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ORIGINAL ARTICLE

A Qualitative Study of Decision-making (DM) in Surgery and Cancer Care: an Indian Perspective

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Abstract

Cancer psychology is a vitally important part of cancer management. Qualitative research is a gateway to exploring this. Weighing the treatment options in terms of quality of life and survival is important. Given the globalization of healthcare seen in the last decade, the exploration of the decision-making process in a developing nation was deemed highly appropriate. The aim is to explore the thoughts of surgical colleagues and care providing clinicians about patient decision-making in cancer care in developing countries, with special reference to India. The secondary objective was to identify factors that may have a role to play in decision-making in India. A prospective qualitative study. The exercise was carried out at Kiran Mazumdhar Shah Cancer Center. The hospital is a tertiary referral center for cancer services in the city of Bangalore, India. A qualitative study by methodology, a focus group discussion was undertaken with the members of the head and neck tumor board. The results showed, in India, decision-making is predominantly led by the clinicians and the patient's family members. A number of factors play an important role in the decision-making process. These include as follows: health outcome measures (quality of life, health-related quality of life), clinician factors (knowledge, skill, expertise, judgment), patient factors (socio-economic, education, cultural), nursing factors, translational research, and resource infrastructure. Important themes and outcomes emerged from the qualitative study. As modern healthcare moves towards a patient-centered care approach, evidence-based patient choice and patient decision-making clearly have a greater role to play, and the cultural and practical issues demonstrated in this article must be considered.

Keywords Decision-making · Surgery · India · Cancer-care · Cancer-surgery · Quality-of-Life · Joint decision-making · Shared decision-making · Patient decision-making

Introduction

Decision-making in oncology is often difficult and is influenced by patient preferences, availability and affordability of viable treatment options, views of the treating clinicians, and also cultural factors [1]. Decision-making in surgery and cancer care is an interesting, challenging, and yet little explored area of surgical sciences research. There can be complex social and ethical dilemmas that need to be tackled when making treatment decisions [2]. A number of other factors play an important role in the decision-making process. These include as follows: health outcome measures (quality of life, health-related quality of life), clinician factors (knowledge, skill, expertise, judgment), patient factors (socio-economic, education, cultural), nursing factors, translational research, and resource infrastructure. In addition, evolving technologies such as artificial intelligence, decision aids, and widely available internet information have only made this process more complex [3].

Decision-making in surgery and cancer care was explored using a methodology of qualitative studies. To derive a more comprehensive view, different specialties were explored: breast, colorectal, and head and neck surgery. The qualitative focus group discussions were undertaken in a tertiary

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healthcare center in Southern India. Qualitative studies were based on focus group discussions.

Participants and Methods

Focus Group

A focus group is a formal discussion with 12 people on a specific topic. The group is facilitated by a moderator who keeps participants focused on the topic of interest. The purpose of a focus group is to collect in-depth information from a group of people who represent the population of interest. This useful, qualitative research tool has been an underutilized research technique for improving theory and practice in health education [4, 5].The qualitative study design, given the exploratory nature of the inquiry and the limited existing evidence on decision-making in surgery and cancer care, was adopted. Focus groups were used to capitalize on group interactions, and to elicit rich experiential data by exploring participants' knowledge and experiences [6]. In addition, focus groups are suitable for examining how knowledge and, more importantly, ideas develop and operate within a given cultural context [7]. The focus group discussion was undertaken with the members of the head and neck tumor board. The study explores the thoughts and attitudes of the care providing clinicians about patient decision-making in cancer care. The participating members were briefed in advance about the research project. The focus group discussion was held prior to a scheduled tumor board meeting. The characteristics of participants in the focus group are illustrated in Table 1.

The focus group discussion explored clinicians' opinions and thoughts about patient decision-making in cancer care in an Indian context. The focus group included head and neck surgeons, oncologists, radiotherapists, psychosocial workers in addition to a senior lecturer and surgeon from Cardiff University, along with the chief investigator, who was running the focus group discussion. The focus group discussion was moderated by the chief investigator and the co-investigator. Stimulus material in the form of abstracts from published papers relevant to decision-making and patient preferences were given to the members. The focus group discussion was audio taped and transcribed. All quotations were anonymized for confidentiality purposes. Qualitative methodology was adopted for analysis. Thematic analysis using a framework approach was done to identify themes and outcomes. Two surgical research fellows analyzed the data separately for accuracy and repetitiveness of the themes and outcomes.

Table 1 Characteristics of participants in focus group

Characteristic (job title)	Focus group participants ($n = 12$)
Professors	1 (head and neck)
Surgical consultant/senior lecturer	1 (colorectal)
Clinical oncologists	3
Surgical registrars	4
Allied health professional	3 (psychosocial workers)

Study Setting

The exercise was carried out at Kiran Mazumdhar Shah Cancer Center. The hospital is a tertiary referral center for cancer services in city of Bangalore, India.

Sampling

Purposive sampling was used to select focus groups from healthcare professionals who make surgical and cancer care decisions routinely.

