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Special Feature

Psycho-Oncology Research in India: Current Status and Future Directions

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Research in the field of psycho-oncology examines the host of psycho-social factors that are likely to have a bearing on overall health and well being of cancer patients and their caregivers at various points in the illness- trajectory. A scan of the psycho-oncology research literature from India was carried out utilizing pre-determined key words on four electronic databases. About one hundred and twenty relevant empirical papers were identified between the years 1977 and 2006. The review indicates that multiple themes (e.g. psychosocial factors related to cancer screening, distress, concerns and coping among patients and caregiver, development and adaptation of assessment tools) have attracted attention of researchers. A fine grade analysis of psychological processes and interpersonal dynamics that affect quality of life and well being of cancer patients and their caregivers as well as development and testing of cost-effective modules for psychological interventions are some of the areas that require urgent research attention. The factors that can impede the integration of empirical knowledge into routine clinical care and further advances in the field are highlighted.

***Keywords**:* Psycho-oncology, Indian research in psycho-oncology, psycho-social issues in cancer

Psycho-oncology research across the globe has a history dating back to the 1950's although it has been formally recognized as a scientific field of enquiry within oncology much more recently (Holland, 1992). The terms psycho-oncology refers to "diverse psychological, social, behavioral and psychiatric issues related to cancer prevention, cancer illness and treatment and cancer survivorship" (Breitbart & Chochinov, 1998). It concerns itself with "emotional responses of patients at all stages of disease, their families and caretakers as well as psychological, behavioral and social factors that may influence cancer morbidity and mortality" (Holland, 1992).

Advancements in any field require periodic stock-taking in order to look back at the paths traversed, to reflect on the journey ahead as well as re-articulate destinations and recommit to collective goals pertaining to research, practice and training in the given area. This paper is confined to addressing the research scenario in the field of psycho-oncology in India. Some part of this exercise has been carried out earlier by way of a few review articles already available (Pandey, 2004; Venkateswaran & Kumar, 2006). These have tended to focus in depth on certain segments/sub fields (e.g., quality of life instrumentation, palliative care). The present report attempts a broader sweep and scan of the research in psycho-oncology in India in order to come up with general observations on its current status as well as future directions that emerge from such observations.

Method

Published psycho oncology research literature from India was surveyed for addressing the purpose of the present report. The electronic databases utilized were: IndMed, PubMed, Medknow and EBSCO host. In addition, issues of the Indian Psychological Abstracts and Review, between the years 1996-2000 were also scanned. The keywords used for search on electronic databases included: Cancer, psychological, psychiatric, psycho-oncology, distress, quality of life, survivors, palliative and India, in various permutations and combinations. Only papers that discuss empirical investigations were included. This criterion resulted in exclusion of several papers from the Indian subcontinent that were theoretical in nature or contained overviews and clinical guidelines or general observations. The method outlined above helped in identification of approximately hundred and twenty papers between the year 1977 and 2006.The studies surveyed are classified into overlapping yet distinct categories on the basis of themes addressed. As indicated earlier, the present report is not aimed at providing either a completely exhaustive coverage or a detailed description of all the studies from India in this field.

Results and Discussion

Cancer prevention and early detection: Psycho-social Issues

The scope for cancer prevention & early detection programs has been well recognized by Indian researchers(e.g., Sankara nrayanan, 1997; Gupta et al.,1986; Dhamija et al., 1993). The role of psychological and social factors that have the potential to influence the implementation as well as the impact of such programs have also been receiving due attention. Absence of symptoms, apprehensions about screening test, pre-occupation with family problems, practical difficulties and lack of approval from spouse emerged as factors linked to non-utilization of a community based cervical cancer screening program in one such study (Basu et al., 2006). Another community based intervention study on breast self examination (Rao et al., 2005) reported that forgetfulness & being too busy appeared to be the two most frequently perceived barriers. On the whole, these studies indicate that it is important to take psycho-social factors within a given community in account, while designing and implementing programs aimed at cancer prevention and early detection.

