Together we can: facilitating posttraumatic growth through cancer support groups

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Abstract: Surviving cancer is challenging and involves a number of demands on the survivor in order to reorganize and readjust their life post cancer. Apart from many unmet needs during these phases of transition between treatment and survivorship, many survivors also report positive changes in their relationships, in priorities and purpose of life, in their approach and attitude to life (existential), in spiritual and personal aspects. These changes are known as posttraumatic growth, i.e., growing stronger and transforming in a positive way, following challenges and adversity. In addition to playing an important role in helping survivors alleviate negative aspects of their experience, support groups serve as an avenue for survivors to learn and grow stronger from the adverse challenges they face. This paper attempts to throw light on the role of support groups in promoting posttraumatic growth among survivors of cancer.

Keywords: posttraumatic growth, support groups, cancer survivors, rehabilitation.

Challenges of surviving cancer

Cancer as a chronic illness is disruptive in all domains of functioning of the survivor. The experience of cancer can be broadly understood in four phases, namely - discovery of cancer (initial diagnosis), treatment, remission and / or recurrence (Goldstein & Phillip, 1998). Right from the time of diagnosis itself, there is a fear of death, of losing one’s independent functioning, of the disease prognosis, and treatment side effects (Sewartz, Werba & Kazak, 2010). The treatment phase is very demanding not only physically but also emotionally for an individual. For example, breast cancer survivors may need to deal with loss of a breast during procedures such as mastectomy. There is an existential threat for the survivor, that poses challenges in accommodating to the ‘new’ normal self. Previously held beliefs about their bodies and the concept of healthy body need to take into the account the ill body and self now (Hellstrom, 2001). These periods of transition when the survivor is grappling with adjusting to the ill body are accompanied by difficulties relating to self and others, and can become more complicated when the issue of identity and body image are not resolved (Piot-Zeigler, Sassi, Raffoul & Delaloye 2010)

There are many unmet needs relating to body integrity especially after treatment of breast cancer. During the follow up phase, there is insufficient emphasis on such needs(Petronis, Carver, Antoni& Weiss, 2003). In cultures such as India, the woman’s altered appearance after treatment procedures like mastectomy leaves a lasting scar on women’s sense of identity. This can be explained by stereotypical views of beauty and womanhood that pervade the Indian socio-cultural
context (Shobitha & Sathiyaseelan, 2013). Similarly, Madhumanti and Sathiyaseelan, (2014), found marital adjustment to be inversely related to disrupted sexual functioning after mastectomy in an Indian sample of breast cancer survivors. Barthakur, Sharma, Chaturvedi and Manjunath, (2016) have mentioned that these body image concerns cause significant psychological distress such as low self-esteem, feeling incomplete and feeling threatened in terms of their sense of being a woman, often leading her to cover her body (Andrzejczack, Markocka-Maczka & Lewandowski, 2013) during sexual contact, implying shame and guilt experienced by them.

The trajectory of survivorship involves several points of transition and one of the most demanding times are of transitioning from a patient to a survivor. Follow up care plans must adequately address women’s needs especially to help them reconstruct their identities which are critical to healthy coping and positive adjustment (Savadatti, Allen & Levy, 2009). A majority of survivors mention experiencing changes in how they understand themselves, others and the world around them. This shift in perspective allows them to be more appreciative of life, and forces them to live more in the present moment, not taking anything for granted. They have to constantly live the paradox of the certainty of the uncertainty of death. The journey of survivorship is unique to each individual (Crowley & Leonard, 2008). Some survivors cope well using their own resilience and support, whereas some need help in harnessing their potential to cope adaptively. It is in this context that the present paper aims to discuss ways in which adaptive coping and personal growth can be facilitated through cancer support groups.

Posttraumatic Growth (PTG)

Posttraumatic Growth refers to the positive adaptive changes (adaptive) that occur in a person, following any traumatic event (Tedeschi & Calhoun, 1996). It is evident in the form of changed interpersonal relationships, reorganized priorities, enhanced appreciation and gratitude and enhanced spirituality. Posttraumatic growth has been explained in terms of a reorganized worldview after one encounters a traumatic event. These adaptive changes are triggered by a life-threatening situation that challenges the assumptions (pre-trauma) an individual has about life. When this reality is challenged, previously held assumptions are shattered and reality becomes difficult to accept. In response to the distress thus caused, individuals display emotional and cognitive processes that help them make sense of the event and their reality. This processing of the event (both emotional and cognitive) are important mediators of post traumatic growth. Cognitive processing involves rumination about the event itself. In the initial time after the trauma, rumination is intrusive, whereas with time, after the initial shock rumination becomes more reflective in nature. This helps the individual to reorganize the assumptive worldview to accommodate the trauma and create a new normal understanding. This engagement with the trauma enables adaptive transformation which becomes evident as a new meaning and appreciation of life, enhanced relationships and reorganized priorities leading to existential and spiritual changes. PTG is seen in many chronic illnesses, more commonly in those which could result in a major threat to life and requires drastic reorganization in one’s functioning. PTG is reported in many different types of cancer (Calhoun & Tedeschi, 2004). Follow up interventions should aim at facilitating PTG among survivors who are unable to resolve their initial shock and distress on their own. Support groups are a feasible platform to mediate such adaptive changes.

