# Are you satisfied with care? : A mixed method study to understand patients' satisfaction with cancer communication

*A Thesis submitted*

*in Partial Fulfillment of the Requirements*

*for the Degree of*

**MASTER OF PHILOSOPHY**

***by***

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भारतीय प्रौद्योगिकी संस्थान हैदराबाद
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***to the***

**DEPARTMENT OF LIBERAL ARTS**

**INDIAN INSTITUTE OF TECHNOLOGY HYDERABAD**

**April, 2015**

**Dedicated**
**To,**

My Parents,
Vijaya and Kiran
Chawak

My Fiancé and
sister,
Madhur and Kashmira

And my thesis
advisor,
Dr Mahati Chittem

## DECLARATION

I declare that this thesis represents my own ideas and words and where others ideas or words have been included; I have adequately cited and referenced the original sources. I also declare that I have adhered to all principles of academic honesty and integrity and have not misrepresented, plagiarized, fabricated or falsified any idea/data/fact/source in my submission. I understand that any violation of the above will result in disciplinary action by the Institute and can also evoke penal action from the sources that have not been properly cited or from whom proper permission has not been taken when needed.

Signature of candidate

---------Shweta Chawak---------------

Name of candidate

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## CERTIFICATE

It is certified that the work contained in the thesis entitled "Are you satisfied with care? : A mixed method study to understand patients' satisfaction with cancer communication" submitted by Ms Shweta Kiran Chawak, LA13M1002 in partial fulfillment of the degree of Master of Philosophy to the Department of Liberal Arts, Indian Institute of Technology Hyderabad, is a record of bonafide research work carried out by him/her under my supervision and guidance. The results embodied in the thesis have not been submitted to any other University or Institute for the award of any degree or diploma.

**Dr Mahati Chittem**

Department of Liberal Arts
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## CERTIFICATE

This is to certify that Ms Shweta Kiran Chawak, LA13M1002 has satisfactorily completed all the course requirements for the M.Phil. Program in Psychology. Ms Shweta Kiran Chawak was admitted to the candidacy of the M.Phil. degree in August, 2013.

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## Approval Sheet

This thesis entitled "*Are you satisfied with your care?: A mixed methods study to understand patients' satisfaction with cancer communication*" by Shweta Chawak is approved for the degree of Master of Philosophy in (discipline) from IIT Hyderabad.

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# ABSTRACT

**Background**: Cancer communication has been found to play an important role in cancer care. The aim of this study was to understand the effect of patient-physician relationship in treatment and illness perception. In-depth interviews also explores the patient's perception about the patient-physician relationship and process of cancer communication.

**Method:** The study uses a mixed methods design where qualitative and quantitative study was conducted to understand the patient-physician communication. The qualitative study consisted of patients (n= 26) undergoing treatment at hospital in Mumbai, India. Here, the patients were interviewed about their perception related to patient-physician communication. The interviews were further transcribed and analysed using Interpretive Phenomenological Approach (IPA). Patients (n= 196) were undergoing treatment at hospital in Mumbai, India participated in the quantitative study. The participants answered questionnaires on quality of life, locus of control, patient satisfaction with communication and psychological distress. Further, statistical analysis was carried out using Statistical Package for Social Sciences (SPSS) version 16.0.

**Results:** The emerging themes in the qualitative analysis were: (1) illness beliefs (initial reaction, change in reaction, illness perception, coping behavior) (2) treatment perception (initial reaction, change in reaction, accessibility/availability (3) supportive care needs (role of caregivers, information needs, psychological and social needs) (4) patient-physician relationship (patient's role, physician's role, patient-physician communication) (5) locus of control (doctor, chance, God). The quantitative analysis indicated the variables associated with patient-satisfaction with cancer communication. It shows how well-being and patients relationship with doctor influences the cancer communication.

**Conclusion:** This study highlights the importance of patient-physician communication in treatment process. The interviews reveals the role of physician, while statistical analysis shows the variables involved in patient's satisfaction with patient-physician communication. The study also implies the need to enhance the patient-physician relationship.

# SYNOPSIS

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Pre-submission Seminar

## Are you satisfied with your care? : A mixed method study to understand patient satisfaction with cancer communication

Cancer diagnosis causes a psychological and emotional upheaval in patients. Patient-physician communication is found to be associated with a range of patient outcomes such as psychological distress, coping, quality of life, adherence to treatment and so on. This project attempts to understand the association between patient satisfaction with cancer communication, quality of life, psychological distress and locus of control. The project employed a mixed method approach, i.e., it used qualitative methods (semi-structured interviews) and quantitative methods (questionnaires). Twenty six cancer patients participated in qualitative study and this data was analysed using Interpretive Phenomenological Analysis (Smith, Jarman & Osborn, 1999). For the quantitive study, 196 cancer patients were recruited and this data was analysed using correlation and multiple regression analyses. All the data was collected at Dr Balabhai Nanavati Hospital, Mumbai, India during May to December 2014. This project received ethics approval from the Institute Ethics committee (IEC), Indian Institute of Technology Hyderabad, Hyderabad, and the ethics committee of Dr. Balabhai Nanavati Hospital, Mumbai.

The dissertation consists of four chapters these are as follow:

**Chapter 1**

This chapter reviews past studies focusing on cancer communication, particularly that between patient and physician. It talks about the various communication styles such as patient focused and physician focused communication. This chapter also discusses the relationship between cancer communication and patient outcomes such as compliance, decision making, and emotional well-being. Interestingly, satisfaction with communication on the part of the physician was noted to be closely associated with quality of life, locus of control, psychological well-being. It also briefly reviews interventions conducted to enhance cancer communication worldwide. Lastly, it reviews the research related to psycho-oncology in India. Although a need to study cancer communication is seen, very few studies in India focus on cancer communication. Hence, this project aims to understand patients' perceptions about their individual communication with their physician, especially with regard to their expectations and levels of satisfaction. Further, the project seeks to examine the relationship between satisfaction with communication and quality of life, psychological distress and locus of control.

**Chapter 2**

This chapter describes the qualitative study. The aim of this study is to explore patients' (n = 26) expectations and perceptions of physician communication with them. In-depth interviews were carried out which focused on patient's perceptions related to the illness, treatment and particularly their patient-physician communication. Average length of the interviews were 30 minutes. The data were analysed using Interpretative Phenomenological Analyses (Smith, Jarman & Osborn, 1999). The results revealed patients' perceptions about the physicians' role and its association with illness beliefs and treatment perceptions. It also revealed the supportive care needs of patients from family and friends. Strikingly, patients assigned specific roles to physicians, family and friends. The study emphasized the need to understand patients' perceptions of physician communication and its association to various patient outcomes like locus of control, quality of life and psychological distress. These findings were used to design the quantitative study.

## Chapter 3

This chapter describes the quantitative study. The aim of this study is to examine patients' (n = 196) satisfaction with cancer communication and its relationship with quality of life and psychological well-being. The following questionnaires were completed by the patients: Medical Interview Satisfaction Scale (MISS-21), Functional Assessment of Cancer Therapy-General (FACT-G), Brief Illness Perception Questionnaire (BIPQ), Hospital Anxiety Depression Scale, Multidimensional health Locus of Control-Form C (MHLC), and God Locus of Health Control Scale (GLHC). Statistical analyses were conducted to examine the relationship between patients' satisfaction with their medical consultation and quality of life, locus of control, illness perception and psychological distress. Variables that were significantly correlated with the MISS-21 scales and their sub-scales of Distress Relief, Communication comfort, Rapport and Compliance Intent were further analysed using multiple regression. If patients perceived their relationship with their physician to be positive one, then:

1. Distress relief was reported to be lowered. Lower distress relief was related to improved functional well-being, decreased levels of anxiety, and an external locus of control (subscales of *chance* and *doctor*).
2. Comfort with communication was reported to be higher. Increased comfort with communication was related to improved emotional well-being, improved functional well-being, decreased levels of anxiety and depression, an external locus of control (subscale of *doctor*), and increased compliance intent.
3. Rapport was reported to be higher. Increased rapport was related to an internal locus of control, an external locus of control (subscales of *chance* and *other people*), decreased comfort with communication, and increased compliance intent.
4. Compliance intent was reported to be higher. Increased compliance intent was related to an external locus of control (subscales of *chance*, *doctor* and *other people*).

Hence, these findings show that satisfaction with the physicians' communication reduced patients' levels of distress, was related to patients' external locus of control, and improved their functional and emotional well-being.

**Chapter 4**

This chapter summarizes the findings of the two studies. The present project found that using a mixed method approach provided rich and interesting data which aided in a better understanding of the patient-physician relationship. Using a qualitative study followed by a quantitative study, this project highlighted the importance of cancer communication in patient satisfaction and psychological outcomes such as quality of life and levels of distress. The qualitative study findings revealed that the physician, family and friends played a key role in shaping patients' illness beliefs and treatment perceptions throughout the cancer trajectory. The study observed that these shifted from negative to positive interpretations of cancer. These findings suggest that it is possible for physicians to reduce the fear of cancer and, consequently, improve compliance through an effective and communicative relationship. These findings were reflected in the quantitative study where it was observed that intent to comply with cancer treatment and care recommendations was positively associated with perceived levels of comfort in communication, rapport shared with the physician and an external locus of control.

Although the study reported a tug-of-war between placing the locus of control over cancer internally and externally (i.e., with the physician, God) among patients, it was unable to explore how this was related to the patient-physician relationship. The quantitative study provided an understanding of the way in which the patient-physician relationship is associated with one's locus of control. The findings revealed that an external locus of control was related to all the key features of satisfaction with a medical consultation, i.e., relief from cancer-related distress, comfort in communication with the physician, rapport shared with the physician, and intent to comply.

Interestingly, the mixed method approach highlighted that while in the qualitative study patients reported not needing the physician for psycho-emotional comfort and described the physician's role more as a medical care provider, the quantitative study revealed that patients did indeed respond more positively to physicians who were able to provide them both medical and psychological support. These findings emphasize the need for mixed method approach in research in order to gain a broader as well as deeper in patient care needs.

The project has some limitations. As the data is specific to a hospital setting in Mumbai, generalizing the data is not possible. Although, the researcher assured confidentiality and anonymity, patients might have given desirable answers assuming that a negative response could hinder their cancer care. Further, for the want of time, it was not possible to interview physicians and caregivers who may have given valuable insights into cancer communication.

Owing to the compelling relationship between communication and patients' mental well-being, this project emphasizes the need to address the quality of patient-physician communication bearing in mind the cultural aspects of this disease in India. Finally, this project's findings can be used to develop intervention programs to enhance communication between patients and physician and perhaps family members too.

# CHAPTER 1

# Introduction

## Summary

Psycho-oncology research highlights the importance of patient-physician communication. This chapter gives a background of patient-physician communication by emphasizing on various factors (like physicians' personal characteristics, culture, locus of control and so on) that contribute in the communication process. Review of past research in cancer communication, also talks about the influence of patient-physician relationship on patient outcomes: psychological well-being, quality of life, adherence to treatment. The review also talks about various intervention programs that were implemented to enhance the patient-physician communication. Lastly, it reviews research done in India and highlights how Indian studies failed to look at patient-physician relationship and its influence on cancer communication, while stressing the need to study the topic.