Prevalence and detection of psychiatric morbidity and psychological distress

Several studies have attempted to examine the prevalence of psychiatric morbidity in heterogeneous samples of cancer patients in India (Alexander, Dinesh & Vidyasagar, 1993; Chakravorty et al., 1993; Chandra et al., 1998a; Mishra et al., 2006). The reported prevalence of diagnosable psychiatric conditions in these studies tends to range between 40 % and 80%. A handful of studies have examined psychological morbidity in groups of cancer patients homogenous with respect to cancer sites (Kulhara, Ayyagari & Nehra, 1988; Mehta & Abrol, 1982; Patel et al., 1987; Satpathy & Das, 1997).There are a few published studies on prevalence of psychological distress & morbidity in children suffering from cancer (Rao, Malhotra, & Marwaha, 1992; Sharan, Metha, Chaudhry,1995a & 1999a). Depressive disorders (adjustment disorder with depressed mood & major depression) have been most commonly reported in the above-mentioned studies. These findings are in keeping with the available literature from the West (Derogatis et al., 1983). The results of one study suggested that referral rates for psychiatric/psychological services for cancer patients (even in institutions where such services are available) might be low (Chakravorty, De Souza & Doongaji, 1993). The extent to which this pattern is common across settings and the probable factors associated with low detection and/or referral rates are two issues that merit extensive exploration.

Awareness of diagnosis, prognosis and distress

The association between awareness of cancer diagnosis, prognosis, and psychiatric status have also been the subject of investigation in at least three published studies (Alexander, Dinesh, & Vidyasagar, 1993; Chandra et al., 1998; Mishra et al., 2006). These studies indicated that roughly 54% to 66% of patients were aware of cancer diagnosis (Alexander, Dinesh, &Vidyasagar, 1993; Chandra et al., 1998a; Mishra et al., 2006; Purakkal, Pulassery, & Ravindran, 2004a). However findings across these studies are not consistent regarding the association between awareness and psychiatric status. There is a need for further research to differentiate between concepts such as ignorance, denial, non-disclosure etc. One study (Gautam & Nijhawan, 1987) examined the preferences of patients suffering from cancer & their relatives regarding communication of diagnosis. Most patients (who were aware of their diagnosis) wanted to be told. However, most caregivers wanted to know the truth without the patients being told. A survey (Purakkal; Pulassery, & Ravindran, 2004b) in a teaching hospital in a southern Indian state examined the preferences of medical undergraduate students and faculty about disclosure of life threatening illness using two hypothetical questions. The findings indicated that 85% of clinical students and 89% of doctors stated that the diagnosis should be revealed. Interestingly, another study (Purakkal; Pulassery, & Ravindran, 2004a) in the same medical college attempted to ascertain the proportion of patients attending radiotherapy services who were aware of their diagnosis. 62% of respondents were aware of their disease. However, only 46% of patients said they had received their diagnosis from their doctors. Empirical examination of the practices related to diagnostic and prognostic disclosures across oncology settings as well as factors associated with such practices from multiple perspectives (doctors, patients and family caregivers) are issues that require a closer attention by researchers.

Dynamic nature of distress & well-being

The changing patterns of psychological distress over time following cancer diagnosis have also received attention in a few studies (Chaturvedi et al., 1996; Chawla et al,, 1999; Mehrotra & Mrinal; 1997, 1996; Kausar & Illyas, 2000; Chaturvedi et al., 2000). On the whole, these indicate that psychological distress is not a transitory phenomenon for many cancer patients. One study (Chawla et al., 1999) showed declining QOL following 3-4 weeks of radiotherapy. Although QOL showed improvement at three months following radiotherapy, the levels were not restored completely. More studies are needed that throw light on psychological disturbances over the entire span of cancer trajectory starting from the point of exhibiting risk, engaging in screening, diagnosis, active treatment, remission, recurrence and beyond. Such studies also need to focus in depth on the role of biological, psychological and social factors that impact on the wellbeing of individuals during the cancer trajectory.