Cancer support groups

Self-help groups or support groups are becoming an integral part of addressing the needs of cancer patients, especially psycho-social concerns (Mathews, 2000). Support groups vary based on their nature. Some are peer-led informal groups, whereas some are professionally-led formal groups. Stevenson, Lydon and Amir, (2010) examined group characteristics, leadership and training needs in both these categories and found that they function similarly and serve the same purpose. However professionally-led groups identified more training needs in comparison with peer-led groups. Training needs however were found to be similar across both kinds of groups. Since there is a dearth of trained professionals in many developing nations, it would be a good idea to encourage more peer-led support groups to bridge the gap in meeting survivorship needs.
Across cultures, the meaning and understanding of cancer varies, and this needs to be considered in any support group. Through their informal interactions, the members must be able to talk about their cancer experience and make sense of it through their own cultural beliefs and assumptions about health and illness. This will enable all members to validate their own coping experience and help others broaden their perspective (Matthews, 2000). Support groups can also provide a glimpse into beliefs about cancer that the participants hold. For instance, while wanting to examine cancer beliefs’ role in health promoting behaviors, Costanzo, Lutgendorf, and Roeder (2011) found that women who believed that cancer can be prevented or recurrence can be delayed by making changes in health behaviors, were likely to sustain changes in their lifestyle even after treatment ended. Therefore, providing a space for an evolving understanding of their health beliefs will aid development of interventions that are sensitive to the groups’ needs. Davey, Bilkins, Diamond, Willis, Mitchell, Davey and Young (2016) conducted a needs assessment of patients’ psycho-social support requirements and perceived barriers to treatment. Among many unmet needs as reported by earlier studies, they also found a strong need for culturally sensitive couple / family based psycho oncology services. This study comprised of seventy three percent African American adults, and therefore many ethnic and cultural gaps were highlighted in the survey. Haynes-Maslow, Allison, and Johnson (2016) also reported unmet needs with regard to cultural aspects of cancer care.

Napoles-Springer, Ortiz, O’Brien, Diaz-Mendez, and Perez-Stable (2007) surveyed breast cancer survivors and found that not having enough resources to avail psychological support services, not knowing the language (majority of participants were Spanish speaking women) and being unaware of the value of such groups were common reasons cited for non-participation in support groups. Another important aspect that the survey found was an inversely proportionate role of spirituality with sustained attendance in support group meetings. These findings imply the need to address these issues (if unmet) and also to customize support groups so that they become more culturally relevant. Spirituality among these women seemed to have offered an alternate means of support for them.

Chaturvedi (2012) mentions that the most common ways of coping with cancer diagnosis in India are blaming one’s fate/ past deeds, being in denial and feeling helpless, and on a more adaptive note using the support of religion and spirituality. Pandey (2004) reviewed factors that influence quality of life in patients with cancer in India. Peace of mind, spiritual satisfaction and social satisfaction were found to be more important than their individual level of functioning. Support groups must effectively integrate these aspects into their meetings. Lim and Zebrak, (2008) have also emphasized that catering to indigenous needs is important in follow-up care as it plays a big role in enhancing quality of life. They also found that greater social network diversity such as family members, friends, religious/ spiritual group affiliations led to better perceived social support. It is in this context support groups must play a role to expand survivors’ social support network. In cultures where religion and spirituality are important determinants of well-being, it may be useful to discuss about religious support which in-turn would lead to lesser negative affect, enhanced well-being and greater effort to work through their situation (Shaw et.al, 2007).

Expression and processing of emotions are another area where support groups play an important mediating role. Tamagwa, Li, Gravity, Piemme, DiMicelli, Collie and Giese-Davis (2015), studied therapeutic mechanisms in support groups for cancer survivors and found that emotions were expressed in later sessions, while initial sessions merely involved storytelling about their experience. It was also observed that those who had reported more positive aspects while processing their emotional experience had wider social networks and were able to utilize social support. Earlier in 2005, Hoybye, Johansen and Tjornhoj-Thomson had reported similar benefits, in an online breast cancer support group, wherein participants were able to deal with social isolation more effectively. Liberman and Goldstein (2006) investigated emotional expression in an online support group and found that those who expressed more anger had better scores on quality of life in comparison to those who expressed higher levels of fear and anxiety who showed greater scores on depression and lower scores on quality of life. These findings suggest that support groups can be a medium through which patient needs can be identified, simultaneously allowing for expression of different kinds of emotions in order to help patients process the experience. Lewallen, Owen, Bantum, and Stanton (2014), have
pointed out that linguistic aspects like how a person introduces oneself, and how they choose to discuss their illness experience can enhance how the group responds and learns from each other. This promotes cohesion and engagement among its members. The role of social support processes like giving and receiving emotional validation (Kim, Han, Moon, Shaw, Shah, Tavish & Gustafson, 2012), and advice giving (Silence, 2013), seem to be significant in overall psycho social health outcomes of participants in online platforms. Personal experiences serve as a safe way to give advice as it is not direct but yet conveys contextual and personal meaning. This enables the receiver to draw parallels and relate to the experience being shared.