# Introduction

## Background

A cancer diagnosis often results in emotional and psychological upheaval for the patient. The patient has to make sense of complicated treatment- and disease-related information and make decisions accordingly. As a result, patients often use active coping styles such as information seeking and problem-solving than passive coping styles (Diefenbach et al., 2009). It is seen that detailed and carefully explained diagnostic information increases the patient's involvement in the treatment procedure (Murtagh, Furber, & Thomas, 2013). Hence, effective physician communication and successful patient question-asking are considered the fulcrum of optimal cancer care.

## Cancer communication

Communication between patient and physician is considered to be complex and important (Diefenbach et al., 2009). It is emotionally overwhelming as it involves interactions between non-equal individuals dealing with topics of immense consequence (Ong et al., 1995). Some topics of major focus in research on cancer communication are patients' preferences (Wright et al., 2004), influence of cancer communication on patient outcomes such as adherence to treatment, psychological and emotional well-being, recall (Ong et al., 2000, Stewart, 1995), and improvement of the medical consultation (Fujimori et al., 2007).

Research suggests that the physician's style of communication (e.g., authoritative vs. autocratic) is related to the patient's perceptions and satisfaction with quality of care (Dowsett et al., 2000). Indeed, it is observed that physicians' affective behavior, shared decision making, active participation in future plans and so on, such qualities of physician communication are considered optimal for patient psychological outcomes, such as their long term adjustment with the treatment and their illness-related decisions (Fujimori et al., 2007). Poor communication has also been found to be related with psychological distress (anxiety, depression), non-compliance, and uncertainty and coping difficulty (Ong et al., 2000). A meta-analysis of studies on patient adherence and health status by Haskard et al. (2009) observed that, patient adherence had a high correlation with healthcare communication and patient adherence, results showed that there was 19% likelihood of non-adherence among patients, whose physicians communicate poorly than whose physicians communicate well.

Poor communication has also found to aggravate the side-effects of quality of life. A study indicated that, patient with physical problem and insufficient information about the problem had worsen quality of life (Kerr et al., 2003). An intervention study showed that use of Health related quality of life in communication contributed in patients feeling of satisfaction with emotional support received from the physician (Detmar et al., 2002)

## Communication styles

There are two kinds of approaches to communication in cancer: patient-centered and physician-centered communication. The former consists of a combination of patients being active participants in the decision-making process and physician’s empathic behavior. The latter is a task-oriented approach that involves controlling behavior on the part of the physician and little empathy (Dowsett et al., 2000). Since cancer communication is related to patients’ psychological well-being, studies have tried looking at patients’ preferences in physicians’ way of communication (Stewart, 1995;

Ong et al., 2000). Patients prefer communication in which patients are involved in the communication process, physicians shared information (negative and positive), physicians are actively involved in future plans, and also when patients are involved in treatment-related decision-making (Fujimori et al., 2007). Including patient preferences in the communication process is called patient-centered communication. Patient-centered communication, that is where the patient asks questions and actively participates in the treatment process, is found to be the most frequently preferred approach to medical decision-making (Ong et al., 1995). A patient-centered patient-physician relationship includes certain characteristics: physicians who have a biopsychosocial perspective on health, physicians who have a comprehensive (i.e., psychological, familial, spiritual and emotional) understanding about the patient, where power and responsibility are shared, where there is an affective element in the therapeutic process, and to understanding the influence of physician's personal characteristics on the patient (Mead & Bower; 2000). Indeed, Ong et al (1999) observed that physicians' personal characteristics (e.g., empathic tone, affective behavior) was found to be associated with patients' satisfaction with cancer consultation. The authors also noted that while the physician's interest in the patient had a greater impact on patient satisfaction, the physician's unpleasant behavior (e.g., showing anger, irritation) was found to have a negative impact on patient.

Hashimoto & Fukuhara, (2004), found that patients' preference in communication was related to patients' locus of control. It was seen that, patients with external locus of control related to the illness were more likely to seek emotional support from their physician. Hence along with physicians' personal characteristics patients' communication preference was also related to patients' locus of control.

## Culture and cancer communication

Along with physicians' personal characteristics, studies have also seen how cultural background influences patient-physician communication. In a review of intercultural studies looking at influence of race, ethnicity on quality of patient-physician relationship, by Ferguson & Candib, (2002) indicated that, physicians' race and ethnicity influenced the patients' perception about the physician and in turn influenced the relationship shared with the physician. Illustrating this, Schouten & Meeuwesen (2006) reported that patients' culture influenced whether the physician will show verbal affective behaviour, that is if the patient and physician were of the same culture the latter was more verbally empathic towards the patient. Further, it was also found that, physicians' cultural background also influenced the patient's perception about the physician (Ferguson et al., 2002). Patients preferred communicating with and chose physicians belonging to same cultural group. Interestingly, physicians were more confident about their ability to communicate and respond to culture-specific requests if they belonged to the same or similar culture (Chittem & Butow, 2015)

## Communication skills training (CST) for physicians

Studies have indicated two kinds of intervention: patient directed and physician directed training program. The former training program looked at training patients by educating and providing them with necessary information prior to consultation. For instance, Patient Communication skill training program, a patient directed intervention program was conducted in Ohio University, here the patients were trained by providing them with training booklet and also face to face session prior to consultation. Results showed that trained patients engaged in significantly more information seeking than the untrained patients. Hence, the study showed that such intervention increases patient's participation in health care and also increases the quality of health care (Cegala, Post & McClure, 2001).

On the other hand, physician directed intervention program looks at training physicians to enrich their skills in dealing with patients. One such intervention was conducted by Baile et al., (2000), where a protocol (SPIKES) was developed to disclose unfavorable information to patients. The aim of this study was to enable physicians to gather information from the patient, effectively communicate information to patients, and to develop treatment plans in collaboration with patient. Oncologists, oncology trainee and medical students who underwent this training program reported an increase in confidence in discussing unfavourable medical information with the patient (Baile et al., 2000).

Another Communication skills training program for physicians was incorporated in Japan by keeping in mind the patients' communication preference. This training program is based on SHARE model: SHARE refers to setting up supportive environment, considering how to deliver bad news, discussing addition information and providing reassurance with empathetic response. SHARE model has been found to be effective for patient as well as physician. It was also found that this additional communication skills has enhanced physicians dealing with difficult situation and has decreased patients' psychological distress without increasing the physicians' consultation time. (Fujimori, 2014).

## Research in India

Indian studies have focused on patient satisfaction with Health care and improvement in quality of health care (Sodani et al., 2010), illness disclosure (Chittem, Norman, Harris, 2012), supportive therapy and quality of life (Vadiraja, 2009). There have been intervention studies on prevention of cancer (Mehta et al., 1982). Research in India saw that patients' satisfaction with health care was related to behavior of physicians and health-care staff. Patients' satisfaction with health care was also found to influence by the accessibility of the hospital and the time spent prior to consultation. Hence, the author highlights how there is a need for hospital infrastructural development for enhancing comfort related to health care. (Kumari et al., 2009). Gopinath et al. (2000), patients reported that they received inadequate medical information. Patients who perceived receiving insufficient information were likely to report less satisfied with consultation process, this in turn was found to affect the patients' compliance with the treatment. Hence, physician-patient communication was found to be associated with patient compliance. Another study conducted by Gautam & Nijhawan (1987), indicates that, presence of family had an influence on the patient-physician communication. It was seen that physician's disclosure of information to the patient was affected by the caregivers' perception about the illness. However, the above cited studies centers around cancer communication but, they fail to highlight the importance of patient-physician relationship and its influence on cancer communication.

## Aims of the current project

Using mixed methods (i.e., qualitative and quantitative studies), the current project aims to:

1. To explore patients' experiences of cancer and how it is related to their relationship with their treating physician.

2. To examine the relationship between patients' satisfaction with their medical consultation and their psychological well-being.
3. The study not only looks at the factors influencing cancer communication but also tries to gain a phenomenological understanding about the patient-physician communication by looking at it descriptively.

# CHAPTER 2

## Patient experiences of their relationship with their treating physician:

## A qualitative study

### Summary

Qualitative psycho-oncology research reveals that the patient-physician relationship is vital in how patients perceive and respond to their illness throughout the cancer trajectory. The aim of this study is to understand patients' experiences of the patient-physician relationship, especially in terms of their perceptions of, response towards and expectations from this relationship. In-depth interviews were conducted with 26 cancer patients undergoing treatment at Dr Balabhai Nanavati Hospital, Mumbai India. Using interpretative phenomenological analysis, five major themes were revealed: (i) illness beliefs, (ii) treatment perception, (iii) Supportive care needs, (iv) patient-physician relationship, (v) locus of control. The findings suggest that patients' relationship with their physician, family and friends can shape their perceptions of cancer, its treatment and even their supportive care needs. Interestingly, patients were able to identify specific roles for their family and friends, however they assigned the physician with the only a medical care provider.

# Patient experiences of their relationship with their treating physician:

# A qualitative study

## Introduction

Psycho-oncology research in patient-physician relationship has focused on a variety of topics ranging from patients' expectations of their physicians, role of the physician in patient psychological outcomes, examining the most effective or optimal relationship between patient and physician and so on (Ong, et al., 1995; Stewart, 1995). However, a large body of psycho-oncological research is devoted to exploring the communication needs of patients from their physicians (Wright et al., 2004). Although there are more quantitative studies on the patient-physician relationship and communication both worldwide and in Asia (see Karim et al., 2015; Fujimori et al., 2005; Liu et al., 2014; Lam & Fielding, 2003), there are few qualitative studies.

Qualitative studies in patient-physician communication have primarily focused on exploring topics pertaining to how patients perceive and respond to their illness throughout their cancer trajectory. For example, Kvale (2007) reported that one of the ways in which patients reduced their distress and coped with their cancer was through communicating with their physician. Further, qualitative research also focussed on patients' expectations from and perceptions of physician communication. In a study exploring how breast cancer patients wanted their physician to communicate with them, Wright, Holcombe & Salmon, (2004) reported that patients were not concerned about the physicians' communication skills, but laid more emphasis on characteristics such as their level of expertise, their capability to form individual relationships, and were respectful of the patient. Indeed, Ferguson and Candib (2002) observed that minority patients prefer communicating and chose physician belonging to minority group. Thus, research has highlighted that physician characteristics and cultural background may play a key role in optimal communication rather than their training.

The above studies highlight that the patient-physician relationship is complex and nuanced, and can vary from culture to culture. Although psycho-oncology research in India has explored topics related to cancer communication, it has mainly been about nondisclosure of cancer (see Chittem et al., 2014; Chandra et al., 1998). Therefore, the current study aims to understand patient experiences of cancer and how this relates to their relationship with their treating physician.

## Methods

### Participants

Using convenient sampling, patients diagnosed with cancer and undergoing treatment at Dr. Balabhai Nanavati Hospital, Mumbai, were recruited for the study. Semi-structured interviews were conducted with 26 patients (mean age = 54 years), with a mean age of 54 years (see table). Ethics approval for the study was received from the Institute Ethics committee (IEC), Indian Institute of Technology Hyderabad, Hyderabad, and the ethics committee of Dr. Balabhai Nanavati Hospital, Mumbai. Participants' demographic and medical details are described in Table 2.1.

