

Cancer and Relationship Dynamics: Challenges and Key Issues

Abstract

There are about 25 million people living with cancer in the world today, the majority of them live in the developing world. 10 million cancer cases occur annually throughout the world. Cancer affects not just those who have the disease but also their caregivers, families and friends. The complex emotions and lifestyle changes that follow a cancer diagnosis can be almost as overwhelming for family members and friends as they are for the person with cancer. It's entirely possible that everyone in the family and in circle of friends will be supportive throughout the recovery. But chances are that one may run into a few relationship obstacles. Cancer care and its support structure pose a herculean challenge for the stakeholders within it. This paper highlights central issue about the position of family members, their support configuration vis-à-vis cancer patients. This paper will also propose to examine the family complexity in negotiation with cancer as well as the implication of professional intercession in comprehensive care of the cancer patients.

Keywords: Cancer Management, Support System, Long-term Survivors, Pain-Management, Relationship Issues.

Introduction

Cancer! The word still conjures up unfathomable fears of a hushed slayer that skulk up on us without much forewarning. It evokes such desperation that it has become a metaphor for grief and pain, a scourge straining our intellectual and emotional resources. The numbers are such that each of us will be touched either as a patient, a family member or a friend. Cancer impinges on social relations in distinctive ways and the intricate emotion and lifestyle alterations that follow a cancer prognosis can be almost as devastating for family members as they are for the cancer patients. Cancer rates soar up with each passing day. There were 14.1 million new cancer cases, 8.2 million cancer deaths and 32.6 million people living with cancer (within 5 years of diagnosis) in 2012 worldwide. 57% (8 million) of new cancer cases, 65% (5.3 million) of the cancer deaths and 48% (15.6 million) of the 5-year prevalent cancer cases occurred in the less developed regions. (GLOBOCAN, 2012) Cure and supportive care of cancer patients apart from the treatment is a necessity. "Care" is a broad term and it encompasses all sorts of concern, be it medical, social, psychological, economic and so on. Cancer is a devastating disease and cancer management is a multilayered process. Family-focused research in cancer places emphasis on the following key areas that serve as repertoire for future investigation in family centered research locales:

1. Families try to manage with both the blow of the cancer and with tension in the family heightened by the cancer.
2. Family members are strikingly distressed when a member has been detected with cancer.
3. Family members are not always in a knowledgeable position to appreciate and reflect upon the articulated feelings and activities of other family members about the cancer.
4. Although family members effort to retain their functional nucleus intact when one of them is a long-term survivor, still high-functioning families often fight hard to maintain that momentum for long. (Lewis, 2004) Studies have demonstrated emotional suffering and behavioral disturbance in women with breast cancer and in her relation with her husband.

Cancer & Conjugality

Conjugality undergoes severe strains during cancer. Up to three years of prognosis heightened level of stress has been documented in some studies for the couples (Gotay 1984; Baider, De-Nour, 1984; Hoskins, 1995; Hoskins et al., 1996.; Northouse, Swain, 1987; Ptacek et al., 1994; Toseland et al., 1995; Omne-Ponten et al., 1993) Couples in cancer treatment are known to strive for survival. During that time



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competing demands sidetrack them from attending to each other's needs in particular and support about the cancer in general. Although scanty is known about the couples' communications with each other for those who are long-term survivors, two extremes that is either identifying positive facets in the cancer experience or sharp interpersonal strains in the couples' relationship can be deciphered from such complexes. But which one of the two has an edge over the other that remains an elusive affair. In sexual activity, cancer treatments can often come in the way of libidinal drives. For female partner, extreme pain during sexual intercourse due to vaginal dehydration, concerns regarding fertility or treatment-induced menopause always remain some of the common issues. For males, disease or treatment induced erectile and ejaculatory dysfunction particularly for urogenital and colorectal cancers as well as for cancers in the brain, leukaemia and lymphoma can hamper healthy conjugal life. (Nazareth, Lewin and King, 2001) Chronic illnesses in general and certain cancer forms in particular may influence physical intimacy and sexuality, and thereby divorce rates. In addition, altered physical appearance due to e.g. a stoma, limb amputation or removal of a breast may affect sexuality both for men and women, and fatigue and chronic weakness may decrease libido. (Schover, 2005) Limited study has been done on cancer affecting reproductive organs and sexual experiences thereafter. (Harden, Schafenacker, Northouse, et al. 2002; Wellisch, et al. 1978; Sanders, Pedro, Bantum, Galbraith, 2006; Maughan, Heyman, Matthews, 2002)

