

Experience of Cancer Patients on their Visit to Cancer Outpatient Department: A Qualitative Study from a Regional Hospital in Mauritius

ABHISHEK KASHYAP¹, INDRAJIT BANERJEE², AKASH THAKUR³, VAISHALI NOTWANI⁴, MITANSHI RAGHUVANSHI⁵

ABSTRACT

Introduction: Cancer care studies suggest that being diagnosed with cancer, the patients and their families face various hardships such as financial crisis, increased mental stress, difficulty in managing their relationships and routine lifestyle activities. Moreover, psycho-oncological studies also describe the intense distress and disbelief experienced by patients on their initial diagnosis. The role of cancer care needs to be understood as well as implemented in cancer treatment, thus further enriching the insights of the treating oncologist about their patient's state of mind. This ultimately allows for the betterment of treatment compliance.

Aim: To study the experience of cancer patients on their visit to the cancer clinic and the emotional turmoil after diagnosis and throughout treatment.

Materials and Methods: A descriptive phenomenological qualitative study was designed and conducted from August to September 2019 at the Oncology Department of Victoria Hospital, Mauritius. Participation in the study was voluntary, and written consent was taken from each of the study participants.

The data was collected on an in-depth one on one interview basis and was recorded, and the purposive sampling technique was used for collecting the data.

Results: Out of 12 patients, the male/female ratio equated to 5:7, these patients were from the ages of 23 to 70 years and the mean age of the participants was 48.2 years. A total of 25 different codes were generated in the study, seven main themes were established there from (Motivational factors, Psychological factors, Society, Message for others, Awareness about the disease, Economic factors and Perception towards the healthcare environment).

Conclusion: The main implication that emerged from this study is the notion of the lateral views of informal caregivers, family members and medical professionals, towards the patient's feelings and emotional reactions in respect to their experience of cancer. It has been noted that the positivity of the caregiver corresponds directly to positive outcomes in the cancer treatment whilst simultaneously decreasing the psychological ramifications of the process.

Keywords: Continuity of patient care, Empathy, Health status, Hermeneutics, Physician-patient relation, Quality of life

INTRODUCTION

Cancer is defined as an abnormal growth of cells that is uncontrollable, which has the ability to invade any part of the body. According to the WHO report (2018), cancer is the second most common cause of death worldwide, as it accounts for 9.6 million deaths globally. This figure translates to one in every six deaths being attributed to cancer [1]. According to the Health and Statistics report of the Island of Mauritius and the island of Rodrigues 2018, deaths due to cancer accounts for 12.8/10,000 mid-year population, and it was the third leading cause of death in the country. Among all of the deaths due to cancer, cancer of the trachea, bronchus, lung, and breast carcinoma were most common. This was followed by colonic carcinoma, prostatic carcinoma, stomach carcinoma, and leukaemia. Among all the admissions of general and private hospitals across Mauritius, cancer was the sixth leading cause of hospitalisation [2].

The disease burden of cancer on the global scale is intensifying rapidly, and it exerts an enormous amount of strain not only physically but also emotionally as well as financially on the patient and the family of the patient [1]. On being diagnosed with cancer, great difficulty in coping with the news is experienced by both the patient and family members. Cancer Care studies suggest that on being diagnosed with Cancer, patients and their families face various hardships such as financial crisis, increased mental stress, difficulty in managing their relationships and routine lifestyle activities. Moreover, psycho-oncological studies also describe the intense distress and disbelief experienced by patients on their initial diagnosis [3]. According to psycho-oncologists, the

emotional reactions of a cancer patient upon diagnosis of cancer were divided into three phases viz., the initial reaction being shock and disbelief for most of the patients followed by distress and adjustment [4].

Nowadays, with the advancement of treatment facilities and the improved outcome of the disease, patients tend to cope better with the commencement of their treatment. Furthermore, the anxiety among the patient reduces when they learn more about the disease, manage their personal issues, and adapt with the routine changes which may be due to their frequent visits to the cancer clinic [5]. The most frequent reaction response is whether the patients were going to survive or not [6]. The role of cancer care needs to be understood as well as implemented in cancer treatment, thus further enriching the insights of the treating oncologist about their patient's state of mind. This ultimately allows for the betterment of treatment compliance. The aim of the study was to find out the experience of cancer patients on their visit to the cancer clinic and the emotional turmoil after diagnosis and throughout treatment.