**Table 2.1: Participants' demographic and medical details**

| | | |
|---|---|---|
| **Age (range)** | | 28 – 78 |
| **Gender** | Male | 16 |
| | Female | 10 |
| **Average monthly income** | 7,909/- | |
| **Time since diagnosis** | Below 3 months | 13 |
| | Above 3 months | 10 |
| | Reoccurrence | 3 |
| **Type of cancer** | Mouth | 8 |
| | Breast | 5 |
| | Uterus | 3 |
| | Stomach | 3 |
| | Prostate | 2 |
| | Other | 5 |
| **Type of treatment(s) received** | Surgery | 1 |
| | Chemotherapy | - |
| | Radiation therapy | 1 |
| | Surgery & chemotherapy | 1 |
| | Surgery & radiation therapy | 19 |
| | Chemotherapy & radiation therapy | 4 |
| | Surgery, chemotherapy & radiation therapy | 5 |

## Procedure

Patients were approached by the principal investigator while they were receiving treatment at the hospital. They were informed about the study and were given ample of time to consider their participation and all their questions were answered to their satisfaction. Following this, signed consent to participate in the study was taken before commencing the interview.

The interview consisted of open-ended questions pertaining to a range of topics on patient experiences of cancer and their relationship with their treating physician. Table 2.2 shows the interview topics. Although in some instances caregivers' inputs were taken into consideration during the interview, they did not form a part of data analyses. Probing questions and cues were used whenever needed. The interviews were conducted in English (n = 1), Hindi (n = 18) and Marathi (n =7). The average length of the interviews was 30 minutes.  The interviews were transcribed in English and verified for authenticity in translation before analyses.

**Table 2.2: Interview topics**

| Topic | Sample Questions |
|---|---|
| **About the treatment process** | *What is the treatment that you are undergoing? Who provided with the information about the treatment?* |
| **First consultation** | *What happened during your first consultation? In what ways do you think your first consultation helped you?* |
| **Patient-physician relationship** | *What ways do you think the oncologist could have revealed the illness to you? Apart from talking about your treatment, what does your oncologist talk to you about?* |
| **Experiences of cancer** | *Who helps you through the cancer process? How do you cope with the illness?* |

## Analysis

The study used interpretative phenomenological analyses (IPA) to analyze the interviews (Smith, Jarman & Osborn, 1999). IPA is a qualitative analysis method that assesses individual's perception and views about a specific concept or event (Smith, Jarman & Osborn, 1999). The analysis was carried out by first reading and re- reading the transcripts, paying close attention to common trends and patterns. Emergent themes were grouped based on these common trends and patterns which formulated the subordinate themes. Further, similar emerging subordinate themes were clustered together to form superordinate themes. The second investigator individually analysed the transcripts and a comparison was made to ensure accuracy in analyses. Each transcript was treated individually and iteratively until no new themes emerged. This thematic saturation was achieved by the 15th interview, following which eleven interviews aided in consolidating the themes. Quotes from the interviews were used to represent each subordinate theme. Pseudonyms were used to maintain confidentiality.

## Results

This study examined patient experiences of cancer and how this is related to their relationship with their treating physician. Using interpretative phenomenological analysis (IPA), six major themes emerged: (i) illness beliefs, (ii) treatment perceptions, (iii) supportive care needs, (iv) patient-physician relationship, (v) locus of control.

### Illness beliefs

When they were first told they had cancer, 19 patients reported negative perceptions of the illness. Patients recollected their initial reaction as being scared, denial, feeling helpless, and self–blame.

> *"I was in doubt how it could be cancer as I didn't have any addiction" (MA, 8)*
>
> *"Whether it is curable or not. When a person suffers from cancer there is always doubts whether it would be cured or not. That's what I am scared of. Still now I am scared" (NA, 14)*
>
> *"There were few feelings…like we never think that we should ever have cancer…so whoever comes to know about it…it's like they have been sentenced to death…don't know what to do….." (SK, 14)*

However, overtime, a change in reaction towards the illness was reported with more patients (n = 10) experiencing lesser fear, more acceptance and having an overall positive attitude towards cancer.

> *"Changes I mean I see positivity… whatever you have you just accept it and take it ahead… what can we do? We can't avoid it" (RE, 22)*

Patients reported various factors that caused this change in their illness beliefs, mainly citing experiences with the treatment overtime, believing that stress can impact their health, and talking with fellow patients as reasons for this change.

> *"I feel till now that…God has kept me away from that thing…fear has never come near me…later too we will keep courage (Himat) and deal with it" (NA, 10)*
>
> *"It was already known that many people have it and many get it…so knew most of it. I saw some with cancer….I didn't feel that much" (Ra, 18)*
>
> *"No…I don't take any mental stress…There is no use of taking this kind of stress…what is going to happen will happen…It just increases problem… I have pressure problem… So if I take any mental stress my pressure increases." (GA, 34)*

Patient diagnosed with a terminal disease also showed positive reaction towards the illness overtime. These patients reported that acceptance, fighting spirit and having a positive attitude was their coping strategy with the illness and its treatment.

> *"Doctor at first only had already told us that it cannot be treated, but I had a wish to chase it and I still have hope that I will deal with it… I undertook a treatment and then it relapsed. I then understood that it is developing more…but still I was still trying…it disturbed a little… but let's see what is supposed to happen will happen" (SK, 18)*

## Treatment perceptions

Patients recounted their reactions to their first experiences with the treatment. Eight patients reported that they were scared while taking treatment for the first time.

> *"I was scared at first… everyone tends to be first…I was scared about what is radiation…I have never had taken an injection since childhood and all of a sudden this illness…but what to do this is what God's given… there were questions on what will it be" (SG, 70)*

A change in perception was seen in the later phase of treatment, with patients (n = 5) reporting being less scared and as the only choice for a cure:

> "*What to do….we have to take the treatment even if we feel scared…but only at the beginning it was scary later it was fine…" (NS, 38)*

The availability of and accessibility to the treatment was reported to be related to the way the patients perceived their treatment and delay in seeking treatment,

> *For me by the time we got results for my biopsy and got date for operation one month had passed. Within a month it increased and this big needed to be done (JO, 14)*

However, some patients reported that the delay in seeking treatment was because they were afraid of the treatment, stigma and were not aware about the treatment procedures.

> *"If you get it operated it won't spread further…but then I was scared and didn't get it done. But now it increased so have to take light so that doctor sent us here for radiation then I was scared and didn't get it done." (JB, 34)*

> *They said surgery is needed but I cannot get that thing done…that bag will smell and people will not come near me and cannot get it done…they explained me but would prefer dying then getting the surgery done…*" (MJ, 15)

> *"All treatment…all kinds of them…whatever investigation they needed to do they did it…the whole body is destroyed (Nash) because of that" (SI, 8)*

Only seven patients reported knowing about the side-effects of treatment. Interestingly, while one patient reported that being aware about the treatment side-effects helped patients be better prepared, two patients reported knowing about treatment side-effects may have a negative effect on how the treatment was perceived by patients.

> *"About is there any side effects like it happens in chemo…so before only if we know something, we can prepare ourselves for it… we have something that we can fight with…like if we have fever then we can deal with it till we can bear it…" (UK, 48)*

> *"No, they shouldn't be told. It should not be told to a patient who has cancer and if there is so much pain than before taking the injection itself they will be scared. Then they won't have courage in them and that's the reason nor the patients say anything nor do they ask. Even when you meet some other patients, like even when I meet other patients and then they ask what happens after chemo…we just say nothing everything was fine." (HK, 46)*

Beliefs about cancer treatment were also found to be related to the cost of the treatment such that an improvement in the patient's health was seen to be in relation to how expensive the treatment was.

> *"There is improvement now…after surgery its better…we are also spending so much of money here." (RE, 32)*

The hospital set-up, communication by the physicians and also by the hospital staff was reported to be related to way the patient perceived their treatment:.

> *"I had a doctor in Tata memorial, definitely there are social charitable work going on but there is so much rush that there is no queue system. You have no idea when your number will come. But then there the medicines didn't suit me and there were problems in line after this when I came to Raheja hospital in Mahim, under Dr Adwani to meet him. So I have complete co-operation from them" (NA, 42)*

> *"We feel that if we go to a bigger hospital then only these things happen…but experience is what matters… to help encourage the patient doctor needs to have experience. So it's not just that these things happen in famous and big hospital, but it is just that experience matters. This hospital was not even known one…or somewhere centrally located." (Va, 30)*

**Supportive care needs**

As the diagnosis of cancer is given, patients have questions about the illness and its treatment. It is noteworthy that most patients had information needs, especially those related to the causes of their cancer. Interestingly, they preferred to get the information from friends and family rather than from the physicians.

> *"My son had asked the doctor…but they don't give proper reply. They (Friends and Family) say that some get it because its genetic, if mom dad gets it then it may happen to the child, but then it may not always be genetic…then some say*

> *it's because of tension. Doctors don't say that but then some people did say that it's because of tension…" (Ha, 20)*

Further, patients also get information about the treatment and its side-effects mainly from their family members, friends and other patients with similar problems.

> *"My uncle's daughter she has breast cancer it's been many years… so she told me all the story…after that I had no worries…Other thing means I had gone to remove PET scan that time there were people who had come. Somebody had lost their hair…so I had asked them…they told me…There is hair loss, this and that…"* (SP, 20)

As the patient goes through the various treatment processes, their care needs were reported to have changed to those of psychological, financial and logistical support needs. These needs were primarily met by the patient's family and friends.

> *"My family is with me… they are always behind me supporting me, they always tell me whatever is there we will face it… and accept it…" (RE, 26)*

> "*I had my relatives who helped me...they gave me all the help…they helped us little by little they gave us lot of support in that way I could give fees to the doctor…"(Ks, 35)*

The patients also get information about:

Information was not only pertaining to cancer and its treatment, but was also about which physicians and hospitals to approach. This information was sought from their relatives and family members. Relatives with past experiences of similar illnesses were considered to be of particularly important source of information because they were able to talk to patients about which oncologist to refer to and were also able to explain the different treatments available and share their experiences of these treatments.

> *"My friend she had got it done from here…she told me to come here and get it done under Dr N. She said just go to him and not anyone else…she also did it here…" (Va, 45)*

Further, information was also shared with other patients while they waited in the hospital either for their medical consultation or treatment. This information was mainly about their treatment, side-effects and the hospital in general.

> *"No…nothing like that, just while sitting we tend to talk…like the way we are talking, when we are siting we tend to talk and share…not specifically to ask questions or to know something…but just like that when we have time we either talk or watch TV. So, if we have to come every day then we tend to talk…" (HA, 60)*

One of the patients observed that although the initial support may be given by and sought from the doctor, but later this shifted to family members, thereby highlighting the vital role family plays in patients supportive care needs.

> *"First time obviously I got it from the doctor and later on from family members…they said whatever has come is fine…we accepted it." (SA, 47)*

Indeed, the relationship that patients shared with the physician in terms of their informative or other needs was kept to a minimum with physicians being approached only when patients wanted to find out their diagnosis (i.e., initial consultations). Moreover, if there was a physician in the patient's family then these informative needs were met by them.

> *"I didn't have much issues…because since start we have a doctor in the family so whatever problems happen then immediately he looks at it. So as soon as this happened he started researching on it. That way there was no problem we came to know in the first stage itself." (Ma, 28)*

**Patient-Physician relationship**

All the patients reported that physicians are authoritarian and unapproachable figures. However, in spite of being unable to spend extended amount of time with their physicians, most patients reported that the patient-physician communication was important in the treatment process.