Another issue is that a person's gender identity and 'sense of self' may be disturbed because of cancer in reproductive organs, with implications for the sexual desires. (Fobair, Stewart, Chang, D'Onofrio, Banks and Bloom, 2006) However, the dynamics of the care giving relationship and social constructions surrounding what constitutes appropriate sexual conduct after cancer may also interfere with a couples' sexual relationship. For example, partners who provide a great deal of intimate physical care to the person with cancer (such as helping with toileting or feeding) can experience difficulties in continuing to see them as a sexual person and reposition them as a "patient" or as asexual. Broader cultural constructions of normative sexuality may also be influential in determining the ability of couples to renegotiate sexuality and intimacy after cancer, particularly when sexual intercourse is no longer possible. As Judith Butler (Butler, 1993) has argued, our understanding of sexual subjectivity is confined within a "heterosexual matrix," within which masculinity and femininity are performed through engagement in normative sexual practices described as the "coital imperative," (with failure to perform coitus positioned as "dysfunction" and other practices referred to as not "real sex". This provides a theoretical framework for understanding why many heterosexual couples who cannot physiologically engage in sexual intercourse after diagnosis and treatment of cancer cease all expression of sexual intimacy. It also suggests that the dynamics and pressures of the caring role, as well as constructions and beliefs about what is acceptable or appropriate sexually after cancer, are worthy of investigation.

According to a study presented at the annual meeting of the American Society of Clinical Oncology, terminally ill cancer patients have a higher divorce rate, and it's almost always the husband departing his sick wife. Dr. Mike Glantz, a neuro-oncologist at the University of Massachusetts Medical School, and co-author of the study, said when the woman was affected by the brain tumor, the men left the marriage with really shocking regularity, it didn't seem to happen the other way round. He thinks men aren't emotionally prepared for the dual 'burden' of having to care for a sick wife and having to take over the household daily chores. "In our culture, men just aren't accustomed, aren't trained, aren't exposed to being the primary caregiver in the setting of a devastating illness," he said. (Cohen, 2001) A 1996 study (Twombly, 2001) in *Cancer Practice* found that husbands of terminally ill patients are at higher risk of depression than wives with ill husbands and cannot adjust to the burden of caring for their wives during illness. The authors attribute this finding to less social support in men's networks than in women's. Anger and helplessness-these are frequently men's responses to lack of control over their partner's cancer and it's especially important that they know these responses are normal and not something to beat themselves up. Corrosion of intimate feels sprouting from altered self and social image concerning body-mind complex and the resulting fear and negativity take its toll in sexual relations among spouses and thereby its future prospects. Females have a usual fear of their breast- loss, acceptance to their husbands whereas males are preoccupied by qualms concerning erection, penetration, ejaculation or intensity in orgasm. Ineffective communication results from altered and possibly unfamiliar mutual identities and social roles. Quality of life for most people includes maintaining intimate relationships and particularly expressing themselves as conjugal beings. Overcoming these problems require an adjustment, a rearranging of priorities and an open expression of the concerns and an intellectual revisit and rectification of gender roles.

Experiences of Children vis-à-vis Cancer

Children experiences of their parent's cancer have been till date restricted to two years after prognosis where it has been seen that children whose mothers had breast cancer or diabetes and at children whose mothers were healthy, the former tended to have lower self-esteem than the later. (Armsden & Lewis, 1994) Children experience relates directly to the child's illness-related qualms, as well as to the real and symbolic intimidations to the child's logic of security. (Armsden & Lewis, 1993; Lewis et al., 2000; Lewis, 1999) In a 2001 study of school-children, it was found that more than 80% of children whose mothers had early breast cancer feared that their mother will be surely going to die from cancer. (Zahlis, 2001; Lewis & Darby, 2004 & Compas et al., 1994) There is considerable confirmation that the quality of parenting is affected when a parent has got cancer. (Shands et al., 2000 & Zahlis & Lewis, 1998; Zahlis, 2001) On the other hand, for most parents, hardly anything is as fear-provoking as hearing from the doctor that their child has been detected with cancer. Parents face the uphill task of helping their child understand his or her

cancer. Children who have no clue about their cancer often use their imaginations to fill in the knowledge gaps since they are greatest listeners but worst interpreters. For example, they may relate their illness to punishment for doing something wrong. Furthermore, this uncertainty about their wrong-doing may cause anxiety, stress, and fear in children. Most children may not be feeling fine or may wonder about frequent visits to the doctor or hospital. Whether it is the cancer of the children or their parents, children may become overly impetuous and withdrawn from family and out of family activities. Alteration in their self appearance or appearance of their parents can cause a reality shock with which they find hard to negotiate. To effectively manage these issues, precise and logical information should be given to the children without flooding them with facts. They have to be given verbal as well as symbolic assurance of parent's love and security so that they do not feel alienated and can come to terms with the reality progressively.