There is a dearth of Qualitative research on the experiences of the cancer patients, their feelings and emotions on being diagnosed with such a disease as well as the concomitant challenges faced by them [7,8]. To the best of our knowledge, no study has ever explored the experiences of cancer patients who were diagnosed with cancer in Mauritius, hence the present research was conducted with the aim to explore the experiences, feelings and emotions of cancer patients, hence to assist the oncologists and aiding them to help the patient cope with the situation.

MATERIALS AND METHODS

The study was conducted from August 5 to September 15, 2019 at the Oncology Department of Victoria Hospital, Mauritius. Victoria hospital is the only hospital in the country which delivers chemotherapy and radiotherapy to a patient for cancer care. All the patients seeking chemotherapy and radiotherapy are referred to this hospital. It is one of the five regional hospitals situated in the country [9-11].

This study was approved by the Institutional Review Board and the Institutional Ethical Committee, Sir Seewoosagur Medical College, Mauritius. Permission was also obtained from the Regional Health Director of Victoria Hospital and Head of Oncology Department at Victoria Hospital, Mauritius, under Caldicott principles prior to conduct the study. (Letter no./Ref no.19/08-21). The Research was conducted as per the latest version of the Declaration of Helsinki-Ethical Principles for Medical Research involving Human Subjects guidelines.

Study Design, Participants and the Collection of Data

A descriptive phenomenological qualitative study was designed and conducted. This research was conducted in order to obtain an insight into experiences that cancer patients go through when they visit cancer clinics after their confirmed diagnosis. Responses included their interactions with the hospital staff, their motivation factors, human experiences, and how their life had changed after diagnosis. Participation in the study was voluntary, and written consent was obtained from each of the study participants.

Inclusion criteria: To ensure diverse representation based on diagnosis, age and financial status, a purposive sampling technique was used in study. Moreover, patients who had already completed atleast one chemotherapy prior to interview were selected for this study, as they were experienced with the cancer care.

Exclusion criteria: The patients who were unwilling to participate in the interview and those who were severely ill were excluded from the study.

Sample size calculation: The study was a qualitative study conducted on a total of twelve patients who were diagnosed with cancer. The data was collected according to the guidelines of Glaser BG et al., Interviews were conducted and continued until saturation, where there were no new codes that could be generated from an interview [12].

The data was collected by in-depth interviews of volunteer cancer patients in the male and female wards. Interviews were guided and digitally recorded by authors, which were later transcribed verbatim for analysis. While conducting the interview, more than one interviewer was present who duly noted patients' expressions and body language. The participants were given full right to decline to answer any questions, to step out of the interview, and to withdraw their participation from the study. They were assured of the maintenance of their anonymity. All the participants were also informed about why this study was crucial and that their statements will be used to extract information to be used in the study.

Questionnaire Design

After an extensive review of literature, a semi-structured, open-ended questionnaire was formulated to conduct the interview. A pilot study was conducted on two cancer patients to check the understanding and feedback were taken from the patients. No leading questions were asked. The data was analysed and the questionnaire was modified after agreement among all the researchers. The revised and modified questionnaire was used to conduct in-depth one on one interview in the main study. The average duration of interviews was 30 minutes. Questions included demographic details, diagnosis, living with cancer, information about cancer, support from family and relatives, financial support, message for others, experiences and expectations from health care.

STATISTICAL ANALYSIS

The recorded data was transcribed by the team members. The transcribed data was analysed via the use of Braun and Clarke's Six Phases of Thematic Analysis [13]. The transcripts were analysed and similarities in the patterns of responses were identified and clubbed. (Phase 1). These responses were used to generate the initial code (Phase 2). Thereafter, themes such as- Perception towards the healthcare environment, Motivational Factors, Psychological Factors, Society, Awareness about the disease, Message for others, and Economic Factors were generated based on the initial codes (Phase 3). The relation between the transcribed data and the generated themes was verified (Phase 4). Afterwards, each theme was defined and poignant themes were highlighted (Phase 5 and 6).

The method followed for initial coding was as follows:

(Procedures for working with text during qualitative data analysis by Strauss-2010) [14]. By means of open coding, these responses were then categorised into different Codes such as willpower, understanding, Family and relatives, genetics, and so forth. To create different branches of codes, axial coding was used, and finally, all the codes were interconnected by using selective coding.

RESULTS

Out of 12 patients, the male/female ratio equated to 5:7, these patients were from the ages of 23 to 70 years and the mean age of the participants was 48.2 years [Table/Fig-1].