Development and adaptation of psychological assessment tools

A large proportion of studies specifically focus on advances with respect to development and /or adaptation of psychological assessment tools suitable for use in Indian psycho- oncology contexts (Budrukkar et al., 2006; Chaukar et al., 2005; Chaturvedi et al., 1994; Koshy et al., 2004; Pandey et al., 2004; Saxena, Mendoza & Cleeland 1999; Thomas et al., 2004; Vidhubala et al., 2005). Apart from development of new measures, examining cultural appropriateness of tools, development of local norms, identification of cut-off points have been some such exercises taken up by these researchers. Assessment of quality of life, anxiety, depression, general distress and pain has attracted maximum research attention in psycho-oncology.

Personality and stress:

A few earlier studies have dealt with examining personality profiles of cancer patients and differentiating the same from various control groups (Seth & Saksena, 1977). Early childhood experiences have also been analyzed in retrospective studies that report recurrent loss experiences and disturbed interpersonal & parent-child relationships to be commoner in cancer patients compared to controls (Mandal, Ghosh & Nair, 1992; Nair, Deb & Mandal, 1993). A few studies have noted significant findings with respect to neuro-endocrinal measures of arousal in cancer patients (Bandyopadhyay, et.al, 1987, 1988, 1986). Neuroticism, emotional de-surgency, incommunicativeness are some of the personality features that have been implicated to be differentiating between cancer patients and healthy controls, hypertensive and individuals with psychosomatic conditions (Nair, Deb & Mandal,1993; Bandyopadhyay et al., 1988, Vaidya, Srivastava & Srivastava, 1985). Although most of the studies have used controlled groups, various methodological limitations including cross sectional and retrospective nature of enquiries impose constraints on commenting on causative nature of the variables examined. However, these studies provide important leads that merit investigation using rigorous research designs. A more recently conducted controlled study (Doongaji et al., 1985) examined probable association between malignancy and psychosocial stress. Information about life change events was elicited over a period of three years rather than during the year just preceding the illness. The life change stress scores were high in the third year and in the year preceding the illness in the index group vs. the control group.

Concerns: patient perspectives, coping and adaptation

A few studies have explored concerns of cancer patients in Indian oncology settings. One study (Chaturvedi, 1991) utilizing interview methodology reported that peace of mind, spiritual and social satisfaction were considered to be very important for two-third of the cancer patients and level of satisfaction was valued higher than level of functioning. Having low income, having a widowed/ divorced status, presence of pain and advanced tumors at presentation have been reported to positively correlate with psychological distress (Pandey, 2006). Younger patients and those with early stage of cancer showed higher death anxiety than older patients and those with advanced malignancies (Feroz & Beg, 1987). Another study (Pai, Mehrotra & Vidyasagar, 2003a) on patients undergoing radiation found that the common sources of distress were spread across five different domains viz. financial, physical, role disruptions, interpersonal and spiritual domain. The most frequently reported distressing thoughts of patients were that they were a burden on their family, their illness was worsening and that their illness was a punishment from God. A pilot study (Pandey et al., 2003) assessed the concerns and coping strategies of patients with oral cancer patients. The results indicated that communication with family, friends and medical persons was most commonly affected domains followed by withdrawal from social activities. Turning to religion (leaving the responsibility of cure to God) was the most common coping mechanism among 80% of the patients. Another group of researchers (Awasthi, Mishra & Shahi, 2006) examined illness beliefs and health seeking behavior of educated, uneducated, rural and urban women suffering from the cancer of cervix in northern India. The findings revealed that individual and psychosocial causes were more strongly represented in the belief system of patients than environmental or supernatural causes. The perceived consequence of illness was negatively correlated with the degree of social support available to patients. Yet another study (Vidhubala et al., 2006) reported that head and neck patients adapted both emotion oriented and problem oriented coping during the course of illness. The need to separately examine changes in multiple dimensions of QOL was well illustrated in a short-term prospective study (Chandra et al., 1998b) of radiotherapy patients. The role of religious and other belief frameworks has been the subject of investigation in a few Indian studies which indicate that beliefs in God's will, belief in Karma and fate are three causal explanations evoked by cancer patients in India ((Awasthi, Mishra & Shahi, 2006; Kohil & Dalal, 1998; Dalal, 2000). However, the role of these beliefs in psychological recovery needs to be more clearly delineated. Much more philosophical–religious attitudes towards life have been noted in Indian cancer patients than reported in Western research literature (Patel et al., 1987; Pai, Mehrotra & Vidyasagar, 2003). Severity of pain, poor religious belief system, perception of illness as fatal, poor support, high stressful life events were reported in yet another study (Babu et al., 1997) to be associated with increased risk of major depression in cancer patients attending a pain clinic in India.

