The Psychological Landscape of The Cancer Journey: Perspectives of Patients, Caregivers, And Oncology Nurses

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***Abstract*—Cancer is a psycho-social and inter-personal as well as a bio-medical disease. Patients can feel anxious, depressed, frightened about recurrence, non-belonging, body issues, loss of control, reticent to death, and eliminating from society through diagnosis, treatment, survivorship, recurrence, and end-of-life care. Family carers can feel burdened by the practical, emotional, financial and decision-making expectations that their role entails, as well as worry, experience depressive symptoms, grieve in advance, and experience role strain. While a vital component of a cancer patient's treatment is the constant emotional and clinical support these nurses offer, they face repeated exposure to suffering, death, moral conflict and excess workload that can result in the development of compassion fatigue/burnout and/or secondary traumatic stress, and moral distress. The three aspects of distress are reviewed in conjunction, and the authors suggest that distress in cancer care is a shared system level phenomenon. Efficient psycho-oncology therefore needs the periodic distress screening, care directed to the caregiver, issues of nurse well-being, communication support and merging palliative care and psychosocial care.**

***Index Terms*—Cancer journey; psycho-oncology; psychological distress; cancer patients; family caregivers; caregiver burden; oncology nurses; compassion fatigue; burnout; moral distress; emotional wellbeing; anxiety; depression; survivorship; palliative care.**

I. INTRODUCTION

Being diagnosed with cancer can suddenly disrupt a person's emotional life, family roles, future, and how one imagines his or her body. Initial reactions include shock, fear, and disbelief, and a feeling that "life as I knew it" is over. Some studies within the field of psycho-oncology indicate the presence of depression, anxiety, psychosocial difficulties in adjustment and general distress throughout all the cancer care settings including oncology, haematology, survivorship and palliative care (Mitchell et al., 2011; Gao et al., 2010). The causes of these challenges could include uncertainties about prognosis, painful treatments, economic toxicity, body image issues, functional decrease, and worries about leaving loved ones behind.

Those who provide care themselves share the cancer journey also. Family members often serve as emotional support, appointment schedule, medicine watchers, financial planners and decision-makers. Oncology nurses are at the core of clinical and emotional management, confronting patients in their suffering, their uncertainties, their recollections, and their deaths, while attempting to remain professionals, composed. Thus, cancer-related distress is considered to be a useful experience and is studied not as a patient problem, but as a triadic problem between patients, caregivers and oncology nurses. This view can facilitate a focus on support offered by relations and institutions rather than coping as one individual.

II. PATIENTS: DISTRESS ACROSS THE ILLNESS TRAJECTORY

Patients' psychological distress varies over the course of cancer. Distress at diagnosis is many times

associated with fear of death, lack of knowledge of prognosis and information overload. There are many patients who have to make rapid decisions of treatment with still an incomprehension of the complex medical terms employed. Treatment's side effects like fatigue, pain, nausea, hair fall, neuropathy, sexual dysfunction, infertility and manifestation of body changes may aggravate anxiety and sadness. Treatment also may diminish independence and produce a fear of being a 'problem' for the family.

Being a survivor doesn't necessarily provide a psychological end to the experience. Many survivors still feel that it could happen again, suffer from anxiety stemming from the scans, have chronic symptoms and struggle to resume working or family life. Symptoms of depression, anxiety and distress could remain in LTCS, which suggests psychosocial support should be ongoing after the completion of active treatment, as presented by Brandenbarg et al. (2019). Later in the disease process psychological needs may change to include: Meaning, dignity, unfinished life goals, family communication, spiritual issues, and fear of suffering. Therefore, throughout the disease process, patient-centred oncology should incorporate symptom management and emotional support.

Patient distress should be evaluated multiple times; not just at diagnosis. Changing needs can be detected through screening at transition points, recurrence visits, survivorship visits and at referral to palliative care. Supportive/expressive therapy, CBT, mindfulness, meaning-centered therapy, psychoeducation, and EPC can assist patients with naming fears, bolster coping, facilitating family communication, and maintaining dignity.

III. CAREGIVERS: INVISIBLE EMOTIONAL LABOR

While family caregivers play a vital role in the care of a person with cancer, their needs can be less prominent than the patient's. They may help care-takers receive transportation, make appointments, set up medication schedules, check on symptoms, assist with personal care, liaison with doctors and continually reassure. This can lead to caregiver burden, which is a multi-faceted burden, including emotional, time, financial strain, sleep loss, social isolation, and changes in personal goals.