Serial no.	Age (years)	Gender	Duration of disease	Diagnosis
1	25	Female	>1 year	Brain Tumour
2	32	Male	>1.5 year	Testicular cancer
3	24	Female	>1 year	Lung cancer
4	67	Male	>2 years	Osteosarcoma
5	62	Female	>1.5 year	Breast cancer
6	70	Female	>2 years	Cervical cancer
7	54	Female	>1 year	Cervical cancer
8	57	Male	>11 months	Prostate cancer
9	70	Female	>1 year	Cervical cancer
10	57	Male	>1.5 years	Colorectal cancer
11	23	Male	<12 months	Kidney tumour
12	38	Female	>7 months	Breast cancer

[Table/Fig-1]: Demographic data of patients and diagnosis.

A total of 25 different codes were generated in the study and from the codes, seven main themes were established, which is depicted in [Table/Fig-2,3], respectively.

Theme 1 – Motivational factors:

The codes of will power of the patient, spirituality, support of family and friends, together generated the theme of Motivational factors. These are the drivers of human behaviour related to the intrinsic nature of the person, irrespective of the surrounding environment.

Theme 2 – Psychological factors:

The codes which were generated during the study were worrying, scared, curiosity, irritated, denial/acceptance, crying, strong and relieved. These codes generated the theme -Psychological factors. These are the factors which affect the mental states influenced by the situation and the reaction of individuals to it, be the reaction positive or negative in nature.

Theme 3 – Society:

The codes that were generated were real/fake friends and understanding. The codes show the difference in the views of the people surrounding the patient. Their behaviour towards the patient during this difficult time as compared to before the diagnosis. It portrayed the difference between real friends who stood by one as well as fake friends who flaked in the times of difficulty. These codes

Codes	Description	Narratives
Will power	The belief of fighting every hurdle can help in overcoming the disease.	"Be good do good." (P1)
God/Spirituality	The one who created us will do everything for our good.	"God is present in you itself." (P5)
Close one's	Everyone needs moral support from their close one's during their difficult time to fight the disease.	"Having family around is very helpful." (P2)
Worrying	It is natural to be worried when you are suffering from something which only the sufferer know.	"I was definitely worried at the time of diagnosis." (P8)
Scared	Everyone is scared to lose their life.	"I was scared but then I decided that I have to get better for my family." (P2)
Curiosity	Everyone should be curious to know about the disease which the one is going through to maintain themselves accordingly.	"When I was diagnosed with cancer, I was curious to know about my disease." (P11)
Irritated	At some point, after taking many medicines, different treatments without getting positive results make the person irritated.	"It was irritating for me in starting because we have to take many medicines." (P12)
Denial/acceptance	As early as possible if accepted the fact is good for our health mentally and physically.	"At the end we are the sum of our own decisions." (P4)
Crying	The severity of pain makes them cry.	"It is very painful for me, and I cry out of pain." (P6)
Strong	With family support, self motivation the person can feel strong which will be beneficial for the health.	"I would like to see the world again, roam around & eat a lot." (P3)
Relieved	The positive results of the treatment make everyone relieved and safe.	"I do feel relieved and happy to start again my life with my wife." (P9)
Real/fake friends	The most difficult times always teach us the difference between real and fake friends.	"There are some who come here for formality and some who actually want to be here." (P8)
Understanding	Others understanding of your disease make the person happy and highly motivated.	"There are some people understand everything." (P7)
No regrets	The key to life is to accept every up and down coming in our way.	"When we die we should not have any regrets." (P9)
High moral	Moral support helps a lot in defeating diseases.	"If you keep moral high you can easily fight through the journey." (P5)
Faith in yourself	The positive thinking, positive vibes	"I knew I could get through it." (P1)
Genetics	Some problems run in every family which affect many individuals of the family in despite of their daily routines, healthy life which they have to face.	"My elder sister died of cancer." (P2)
No family history	When there is no such thing present in their family tree.	"This is for the first time, and I was completely unprepared for the diagnosis." (P8)
Disease progression	General knowledge of the disease they are suffering is necessary for every individual which help them to overcome any complication.	"I researched about the disease and found out that it doesn't that deadly." (P4)
No prior information	Some are updated about every common disease happening around.	"I only heard about brain tumour and I knew it was fatal but in general basis I didn't knew anything about cancer." (P12)
Government aid	Government plays very crucial role in many places for providing free medical services.	"Government provide us pension which help us a lot." (P11)
Family and relatives	There is always family and relatives who help in every economic problem.	"My son and daughter used to arrange money for my treatment." (P3)
Organised	Hospital management is always well organised to manage patient's requirement.	"Hospital staffs are well organised." (P10)
Clean environment	Hygiene is very important everywhere which helps us in eradicating many diseases.	"They clean our bed regularly." (P2)
Facilities	Proper food, proper treatment, behaviour with patients all these things help in making a good hospital with good ambience.	"They are very helpful even they motivate a lot." (P9)

[Table/Fig-2]: Codebook framework.

