



Cancer and Spirituality—Underutilized Resource for Cancer Care in India

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Abstract

Living with cancer is a challenge to the individuals and their families. This is a personal perspective of a person living with a diagnosis of cancer for over a decade and as psychiatrist supporting others in a similar situation and their caregivers. The challenges are medical, psychological, social, and spiritual. In the care of persons living with a diagnosis of cancer, there is a need to mobilize all of the resources toward relief and recovery. In the Indian context, to make sense of the uncertainties, spirituality in various forms is harnessed by the patients and their families. Epics and religious stories are routinely used to make sense of the pain, distress, and uncertainties of living with cancer. It is for the caregiving professionals to understand this rich resource in India, and develop ways of maximizing the value of spirituality in the care programs. Systematic study, documentation, and adaptation of the spiritual resources of different religions and communities in the cancer care could be an important Indian contribution to cancer care in the world. Such a development could be similar to the universal acceptance of the value of yoga in the recent years.

Keywords

- ▶ spirituality
- ▶ uncertainty
- ▶ religion
- ▶ gratitude
- ▶ culture

Introduction

The diagnosis of cancer is a life-changing experience for the affected individual and their families. Recently, a friend called to share the news of being diagnosed with cancer, “my life as I knew is not there now!” It brought back several personal memories of the time I came to know of my diagnosis of colon cancer in 2013. The first thought, I shared with my wife, following the colonoscopy and diagnosis of cancer, was this: “Life as we know is over, but we can build a new life.”¹

This personal perspective is based on the experiences of living with a diagnosis of cancer for over a decade and as psychiatrist supporting others in a similar situation and their caregivers.

It addresses the following aspects of cancer care, namely, (1) impact of cancer diagnosis, (2) the Indian scientific

literature on cancer and emotional health, (3) international research in this area, (4) some clinical anecdotes of use of spiritual resources in caregiving as a psychiatrist, and (5) reflections for future work to fully utilize the spiritual resources as an essential and integral part of cancer care.

Impact of Cancer Diagnosis

Current Chief Justice of India, Honorable D. Y. Chandrachud, on December 17, 2023, as part of Sri. E.S. Ventaramaiah Centenary Oration, at Bangalore, Karnataka, India, shared his experience with cancer as follows: “in my own personal life, I was the sole caregiver of a spouse who was battling cancer for almost a decade.” Ms. Harmala Gupta, founder of CANSUPPORT in Delhi, has written her experiences (“Cancer, the life changer”) in the book, “Life After Cancer” published by the Indian Cancer Society as follows: “There is no getting back to

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the way it was, for you and the members of the family.”² It is significant that she has utilized the pain of her personal journey, to establish the biggest free home care palliative care program in Delhi. Similar are other experiences: “Suddenly at [age] 35, I get this stage 4 cancer diagnosis, and it’s just like a bomb went off and everything around me is debris.”³ “But you are immobilized with uncertainty. It takes a long, long time to push despair away and bring hope back into your life. I will miss a whole bunch of things that I love. But that is what dying is all about. You get one life, you enjoy it as responsibly as you can, and then you die.”⁴

Cancer and Emotional Health Studies from India

Epidemiological studies have shown that persons living with a diagnosis of cancer have higher rates of emotional disorders in all countries.^{5–7} Indian research in the area of psycho-oncology has addressed the prevalence of emotional health problems,^{8–11} need for assessment of needs,^{12–14} importance of family,¹⁵ issue of suicide,¹⁶ need for emotional support,^{16,17} and the importance of communication in cancer care.¹⁸ A special area of studies have been in spirituality.^{19–24} Gielen et al²² report that more than half of the Indian cancer patients need spiritual care. An Indian measurement has been developed to measure spirituality and its utility has been evaluated.^{23,24} Value of yoga has been reported.²⁵ Another area of recent interest is the scope for posttraumatic growth (PTG) in cancer experiences.²⁶

Scientific Evidence of Relationship between Cancer and Spirituality

Koenig⁶ reports on 29 studies relating to cancer and spirituality to the relationship between religion/spirituality (R/S) and either the onset or outcome of cancer, including cancer mortality. Of those 16 (55%) found that those who are more R/S had a lower risk of cancer or a better prognosis, although 2 (7%) reported a significantly worse prognosis. Of the 20 methodologically most rigorous studies, 12 (60%) found an association between R/S and lower risk or better outcomes and none reported worse risks or outcomes. The results from some of these studies can be partially explained by better health behaviors (less cigarette smoking, alcohol, abuse, etc.), but not all effects are explained by better health behaviors, it could be explained by lower stress levels and higher social supports in those who are more R/S. Although cancer is not thought to be as sensitive as cardiovascular disorders to show psychosocial stressors, psychosocial influences in cancer incidence and outcome are present.