The stimulus material (Appendix 1) for use in focus group discussions was developed following a review of the literature. Abstracts of the relevant papers on decision-making and patient preferences were used. The abstracts used as stimulus material are illustrated in Appendix 1.

The focus group discussion was always preceded by a standard presentation by the researcher on the focus group discussions and a brief introduction to decision-making in surgery and cancer care. This was followed by distribution of stimulus material, with time to read the abstracts. The researcher would initiate the discussion and moderate the session.

Data Collection

With the consent of participants, the focus groups were tape recorded and transcribed verbatim. The data was anonymized for confidentiality reasons.

Analysis

Qualitative data analysis is a notice, collect, and think process [8]. Interesting findings on the transcribed data were marked and coded alphabetically or numerically, as appropriate. The codes were then sorted and sifted through the data. Codes were summarized, synthesized, and sorted from many observations made from the data. The thinking process involved searching for types, classes, sequences, processes, patterns, or wholes. This process led to a reconstruction of the data in a meaningful and comprehensible fashion, identifying recurrent concepts as themes. Two researchers read the transcripts individually (NS: author and BJ: co-researcher), and independently noted down the core themes that emerged. The notes were compared, and any discrepancies were resolved by consensus. Each researcher took the lead to identify sub-themes (NS analyzed the themes). Solutions were carved out for the problems identified from the focus group discussions, and these were called “outcomes.” Anonymized quotations were considered within the context of the focus group discussions, and the important ones with key messages are part of this document.

The quotations have been selected to illustrate the themes raised by participants and they are indicative both of typical responses and of the diversity of views obtained.

Decision-making processes in malignant conditions were methodologically evaluated using qualitative methods. Qualitative tools used included focus group discussions. Thematic analysis of the collated data was done using the framework approach, thereby identifying themes and outcomes. Analysis of qualitative research data was carried out using a validated technique.

Results

The emerging themes and outcomes are shown in Table 2.

Quotations

Cost and Affordability

> **R:** Money is the first thing … actually the most important factor, if they cannot afford the treatment, there is no point in telling [the patient about it].
>
> **R:** When the patient comes to the hospital in Britain, nobody talks of money. Here, the first thing is how much it costs.

Quality of Life

> **R:** They do not talk about quality of life.
> **R:** The best option, whether it is debilitating or low quality of life, we have to offer it. He has an option of refusing it, but just because you may not like it, we should not refuse that option.
> **R:** When the patient comes to the hospital in Britain, nobody talks of money. Here, the first thing is how much it costs. They do not talk about quality of life that is all.

Case Complexity and Choice of Therapy

> **R:** If there is a clear-cut answer to a problem, there is no discussion. A discussion comes when there are multiple options.

Ease of Communication

> **R:** Patients feel [more] comfortable communicating with doctors than nurses.

Decision-making

> **R:** They know what was discussed here, that will be conveyed to the patient and then we come up with a decision.

Table 2 Emerging themes and outcomes

Emerging themes	Derived outcomes
Patient factors	
Cost and affordability	Shift from healthcare provider and to healthcare insurer
Quality of life	Raising awareness of health outcome measures
Patient choice and demand	Respect patient choice/demand/trust and beliefs
Trust and beliefs	
Patient knowledge	Raise patient knowledge
Socio-economic and educational status	Consider socio-economic/educational status while decision-making
Family and social support	
Clinician and clinical factors	
Communication, risk, and consent	Train clinicians in risk communication/consent
Patient advocate	Encourage patient groups/voice
Information technology	Direct patients to evidence based, reliable, specialty-based websites
Clinician knowledge	Raise clinician knowledge
Psychosocial workers/nursing	
Sharing and support	Increase nursing input in patient care

Patient Choice and Demand

> **R:** We will have some definite plan that was made, and sometimes the patient has a completely opposing treatment plan, and we strongly feel that patient needs to be counseled, therefore we try our best to counsel, but sometime the patient will be against us.
> **R:** We have had a few patients who come demanding for a particular type of therapy.
> **R:** I mean it is not really uncommon for people to come with some particular treatment in their mind, it need not be the best possible option.

Trust and Beliefs

> **R:** Totally curable, but patient is going to go for Siddha ayurvedic treatment. We tried to explain that this is curable, but he is against it, we cannot force the patient, but we said we will keep an eye on the patient. I am helpless.
> **R:** I have belief in surgery, but sometimes belief is what patients [have too]. So, all of us have certain bias based on it. Patients have their own perspective about life and treatment.
> **R:** A man working at a vice president level in an IT company is telling me that his uncle told him that radiotherapy will disfigure her, so she did not take radiotherapy, now she is left with an expected life survival of three months. So, it is an interesting concept, but there are lots of social issues attached to it and we will be very happy to choose the patients who get involved during decision making.
> **R:** One of our very senior oncologists is considered as God in India. They will go and touch his feet, the only thing he does is to tell to them, they will be cured. We know that he is giving the patient hope. He sells hope. He is so popular that he travels across India. He sees patients in the airport, anywhere and everywhere, and he is God, people love him.

