom, 18(1), 1003504. https://doi.org/10.1371/journal.pmed.1003504

Hemmati, A., Chung, K. S. K., & 2014 IEEE/ACM International Conference on Advances in Social Networks Analysis and Mining (ASONAM) China 17 August 2014 - 20 August 2014. (2014). *In Associations between personal social network properties and mental health in cancer care.* 828–835. https://doi.org/10.1109/ASONAM.2014.6921682

Kim, J., Kim, J., Han, A., & Nguyen, M. C. (2021). Leisure time physical activity, social support, health perception, and mental health among women with breast cancer. *Leisure Studies, 40(3),* 352–362. https://doi.org/10.1080/02614367.2020.1869290

Lam, W. W. T., Li, W. W. Y., Bonanno, G. A., Mancini, A. D., Chan, M., Or, A., & Fielding, R. (2012). Trajectories of body image and sexuality during the first year following diagnosis of breast cancer and their relationship to 6 years psychosocial outcomes. *Breast Cancer Research and Treatment, 131(3),* 957–67. https://doi.org/10.1007/s10549-011-1798-2

Leung, J., Pachana, N. A., & McLaughlin, D. (2014). Social support and health-related quality of life in women with breast cancer: a longitudinal study. *Psycho -Oncology, 23(9),* 1014–1014. https://doi.org/10.1002/pon.3523

Lundquist, D. M., Berry, D. L., Boltz, M., DeSanto-Madeya, S. A., & Grace, P. J. (2020). I'm still mom: young mothers living with advanced breast cancer. *Oncology Nursing Forum, 47(4),* 405–414. https://doi.org/10.1188/20.ONF.405-414

Mallinger, J. B., Griggs, J. J., & Shields, C. G. (2006). Family communication and mental health after breast cancer. *European Journal of Cancer Care, 15(4).* 335-361. https://doi.org/10.1111/j.1365-2354.2006.00666.x

Montazeri, A., Jarvandi, S., Haghighat, S., Vahdani, M., Sajadian, A., Ebrahimi, M., & Haji-Mahmoodi, M. (2002). Anxiety and depression in breast cancer patients before and after participation in a cancer support group. *Patient Education and Counseling, 45(3),* 195. https://doi.org/10.1016/S0738-3991(01)00121-5

Schmid-Büchi, S., Halfens, R. J. G., Dassen, T., & van den Borne, B. (2008). A review of psychosocial needs of breast-cancer patients and their relatives. *Journal of Clinical Nursing, 17(21),* 2895–2909. https://doi.org/10.1111/j.1365-2702.2008.02490.x

Susan G. Komen. (2021, June 8). The Who, What, Where, and Sometimes, Why. Susan G. Komen. https://www.komen.org/breast-cancer/risk-factor/

Skeels, M. M., Unruh, K. T., Powell, C., & Pratt, W. (2010). Catalyzing social support for breast cancer patients. *Chi -Conference-, 1,* 173–182. https://doi.org/10.1145/1753326.1753353

Vlahovic, T. A., Wang, Y.-C., Kraut, R. E., & Levine, J. M. (2014). Support matching and satisfaction in an online breast cancer support community. *Chi -Conference-, 2b,* 1625–1634. https://doi.org/10.1145/2556288.2557108

World Health Organization. (2021, March 26). Breast cancer. World Health Organization. Retrieved September 23, 2021, from https://www.who.int/news-room/fact-sheets/detail/breast-cancer.

Wang, X., Cosby, L. G., Harris, M. G., & Liu, T. (1999). Major concerns and needs of breast cancer patients. *Cancer Nursing, 22(2),* 157–63. https://doi.org/10.1097/00002820-199904000-00008