The stress of caregivers is influenced by the patient's symptoms, prognosis, functional loss, and emotional status. For the patient, caregivers sometimes feel helpless and overwhelmed when they are anxious, in pain or physically dependent. Quite high levels of anxiety and depression were found in caregivers of cancer patients in reviews (Geng et al., 2018; Bedaso et al., 2022). Caregivers can also minimize their own suffering by making it appear as though they don't want to let themselves feel it. This suppression can lead to a delay in seeking help and to exhaustion. For a few families, caregiving also involves disagreement in treatment options, money, duties, or contacting doctors.

As cancer progresses, there are other psychological aspects to deal with. They can have anticipatory grief - that is, feel the need to grieve before the patient dies. They may experience emotions of grief, guilt, anger, fear and emotional readiness for loss and attempt to maintain hope and assistance. Role changes can hurt; them turning into your medical caregiver, your adult child making the decisions, or your parent becoming a full-time advocate can all cause pain. These shifts can cause feelings of closeness or closeness but they can also lead to feelings of loneliness, resentment, and guilt.

The wellbeing of caregivers is an important element of quality cancer care, as it impacts on adherence to treatment, symptom management, patient comfort, and decisions regarding end of life. There is some evidence that interventions for familial caregivers can lead to increased coping and decreased burden (Northouse et al., 2010) and newer evidence that psychoeducational, psychosocial, and dyadic interventions can be effective for familial caregiver distress (Secinti et al., 2023). Practical support should comprise of information, skill training, respite care, emotional counseling, financial guidance and bereavement preparation. Cares takers to be included in care planning with their permission and screened for distress.

IV. ONCOLOGY NURSES: COMPASSION, BURNOUT, AND MORAL DISTRESS

Oncology nursing is in a unique psycho-social role within cancer. They monitor the symptoms, administer medication, educate the person about their symptoms, plan treatment, give emotional support, assist the

family and ensure end-of-life care. They have to be at the same time methodical and vigilant emotionally. They frequently have to be calm and deal with fear, pain, decay and family issues. Experiences over time of suffering, failure to treat or cure, recurrence and death can impact on professional quality of life for nurses.

Oncology nursing is one of the most talked about psychological risks, namely Compassion Fatigue. A lack of feeling; a sense of emptiness that result from exposure to pain for an extended period of time. The compasion fatigue of oncology nurses goes not so much from a lack of compassion, as it does from being repeatedly called upon to be compassionate under circumstances that are full of emotions. Structured types of review have associated oncology nursing with the idea of ‘compassion fatigue’, ‘burnout' and ‘secondary traumatic stress' as well as identified compassion satisfaction as a protective factor of meaning (Ortega-Campos et al., 2019; Xie et al., 2021).

The elements of burnout are emotional exhaustion, depersonalization and diminished professional accomplishment. Working in an oncology environment can exacerbate the sense of burnout due to staffing limitations, a high patient census, pressure from administration, frequent deaths, and interpersonal dynamics that create anxieties or emotional challenges. Buoyed by a lack of empathy, impaired communication, rising rates of turnover, and impacts on care quality are a result of burnout. For this, nurse wellbeing simply isn't just an occupational problem – it is a patient-safety and care-quality problem as well.

An additional and important worry is that of moral distress. When nurses feel that what is ethically right for them is not possible due to institutional or family restrictions, treatment choices, or limited resources. Nurses, for instance, might suffer from unnecessary distress from a feeling of over aggressiveness in the treatment, inadequate alleviation of suffering, or ambiguity regarding prognosis. According to Eche et al. (2023), moral distress in nurses working in oncology requires a link with burn-out and compassion fatigue. Solving the problem of moral distress takes good leadership, ethics consultation, team communications, and room to express thoughts.

However, being an oncology nurse can be very fulfilling. Compassion satisfaction is when nurses feel a sense of purpose, connection and fulfillment in caring for patients and families. This is a good aspect which cannot be overlooked. This can be achieved by the presence of supportive teams, sufficient staffing, reflective practice, recognition and enjoyable ethical workplaces for the nurses.