Gender specific issues:

Psychological issues in women with breast cancer and cervical cancer have also received attention from Indian researchers. Results of one such study (Sharma et al., 2003) indicate that subgroups of women with reproductive organ cancers may have different profiles of stress, distress & coping. Another study (De Souza & De Souza, 1979) way back in the year 1979, reported that 83% of the Indian women who underwent mastectomy would have preferred more information prior to their surgery. 94% of the women wanted a good prosthesis as soon as possible after mastectomy. Only 4% of the women clearly and consistently desired re-constructive surgery. On the other hand another more recent study (Khubalkar & khubalkar, 1999) conducted in a different setting indicated that mastectomized women were high on submissiveness than women operated for other problems and that they had low awareness about prosthesis/reconstructive facilities. The possible reasons for differences between the results of such studies need exploration. There are a handful of studies (Khalid & Gul, 2000; Khan et al., 2000) that have focused on distressing issues among women cancer patients.

Survivorship:

Relatively speaking, psychological issues in long term cancer survivors have received little attention in Indian research literature although survival rates, follow up compliance etc. have been the subject of examination (Bakshi et al., 2005). Positive thinking, purpose in life and strong family support were noted to be important for treatment completion in a study that employed qualitative methodology to explore coping in women survivors of breast & cervical cancers (Ramanakumar, Balakrishna & Ramarao, 2005).

Palliative care:

The issues related to organization of palliative care services especially in terms of outpatient facilities supplemented with active supportive home care has received attention of practitioners in the field of oncology (Kumar, 2005; Muckaden et al., 2005; Paleri & Numpeli, 2005). There is scope for empirically examining the psychosocial aspects involved in the design and delivery of such services.

One study (Chaturvedi, 1994) documented concerns of Indian patients in a palliative care setting. Cancer pain, physical health, finances and future emerged as commonly reported concerns. Another study (Pahwa, Babu & Bhatnagar, 2005) qualitatively explored emergent themes in a sample of terminally ill cancer patients. The following seven themes emerged: concerns about physical pain, anxiety and depression (related to unfulfilled dreams and concerns about the welfare of the family), body- image issues, social withdrawal, disease viewed as bad karma, desire for hastened death and hope. Awareness, clinical knowledge, and education and training aspects of palliative care among the clinical residents of a tertiary care hospital were examined in a study the results of which indicated that "total care" concept in palliative care and QOL issues needs to be more emphatically addressed during training in India (Mohanti et al., 2001).

As approximately, fifty percent of newly diagnosed cancer patients in India and other developing countries present with advanced disease, the benefits of setting up a palliative care unit within radiation department were explored in a hospital in northern India. It was observed that distressing physical symptoms and pain were not being assessed adequately during routine care and that enhanced attention to palliative care needs improved patients' and relatives' satisfaction (Bansal et al., 2003).

Family caregivers:

Family caregivers have received very little attention in published literature from India. This is surprising as the family forms the backbone of support in a collectivistic society like India with limitations in terms of availability of tertiary supports. A few studies have examined prevalence of psychological distress, diagnosis – awareness and disturbances in family functioning following cancer diagnosis (Sharan, Mehta & Chaudhry, 1999b, 1995b).One study reported that a substantial proportion of relatives of cancer patients undergoing radiation therapy felt unable to listen to their anxieties and concerns regarding cancer (Kuruvilla & Singh,1985). Disturbed family adjustment in 65% of the laryngeal carcinoma patients was reported in a study by Mehta & Abrol, 1982. Doubts regarding accuracy of diagnosis were entertained by almost 90% of the parents of leukemic children and significant financial, social burden on the family was observed (Rao, Malhotra, & Marwaha, 1992). Perspectives of family caregivers in terms of felt unmet needs, processes that impede or facilitate care-giving, communication barriers between caregivers and patients as well as between caregivers and treating teams are matters that need to be addressed in future studies.

