

Treatment Decisions Following Cancer Diagnosis: A Qualitative Analytical Summary of Perspectives in Delhi, India

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Abstract—Lack of health seeking for cancer preventive activities after diagnosis of cancer most families are in shock and make decisions detrimental to good health outcomes. Using mixed methods research a study was conducted to understand beliefs and motivation behind delayed treatment-seeking and communication barriers. Key findings included information-awareness gaps, cultural nuances, isolation and negative beliefs around palliation.

1. INTRODUCTION

An estimated 12.7 million new cancer cases reported worldwide in the year 2008 by GLOBOCAN 2008; 56% of new cancer cases and 63% of cancer deaths occur in the less developed regions of the world [1]. Estimates of deaths in the future in India are likely to rise 0.51 million in 2016. Many of the common cancers are those amenable to screening and primary prevention and early treatment. However there is a general lack of motivation for screening tests and significant delays and treatment abandonment. The research was attempted to understand the reasons behind these factors.

2. METHODOLOGY

2.1. Overview

Qualitative research is now used to explore and understand a diversity of social and public policy issues. It can help us understand complex behaviours, needs, system and cultures. Exploring how patients cope with a cancer diagnosis, its implications as well as treatment.

2.2. Mixed Methods Design

Qualitative techniques provide much-needed information when venturing into new areas, to check assumptions and refine research questions that are valuable across and within cultures. Mixed methods research that blends qualitative

research along with quantitative methodologies helps gain a meaningful and a rich understanding of cancer patients' needs, quality-of-life, coping, psychological distress and so on.

Selection of Study Sites: Three districts of Delhi (the capital city of India) were selected by a random process after listing all districts of Delhi. Two of these were intervention districts and one district was control. North district was selected as a control region and South and South-west districts as test regions.

The study was divided into three phases. The phase I included rapid assessment of facilities (Part I), community needs assessment utilizing qualitative (Part II) as well as quantitative methods (Part III). Study sample: Purposive sampling was done keeping in view the convenience and quality of data collection. In each district one non slum area and one slum cluster was picked up by the random process after listing.

2.2.1. Stakeholders for Qualitative Assessment.

In depth interviews were conducted with 8 stakeholder groups, namely:

- i. 6 + 1 = (7) Program planners and Managers; MCD Officer In-charge NCD
- ii. 6 + 6 = (12) Allopathic doctors (working in Government and private sectors)
- iii. 6 + 6 = (12) AYUSH doctors (working in Government and private sectors)
- iv. 6 + 6 = (12) Nurses / Compounders (working in Government and private sectors)
- v. 6 = (6) Medical Social Worker(s)
- vi. 24 = Facilitators + NGOs + Leaders
- vii. 48 = Community members (in the 15 to 65 age group)
- viii. 24 = Patients / caregivers

2.2.2. Rapid Assessment Procedure. A methodology based on RAP (Rapid Assessment Procedure) was used, as it permits quick and systematic data collection. This approach synthesizes multiple sources of information to rationalize and objectively balance evidence. Data were collected through in depth interviews and Focus Group Discussions (FGDs) with all categories of stakeholders identified for the study.

2.2.3. Identification and Stratification of Study Objects. Out of the selected three districts, at least one stakeholder from non-slum and slum area was interviewed. Community members were stratified according to age and in each category at least two stakeholders were interviewed. A total of 109 in-depth interviews, and 6 FGDs were conducted - three with community members (one in each district- two in slum and one in a non-slum area); three interviews were also conducted with nurses, compounders and social workers (one in each district).

2.2.4. Development of Study Instruments. A multidisciplinary team comprising of clinicians, social scientists, public health specialist and epidemiologist formulated the study instruments after multiple discussions. The instrument was open ended and pre-tested.

2.2.5. Quality Assurance Measures. All measures were taken to ensure the collection of valid and reliable data, including: training of the Research Associates (from social science background); supervision of first 30% interviews by the senior investigators trained in interview techniques; recording of all interviews; checking of all transcripts; monitoring visits during data collection; data triangulation; cross checking of coding and domain identification. Method and data triangulation incorporated.

2.2.6. Data Analysis. The data were cleaned on the basis of transcribed text. The responses were free listed and grouped into domains that emerged from free listed responses. Thereafter the free listed responses were coded into domains and entered into the computer and data analyzed in consonance with objectives of the study. Atlas TI as well as manual approach were used for analysis.