> *"He has come with such a big degree how can we ask them questions…But they have their own work. They won't sit and answer our questions." (HA, 26)*
>
> *"You have believe whatever the doctors say we have to believe, so far we don't have clue about medical condition of the people so we just have to believe in whatever they say…" (AJ, 12)*
>
> *"Doctors if talk nicely to you, whenever your number comes they should properly attend to you. Then I think that is better, so the time that they give, when you sit in queue for more than 2 hours, then at least they should help provide attention to the patients." (NA, 38)*

Patients understood that physicians were overloaded with work and they consequently cannot provide personalized attention to each patient. They considered physicians as experts in their fields and hence followed their oncologists' advice/recommendations without any questions.

> *"Like if you are having any problems at mid night also then they should provide with the needed because doctor is also human in the end, he also has to rest. He may have a feeling to rest or may want to give some time to his children. Because of the population of India….all good doctors have so much crowd that they might not be able to give that much time to their family as well. In this profession they have to upgrade themselves and for that they may have to learn more…this means that, the amount of time they are giving and looking at the population I feel that they doing a better job." (NA, 40)*

Indeed, patients believed that being perceived as an authoritative figure helped physicians to effectively ensure patients' adherence in terms of treatment and care recommendations as well as build a rapport with patients.

> *"They used to come regularly…and after surgery I got scared and I would keep on sleeping, so that time they said that you didn't get come you should get up and walk a little…then he just scolded me…that if I don't find you up and walking I will not come to visit you…" (VA, 29)*

Sharing a similar geographical and, therefore, cultural background with their physician was also perceived to be associated with a building rapport and closeness..

> *"My doctor is from Ludhiana actually we are also from Ludhiana so she treated us very much like a family member" (SA, 41)*

**Locus of control**

Patients reported having an external locus of control over their cancer in terms of causal attributions as well as their treatment outcomes. Fourteen patients reported that the cause of the illness is due to external factors that are not within their control such as karma, their past life and was due to God.

> *"It is normal….You should not think much. It's what God has given, till the time we have life we have to live." (HK, 56)*

> *"I believe that I am thankful to whatever God has given me…God has given me lot. Today also if I feel that I have got pain….if you are a Hindu and you believe in Hindu Vedas and scriptures. Then Hindus believe that…We take many births and in every birth we have to pay something…so when I have pain in this birth I don't know is for the things I did this birth or other births." (NA, 48)*

Some patients reported that one needs to have a strong internal belief and will power ensure positive treatment outcomes.

> *Mentally I get this will power. I believe that internal strength helps you a lot to keep this hope going. If you yourself break then you will fall more ill… (NA, 12)*

> *That is what I meant. Keep Courage. If you get scared then illness will kill you half. I don't take tension (SP, 10)*

Although patients spoke about illness being external in control, they showed a need to keep faith and continue the treatment. They reasoned that just as cancer was given by god, so was the treatment for cancer. Therefore, patients believed that one needed to keep the spirit of hope and continue their treatment.

> *"So many things I believe if we think spiritually can also work many times….when all of a sudden disease is diagnosed to you. I think that, People die of Heart attacks or all of a sudden due to road accidents, 15 thousand people went to pay homage to God and suddenly due to natural calamity they lost their*

> *lives. So people who just went to worship God and died. So I feel that when there is something like this where treatments are available. So you should keep hope and go ahead…and believe that it's not something sudden. Whatever God has given we should feel is good and for good...If you would have died of accident or Tsunami what could you do…nothing...so this should be kept in mind…and it will surely help in keeping the hope high…" (NA, 48)*

## Discussion

The current study explored patient experiences of cancer and how this relates to their relationship with their treating physician. Using interpretative phenomenological analyses (Smith et al., 1999), five major themes emerged from the study: (i) illness beliefs, (ii) treatment perception, (iii) supportive care needs, (iv) patient-physician relationship and (v) locus of control. The study found that although patients reported having negative illness beliefs and treatment perceptions they reported a change in these overtime. The study also revealed that patients had mainly information needs about cancer, its treatment and the side-effects of treatment which were primarily sought from and given by family and friends. Patients reported having external locus of control wherein they made causal attributions and believed treatment outcomes to be due to karma, their past lives and God given. Finally, it was found that patients perceived physicians to be authoritative figures who were unapproachable but were successful in ensuring treatment and care adherence among patients.

The current study found that illness beliefs changed from negative to positive ones overtime in the cancer trajectory. Patients' treatment experiences, belief that stress can have negative impact on their health and talking with fellow patients and were reported to contribute these changes in illness beliefs. These findings are in accordance with previous research that found shifts in illness perceptions due to societal influences and treatment experiences (Lam & Fielding, 2003).

Similarly, changes in treatment perceptions were observed with patients reporting this shift to have occurred mainly because of their experiences of the treatment trajectory. Treatment perceptions were also related to knowledge about the treatment side-effects, accessibility to and availability of treatment, and the communication by healthcare staff including the physicians. These findings are also in accordance with previous research (Rutten et al., 2004). Interestingly, patients reported positive treatment perceptions when the cost of treatment was high, suggesting a perceived link between expense incurred in treatment with its efficacy. This finding is novel and may be indicative of the economic environment in India where there is no nationalized healthcare system (Patel et al., 2011) and most people may believe that the most expensive treatment is the best treatment. Further, the current study highlighted that while patients reported having psychological, emotional, financial and logistical care needs, their primary need was that of information. Strikingly, patients reported seeking and gaining information about which physician to consult, which hospital to go to, about cancer in general, and about the treatment and its side-effects mainly from family, friends and sometimes fellow patients and not from the physician. This finding is contradictory to previous research that found patients to obtain information on treatment from physicians and other healthcare professionals (Rutten et al., 2004; Bilodeau and Degner, 1996). There may be some reasons for patients gaining cancer-related information from family and friends and not from physicians. First, owing to India being a collectivist society (Chadda and Deb, 2013), family plays a major role in the patient's life in almost all domains, including information needs. Second, patient see themselves as passive participant in treatment decision and hence follow the physician. Third, physicians are continued to be viewed as authoritative figures in India, thereby making them unapproachable.

Indeed, the current study highlights this perceived authoritative role of the physician wherein patients reported physician's recommendations were to be followed without any questions. A novel and striking finding was that patients expected physician to encourage them with an authoritative tone too, thereby emphasizing the physician-centric expectations of care and information provision. This strong belief in physician's role as almost God-like can be due to several reasons. First, in India physicians are revered as they provide life to their patients (Neki, 1973), thereby equating them to God. Second, due to the poor levels of health literacy (Kichbusch, 2001), patients often are awed by and, consequently, believe that physicians knows best due to their knowledge, training and experience. Third, physicians' attitudes towards patients are also authoritative in nature with almost all medical colleges in India not having any course on psychological care, communication skills training and so. Therefore, physicians are not trained in shared decision-making and detection of distress in patients.

The current study found that patients reported an external locus of control especially in terms of the cause and outcomes of their treatment. It was observed that there was a tug-of-war between wanting to stay in control of the illness through keeping faith, will power and having a strong sense of inner belief, but also believing that cancer was a disease that was ultimately in the control of karma or God. This finding reflects the general cultural/spiritual beliefs in India (Dalal, 2000), as well as about cancer (Kishore, 2007).

The current study has several limitations. First, as this study was qualitative it is difficult to generalize these findings. Second, the study did not take into consideration physicians' experiences of cancer care and the patient-physician relationship, thereby not allowing for a richer and better understanding of both sides of the relationship. Third, since patients were at different stages of their illness their experiences and expectations of the physician may vary.

In spite of these limitations, the study highlights some key implications. First, the study found that illness beliefs and treatment perceptions changed with time but also through talking with other patients. Hence, it may be beneficial to have support groups for patients newly diagnosed with cancer to aid in a better understanding of the illness and its treatment. Second, patients believed there was a link between cost of treatment and its efficacy. It may be helpful to address this by improving patient knowledge about treatment modalities, types of drugs available and the expected impact of these drugs allowing them to make informed decisions rather than those based on expense incurred. Third, a key finding was that patients relied on family and friends as information providers and not physicians. This was mainly due to a perceived authoritativeness in physicians by patients. This may be addressed by training physicians in communication skills such that they are more approachable as well as train patients in how to ask questions. Research indicates that techniques such as using patient prompts have helped patients ask physicians key questions and were, consequently, more satisfied with their consultation (Dimoska et al., 2008).

# CHAPTER 3

## Patients' satisfaction with medical consultation and psychological well-being: Quantitative study

### Summary

Quantitative research in psycho-oncology shows that patient-physician relationship is associated with patient health outcomes. The studies have found a relation between satisfaction with cancer communication and psychological well-being, compliance and adherence to the treatment. The aim of the study was to examine the relation between patient satisfaction with medical consultation and psychological well-being. Questionnaires were administered on 196 patients diagnosed with cancer undergoing treatment at Dr Balabhai Nanavati Hospital, Mumbai India. The variables were analysed using correlation and multiple regression. The findings indicate, the importance of relationship with doctor on various aspects of patient- satisfaction with consultation like rapport, distress relief. It also highlighted the relation between external locus of control, compliance and rapport.

# Patients' satisfaction with medical consultation and psychological well-being: Quantitative study

## Introduction

Quantitative research in psycho-oncology have focused on looking at patient-physician communication and its relation to health outcomes, patient satisfaction with cancer care and treatment process (Buller & Buller, 1987, Ong et al., 1999; Street et al., 2009). Various cross sectional studies have been conducted within Asia focusing on understanding association between patient-physician communication, health outcomes and patient- satisfaction (Ishikawa et al., 2002).

Studies have also looked at role of physician on patient's satisfaction with patient-physician communication. For example, Griffin et al (2004), showed that patient's satisfaction was associated with physician's communicative behavior and patient's health behavior. It was found that physician's behavior like attentiveness and empathy affected the patients' satisfaction.

Quality of life has been studied widely in psycho-oncology. Ong et al., (2000) have looked at quality of life and its influence on psychological well-being and health outcomes. While another study has looked at quality of life, fatigue and spiritual well-being. The results indicated that fatigue has an effect on physical, social and emotional well-being of an individual. It has also been seen that quality of life has a negative correlation with helpless/hopeless and positive correlation with fatalism (acceptance of the illness). Spiritual well-being has also found to be positively correlated with quality of life (See, Cotton et al., 1999). Studies have also looked at how locus of control influences patients' preference in cancer communication (Murray and McMillan, 1993).

The above study highlights patient-physician communication has an influence on health outcomes. It has found to be associated with quality of life and psychological well-being. Cancer research in India has looked at patient satisfaction with Health care mainly focusing on quality of health care (Sodani et al., 2010). Some other quantitative study conducted in India was on understanding illness perception (Chittem et al., 2012), supportive therapy and quality of life (Vadiraja, 2009). Studies also looked at intervention programs for preventing cancer (Mehta et al., 1982). Although the studies looked at understanding illness, prevention and enhancing quality of health care, the studies have lacked focus on understanding patient-physician communication and its influence on patient's health outcomes. Therefore the current study aims at understanding patient's satisfaction with medical consultation and its relation to psychological well-being.

## Method

### Participants

Using convenient sampling, patients diagnosed with cancer and undergoing treatment at Dr Balabhai Nanavati Hospital, Mumbai, were recruited for the study. Questionnaire was administered on 196 patients (female = 102, male = 94), with a mean age of 55.85 (See table 3.1). Ethics approval for the study was received from the Institute Ethics committee (IEC), Indian Institute of Technology Hyderabad, Hyderabad, and the ethics committee of Dr. Balabhai Nanavati Hospital, Mumbai. Participants' demographic and medical details are described in Table 3.1.