Professional caregivers

Psychological issues in oncology staff and cancer care volunteers in India are yet to be examined adequately. One study (Vikraman & Chandra, 2005) indicated that majority of staff had joined a palliative care organization (hospice) not for monetary benefits but for finding meaning in life. The study results also indicate that the though the staff effectively provided physical care, they felt ill equipped to manage psychosocial and spiritual aspects of care. The systematic and intense involvement of community in providing palliative care is a notable initiative in a southern Indian state (Kumar, 2005).Communication skills training programs for volunteers providing palliative care have been developed under this umbrella (Chittazhathu & Moideen, 2005). However, empirical assessment of the process & outcomes issues in such programs merits attention of researchers. The impact of five weekly lectures on palliative care was examined in a sample of nursing and medical students (Velayudhan et al., 2004).The authors concluded that inclusion of palliative care in the undergraduate teaching of medical and nursing students in India is feasible, but requires careful examination of curriculum content, teaching methods and evaluation techniques.

Interventions:

Studies that test the feasibility and efficacy of various psychological interventions for cancer patients are scarce. Three low budget interventions namely, transcendental meditation, yoga and group counseling modules were tried in a group of ambulatory cancer patients (Joseph, 1983). The patients were followed up for two months after the intervention. As per subjective reports of the participants, the programs positively contributed to improvement in QOL for them. Another study (Ashraff et al., 2004) in a military service setting assessed the efficacy of providing six weeks of psychopharma cological and supportive psychotherapy treatment for cancer patients with probable psychiatric disturbance. Significant reduction in depression following short-term psychiatric intervention was reported. Another study (Pai, Mehrotra & Vidyasagar, 2003a, 2003b, 2005) examined the feasibility, process and outcomes of a controlled trial of brief group interventions in hospitalized non- terminally ill patients, undergoing radiotherapy. It demonstrated short-term beneficial outcomes of interventions utilizing supportive and cognitive behavioral components. The study findings indicated that feasibility of group interventions in Indian oncology settings is likely to require a significant departure from convention group therapy formats.

***General Observations -* Content Coverage:**

The scan of research-literature from India indicates that prevalence of psychiatric morbidity has been frequently examined in different samples in cancer care settings. The association of psychiatric morbidity with basic socio-demographic and disease variables has also been examined to some extent. Comparability among studies is limited in view of heterogeneous methodologies and samples utilized across studies. However, the prevalence rates and patterns mirror those reported in western studies. A few studies have documented concerns and sources of distress, satisfaction with information provided as well as variations in levels of well-being and quality of life over time. More research is needed on preferences of patients and families as well as professional caregivers in terms of disclosure of diagnosis and prognosis and related factors and outcomes. Although several studies have documented the role of within - person resources for coping as well as social support, a fine grade analysis of intra-personal processes and interpersonal dynamics in adaptation has been overlooked. The process issues related to adaptation to cancer and the role of global belief frameworks (including spirituality-religiosity) in the Indian cultural contexts have begun to receive due attention. Several studies have attempted to delineate the role of personality variables in cancer vs. other medical conditions/healthy controls. Majority of the studies are on adult cancer patients. Studies exploring psychosocial issues in the terminally ill as well as in cancer survivors are fewer in number compared to those focusing on other phases of cancer trajectory (e.g. during active treatment). Very few studies have family caregivers as their primary focus. The issues related to measurement in psycho-oncology have attracted a great deal of research attention by the researchers India and this has resulted in adaptation and development of relevant tools. Women-issues have been addressed in a few studies whereas issues specific to men with cancer have not attracted research attention. This is similar to the trend in the Western literature wherein psychological issues in men with cancer began to be examined much later in the evolution of psycho- oncology research (Holland, 1992).