Relationship Issues & Its Matrix

Cancer can be upsetting for the family, extremely affecting both the family's daily functioning and economic condition. Anxiety (a feeling of worry or unease), fear, uncertainty, anger, and sadness are common feelings that patients and families sometimes have when coping with cancer. They are normal responses to the stress of cancer, especially when the cancer is first diagnosed. Some people mourn the changes in their bodies, and the loss of the healthy future they may have expected. Fears concerning loss of independence, changes in relationships with loved ones, and becoming a burden to others may overwhelm the patient and complicate family life. There are cases where someone close to the patient deliberately avoid talking of cancer either because he doesn't want to upset the person or in a confusion of what to say. This can easily be gauged by the person having cancer. Therefore any kind of hush-hush can be replaced by easy & fluent discussion on the topic so that the person with cancer can unburden their worries while talking. Regarding decision on ongoing-treatment, in my doctoral work on 110 cancer patients from Cancer Centre Welfare Home & Research Institute, Thakurpukur, Kolkata, I have found, that majority of patients (56.36%) decisions are taken by family members with no involvement of patient whatsoever. Only 18.18% patients responded decisions about treatment are taken jointly. In case of priority towards decision making in the family after the disease, 66.66% of the males have been seen to be enjoying such decisions where as a meager 19.71% of females enjoy such decisions after their disease. Regarding neighbour's role I have seen that 13.63% neighbour provided unexpected help whereas 0.9% provided economic support and 19.10% have caring attitude but a majority of the 62.19% neighbours either provided no support or have discontinued relation as they thought the disease as contagious. (*My thesis is entitled 'Health Hazards & Care of Cancer Patients: A Sociological Analysis' under the guidance of Prof. Ruby Sain, Dept. of Sociology, Jadavpur University, 2005.*) One in four of the 325,000 people diagnosed with cancer in the UK each year (Facing the Fight Alone, 2013) could lack the support of family or

friends during their treatment and recovery, according to a Macmillan Cancer Support survey of people living with cancer. One in 14 people (7%) diagnosed with cancer – representing around 20,000 people in the UK each year – receive no help whatsoever, facing cancer completely alone. A further one in six (16%) only have support some of the time or occasionally. Over 90 percent of healthcare professionals have treated cancer patients who do not have any support at all from family or friends. More than half (60%) have seen patients in this situation in the past month. For some cancer survivors, the isolation goes beyond their initial treatment and recovery. One in six people (17%) who were diagnosed with cancer more than 10 years ago have not been visited at home by a friend or family member for at least six months. Overall, women are more likely to be isolated than men. Almost three quarters of men with cancer say they are fully supported during their treatment and recovery, compared with only just over half of women. Women are twice as likely as men to say that a lack of support has left them feeling isolated, lonely or abandoned.

There is evidence that family members attempt to deal with tension in the family system, caused by the cancer (Lewis & Hammond, 1996; Lewis et al., 1993; Lewis & Hammond, 1992) and "coping" has become a fashionable concept in behavioral medicine. (Manne, 1994 & Wenzel et al., 2002). Caregivers in the family may reflect on what support the professionals can offer and they require effective coordination with health care providers. Symptom management, either sprouting from the cancer or from side effects of cancer treatment, becomes a vital caregiver activity. Palliative care or pain management and other symptom control may be particularly burdensome for family caregivers due to the intricacies of symptom-management schedules, lack of information concerning "acceptable" symptom severity, and communication lapses with the health care team. Effective communication is highly essential because without emotional support, people can struggle unguided with complex questions about quality and quantity of life, and with the saddle of coping with treatments and suffering that drain their physical and emotional reserve. (Decker & Young, 1991)

Conclusions & Suggestions

Most family caregivers of dying cancer patients report that their role is physically and emotionally demanding and that they require additional support and information from health professionals. There is a consistent request for support-focused family caregiver interventions from caregivers and researchers, supported by appeals from health care organizations. However, few supportive palliative-stage family interventions have been conducted, not to mention rigorously evaluated. It appears that psycho-educational approaches directed toward individual primary family caregivers, rather than groups, may be worth pursuing. New interventions should be evaluated over time and, ideally, by way of randomized controlled trials. Unless new evidence-based supportive strategies for families are realized, there is a real danger that health care professionals will not be meeting the core elements of family centered delivery of palliative care. Therefore,

there is an urgent need for new strategies to be designed and tested; otherwise the principle of the family as the unit of care will not be upheld. Policy and environmental changes can affect large segments of the population simultaneously. Adopting healthy behaviors is much easier if we establish supportive community norms and adopt a philosophy that embraces health in all policies and settings. We must promote proven social, environmental, policy, and systems approaches that support healthy living for individuals, families, and communities.

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