3. BACKGROUND TO DECISION-MAKING

The study examined the decision-making process and explored the reasons behind actions taken, related to cancer diagnosis and treatment, in a project mode. The aims of the project were to identify the reasons behind the choices and actions taken after the diagnosis of cancer was shared with the patient and their family.

3.1. What Indian Patients Do After They Have Been Diagnosed with Cancer

3.1.1. They often go into the ‘Denial mode’. The diagnosis of cancer is most often received with shock and denial. This phase lasts for a longer time than in many other societies. A review study on breast cancer clinical stage for 10 high-

income and 13 low-income countries on the time intervals from symptom discovery to cancer diagnosis and treatment indicated that most breast cancer patients in low-income countries suffer very long delays and are diagnosed in advanced stages.

3.1.2. They may seek alternative treatments. Post-diagnosis, sometimes patients embark on a “doctor-shopping” spree - hoping to find a physician who will give them a more acceptable diagnosis or seek therapy in alternative medicine (which is perceived as ‘less toxic’); and many alternative medicine practitioners “guarantee” cure. The reason for this is paucity of knowledge about cancer and treatment options.

3.1.3. The Fear Factor. Another major impediment to taking positive steps towards seeking appropriate treatment is the fact that cancer is perceived as a ‘punishment’ [2] and is a difficult diagnosis to accept. The patients and family are made vulnerable by this paralysing fear and this leads them to solicit advice from ill-informed sources or take rash measures— like refusing treatment or going for untested treatment as a first option. The negative story about “a relative who was diagnosed with cancer and died soon thereafter” (sic); is a commonly repeated anecdote.

3.1.4. Choice of treatment/treatment seeking decisions. The delay or reluctance in seeking conventional chemotherapy or surgery is seen in almost all cancers, unless the patient is critically ill or in pain. When given treatment options, almost all patients express alarm and concern over side effects of chemotherapy; they often move away from conventional therapies to seek options – like alternative therapies or complementary medicine.

Not seeking treatment or going to untrained providers or faith healers is may be attributed to the influence of freely given opinions of well-meaning (but frequently highly ill-informed) people. Indian culture rarely questions motives or the knowledge-base of advice-givers, as such people are considered altruistic. This is compounded by the general morbid fear of modern cancer treatment results and results in low information seeking behaviour. Justification for not following medical advice and doing what “people say” [3] is that they have to live in their society. The belief in magical cures persists among all socio-economic segments including educated and well-informed families.

4. TREATMENT RELATED ISSUES

4.1. ‘Can I be treated successfully?’

Hardly anyone in the study sample had insurance, only government employees enjoyed benefits of subsidized health coverage. Some government resources are available for treatment, but these are difficult to access and take many months of paperwork. Moreover, the out of pocket expenses for cancer treatment include cost of chemotherapy, and supportive medicines, transport, nutrition and stay near

treatment centre. The prevalent truths about cancer therapy are disheartening – even if treated, the ultimate results may not be good. Moreover, the concept that early diagnosis results in better cure is poorly understood and not well accepted. The Indian media does not carry many stories of successful cancer cures, except for rare celebrity narratives [4].

4.1.1. Self-belief regarding conventional therapies for cancer treatment. Chemotherapy is a word articulated with fear and foreboding. Interview data revealed that though the exact cause of fear was never elucidated – it conjured words like ‘painful’, ‘difficult’ or ‘too strong’. When asked about the quality of treatment from hospitals, some respondents said that they found it useful — they had all come with the hope that their cancers could be cured as a result of taking these therapies.

The majority did not know what kind of disease it was beyond the fact that it was ‘deadly’; cancer represented a ‘death sentence’ and was untreatable. A minority of respondents had a slightly different opinion, those who were not so scared, still felt it to be dangerous; treatment (if recommended) was painful and expensive.

4.1.2. Barriers to seeking treatment. A large section of the study sample accessed larger government hospitals for cancer treatment; although approximately 20% of the study sample were still going to local doctors and treating cancer with home remedies. Delays in seeking treatment from an oncologist can also be attributed to fear and avoidance behaviours.

As a woman Medical Social Worker from a residential colony in South-west Delhi said, “First they are taken to the personal physician and then if any big problem has been diagnosed, then they are taken to a specialist or a hospital, there are other support systems which are in existence. Relatives or kith and kin share their opinion on this subject”.

4.1.3. Beliefs and fears related to conventional therapies. The awareness about any kind of treatment modalities among respondents was low and information about effective treatment was even lower.

“There is one thing in everyone’s mind “FEAR”. People think it non-curable. But it is curable and treatment is very painful and expensive. One cannot say that he /she is disease- free.” (Statement by a resident of South Delhi from the patient/caregiver category).