**Table3.1:-** Demographic details of patients participated in the quantitative study (N= 196)

| **Demographic details** | | |
|---|---|---|
| **Age (Range)** | 84- 20 | |
| **Gender** | Male | 94 |
| | Female | 102 |
| **Average Monthly Income** | 9,203. 59/- | |
| **Time since diagnosis** | Below 3 months | 29 |
| | Above 3 months | 152 |
| | Reoccurrence | 15 |
| **Treatment undertaken** | Chemotherapy | 11 |
| | Radiation therapy | 37 |
| | Surgery | 2 |
| | Chemotherapy + Radiation therapy +Surgery | 42 |
| | Radiation therapy + Surgery | 81 |
| | Chemotherapy + Surgery | 3 |
| | Chemotherapy + Radiation therapy | 20 |
| **Types of Cancer** | Head and Neck | 60 |
| | Uterus | 34 |
| | Breast | 56 |
| | Lung | 9 |
| | Rectal | 5 |
| | Kidney | 5 |
| | Prostate | 11 |
| | Brain | 3 |
| | Metastatic | 6 |
| | Stomach | 7 |

**Measurements**

1. ***Medical Interview Satisfaction Scale***- MISS-21 (Meakin & Weinman, 2009) is a 21 item questionnaire, which assess the patient satisfaction in the Patient- physician consultation. The item is scored on a five-point Likert scale. MISS-21 consists of four subscales: distress relief, communication comfort, rapport and compliance subscales). The subscales were found to be internally consistent the Cronbach's alpha ranged from 0.46 to 0.65. MISS-21 is also found to have high construct validity (0.21 to 0.63). (Meakin & Weinman, 2009)
2. ***Brief Illness Perception Scale***- Brief IPS (Broadbent et al., 2005) is a 9 item scale designed to assess emotional and cognitive representation off illness. The response is rated on a scale of 0 to 10, except for one causal question. High score on the scale indicate threatening view about the illness, while low score indicates benign view about the illness. The scale showed good test- retest reliability correlation coefficient ranging from 0.42 to 0.73. It was also found to have good discriminant and predictive validity (Broadbent et al., 2005).
3. ***Hospital Anxiety Depression Scale***- HADS (Zigmond & Snaith, 1983) is a 14 item scale with two subscales Anxiety (7 items) and depression (7 items). The item are scored on a four point likert scale (0 to 3). HADS provides a screening for anxiety and depression among the non-psychiatric patients.
4. ***Functional Assessment of Cancer Therapy- General (FACT-G)*** (Cella et al., 2004) FACT-G measures the health related quality of life in cancer patients. This scale has 4 subscales- physical, social, emotional and functional well-being. The items are measured on a 5 point likert scale except for the overall well-being questionnaire that is measured on a 10-point scale. The psychometric properties of construct validity and

inter consistency reliability showed that FACT-G is a reliable and a valid test. The cronbach's alpha was found to be at 0.89 for total scale and for subscale it was found to be 0.78 to 0.90 (Cella et al., 2004).

5. ***Multidimensional health Locus of Control- Form C (MHLC)*** MHLC (Wallston et al., 1994) is a scale used to measure Health Locus of Control of an individual. The MHLC consists of 3 forms: Form A and B are general, while form C is condition specific. It is used in any medical and health related condition. It consists of 18 items and 4 subscales: internal, chance, doctor, and other People. The items are rated on a 6 point likert scale with response ranging from strongly disagree (1) to strongly agree (6). The inter-consistency reliability was found to be desirable for Form C ($\alpha \geq 70$). The Test- retest reliability for form C was found to be lower after a longer period of time. Form C was found to have a considerable convergent and discriminant validity (Wallston et al., 1994).
6. ***God Locus of Health Control Scale (GLHC)*** GLHC (Wallston et al., 1999) is a 6 item scale developed to assess the extent of individual's believes that god control his/her health status. The GLHC scale is an adjunct to the MHLC scale. Internal consistency reliability was found to be at 0.87 to 0.94 (Wallston et al., 1999).

**Procedure**

Patients were approached by the principal investigator while they were receiving their treatment. They were informed about the study and were given ample of time to consider their participation and all their questions were answered to their satisfaction. Following this, signed consent to participate in the study.

Questionnaires were given to patients to answer at their own convenience. The questionnaires were translated and back-translated in Marathi and Hindi for patients who were unable to read English. For patients who were illiterate and physically weak (n = 193), the researcher read out the questionnaires and recorded the answers**.**

## Statistical analysis

Statistical analysis was carried out using Statistical Package for Social Sciences (SPSS) version 16.0. The sum scores of each scale and subscale for every patient were entered. Demographic variables (e.g., age, diagnosis, treatment time) were converted to ordinal scale and entered. Further, Pearson correlation was carried out to understand the relationships between the variables. Significant correlations were further analysed by using multiple regression to understanding the way in which the variables are correlating.

## Results

**P**articipants (N= 196) answered the questionnaire. Table 3.1 gives a summary of the patients' demographic information, type of diagnosis, time since diagnosis and time of treatment. Age, time of diagnosis and treatment were included in the statistical analysis.

Means and Standard deviations for each variable are given in Table 3.2. Further, Pearson correlation was calculated to understand the correlation between variables and to further analyze the variables that have a statistically significant correlate. Table 3.3 gives a matrix that depicts the alpha coefficient with significance level at .05 and .01 level. The variables that significantly correlated were further analysed to see the way the variables are related.

**Table3.2:-** Means and standard deviations of the variables from quantitative study (N= 196)

| Variables | Means | Standard Deviations |
|---|---|---|
| Brief illness perception | 40.69 | 12.53 |
| Physical well-being | 16.00 | 5.69 |
| Social well-being | 16.25 | 2.78 |
| Relationship with doctor | 12.51 | 2.29 |
| Emotional well-being | 13.38 | 2.90 |
| Functional well-being | 18.77 | 4.84 |
| Anxiety | 10.11 | 3.07 |
| Depression | 9.72 | 2.67 |
| Distress Relief | 29.62 | 4.26 |
| Communication comfort | 13.82 | 3.88 |
| Rapport | 37.79 | 6.26 |
| Compliance intent | 12.26 | 2.72 |
| Internal LOC | 22.55 | 3.43 |
| Chance LOC | 27.39 | 3.10 |
| Doctor LOC | 15.82 | 1.96 |
| Other people LOC | 8.15 | 1.72 |
| God health LOC | 24.56 | 6.17 |
| Age | 55.91 | 12.53 |
| Gender | 0.48 | 0.50 |
| Type of cancer | 3.12 | 2.43 |
| Time since diagnosis | 2.19 | 0.78 |
| Time since treatment | 1.50 | 0.63 |

## Table3.3:- Correlation matrix of the variables included in quantitative study (N= 196)

| | **BIP** | **FP** | **FS** | **FR** | **FE** | **FF** | **A** | **D** | **DR** | **CC** | **R** | **CI** | **I** | **C** | **D** | **OP** | **G** | **AGE** | **GE** | **TY** | **DIG** | **TRE** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **BP** | 1 | | | | | | | | | | | | | | | | | | | | | |
| **FP** | .481$^{**}$ | 1 | | | | | | | | | | | | | | | | | | | | |
| **FS** | .207$^{**}$ | .078 | 1 | | | | | | | | | | | | | | | | | | | |
| **FR** | .045 | .072 | .205$^{**}$ | 1 | | | | | | | | | | | | | | | | | | |
| **FE** | .129 | .184$^{**}$ | .010 | .047 | 1 | | | | | | | | | | | | | | | | | |
| **FF** | -.166$^{*}$ | -.123 | .013 | .062 | -.227$^{**}$ | 1 | | | | | | | | | | | | | | | | |
| **A** | .264$^{**}$ | .031 | -0.60 | .040 | .259$^{**}$ | -.298$^{**}$ | 1 | | | | | | | | | | | | | | | |
| **D** | .052 | .147$^{*}$ | -.109 | -.045 | .256$^{**}$ | -.369$^{**}$ | .315$^{**}$ | 1 | | | | | | | | | | | | | | |
| **DR** | -.069 | .120 | -.008 | .404$^{**}$ | -.093 | .204$^{**}$ | .350$^{**}$ | -.129 | 1 | | | | | | | | | | | | | |
| **CC** | .056 | .016 | -.060 | -.288$^{**}$ | .170$^{*}$ | -.285 | .162$^{*}$ | .148$^{*}$ | -.101 | 1 | | | | | | | | | | | | |
| **R** | -.039 | .001 | -.086 | .284$^{**}$ | -.031 | .083 | -.049 | .007 | .130 | -.209$^{**}$ | 1 | | | | | | | | | | | |
| **CI** | .051 | .100 | -.043 | -.163$^{**}$ | .102 | -.098 | .070 | .139 | -.017 | .156* | -.233$^{**}$ | 1 | | | | | | | | | | |
| **I** | .005 | .000 | .019 | -.130 | -.088 | .001 | -.002 | -.004 | .003 | -.006 | .213$^{**}$ | -.136 | 1 | | | | | | | | | |
| **C** | -.002 | -.038 | -.049 | .113 | .260$^{**}$ | .143$^{*}$ | .046 | -.043 | .161$^{*}$ | .041 | .160$^{*}$ | -.159 | -.104 | 1 | | | | | | | | |
| **D** | -.099 | -.018 | -.054 | .163$^{*}$ | -.048 | .116 | -.148$^{*}$ | -.054 | .165$^{*}$ | -.176* | .006 | .306$^{*}$ | -.162$^{*}$ | -154$^{*}$ | 1 | | | | | | | |
| **OP** | .003 | .024 | .066 | .029 | .005 | -.089 | .156* | .067 | .093 | .130 | -.181$^{*}$ | .266$^{*}$ | -.168$^{*}$ | -.111 | .194$^{**}$ | 1 | | | | | | |
| **G** | .120 | .108 | .044 | .117 | .123 | .055 | .121 | -.055 | .019 | .059 | .124 | -.119 | .026 | .220$^{**}$ | .009 | -.144$^{*}$ | 1 | | | | | |
| **AGE** | .087 | .056 | .055 | -.036 | .107 | -.084 | .071 | .005 | -.076 | -.034 | .041 | .009 | .019 | .047 | -.072 | .003 | .093 | 1 | | | | |
| **GE** | -.028 | -.022 | -.116 | -.096 | -.134 | .002 | .087 | -.022 | -.060 | -.075 | .094 | -.005 | .147* | .035 | -.069 | -.124 | .077 | .091 | 1 | | | |
| **TY** | .133 | .121 | .026 | .006 | .111 | .032 | .022 | .037 | .038 | .028 | .022 | .065 | .034 | .059 | -.120 | -.200$^{**}$ | .165$^{*}$ | .132 | .065 | 1 | | |
| **DIG** | -.036 | .051 | .144$^{*}$ | .112 | .059 | -.045 | -.024 | -.113 | .057 | -.013 | -.115 | .008 | -.126 | .081 | .103 | .059 | .053 | -.143$^{*}$ | -.155$^{*}$ | .031 | 1 | |
| **TRE** | .030 | .019 | .057 | .121 | .068 | .016 | -.001 | -.095 | .090 | .025 | .036 | .028 | -.073 | .104 | .128 | .110 | .049 | -.115 | -.220$^{**}$ | -.021 | .759$^{**}$ | 1 |