V. A SHARED PSYCHOLOGICAL SYSTEM

There is a complex relationship between patient, carer and oncology nurse psychological experiences. If the patient is distressed, he or she might need more from a caregiver both emotionally and practically. A caregiver under distress can have problems keeping cool, may have difficulties with calcium medications, giving meds, or helping in making decisions. When a nurse has a major burn-out, they may not be able to relate with patients or families as much as they need to. On the other hand, a supported nurse can calm fears by making excellent communications and a supported caregiver can enhance the patient's security.

This review therefore, suggests a Relational Psycho-Oncology model. This model is three-fold with distress passing from patients to caregivers, and caregivers to oncology nurses. Every group has its own needs and no group is in isolation. How the emotional labour is recognized and supported at all levels – individual, family and system – will determine the quality of psychological care. It is not to point fingers at any group but that of indicating that psychosocial oncology needs to be organized as a shared system of care.

VI. IMPLICATIONS FOR PSYCHO-ONCOLOGY PRACTICE

All of these indicate that it is time to integrate the psycho-oncology approach into all aspects of standard cancer treatment, instead of it being called on only when it becomes more obvious that intense distress has arisen. Repetitive distress screening should be conducted at diagnosis, transitions of care, recurrence, survivorship and palliative care. When relevant, the caregiver should be included in assessment and education as this is a key factor in the wellbeing of the person as well as family functioning and care outcomes. Emotional work

should be acknowledged as an aspect of nursing practice within the institution, to support the oncology nurse.

Brief distress screening, clear pathways for referral, family-inclusive communication, early palliative care, caregiver psychoeducation, peer support (for nurses), moral distress debriefing, and reflection (team-based) are all important practice strategies. Don't put all of the responsibility on individuals. Patients cannot be asked to recover without support, caregivers cannot be assumed to be limitless resources, nor should nurses be expected to be the only ones to be responsible for reducing burn-out by the level of personal resilience they exhibit. To provide sustainable care for cancer patients needs a whole array of things: structure, personnel, psychosocial care and emotionally intelligent leadership.

A practical model would be to screen for distress using brief tools with patients and caregivers alike, then provide referral to psycho-oncology and/or social work to patients with high levels of distress, involve caregivers in patient education sessions, and provide structure debriefing for nurses when they have experienced difficult patient deaths and/or ethically challenging cases. Emotional and family issues should be included in multidisciplinary meetings, moreover biomedical update. This can result in better communication, a decrease in crisis care, and help to maintain dignity throughout the course of the illness.

VII. RESEARCH GAPS AND FUTURE DIRECTIONS

There are several issues that need to be addressed in the literature. One, many of the studies address the patient or carer or nurse individually, whereas their experiences are interrelated. Future studies need to adopt triadic designs encompassing the patient, caregiver and oncology professional in the same research model. Second, distress is not routinely assessed in the routine care of patients with cancer. If patient care is under the care of caregivers who perform significant care activities at home, screening should not be restricted to the home.

Thirdly, there is a need to shift the focus of nurses' wellbeing research more than individual resilience. While mindfulness and self-care can be good, it is a poor substitute for unsafe staffing, poor communication, moral conflict and lack of support from leadership. Future interventions should integrate individual and team and institutional interventions. Finally, additional research should be more culturally diverse in the context in which family care is being provided, but there may not be opportunities to provide psychosocial services. Distress manifestation and management is related to cultural beliefs regarding cancer, death, family obligation and seeking

VIII. CONCLUSION

Patients, caregivers and oncology nurses experience a complicated psychological journey as part of their cancer experience. Treatment burden, existential concerns, fear and uncertainty are some of the issues patients' experiences. Emotional labor, role strain, anxiety, depression and anticipatory grief are experienced by caregivers. Counseling with each other's emotional burden, oncology nurses deal with patience's suffering, moral conundrums, and end-of-life issues over and over again. These experiences are inter-related, with distress affecting one group potentially impacting wellbeing/functioning for the other groups.

A holistic psycho oncology model should thus not be limited to the patient. It should involve regular patient and carer distress assessment, carer focused interventions, nurse well-being programs, learning about communication, including palliative care, and an institution-wide approach to address burnout and moral distress. All three of these groups must all be supported in order to provide humane, sustainable and high-quality cancer care.

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