Emotional Health Support as Part of Cancer Care

There is growing evidence that support of different varieties of psychosocial interventions can alleviate the distress and in some cases improve the survival time. However, there are two challenges in receiving/providing emotional support to

persons living with a diagnosis of cancer. First, there is limited mental health professional resources in cancer care facilities in India. Second, there is reluctance of the people to utilize the available mental health specialist services because of stigma and discrimination associated with mental disorders. This is a paradoxical situation, as the diagnosis of cancer is the time you need the greatest support and it is at that time point that you feel most isolated. Faced with the multidimensional challenges, namely, medical, personal, family, financial, social, and spiritual challenges, there is need for support in all of these areas. It is for all of these reasons of the great need and difficulties of providing the needed emotional care, measures to address the need through “self-care” become urgent.

There is an urgent need to not only think of services and supports for emotional health care, but also strengthening the individuals living with a diagnosis of cancer and their caregivers, by harnessing the resources within. In India one of the preexisting sources of support is the spiritual resources. Spirituality, in all religions, addresses the problems faced by a person experiencing pain, suffering, fear of death, and to find meaning of life in adverse life situations. As noted earlier, the diagnosis of cancer is a life-changing situation and is eminently suited for utilizing the preexisting spiritual supports.

Professional Experiences of Providing Emotional Support in a Cancer Hospital

Following my own life journey with cancer,¹ I wanted to utilize my personal/family experiences and mental health professional expertise to assist people living with cancer. I worked as a volunteer psychiatrist at the Sri Shankara Cancer Hospital (SSCH), Bangalore, Karnataka, India for about 2 years. The experiences described below illustrate the importance of spirituality in cancer care in India.

When I started work at the SSCH, in 2015, there was already a professional social worker with decades of cancer care experience, and a senior and experienced psychiatrist providing psychosocial care. When I met them for the first time, both of them said to me, “why are you coming, patients do not come even when they are referred by the oncologists.” Further, about spirituality, one of them said: “the topic is of interest to me but I am a little curious/apprehensive to know if people would be open to talk about spirituality...or perceive it to be a private personal affair.”

These responses puzzled me, as it was contrary to my personal experiences. However, I went on to work there for nearly 2 years and found their conclusions were not correct. I understood the reason for the reluctance to seek professional help. The two professionals were using the referral and specialist approach rather than working to empower the people/families living with a cancer diagnosis. For the first few months, I worked with all patients receiving chemotherapy. The focus of my interaction was to understand the needs of the people and the ways they were addressing the challenges of diagnosis, treatment procedures, the side effects, cost of care, interpersonal relationships within the

families, uncertainties of life, and the resources they were utilizing to address these needs. I used to begin with the two questions: how has your life changed with a diagnosis of cancer? What has helped you in this journey with cancer? Following these I would ask about how I could help them. Unexpectedly, during these open-ended conversations to understand the cancer journey, I understood that persons living with cancer and the caregivers were most often utilizing their spiritual resources, to cope with the multiple challenges. Here are few examples of the use of spirituality as part of cancer journeys.

Pain

One person with severe pain shared what helped her: "I have read somewhere that when Shri Raman Maharshi was enduring the pain of Osteocarcinoma, someone asked him "Swamyji, is it not painful?" to which he answered, "It's not 'me' but it is 'the body' which is undergoing the pain. I am aware of the pain." These words appealed to her greatly during the chemotherapy days and she would repeatedly tell her mind that "it's my 'body' not 'me' who is undergoing the pain." The spiritual story provided a role model to address a life challenge.

End of Life

An elderly lady with terminal cancer was calm about her life situation and the uncertain future. On enquiry about what helped her, in the challenging life situation, she said: "doctor, I read every day Sunderakanda for about 90 minutes and it gives me peace." On further enquiry, she said: "In Sunderakanda Matha Sita is in Ashokavana and for all practical purposes there was no hope. However, she maintained hope and a solution came. I believe something similar will happen in my life." I saw how comparing personal life situation to a spiritual situation helped navigate the uncertainties of future.

Fear of Recurrence

One of the fears of persons living with cancer during the recovery face is the "fear of recurrence." A 35 years old lady with triple negative breast cancer shared as to how she addresses this challenge. She narrated the story from Mahabharata. She said, "Faith and Fear can't co-exist." The story was that of Krishna and Balarama walking through the forest and meeting a demon. The fear of Balaram makes the demon huge while the faith of Krishna reduces the demon to a puppet.

Accepting Death

During the last 1 year I was partner in the end of life journey of a senior psychiatrist and a dear friend,²⁷ we examined the issues of end of life situation, from both personal and professional viewpoints. It was a rich learning experience for me and taught me that it is possible to face death positively, as my friend did. One interaction stays in my mind forever. In one of the conversation, in response to issue of death, he said, "How hard one may strive, death is a reality. Even Hiranyakasyap and Ravana, who were blessed with immortality, had to die. Death is a blessing. It creates space

for new viable life." Looking at this interaction of many sessions/hours, I can say that my friend found more solace from spirituality than my professional skills.

Overcoming Guilt

About three decades back, I was treating a middle-aged lady with severe depression, associated with the death of her younger brother who had chronic renal condition. She felt guilty about not donating her kidney and save her brother. Literally nothing worked in my therapy. At one point, I shared the story of Buddha and Kissa Goutami and the reality of death. This story was so effective that we could start a new therapeutic journey to recovery. Here, spirituality was more powerful to open new avenues for recovery.