**Correlation is significant at the 0.01 level (2 tailed)

*Correlation is significant at the 0.05 level (2 tailed)

Variables: Illness perception (BP), Physicial Wellbeing (FP), social wellbeing (FS), Relationship with doctor (FR), Functional wellbeing (FF), Emotional wellbeing (FE), Anxiety(A), Depression (D), Distress relief (DR), Communication comfort (CC), Rapport (R), Compliance Intent (CI), Internal (I), Chance (C), Doctor (D), Other people (OP), God LOC (G), Age (A), Gender (GE), Type of cancer (TY), Time since diagnosis (DIG), Time since treatment (TRE)

**Table3.4:-** Summary table with R, R squares and change statistics of outcome variables

| **Outcome Variables** | **R** | **R Square** | **Adjusted R Square** | **Standard Error of Estimate** | **Change Statistics** | | | | | **Durbin Watson** |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | R Square Change | F Change | df1 | df2 | Sig F Change | |
| DR | .57$^a$ | .32 | .30 | 3.56 | .322 | 18.03 | 5 | 190 | .000 | 2.12 |
| CC | .45$^a$ | .206 | .172 | 3.527 | .206 | 6.064 | 8 | 187 | .000 | 1.761 |
| R | .45$^a$ | .206 | .180 | 5.668 | .206 | 8.157 | 6 | 189 | .000 | 1.953 |
| CI | .469$^a$ | .220 | .195 | 2.442 | .220 | 8.890 | 6 | 189 | .000 | 1.911 |

## Factors associated with distress relief

Table 3.3 shows us the correlates of subscale of MISS-21 distress relief. Multiple regression was carried out to understand the influence of each variables and variable with the greatest influence on the subscale of MISS-21 distress relief.

Multiple regression analysis showed variables predicting distress relief subscale of MISS-21. It was seen that relationship with doctor subscale of FACT-G plays a greater role in predicting distress relief (Beta= 0.389, t (190) = 6.39, p<.001). The b value for relation with doctor was found to be 0.724 indicating one unit change in distress relief can lead to 0.724 change in relationship with doctor subscale of MISS-21. Functional well-being subscale of FACT-G was also found to predict distress relief (Beta= .049, t (190) = .772, p<.01). The b value for functional well-being was found to be .043 indicating one unit change in distress relief can lead to 0.043 change in functional well-being subscale. Chance subscale of MHLC was also found to predict Distress relief (Beta= .136, t (190) = 2.189, p<.01), b value (b=.085) indicated that one unit change in distress relief lead to .085 change in chance subscale of MHLC. Doctor subscale of MHLC was found to be predictor of distress relief (Beta= .065, t (190) = 1.039, p<.300), b value (b=.141) indicated that one unit of change in distress relief leads to .065 change in doctor subscale of MHLC. Similarly Anxiety subscale of HADS also found to predict distress relief (Beta= -.348, t (190) = -5.492, p<.001), b value (b= .484) one unit change in distress relief leads to 0.484 change in Anxiety score. Although for anxiety score the change occurs in negative direction indicating that higher the distress relief lesser the anxiety score.

From the summary table it can be seen that, the correlation between the predictor variables (Relationship with doctor and functional well-being, doctor and chance locus of control, Anxiety scores) and outcome variable (Distress Relief) was found to be R= .57. Indicating that predictor variables have variance of 32.2% on Distress relief ($R^2 = 0.322$, $F_{(5, 190)} = 18.030$, $p < .001$ level). The adjusted $R^2$ was found to be 0.304 indicating high generalizability. Durbin- Watson value indicates that independent variables are independent of each other and have lower chances of collinearity. Average of VIF value was 1.098, indicating no collinearity between the variables. Hence, it can be seen that all the assumptions are met and the model significantly predict the outcome variable.

**Factors associated with communication comfort**

Table 3.4 shows the correlates of communication comfort subscale in MISS-21. To understand the way these variables are correlated. Multiple regression was carried out to understand the influence of each variable and to understand the variable with most influence on outcome variable (communication comfort).

Multiple regression analysis showed that relationship with doctor subscale of FACT-G had greater impact on communication comfort (Beta= -.214, $t_{(187)} = -3.035$, $p<0.001$). The b value for relationship with doctor subscale of MISS-21 was found to be -.363, indicating that one unit change in communication comfort subscale leads to 0.363 change in relationship with doctor subscale. The change is found to be in negative direction that is increase in relationship with doctor leads to decrease in communication comfort. Anxiety subscale of HADS was found to be predictor of communication comfort (Beta= .53, $t_{(187)} = .733$, $p<0.464$), b value (0.67) indicated that one unit change in communication comfort leads to 0.67 change in communication comfort. Depression subscale of HADS was also found to be predictor of communication comfort (Beta= .002, $t_{(187)} = .025$, $p<0.980$), b value (.003) indicate one unit change in communication comfort leads to 0.003 unit change in depression score. Functional well-being of FACT-G was also found to predict communication comfort (Beta= -.159, $t_{(187)} = -2.727$, $p<0.007$). Doctor subscale of MISS-21 also predicted communication comfort (Beta= -.137, $t_{(187)} = -1.096$, $p<0.058$). One unit of change in communication comfort lead to negative change in functional well-being and doctor subscale of locus of control (b value= -.159, -.272) respectively.

The summary table 3.4 shows, the correlation between the predictor variables (relationship with doctor, functional and emotional well-being; Anxiety and depression score; rapport and compliance intent; and doctor subscale of MHLC) and outcome variable (Communication comfort subscale of MISS-21). R was found to be .454. The predictor variables were found to have 20.6% variance in communication comfort ($R^2 = .206$, $F_{(8,\,187)} = 6.064$, $p <.001$ level). The adjusted $R^2$ was found to be 0.172 indicating generalizability. Durbin- Watson value (1.761) indicates that independent variables are independent of each other and have lower chances of collinearity. Average of VIF value was found to be 1.210, also indicating no collinearity between the variables. Hence, it can be seen that all the assumptions are met and the model significantly predict the outcome variable.

### Factors associated with rapport

As it can be seen from the table 3.3 there was found to be significant correlation between rapport subscale of MISS-21 and predictor variables (relationship with doctor subscale of FACT-G; communication comfort and compliance intent of MISS- 21;

and internal, chance and other people subscale of MHLC). Hence, multiple regression was carried out to understand the influence of each variables.

Multiple regression analysis showed that relationship with doctor was a greater predictor of outcome variable, rapport subscale of MISS- 21 (Beta=0.253, $t_{(189)}$ = 3.630, p<0.001) see table 3.4. The b value for rapport subscale of MISS-21 was found to be 0.692, indicating that one unit change in the outcome variable leads to 0.692 change in rapport scale. The MISS-21 subscales of communication comfort (Beta=-.113, $t_{(189)}$ = -1.637, p<0.103) and compliance intent (Beta=-.222, $t_{(189)}$ =-1.384, p<0.168) was found to predict rapport subscale of MISS-21. The MISS-21 subscales of communication comfort (b= -.183) and compliance intent (b= -.222) was found to have negative relation with the rapport scale of MISS-21. The chance subscale (Beta=-.272, $t_{(189)}$ =2.008, p<0.046) and other people subscale (Beta=-.343, $t_{(189)}$ =-1.375, p<0.171) of MHLC also predicted rapport. The b values (b = .272) for chance subscale indicated that one unit change in rapport leads to 0.272 change in chance subscale. While b value (b= -.343) for other people subscale shows change in rapport subscale leads to negative change in other people subscale of MHLC.

The summary table 3.4 shows, the correlation between the rapport subscale of MISS-21 and predictor variables (relationship with doctor subscale of FACT-G; communication comfort and compliance intent of MISS- 21; and internal, chance and other people subscale of MHLC). The correlation was found to be R= 0.517. R square was .206, indicating that Subscales of MISS-21 have variance of 20.6 % on Relationship with doctor scale. The adjusted $R^2$ was found to be 0.180 indicating generalizability. Durbin- Watson value (1.953) indicates that predictor variables are independent of each other have lower chances of collinearity. Average of VIF value was found to be 1.120, indicating no collinearity between the variables. The F value was also found to be 8.157 significant at .001 level. Hence, it can be seen that all the assumptions are met and the model significantly predict the outcome variable.

## Factors associated with compliance intent

Table 3.3 shows the significant correlation between compliance intent subscale of MISS-21 and other predictor variables (relationship with doctor subscale of FACT-G; rapport and communication comfort subscale of MISS-21; and chance, doctor and other people subscale of MHLC). Hence, multiple regression was carried out to understand the influence of each variable and to understand the variable with most influence on the outcome variable (Compliance intent).

Multiple regression analysis showed that doctor subscale of MHLC was a greater predictor of compliance intent (Beta=0.310, $t_{(189)} = 4.556$, $p<0.001$). The b value for doctor subscale of MHLC was found to be 0.431, indicating that one unit change in compliance intent leads to 0.431 change in doctor subscale of MHLC. Communication comfort (Beta=0.124, $t_{(189)} = 1.790$, $p<0.075$) and rapport (Beta=-.130, $t_{(189)} = -1.877$, $p<0.062$) was also found to predict compliance intent. The b value (b = .087) for communication comfort indicate that one unit change in compliance intent leads to 0.087 change in communication comfort. The b value (b= -0.57) indicate that one unit of compliance intent leads to 0.57 decrease in rapport subscale of MISS-21. Chance (Beta=-.061, $t_{(189)} = -.923$, $p<0.357$), doctor (Beta=.431, $t_{(189)} =4.556$, $p<0.000$) and other people (Beta=-.163, $t_{(189)} = 2.406$, $p<0.017$) subscales of MHLC was also found to predict compliance intent. The b value (-.054) for chance indicate that one unit of increase in compliance intent leads to 0.054 decrease in chance subscale of MHLC. The b value (b= 0.431) for doctor subscale of MHLC indicate that one unit of change in compliance intent leads to 0.431 change in doctor subscale of MHLC. The b value (b= .257) for other people subscale of MHLC also indicate that one unit change in compliance intent leads to .257 change in compliance intent.

The summary table 3.4 shows, the correlation between the predictor variables (relationship with doctor subscale of FACT-G; rapport and communication comfort subscale of MISS-21; and chance, doctor and other people subscale of MHLC) and outcome variable (compliance intent). R was found to be .469 and R square was .220, indicating that the predictor variables have 22.0 % variance in outcome variable. The adjusted $R^2$ was found to be 0.195 indicating generalizability. Durbin- Watson value (1.911) indicates that independent variables are independent of each other have lower chances of collinearity. Average of VIF value was found to be 1.141, indicating no collinearity between the variables. The F value was also found to be 8.890 significant at .001 level.

## Discussion

The current study attempted to understand association between patients' satisfaction with medical consultation and quality of life, psychological distress and locus of control. Multiple regression on the subscale of medical interview satisfaction scale (distress relief, communication comfort, rapport and compliance intent) showed,

The perceived relationship with the doctor influenced all the subscales of Medical Interview Satisfaction Scale (i.e. distress relief, communication comfort, rapport and compliance intent. Comfort with communication had a negative relation to rapport and positively related to compliance intent. Rapport was also found to have negative relation with compliance intent. Relief from distress was related to functional well-being, levels of anxiety and external locus of control (chance and doctor). Comfort with communication was also found to be related to emotional well-being, functional well-being, levels of anxiety and depression, external locus of control (doctor). Rapport was found to be associated with internal locus of control and external locus of control (chance and other people). While compliance intent was found to be related to external locus of control (chance, doctor and other people).