Staff stress/needs and assessing outcomes of brief training modules is a rather neglected area of research. Psychological intervention research (for patients and their caregivers) is lagging behind to a great extent. There is a need to develop and test out culturally relevant intervention modules that use feasible, cost effective modes of delivery. The role of psychological factors in survival, mechanisms of change through interventions, moderators of outcomes of interventions, comparisons of different intervention modalities, impact of psychological interventions on multiple outcomes are some of the areas within psycho-oncology which have been cited as important foci for future research worldwide (Helgeson, 2005). Indian researchers too need to take these issues in cognizance.

Methodological issues:

The use of an extremely heterogeneous set of tools makes it difficult to make comparisons between studies addressing similar issues, e.g. prevalence of psychiatric morbidity. Sample sizes have been variable across studies with most studies utilizing group sizes larger than thirty. Although majority of the studies have used quantitative methods, a few have involved qualitative /mixed method designs to explore themes and issues. Most studies are cross sectional in nature and only a few have used short term follow up designs. A more frequent inclusion of measures other than subjective self reports measures (e.g., use of multiple informants and neuro-endocrine measures) and assessment of outcomes across multiple dimensions over longer time-frames would be laudable steps in research designs in the field of psycho-oncology.

The role of personality variables and stressful life experiences has been studied using retrospective methodologies. Although several studies use control/comparison groups especially in personality and stress research, the rationale for/assumptions underlying the choice of specific groups are often not made explicit. Intervention studies have not used control group designs except in one instance. Last, but not the least, there is a need to explicitly utilize theoretical frameworks in designing of the studies to the extent possible.

Challenges:

The research in psycho- oncology by its very nature involves professionals from multiple disciplines who use varied outlets for publications and readership. This makes it difficult to integrate and access research from divergent sub fields. This is probably one of the reasons why research from other Indian studies on psycho-oncology is cited minimally in a typical empirical paper from India. This appears to have taken a toll in the form of lack of sufficient linkages between studies and thereby a cumulative progression of research in the field. The above factor also links up to the quality of studies that can be conducted. Large scale, prospective studies that can provide generalizable findings or point to differences between settings/samples that restrict generalization, often require collaborations between professionals across settings as well as disciplines. To some extent, psycho- oncology has tended to remain an isolated field not well integrated with the practice of oncology across the country. Concentrated efforts from interested clinicians and researchers are needed to bring to light the relevance of psychosocial research in clinical practice. Unless the research is carried out and disseminated in a way that it has impact on routine cancer care, it is unlikely to gain momentum on a large scale. For instance, although there is ample data on the prevalence of psychiatric morbidity and effective methods for quick screening for significant distress, it is unclear whether it has had a visible impact on actual screening for significant distress in Indian oncology settings. A few possible explanations could be: inadequate dissemination of information about availability of such measures, practical constraints in utilizing the results of such screening by accessing or making available appropriate intervention services as well as a lack of conviction about the utility of such services on tangible and valued outcomes (e.g. compliance, overall functioning, and customer satisfaction). On one hand carrying high-impact research requires networking between professionals across settings, on the other hand clinically relevant research needs to be conducted and disseminated adequately for enlarging the network of interested professionals. In other words practice and research issues are co-dependent and have bi-directional impact. Practice of psycho-oncology is dependent on availability of human resources much more than advancements in technology. Future researchers need to take in account the ground realities of practice in limited –resource settings in India as well socio-cultural factors that shape the interactions between patients, family caregivers and health systems. There is an urgent need to develop and test out effectiveness of intervention programs that are acceptable to clients, involve low intervention-costs, are sustainable in the health care systems in India and can be delivered in varied settings. On the whole, the scan of the available literature suggests that that the field of psycho-oncology research in India has witnessed definite ascents and growth as well as multiple challenges. Some of the research issues parallel the observations on evolution of psycho-oncology across the globe (Holland, 1992; Helgeson, 2005). However, there are also a few challenges that are rather unique to India and need to be extensively addressed by future researchers.

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