Sherman, Pennington, Simonton, Latif, Arent, and Farey (2008), recommend involving the patients’ support network in order to sustain participation. On similar lines, Voerman, Visser, Fischer, Garssen, Andel and Bensing (2007) have reported that enhanced participation was observed when patients were made aware of such groups and when support groups were available at short travel distance. Internet based platforms also offer a safe and comfortable zone to discuss issues pertaining to sexuality and body image where participants reported enhanced emotional well-being especially in the context of dealing with the same. Unlike sharing these concerns face-to-face, they felt comfortable sharing virtually. Wiljer, Urowitz, Barbera, Chivers, Quartey, Fergusson, and Classen (2011), have also recommended to have more such online platforms which are feasible and accessible to a wider community.

Stephen et.al (2011), documented the experiences of facilitators in online support groups. Participating in these groups helped facilitators understand the dynamics of important clinical issues such as emotional disclosure about topics such as death and dying, spiritual and existential concerns and lifestyle changes. They reported that adaptive coping mechanisms were discussed in a safe ‘room’ online and it enabled both patient and facilitator to gain valuable insights on the process of healing. However, it was also observed that online platforms can limit articulation and speed up the session by touching on surface level descriptions of experience. This suggests that online facilitators should have necessary skills in sustaining a conversation and be able to delve on subjects that need more deliberation. These findings thus have implications for improved planning and execution of online social support groups. While comparing virtual support to real time engagement, Miller and Slater (2000) noted that it is unfair to compare real-time and virtual groups, as it involves an adapted skill set to engage with groups online, and chose to consider online support groups as complementary and not different or lesser in value.

How can posttraumatic growth be facilitated in survivors through cancer support groups?

Self-help groups and peer counseling are successful as they promote peer learning among the members who have similar life circumstances. Those who have coped well can act as a model for others who have not been able to manage well and help them learn healthier strategies to accept their condition (Taylor, 1983). In an Australian sample of cancer survivors, Jefford, et.al, (2008) have identified dealing with issues concerning side effects of treatment, fear of recurrence and advice on how to cope and return to normalcy as important unmet needs. Most participants who used support services mentioned feeling a sense of community and reported gaining reassurance from fellow survivors. Narratives of survival evolved in the process and inspired other group members. Patients and caregivers often require ongoing support even after the treatment phase is over. They report unmet psychosocial supportive needs, and still struggle with quality of life concerns even at the five-year survival mark (Mollasiotis, Wilson, Blair, Howe & Cavet, 2011).

Support groups may thus serve as a functional platform for its members to continually derive support across different stages of their survivorship and make positive adjustments. Davey, Tubbs, Kissil, and Nino (2011) have recommended a family-centred approach by clinicians while treating cancer patients. Their study with adolescents who took on the role of both physical and emotional caregivers, explored the difficulties in dealing with the changes in family roles and making sense of their suffering/pain. Creating a support group for such adolescents can promote a better understanding of the whole diagnosis and enable them to make adaptive changes in their interpersonal context.
Posttraumatic growth can be facilitated by helping survivors engage with the illness experience in order to process cognitively and emotionally what it means to them. It is safe to conclude that support groups are a felt need among patients, caregivers and healthcare professionals. They offer support by helping patients evolve an integrated (pre-trauma and post-trauma) life narrative. Culturally appropriate mechanisms to deal with survivorship issues need to be developed. Cancer support groups serve as medium for survivors to integrate their new identity and sense of self as a survivor. These platforms help care providers understand and identify survivors’ assumptions and apprehensions with regard to cancer. They can serve as a platform to evolve culturally sensitive coping strategies. However the structure of the groups, content of discussions, and facilitator characteristics will determine how beneficial these groups can be. More groups, virtual or real should be formed to provide ongoing support for survivors, along with enhanced awareness of such facilities to increase accessibility for all. Survivors who have coped well can form peer groups and serve as navigators of positive change for survivors. Therefore, it is recommended to have more meaningfully engaging support group sessions for survivors to mutually learn and grow. This will enable them to make positive adaptive changes in various domains in which posttraumatic growth is evident, such as spiritual, interpersonal, and existential aspects. Together we can promote growth from adversity.

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