Current study indicates that, patient's compliance depends on the level of comfort patients share with their physician. This was found consistent with past research that indicated comfort with consultation indirectly influenced patient's adherence to the treatment (Street et al., 2009).

It was also seen that patients' perception about the relation they share with the doctor influenced the feeling of relief from distress. Patients who experienced patient-physician relationship as a contributor to quality of life felt relieved from distress related to illness. They were also found to be low on anxiety during consultation. Patients' who perceived their routine to be disrupted due to illness were more likely to experience distress during consultation. This was in accordance to past research, which saw association between patients' fatigue and quality of life, indicating that fatigue affects patient's social, physical and psychological well-being (Gupta, Lis & Grutsch, 2007). Relief from distress was also found to be related to patient's perception of control towards the illness. Patients who perceived their illness to be externally (doctor) controlled reported relief from their distress.

Patients who perceived positive relation with their physician were more likely to report comfort in communication. This comfort in communication was also found to have a positive effect on emotional and functional well-being. Past research also showed a relation between communication comfort with the physician and well-being. This experience of comfort has found to lower anxiety in patients (Street et al., 2009).

Rapport shared by the patient with their physician was associated with the relation the patient shares with the doctor and also with patients' locus of control. Building rapport was preferred by patients who saw their illness externally controlled. This finding are also consistent with past research, that saw patients with external locus of control preferred physicians who provided emotional support during consultation (Hashimoto & Fukuhara, 2004).

Patients with external locus of control was found to have higher chance of complying with the treatment. They saw illness related control as external (i.e. towards significant others and doctor), which in turn is reflected in the treatment related decisions. Study conducted by Murray and McMillan (1993), also highlight similar findings, where patients who felt powerful others (healthcare system) were in control of their illness were more likely to comply to undergo Breast Self-Examination.

The current study gives an overview about patient's perception about the satisfaction with medical consultation. The study highlights the role of physician in patients' satisfaction with the communication. Physician was also found to contribute in patients' treatment decisions and their adherence to treatment.

The limitation of the study are as follows:

Although minimal biases was ensured by keeping anonymity of the patient. Patients may give socially desirable response due to perception that expression of negative attitude could hinder their cancer care (Fallowfield, 1992). These findings are specific to the hospital in consideration and hence generalizing the data could not be possible. It is also important to note that the results did not reveal large amount of variance indicating the influence of external variables. Individual influence and relation of variables could not be considered in this study due to limitation of data.

# CHAPTER 4

## Summative Conclusion

This chapter summarizes the findings of the two studies. The use of mixed methods in this project, provided rich information related to cancer communication. The quantitative study highlighted the patients' experiences with cancer was related to the relationship with their treating physician. It also examined the relationship between patients' satisfaction with the consultation, psychological well-being and quality of life. The findings also showed the role of physician and caregivers in the illness and treatment perception. The contradicting findings found in the two studies for instance: qualitative study saw role of physician as centered in medical care, while qualitative study revealed that patients were found to rate high on satisfaction when physicians provide medical and psychological support. This project emphasize the need for such mixed methods research to gain a deeper understanding in patient care. Lastly, it stresses the need to study patient-physician relationship in context of cancer communication to enhance patients' health care experience.

## Summative Conclusion

The present project reflects the importance and contributions of patient-physician communication in treatment process. The study has used mixed methods approach, which has aided in providing rich and interesting findings about patient-physician relationship. Using qualitative method followed by quantitative study highlighted the importance of cancer communication in patient satisfaction and psychological outcomes such as quality of life and levels of distress.

The qualitative findings revealed that, physicians and caregivers play a key role in shaping patients' illness and treatment perception. This was found to contribute in changing patients believes related to illness and treatment, leading to shift from positive to negative in interpretation of cancer. It also suggested that it is possible that physicians could reduce the fear of cancer and consequently improve compliance through effective and communicative relationship. This was also reflected in quantitative study, where it was observed that, intent to comply with treatment and care recommendations was positively associated with perceived level of comfort in communication and rapport shared with the physician. These were found to be in accordance with past research, which showed that, patients who perceived their physicians' communication as effective felt more controlled over the illness, had positive health outcome and in turn improved patient compliance (Zachariae et al., 2003; O'Hair et al.,1987).

The qualitative study reflected the importance of locus of control in patients' perceptions related to cancer, however it was unable to explore how this was related to patient-physician relationship. The quantitative study provided a comprehensive understanding about the way the patient-physician relationship is associated with locus of control. The results showed that, external locus of control was related to all the key features of satisfaction with a medical consultation, i.e., relief from cancer-related distress, comfort in communication with the physician, rapport shared with the physician, and intent to comply. A study by Hashimoto & Fukuhara (2004), also showed similar findings, where patients with external locus of control preferred physicians who focused on building rapport and provided emotional support during consultation. The current research findings were also consistent with a study conducted by Murray and McMillan (1993), who found that women with external locus of control were more likely to undergo breast examination, as they would comply with the powerful others (doctors and health care system).

Interestingly, the mixed method approach highlighted that while in the qualitative study patients reported not needing the physician for psycho-emotional comfort and described the physician's role more as a medical care provider, the quantitative study revealed that patients did indeed respond more positively to physicians who were able to provide them both medical and psychological support. This gap in the need and the behavior of the patients' could be due to, patients' presumed roles related to their physicians and themselves. As they see their physician as authoritative and overloaded with work, while they see themselves as less knowledgeable. This could restrict them from seeking the physician for communicative needs.  It was also seen that, qualitative study showed influence of God on illness and treatment believes. But this was not evident in quantitative study, where God locus of control had no significant relation.

This could be because spirituality is a very elusive concept. Hence, quantifying won't be possible and may need more in-depth understanding of the belief system of the individuals (Coyle, 2002). Hence, these findings emphasize the need for mixed method approach in research in order to gain a broader as well as deeper understanding in patient care needs.

## Limitations

The project has some limitations. The data is from a specific hospital in Mumbai, hence generalizing the data may not be possible. Although, confidentiality and anonymity was assured, patients might have given desirable answers assuming that a negative response could hinder their cancer care (Fallowfield, 1992). Further, for the want of time, it was not possible to interview physicians and caregivers who may have given valuable insights into cancer communication.

## Implications

As the project highlights the importance of relationship between communication and patients' mental well-being, it emphasizes the need to address the quality of patient-physician communication bearing in mind the cultural aspects of this disease in India. The outcome in the past studies done amongst the Japanese population shows the need to develop culture specific intervention programs to enhance patient-physician communication (Fujimori et al., 2007). As this project reflected interesting findings during the quantitative study, which was not highlighted in the qualitative study, indicates the need to develop methods where qualitative study could be followed by quantitative; and again a qualitative study could be conducted to flesh out if any discrepancies are noted in previous studies.

Further research needs to look at physicians' and caregivers' perspective to gain a comprehensive understanding about the working of patient-physician communication. The project also reflects the need for future work in gaining insight related to patients' preference in cancer communication, so as to enhance the patient-physician relationship. Lastly, this project's findings can be used to develop intervention programs to enhance communication between patients and physician including caregivers.

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# APPENDICES

## Appendix A

## Patient consent form for Quantitative study and Qualitative study

भारतीय प्रौद्योगिकी संस्थान हैदराबाद
Indian Institute of Technology Hyderabad

Department of Liberal Arts
Indian Institute of Technology Hyderabad
Yeddumailram
Medak
Andhra Pradesh- 502205

### PATIENT CONSENT FORM

Title of the Project: **A study to understand the patient's satisfaction with cancer communication and its effect on mental health**

Name of Researcher: **Shweta Kiran Chawak**

1. I confirm that I was informed and understood the aim, dated______________ for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my medical notes may be looked at by the named researcher where it is relevant to my taking part in research. I give permission for this individual to have access to my medical records. ☐
4. I am aware that the shared information would be kept confidential and will only be used for the research purposes ☐
5. I agree to take part in the above study.

| | | |
|---|---|---|
| ____________________ | ____________________ | ____________________ |
| Name (printed) | Date | Signature |

# APPENDIX B

## Demographic & Patient Information Sheet

***Demographic:***

- Age (in years):
- Gender:
- Marital status:
- Level of education:_______years, _______class
- Average household income:
- Geographical location:

***Illness***

- Type of illness:
  - Stage:
- Time since diagnosis:
- Treatment:

***Other:***

- Relation to primary caregiver:
- Medical decision-maker:
- Who informed:
- Type of visit:

**Notes:**

## APPENDIX C

## Medical Record

- Type of cancer:
    - Stage
    - Multiple sites:
- Time since diagnosis:
- Time since treatment:
- Treatment/medication:

| | |
|---|---|
| None indicated | |
| Surgery | |
| Radiation | |
| Chemotherapy | |
| Surgery and radiation | |
| Surgery and chemotherapy | |
| Chemotherapy and radiation | |
| Surgery, radiation and chemotherapy | |
| Other (hormonal, BMT etc) | |

- Chemotherapy cycle:
- Current physician/ Oncologist:
- Any hospitals previously attended**:**

# APPENDIX D

## Brief Illness Perception Questionnaire (BIPQ)

For the following questions, please circle the number that best corresponds to your views

How much does your illness affect your life?

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| No affect at all | | | | | | | | | | Severely affects my life |

How long do you think your illness will continue?

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| A very short time | | | | | | | | | | Forever |

How much control do you feel you have over your illness?

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Absolutely no control | | | | | | | | | | Extreme amount of control |

How much do you think your treatment can help your illness?

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Not at all | | | | | | | | | | Extremely helpful |

How much do you experience symptoms from your illness?

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| No symptoms at all | | | | | | | | | | Many severe symptoms |

How concerned are you about your illness?

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Not at all concerned | | | | | | | | | | Extremely concerned |

How well do you feel you understand your illness?