4.1.4. Issues related to palliative care. The alternative option of palliation is not well understood by the community. Many families feel they have no choice but to take treatment- even if it is unlikely to help. Cure is felt to be essential and switching to the goal of care for cancer is seen as something which would invite criticism from their family and society.

Most families refuse to accept palliative care when cure is not possible, preferring instead to go to a ‘better’ doctor; resulting in pain and suffering for the patient. The patient is rarely allowed information on their grim prognosis by well-meaning

relatives. The doctors have to fall in line with this collusion; if not the family often will transfer care to another (more ‘co-operative’) doctor.

5. STUDY FINDINGS

5.1. Information-awareness Gaps

The study provided ground information about the cancer patients’ knowledge of their condition, and perceived effectiveness of modern treatments. Data revealed that there was confusion and paucity of knowledge regarding the treatment of cancer; in fact many were unaware that it was treatable, most related anecdotes of unsuccessful therapy, culminating in death of the patient. We found that seeking information through direct contact with trained providers and health workers was a relatively rare occurrence, especially for those who are poor and disadvantaged. Ironically, these are the cohorts that require health education and information on management of chronic illnesses. Information and communication gaps only served to strengthen their personal beliefs and made it difficult not only to accept the diagnosis and alter their beliefs of cancer, at this crucial time.

In the absence of widespread, culturally appropriate evidence-based information about cancer; the dependence on uninformed opinions leads to the cycle of ignorance, denial and fear. Such family and societal pressures add to the vulnerability of patients and community.

5.2. Gaps in Treatment-seeking

Affordability, acceptability, availability and accessibility of treatment do impact the perception of people regarding any disease, particularly so of cancer. Cancer treatment and “chemotherapy” in particular was perceived as painful and toxic. Several respondents stated that they never wanted to undergo chemotherapy. The study also found that modern cancer therapy is perceived to be expensive or unaffordable. Although Government hospitals provide care free or at nominal cost, these facilities are overburdened and often have long waiting lists for admissions and procedures.

5.3. Cultural Nuances with Regard to Cancer Treatment

Cancer treatment is largely perceived as unsuccessful. Patients usually are diagnosed or opt for conventional treatment when faced with complications of the disease. Culturally Indian patients are all too ready to blame doctors and medicines for all their complaints and do not understand disease processes. That cancer can be transmitted by staying in close contact with a patient is a fear in the minds of family and community. If these fears remain un-addressed, they will lead to isolation of the patient and the family.

5.4. Media Coverage of Cancer Therapies

The media coverage on novel therapies (such as the promise of stem cell and gene therapy) fuel patient beliefs that all

diseases are curable with a simple shot or pill. If the disease is not cured it is believed to be the doctors' fault, either due to lack of skill or errors in medication.

Authors conclude that perceptions of pain and side effects associated with cancer diagnosis and treatment will only be removed by gradual awareness; with more survivors articulating their stories, better supportive care – nutrition, infection management and other patient-care modalities.

6. STUDY RECOMMENDATIONS

The findings of this study can help to identify the basis of patient perceptions on the effectiveness of conventional therapies. Results indicate the need for health education, better patient-provider communication and balanced messages in the mass media. Interventions such as mass media campaigns as well as treatment provision should be supported by counselling services and interpersonal communication in order to improve patient-provider communication and deal with doubts and fears regarding cancer.

Cancer causes isolation, which may or may not be related to stigma. In some cases, physical and emotional neglect occurs. There is a critical need for community support for cancer patients. Survivors, patient support groups (online for those who are computer literate and physical groups for others), NGOs working in counselling, need to get involved in supporting patients, caregivers and families. Increased awareness and community participation is needed to dispel myths and misconceptions about cancer. In terms of affordable cancer treatment, little can be done to change perception of high cost unless the government sets up many more centres to lessen the load.

7. ENDNOTES

- [1] The incidence data for GLOBOCAN were derived from the population-based cancer registries (PBCRs).
- [2] In India a Minister of State for Health made headlines when he said that “Cancer is divine justice...for sins committed” (Indian Express, November 23, 2017)
- [3] A very common statement is “*log kehtehain*” which means ‘what people say’ in Hindi.
- [4] A lead article in the Economist (September 16, 2017), titled ‘Closing in on Cancer’ states “cancer may be relentless, so too is science”. While chemotherapy and radiotherapy improve and cancer is fought in laboratories across the world, the role of policy-makers, taxes and budgeting are as important as “zapping proton beams”.

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