

Navigating the Breast Cancer Journey- a Patient's Perspective

Salisha Baboolal-MA¹ and Jameel Ali-MD, MMedEd, FRCSC, FACS^{2*}

¹Mass Communications, University of Calgary, Alberta, Canada.

²Professor of Surgery, University of Toronto, Ontario, Canada.

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***Corresponding author:** Jameel Ali-MD, MMedEd, FRCSC, FACS, Division of Women's Health, St. James Medical Complex, Breast Surgical Oncology, Trinidad and Tobago.

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Abstract

Introduction: This article deals with an innovative approach to cancer patient care by introducing the concept of 'Cancer Survivorship' which focuses on patient coping strategies that emphasizes quality of life skills as opposed to the traditional concept of 'Survival' - the time construct used in describing patient outcome.

Methods and result: We describe the rationale and basis for the Survivorship program and follow a very personal description of the Survivorship experience of an actual patient who presents her own perspective after completing the program.

Conclusion: This patient's perspectives on the Survivorship program reflects the reactions and responses to this program by the patient participants. That the program be implemented as an integral part of cancer patient care is strongly recommended.

Keywords: Cancer survival; Cancer survivorship; Breast cancer outcome; Cancer patient quality of life

Introduction

Generally, Breast Cancer, like many other cancers, occurs in most patients who do not expect the diagnosis. It is no surprise then that the patient is often completely unprepared to face the countless challenges of this diagnosis. In a previous publication [1], we described these challenges, the patient's perceptions, expectations and how a specially designed Cancer Survivorship Program might influence her ability to cope with a diagnosis of Breast Cancer. We traditionally focus on making a diagnosis based on history, as well as, on physical examination, pursuing a course of treatment, which frequently involves surgical biopsy, description of the pathology followed by a surgical procedure, radiotherapy and /or chemotherapy [2]. However, conspicuously absent in this therapeutic approach are features that address the myriad of patient challenges, as well as, the development of coping strategies, to more effectively deal with these challenges. For instance, depression resulting from both physical and social isolation frequently compounds the clinical response with further exacerbation of the situation [3]. Conceivably, a program with features focusing on factors that mitigates these psycho-social components, such as those included in our Cancer Survivorship program, could be of immense benefit to the patient during her Cancer journey.

In this paper, a patient, Salisha Baboolal, describes her personal experience in dealing with a diagnosis of Breast Cancer and specifically how the Survivorship Program remarkably impacted her Breast Cancer Journey. What follows is her personal account, including her initial apprehension, fear and despair; a description of the program and the pivotal role it played in empowering her on this journey.

Description of My Cancer Journey

On the invitation of Professor Jameel Ali, I am honored to describe this journey which became a source of strength and immense hope, through the impact of this Survivorship Project. I felt that sharing these experiences, from the perspective of a patient, would

assist fellow survivors to cope more successfully with the many challenges of their cancer experience. To accomplish this objective, I will follow this outline:

- A. My initial emotions and needs.
- B. The educational foundations of the survivorship program.
- C. The components of the program.
- D. The extraordinary synergy of the survivor chat group.
- E. Changes which I experienced as the program evolved.
- F. Conclusion.

My Emotions and needs

No one ever expects to develop cancer, so we are unprepared to deal with its challenges. On hearing the ominous words "It's Cancer!" I thought it was the end of my life as I knew it. Those words carry a barrage of negative, pessimistic thoughts punctuated with desperate feelings. After the initial self-blame and the 'why me?' phase, I numbly settled into the routines of 'care' provided by my medical team: preparation for surgery, tests, suture removal, wound care, radiotherapy, medical oncology visits etc. Over several months, in talking with other patients, we slowly began sharing our experiences.

Medical literature traditionally refers to survival in terms of time-but surely, there must be more to my life than merely existing and being consumed with the bitter reality of this disease. I eventually realized that I had 2 choices: slump and wallow or stand and deal. I intrinsically chose the latter even though I could not clearly see my next step. Yet I knew THIS with certainty: I had 2 truths to buoy me-my faith would get me through this, and no matter what, I would not fall into the abyss of negative thinking and hopelessness. As time passed, I continued to feel isolated even among others. My family was supportive but appeared at a loss for finding ways to help me cope. This was compounded by an inability to articulate my own feelings, for them to help me. I finally realized that I needed help to cope. By a twist of fate, I was invited to participate in this Cancer Survivorship project. Although I was initially apprehensive, I thought, " what do I have to lose?"

Educational foundation of the survivorship program

During the project's first session, I was introduced to a novel concept of the difference between the term 'Survival', measured in terms of 'time' versus 'Survivorship', characterized by an enhanced 'quality' of life. I learned that this presents a major challenge, as it requires the development of lifelong coping skills through a deep understanding of effective adult learning that would ensure long term retention. So, in order to prepare us for this foundational part of our journey (developing sustained, quality-enhancing, coping strategies) one of our early sessions focused on understanding the domains of learning and their individual taxonomies forming the Educational Foundations of the Survivorship program.

Following were some of the concepts introduced to the instructors and participants:

i. Definition of Learning as the process of acquiring knowledge, skills, and attitudes (the learning set) which we did not previously have.

ii. Reviewing the Domains of Learning: cognitive (knowledge), psychomotor (skills) and affect (attitudes).

Taxonomy of these domains:

1. Bloom's Taxonomy [3] of the Cognitive Domain begins with remembering, moving on to understanding or comprehension, then application of the knowledge, analysis and evaluation. As we move from simple memorizing of concepts to evaluation, the learned behaviour becomes deeper rooted and long lasting. This ensures that the acquired knowledge becomes incorporated into our daily life activities on a long-term basis.