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Don't understand at all | | | | | | | | | | Understand very clearly |

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Not at all affected emotionally | | | | | | | | | | Extremely affected emotionally |

Please list in rank-order the three most important factors that you believe caused your illness. The most important causes for me:-

1. ________________________________

2. _________________________________

3. _________________________________

## APPENDIX E

### Functional Assessment of Cancer Therapy- General (FACT-G)

**Below is a list of statements that other people with your illness have said are important. By filling in one circle per line, please indicate how true each statement has been for you during the past 7 days**

| | **During the past 7 days** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| 1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| 2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| 3 | I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| 4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| 5 | I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| 6 | In general, I feel sick | 0 | 1 | 2 | 3 | 4 |
| 7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

8 How much does your PHYSICAL WELL-BEING affect your quality of life?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Very much so

| | **During the past 7 das** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| 9 | I feel distant from my friends | 0 | 1 | 2 | 3 | 4 |
| 10 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 11 | I get support from my friends and neighbors | 0 | 1 | 2 | 3 | 4 |
| 12 | My family has accepted my illness | 0 | 1 | 2 | 3 | 4 |
| 13 | Family communication about my illness is poor…. | 0 | 1 | 2 | 3 | 4 |
| | If you have a spouse/ partner or a sexually active, please answer 14-15. Otherwise go to #16 | | | | | |
| 14 | I feel close to my partner (or main support) | 0 | 1 | 2 | 3 | 4 |
| 15 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

16 How much does your SOCIAL/ FAMILY WELL-BEING affect your quality of life

Not at all 0 1 2 3 4 5 6 7 8 9 10 Very much so

| | **During the past 7 days** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| 17 | I have confidence in my doctor(s) | 0 | 1 | 2 | 3 | 4 |
| 18 | My doctor is available to answer my question | 0 | 1 | 2 | 3 | 4 |

19 How much does your RELATIONSHIP WITH THE DOCTOR affect your quality of life?

Not at all 0 1 2 3 4 5 6 7 8 9 10
Very much so

| | **During the past 7 days** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| 20 | I feel sad | 0 | 1 | 2 | 3 | 4 |
| 21 | I am proud of how I'm coping with my illness | 0 | 1 | 2 | 3 | 4 |
| 22 | I am losing hope in the fight against my illness | 0 | 1 | 2 | 3 | 4 |
| 23 | I feel nervous | 0 | 1 | 2 | 3 | 4 |
| 24 | 1 worry about dying | 0 | 1 | 2 | 3 | 4 |

25 How much does your EMOTIONAL WELL-BEING affect your quality of life?

Not at all 0 1 2 3 4 5 6 7 8 9 10
Very much so

| | **During the past 7 days** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| 26 | I am able to work (include work in home) | 0 | 1 | 2 | 3 | 4 |
| 27 | My work (include work in home) is fulfilling | 0 | 1 | 2 | 3 | 4 |
| 28 | I am able to enjoy life "in the moment" | 0 | 1 | 2 | 3 | 4 |
| 29 | I have accepted my illness | 0 | 1 | 2 | 3 | 4 |
| 30 | 1 am sleeping well | 0 | 1 | 2 | 3 | 4 |
| 31 | I am enjoying my usual leisure pursuits | 0 | 1 | 2 | 3 | 4 |
| 32 | I am content with the quality of my life right now | 0 | 1 | 2 | 3 | 4 |

33 How much does your FUNCTIONAL WELL-BEING affect your quality of life?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Very much so

## APPENDIX E

## Hospital Anxiety Depression Scale- HADS

**The following statements relate to one’s feelings.** Please read each statement below and indicate how often this is true of you by circling the response that best describes how you feel. **Do give an immediate response and do not think for too long about their answers.**

**1.** I feel tense or ‘wound up’.

| | | | |
|---|---|---|---|
| **Most of the time** | **A lot of the time** | **From time to time** | **Not at all** |

**2.** I still enjoy the things I used to enjoy.

| | | | |
|---|---|---|---|
| **All of the things** | **Most of the things** | **Some of the things** | **None of the things** |

**3.** I get a sort of frightening feeling as if something awful is about to happen.

| | | | |
|---|---|---|---|
| **Very definitely and quite badly** | **Yes, but not too badly** | **A little, but it doesn’t worry me** | **Not at all** |

**4.** I can laugh and see the funny side of things.

| | | | |
|---|---|---|---|
| **As much as I always could** | **Not quite so much now** | **Definitely not so much now** | **Not at all** |

**5.** Worrying thoughts go through my mind.

| | | | |
|---|---|---|---|
| **A great deal of the time** | **A lot of the time** | **From time to time but not too often** | **Only occasionally** |

**6.** I feel cheerful.

| | | | |
|---|---|---|---|
| **Not all** | **Not often** | **Sometimes** | **Most of the time** |

**7.** I can sit at ease and feel relaxed.

| | | | |
|---|---|---|---|
| **Definitely** | **Usually** | **Not often** | **Not at all** |

**8.** I feel as if I'm slowed down.

| | | | |
|---|---|---|---|
| **Nearly all the time** | **Very often** | **Sometimes** | **Not at all** |

**9.** I get a sort of frightened feeling like 'butterflies' in the stomach.

| | | | |
|---|---|---|---|
| **Not at all** | **Occasionally** | **Quite often** | **Very often** |

**10.** I have lost interest in my appearance.

| | | | |
|---|---|---|---|
| **Very much indeed** | **Quite a lot** | **Not very much** | **Not at all** |

**11.** I feel restless as if I have to be on the move.

| | | | |
|---|---|---|---|
| **Very much indeed** | **Quite a lot** | **Not very much** | **Not at all** |

**12.** I look forward with enjoyment to things.

| | | | |
|---|---|---|---|
| **As much as I ever did** | **Rather less than I used to** | **Definitely less than I used to** | **Hardly at all** |

**13.** I get sudden feelings of panic.

| | | | |
|---|---|---|---|
| **Very often indeed** | **Quite often** | **Not very often** | **Not at all** |

**14.** I can enjoy a good book or radio or TV programme.

| | | | |
|---|---|---|---|
| Often | **sometimes** | **Not often** | **Very seldom** |

# APPENDIX F

## Medical Interview Satisfaction Scale- MISS

**Read the following statement and select your level of agreement to the following statement**

1 The Doctor told me just what my trouble is.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

2 After talking to the doctor. I know just how serious my illness is

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

3 The doctor told me all I wanted to know about my illness

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

4 I am not really certain about how to follow doctor’s advice

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

5 After talking with the doctor, I have a good idea of how long it will be before I am well again.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

6 The doctor seemed interested in me as a person.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

7 The doctor seemed warm and friendly to me.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

8 The doctor seemed to take my problems seriously.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

9 I felt embarrassed while talking with the doctor

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

10 I felt free to talk to this doctor about private matters

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

11 The doctor gave me a chance to say what was really on my mind

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

12 I really felt understood by my doctor

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

13 The doctor did not allow me to say everything I had wanted about my problems

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

14 The doctor did not really understand my main reason for coming

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

15 This is a doctor I would trust with my life

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

16 The doctor seemed to know what (s)he was doing.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|

| | | | | | | |
|---|---|---|---|---|---|---|
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

17 The doctor has relieved my worries about the illness

| | | | | | | |
|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

18 The doctor seemed to know just what to do for my problem.

| | | | | | | |
|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

19 I expect that it will be easy for me to follow the doctor's advice

| | | | | | | |
|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

20 It may be difficult for me to do exactly what the doctor told me to do.

| | | | | | | |
|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

21 I'm not sure the doctor's treatment will be worth the trouble it will take.

| | | | | | | |
|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Very strongly disagree | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree | Very strongly agree |

# APPENDIX G

## Multidimensional Health Locus of Control (Form C)

**Form C Instructions:**

Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circleONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

| | |
|---|---|
| **1=STRONGLY DISAGREE (SD)**<br>**2=MODERATELY DISAGREE(MD)**<br>**3=SLIGHTLY DISAGREE (D)** | **4=SLIGHTLY AGREE (A)**<br>**5=MODERATELY AGREE (MA)**<br>**6=STRONGLY AGREE (SA)** |

| | | SD | MD | D | A | MA | SA |
|---|---|---|---|---|---|---|---|
| 1 | If my condition worsens, it is my own behavior which determines how soon I will feel better again. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2 | As to my condition, what will be will be. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3 | If I see my doctor regularly, I am less likely to have problems with my condition. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4 | Most things that affect my condition happen to me by chance | 1 | 2 | 3 | 4 | 5 | 6 |
| 5 | Whenever my condition worsens, I should consult a medically trained professional. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6 | I am directly responsible for my condition getting better or worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7 | Other people play a big role in whether my condition improves, stays the same, or gets worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8 | Whatever goes wrong with my condition is my own fault. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9 | Luck plays a big part in determining how my condition improves | 1 | 2 | 3 | 4 | 5 | 6 |
| 10 | In order for my condition to improve, it is up to other people to see that the right things happen. | 1 | 2 | 3 | 4 | 5 | 6 |
| 11 | Whatever improvement occurs with my condition is largely a matter of good fortune. | 1 | 2 | 3 | 4 | 5 | 6 |
| 12 | The main thing which affects my condition is what I myself do. | 1 | 2 | 3 | 4 | 5 | 6 |
| 13 | I deserve the credit when my condition improves and the blame when it gets worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 14 | Following doctor's orders to the letter is the best way to keep my condition from getting any worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 15 | If my condition worsens, it's a matter of fate. | 1 | 2 | 3 | 4 | 5 | 6 |
| 16 | If I am lucky, my condition will get better. | 1 | 2 | 3 | 4 | 5 | 6 |
| 17 | If my condition takes a turn for the worse, it is because I have not been taking proper care of myself | 1 | 2 | 3 | 4 | 5 | 6 |
| 18 | The type of help I receive from other people determines how soon my condition improves. | 1 | 2 | 3 | 4 | 5 | 6 |

# APPENDIX H

## The God Locus of Health Control (GLHC) Scale

### DIRECTIONS (for investigators)

The GLHC is designed to assess the belief that God is either the locus of control of one's health status, in general, or the locus of control of one's specific disease status. It can stand alone or be imbedded in Forms A/B or C of the MHLC scales. If, as with Forms A/B, you wish to use it to assess general health beliefs, choose the word "health" in the items below. If, as with Form C, you wish to assess condition-specific beliefs, substitute for the material in parentheses the name of the actual condition you are studying. For instance, in our work with persons with arthritis, the last item (see below) reads: "God is in control of my arthritis." If you choose to embed it within the MHLC, one easy way to do so is to have three MHLC items followed by one of the GLHC items.

The response scale for the GLHC should be the same as for the MHLC scales, which, in our work, is a 6-point Likert scale: "strongly disagree;" "moderately disagree;" "disagree;" "agree;" "moderately agree;" and "strongly agree." [If you use a different response scale, that may be OK; just be consistent.] As with the MHLC subscales, all the items are keyed in the same direction; a high score represents belief in God as a locus of control.

### GLHC ITEMS

1. If my (health; condition) worsens, it is up to God to determine whether I will feel better again.

2. Most things that affect my (health; condition) happen because of God.

3. God is directly responsible for my (health; condition) getting better or worse.

4. Whatever happens to my (health; condition) is God's will.

5. Whether or not my (health; condition) improves is up to God.

6. God is in control of my (health; condition).

# Appendix I

## Interview Schedule

### About the treatment process

1. What is the Illness problem you have been admitted for in this hospital?

2. What is the treatment that you are undergoing?

3. Who provided with the information about the treatment?

4. How long have you been going through this treatment?

5. For how long have you been taking treatment here?

6. Do you think you have sufficient information about your treatment?

7. How did hospital staff like nurses, junior doctors and oncologist helped you in providing with information

### First Consultation

8. What were your expectations from the consultations?

9. What happened during your first consultation?

10. How did you feel after the consultation?

11. In what ways do you think these communication helped you in treatment process?

12. What were the questions that came to you after the consultation?

13. Do you feel the questions were answered by the oncologist?

14. How did the doctor try to answer all your queries?

15. How satisfied did you feel from the consultation process?

16. What are the questions you think wasn’t answered by the oncologist?

**Patient- physician communication**

17. In what way did the oncologist disclosed the illness to you?

18. What ways do you think the oncologist could have revealed the illness to you?

19. Apart from the treatment process what other areas did the doctor disclose to you?

20. After the diagnosis, what is your doctor's contribution in helping you continue the treatment?

21. Do you feel satisfied with the treatment process?

**Preference of Communication**

22. In what other ways do you think your doctor could have helped you deal with your Illness?

23. Do you think there could be some other way in which doctor could help you cope with your illness?