Themes	Codes
Motivational factors	Will power
	God/spirituality
	Close one's
	Worrying
Psychological factors	Scared
	Curiosity
	Irritated
	Denial/acceptance
	Crying
	Strong
	Relieved
	Real/fake friends
	Understanding
Society	No regrets
	High moral
Message for others	Faith in yourself
Awareness about the disease	Genetics
	No family history
	Disease progression
	No prior information

Economic factors	Government aid
	Family and relatives
Perception towards the healthcare environment	Organised
	Clean environment
	Facilities

[Table/Fig-3]: Various themes and codes emerged during thematic analysis.

generated the theme of Society. Society is a group of individuals who are involved in social interactions. These individuals would come to the aid of one another in times of need. It can also be said to be a group of people of whom certain expectation are placed upon.

Theme 4 – Message for others:

The codes that were generated were that of high moral and no regrets. Regret is an emotion that no man should experience; one should make the most out of life. People should do what they believe in and pursue their dreams, support their close ones and achieve true happiness. People should not regret the fact that haven't given enough time to their loved ones. A high moral is a key to defeat disease, and faith in oneself to overcome difficulties generated the theme of Message for others. There's always one message which a person needs to share with everyone after going through a difficult time so as to provide support to those who are going through similar situations.

Theme 5 – Awareness about the disease:

The codes generated were faith in yourself, Genetics, no family history and disease progression. The theme awareness of the disease means what the patient's attitude towards the disease is, his knowledge towards the disease, and how the patients has gone through a tremendous change during these difficult times as a direct result of the disease. Knowledge about the disease such as its causes, prevention, or any information about the disease, together generated the theme of Awareness. Awareness is very important as it helps in coping with the situation and it brings about awareness for future cases.

Theme 6 – Economic factors:

The codes that were generated were Government aid, Family and relatives. The code role of government implies in making proper medical services available to everyone in the country despite their social status (Right to Health). Many countries provide free medical services which aids disease-stricken individuals, Support from family and relatives for the hospital bills, drugs and treatment generated the theme Economic factors. The economical standing of patients play a vital role, as a person has to undergo many treatments for many years with many medications.

Theme 7 – Perception towards the healthcare environment:

The codes that were generated were organised, a clean environment and facilities. The code well organised refers to being orderly and efficient. Things are done on time at the right place whilst maintaining a proper environment/ambience in the hospital setting. Time, place, clean environment and good facilities with a good ambience generated the theme Perception towards the healthcare environment. Hospital staff is equally important for patients as doctors are the surrounding environment, hygiene and motivating spirit from staff helps in the improvement of the mental states of the patient.

DISCUSSION

This study highlights seven fastidious themes that emerged during the thematic analysis. Each theme reflects the critical experiences of cancer patients and provides careful attention to detail. It is paramount to analyse each theme individually as these forms the support for continuity of cancer treatment and recovery. The results show that apart from the urgent diagnosis and treatment, motivational factors which are vital for compliance, like the patient's family support, belief in God and self-worth are vital. Some of the interviews also determined that patients should be provided individual attention as this breaks many psychological barriers like agitation from chemotherapy, denial [15].

Currently, chemotherapy combined with Cancer starvation therapy remains an indispensable treatment for cancer patients both with early and advanced stages of cancer Yu S et al., [16]. Shortfall with regards to the cognizance of the disease and treatment was seen in several domains, for example, the side effects of treatment, stages of cancer and aetiology of the disease. A study conducted by Ma C suggested that the presence of Clinical Pharmacists would aid the patients to better comprehend the side effects, drug reviews thereby aiding the patient in sustaining the therapy and thus decreasing the burden on oncologist [17].