Living in the Present

In a situation of uncertainty, like with a diagnosis of cancer, the past becomes largely irrelevant, the future is uncertain, and the present becomes the only thing to hold on to. However, most of us have not learnt to live in the present, in the truest sense. Learning to live in the present, often referred to as mindful living, has to be learnt, along with putting the past and the future in the back burner.

Religious Texts as Support

A senior academician with multiple recurrences of breast cancer and in an end of life situation, shared how reading Bhagavatham helped her. She said: "Every evening my husband and myself read the book for about an hour. It gives me peace of mind." When I asked to give an example, she related the story of Parikshith. "Parikshith, facing death within one week, chose to leave his kingdom and move to live in Varanasi with the sages and devote time in spiritual practices." She whispered to me, "doctor do not feel bad if I tell you, in my current life situation, my spirituality is greater value than medical help!"

Posttraumatic Growth

One of the important developments in the disaster mental health field is the possibility of PTG. This is reported to occur in about one-third of survivors. There is growing literature of PTG in cancer survivors. Some examples will illustrate this aspect. "I feel a sense of purpose I didn't have when I was 22 and totally adrift. ..there's also at richness to be excavated; in fact, those transitional moments have ultimately been the most powerful and pivotal of my life."²⁸

"This ordeal taught me to cherish life and its simple joys that we all take for granted. More so, I started looking at my relationships in a new light. I started loving those relationships, my friendships that I had often taken for granted."²⁹

"Living with Cancer" Group

During the last few years, I am coordinating a WhatsApp group (myemotionalhealthin.com) of persons living with a diagnosis of cancer and their caregivers. In the group members have been sharing the value of the four "pillars" of cancer care, namely, medical care, psychological support, social support, and spirituality.

Table 1 Approaches to develop practice of spirituality and evaluate its impact (modified from³⁰)

• Examination of the concepts of pain, suffering, death in different religions
• Adaptation of the concepts/practices to modern societal realities in rural, urban, and other settings and different population groups
• The documentation and dissemination of case studies of persons with a diagnosis of cancer/caregivers utilizing these measures and finding meaning of life
• Preparing people living with cancer, to include spirituality in the overall life plans
• Case-control studies of people with varying degrees of spirituality and cancer outcomes
• Longitudinal studies of persons with a diagnosis of cancer/caregivers to understand the value of spirituality in promoting QOL, mental wellness, preventing distress, depression, and coping better with adverse life situation
• Adaptation and standardization of spiritual practices as applicable to cancer care
• Training of all care categories of providers in spirituality as part their work
• Wider dissemination of lessons learnt in the society—people and patients

Abbreviation: QOL, quality of life.

These professional interactions have taught me that spirituality is a resource people harness when they have medical challenges in general and cancer in particular.

Some Reflections

Cancer changes life. There is need for utilization of all the resources to find relief from “distress” and strengthen persons living with a diagnosis of cancer. The scientific evidence points to the value of spirituality, reviewed in this article. However, as noted by my colleague social worker, there is considerable ambivalence in the caregiving professions about the best way to integrate spirituality in their work.

Spirituality is like sunshine. It is available and useful to one and all. Most of us live utilizing the benefits of sunlight without acknowledging it. Some of us will use it for better skin color. Some of us recognizing the medical value, will expose our bodies daily to sunlight for vitamin D. Few others will think of using sunlight, using solar cells, for generating hot water and electricity for a wide range of uses. Thus, the same sunlight can give light, improve appearance, or improve health or be a major source of energy for many activities. I see spirituality in a similar manner. It depends on what each one of us want to put to use in personal and professional work.

Another analogy I would use, to explain the utilization of the spiritual resources in cancer care. In the seashore, you see four broad groups of persons. Sea is vast, rich in beauty, and powerful. There will be some who would sit on the beach sand and enjoy the scenery. The second group will enter the water and remain in shallow waters and find satisfaction. Third group will take a boat and go deep into the sea and find greater joy. The fourth group dives into the deep water and see the rich life and find greater fulfillment.

The approach to spirituality is also similar—minimal to maximal. Everyone chooses his/her path. As medical professionals, our aim is to maximize the resources for recovery. Spirituality is one of the important resources in cancer care.

Agenda for Action

In India, recognizing that there is both scientific basis and cultural practices to support the value of spirituality, there is

a need to develop an agenda for actions by the professionals (► **Table 1**).

Conclusion

Living with a diagnosis of cancer is a multifaceted challenge for the individual, family, and professional care providers. There is need to maximize the positive resources toward recovery, respite, and palliative care. Spirituality is part of humanity. In India, individuals understand and practice R/S at the level of beliefs, practices/rituals, and philosophy of life to guide them through life. There is growing interest in spirituality in cancer care all over the world. It would be to the advantage of individuals, families, and to a greater effectiveness of professional interventions, to make harnessing spiritual resources as part of the total care. Systematizing the spiritual interventions and making it practiceable would be to the advantage of the cancer care programs in the world. Here lies the challenges and opportunities for cancer care practitioners in India.

Conflict of Interest

None declared.

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