2. Taxonomy of the Psychomotor Domain Doto et al [4]. This follows the progression from Conceptualization, Visualization to Verbalization, Practice and Feedback, Skills Mastery and Skills Autonomy-ensuring long-term retention of these skills.

3. The AFFECTIVE component of learning. Affect or Attitude is one of the most powerful, yet almost imperceptible facets of learning behaviour, because it bestows an emotional attachment and a kindred value to what is learned, resulting in a lasting effect. The Affective taxonomy as described by Krathwohl [5] begins with the process of 'Receiving'-the instructor must choose the appropriate time (the teachable moment) for exposing the student to the desired learned behaviour, presenting it in a manner that will resonate with the student, who will share the same value to the learned behaviour as the instructor's ascribed value.

As described by Krathwohl [5] this taxonomy finally leads to the stage of internalization of values, (characterization) resulting in a long-lasting deep attachment to the learned behaviour. When applied appropriately, this technique can result in motivation (a driving desire) to acquire the learning. This motivation may be 'extrinsic' (influenced by an external force, such as an instructor and maybe punitive or rewarding (positive), depending on the stimulus (carrot or stick phenomenon). Conversely, the motivation may be intrinsic, resulting in an inner 'drive.' Although motivation is frequently extrinsic at least initially, the goal should be to foster teaching activities that would result in intrinsic, positive motivation which is self-sustaining and leads to continuing positive self-learning, without the requirement for an external force. Familiarity and a deep understanding as well as practicing of these fundamental aspects of effective teaching and learning in a very interactive manner by both the instructors and participants in the Survivorship program represent the highlights to its success.

The Components of the program

In his introductory session, Professor Ali indicated that the chosen components replace the potentially debilitating preoccupation with the disease process by one of wellness-promoting, joyful activities leading to healthy lifestyle changes. A key element in achieving this goal was to engage well-motivated

patient-care advocates in their fields of expertise, as facilitators, in these disciplines: Nutrition, Practitioners in the psychosocial field, Yoga and Meditation, as well as spiritual support from the clergy (Christianity, Hinduism, Islam).

The Nutritionists not only provided foundational nutrition information but instructed us on healthy food choices in a highly dynamic, interactive and enjoyable manner. This culminated in the provision of a practical manual on health and nutrition. Our psychosocial facilitators educated us on the role of anxiety, depression, body image and disclosure issues, as well as family dynamics in the context of coping with our disease. Our dynamic, resourceful and energetic Yoga expert brought her unique approach to Yoga, meditation and self-awareness in a manner that made us feel uplifted while utilizing the concepts of the Psychomotor learning taxonomy as described above. Our Spirituality facilitators gave us an overall introductory session and made themselves available, on an individual basis, for support, which many found reassuring. In fact, all our facilitators made themselves available to us, outside of the program, which was likewise extremely comforting.

The Magical Synergy of the Survivorship Chat Group

One of the marvels of the project was the unintended formation of the Survivor Chat group, initiated through the patient survivor group itself, with enthusiastic support from our program coordinator. The bond created among us through this group was unbelievable, allowing an avenue for spontaneous communication about a myriad of ideas, ranging from sharing new recipes, strengthening each other through prayer, talking about children and sharing family stories, sharing a song, playing a musical instrument, and so much more. We even called each other to simply say hello and ask how we were doing. I believe what fuelled this was knowing that we were coming from a shared experience of our own cancer, but even with our specific nuances, we were still able to share what makes us different concerning how we deal with our everyday challenges [6]. This bond has become a true source of strength and comfort for us. This unplanned result of our survivorship project created a connection among us that would last for the rest of our lives. For those planning a survivorship project, I strongly recommend having a chat group as one of its components.

Changes I Experienced as the Program Evolved

At the beginning of this presentation, I described how alienated, pessimistic, helpless, alone and apprehensive I was, when I learned of my diagnosis. It was a very dark place. Now, I can say with complete confidence that my outlook is brighter, optimistic, full of hope and confidence. I am unequivocally convinced that this change has resulted from my exposure to the Survivorship program. I am extremely grateful to those who brought this program to us. Additionally, at the inception of the program, we were introduced to the concept of Resilience and its importance in dealing with adversity. Resilience [6] or the ability to recover from setbacks has many components- physical, mental, emotional and social.

Resilience resides within all of us, but it needs to be activated. Without actually recognizing it, as it happened to me, I know now, in retrospect, that this survivorship program activates resilience at all levels.

It is clear to me now, that Resilience was evoked through our program in many ways, leading to my optimism and better quality of life. The difference in outlook is this: Instead of succumbing to reflex negative tendencies because of my disease, I move forward with a positive approach; one that transforms hopelessness and pessimism to hope and optimism with despair converted to comfort and an overall better quality of life, which is the ultimate purpose of the Survivorship program.

Conclusion

Most of us are ill-prepared to face the many resulting challenges posed by a cancer diagnosis. Rather than physical survival alone (a time construct), our goal should highlight a holistic approach including the patient's social and emotional needs to improve quality of life and optimism through developing healthy life coping strategies. We hope that the patient's perspective, presented in this paper by Ms. Baboolal provides clarity on what constitutes Survivorship and its importance to the patient. In a subsequent paper, we hope to provide actual data on the measured impact of this program on quality of life, coping strategies and overall patient well-being during the cancer journey.

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