Some patients were surprised with their diagnosis, despite maintaining a healthy style of living, such as a good diet, not drinking or smoking and keeping their stress level low [18]. The convalescent also quoted that their disease was the by-product of bad deeds and that the almighty is punishing them. An understanding of the illness in terms of medical basis requires a higher level of knowledge which can be attained with medical professionals or subject books [19]. Patients established their own theory regarding the disease, and they looked for self-treatment options in complementary, alternative medicine and pseudo-scientific

methods which correlated with their educational qualifications and economic backgrounds [20]. Some subjects were not prepared for the sickness as they had no family history of this disease. Results also show a correlation between respondents' level of education with different belief systems for example confident or fearful about cancer and its impacts. This clearly indicates a great possibility of collecting negative beliefs, therefore considering two distinct feelings or beliefs of patients, cancer was either a 'death sentence' or 'it is curable disease' [21,22].

Most of the patients firmly believed in their ongoing treatment and were optimistic about the cancer care provided to them via the hospital staff, in fact, many appreciated the cleanliness and facilities provided to them. A study suggests that all healthcare professionals should provide essential psychological support, but in complex cases, experts should be consulted. There are important differences in interactions between health professionals and the patient-care provider interactions [23], it is recommended that health care professionals should monitor these interactions and maintain professionalism along with clinical empathy [24,25].

The study showed the impact of socio-economic factors, for instance, the importance of family and government aid provided to them. The Health and Wellness Ministry of Mauritius provides free treatment to Cancer patients in different public hospitals [26]. Private hospitals also offered paid surgical and non-surgical treatment. Some participants' families showed support and even worked extra time to accommodate their treatment cost during their initial diagnosis in private setups, thereafter shifted to public hospitals. While few had no family support and completely relied on government support. Some patients were breadwinner of the family unit and thus this created financial hardships. It has been seen that financial difficulties are associated with cancer or severe chronic illness due to impermanent or permanent loss of income [27].

The worth of social and human analysis lies in the manner in which awareness of a fact background can bring the advancement of well-being; thus, patients' experience were depicted by a lack of concern by their social care system, coupled with the angst about their diagnosis. According to Luoma JB and Platt MG support networks and groups aid patients in achieving emotional stability during the treatment and diagnosis. These groups also helped them in accomplishing some sort of habitualness, reduced social stigma and understood the importance of 'holding on' [28].

This is the first qualitative study, conducted on cancer patient in Mauritius. This study had some unique insights especially the thematic code that emerged during qualitative interviews and how these factors affect the patients and their treatment. Another important highlight of this study is the missing blocks in the health care system. The role of nursing staff in influencing treatment of cancer patients. Various other factors such as family support and financial barriers played a significant role in continuation of treatment. All of these factors together formed the Cancer care treatment or therapy apart from the treating oncologist.

Limitation(s)

This study was conducted in one Centre in Mauritius, which included the most prevalent forms of cancer. However, the limitation of this study is that the patient's religious beliefs were not put into consideration, as this would also affect patient's psychology and belief in continuity of the treatment. Secondly, as these interviews were conducted on patients with an initial diagnosis and those with ongoing treatment, therefore results might not be relevant to patients who have been cured with Cancer. Thirdly, interviews were conducted with patients, the impact on the family and relatives was not considered during the study.

CONCLUSION(S)

The main implication that emerged from this study is the notion of the lateral views of informal caregivers, family members and medical professionals, towards the patient's feelings and emotional reactions in respect to their experience of cancer. It has been noted that the positivity of the caregiver corresponds directly to positive outcomes in the cancer treatment whilst simultaneously decreasing the psychological ramifications of the process.

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PARTICULARS OF CONTRIBUTORS:

1. Medical Student (2nd Professional), Sir Seewoosagur Ramgoolam Medical College, Belle Rive, Mauritius.
2. Associate Professor, Department of Pharmacology, Sir Seewoosagur Ramgoolam Medical College, Belle Rive, Mauritius.
3. Medical Student (2nd Professional), Sir Seewoosagur Ramgoolam Medical College, Belle Rive, Mauritius.
4. Medical Student (2nd Professional), Sir Seewoosagur Ramgoolam Medical College, Belle Rive, Mauritius.
5. Medical Student (2nd Professional), Sir Seewoosagur Ramgoolam Medical College, Belle Rive, Mauritius.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:

Dr. Indrajit Banerjee,
Associate Professor, Department of Pharmacology, Sir Seewoosagur Ramgoolam Medical College, Belle Rive, Mauritius.
E-mail: indrajit18@gmail.com

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