Evidence-Based Patient Preferences, Patient Choice, or Patient Decision-making

Financially Driven

> **R:** In India, it is a completely different scenario. Our practice is a very bad practice. If he does not like me or the other surgeon, there are enough renowned hospitals in the city where patients can go and if, you know, there are hospitals where the doctors will do whatever the patient say. So, it is a completely different concept.
> **R:** That is exactly opposite what happens in India. The patient has enough and more choices. We see so many patients who shop around the whole of the country and then come to us.

Affordability

> **R:** Affordability is the first thing that is actually the most important factor, if they cannot afford the treatment, there is no point in telling them the various options.
> **R:** When the patient comes to the hospital in Britain, nobody talks of money. Here, the first thing is how much it costs. They do not talk about quality of life.

Socio-economic and Educational Status

> **R:** The level of understanding and education, it is very different among patients. Dr [X] has worked in a centre where the financial status of the patients was very different, so I am sure he has a perspective of that, compared to this hospital where we see more of humble background patients.
> **R:** You know, lots of patients are not educated. They do not understand what is happening. In fact, they do not know what is happening with them.

Clinician and Patient Knowledge

> **R:** So, to involve them, you know, you can make a decision if you have knowledge. We see some patients who do extensive internet search, come to us and seek treatment. That may or may not be the right treatment for them. If somebody does not have the knowledge, it is very difficult to make the patient understand the whole process.
> **R:** I am talking about patients' knowledge. See, day before yesterday I saw one patient, a man working at a senior position in IT Company, somewhere in his 50 s, came to me with his wife's records. She had recurrent astrocytoma grade 3, operated one year back. She did not receive any radiotherapy, because his uncle told him that radiotherapy will disfigure her.

Family and Social Support

> **R:** They do not understand what is happening with them. There is a decision maker in the family who takes all the decision.
> **R:** Sometime I do not communicate everything to the patients; difference being family psychology in India is different from UK.

R: Here sometimes, there is one leader in the family, or we might talk to that particular person and then they will communicate gradually to the patients. So, we may not deliver everything to the patient. The family network is very, very strong in India.

Information Technology

R: They could do internet search. Most of the search is done on websites like Google, which will not give you what is the best therapeutic option for the patient. It will just give some kind of a treatment and majority of the patients come with treatment options which are not actually significant.
R: We see a lot of patients who come [asking for] interesting drugs or techniques which are in phase 1 and phase 2 trials, because that is what forms headlines in newspapers or articles. So, we always face this problem.
R: We did try to divert them to more reliable sites. We offered them what we have.

Analysis of Multidisciplinary Team/Tumor Board Meetings

R: I think that it is the rule for the Tumor Board to make the right decision. Of course, the patient has choices to schedule the treatment.

Patient Advocate

R: As a clinician, we have a tradition of making the right decision for the patient.
R: The ultimate aim of the clinician is to work for the patient, but at the same time, it is our job to make right decision.

Communication with Patients/Risk Communication

R: We fight for the patient, we try to bring the family and discuss in detail, and communication can be a problem.
R: Let's say that, I have a break in my communication, sometimes you do not gel well with the patient, and then I feel that you should seek a colleague's help.
R: I think that we cannot ask the nurse to communicate for you.
R: But, we cannot delegate a nurse to communicate fully, that is not we are working for. We should make time for communication with patients.
R: In fact, the initial communication is the key, you can step aside after the treatment is initiated, but if the initial communication is lacking, I think there is a major error.
R: If time is an issue, increase the manpower.
R: Nurses in the UK know the patient very well, but some patients need things to be told 10 times for them to remember. That is where those nurses kick up that extra number of conversations.
R: I will say what the expected complications or sequela of the treatment are.

Nurses

R: In India, the role of nurses in communication with regard to the cancer care is minimal. Most of it is done by the clinicians.
R: I think that we cannot ask the nurse to communicate for you.
R: But, we cannot delegate nurses to communicate fully. That is not we are working for.
R: Nurses in the UK know the patient very well, but some patients need things to be told 10 times for them to remember. That is where those nurses kick up that extra number of conversations.

Medical Social Workers

R: Medical social worker, he plays the same role in communication as a specialist nurse practitioner. His background is science graduate, he has done a Masters in medical social work, and when they, he/she, comes to us, he may not have much experience in cancer, and they sit with us in the Tumor Board meetings, and learn what is necessary.

Sharing and Support

R: We do not have, but we are trying to develop patient support groups.

Patient Voice

R: I think we need the patient voice to say what is important.

Individualization of Treatment

R: We have to individualize treatment.

Consent

R: The consent process is not very, very strict. We would tell everything, but we do not write down all the possible complications. I heard [that in the] US that they write down every possible individualized consent form, write everything possible. You can imagine that consent form.

R: That will protect you, medico-legally to certain extent.

Discussion

There is growing interest towards patient-centered care [9] and patient-centered decision-making [9]. Patient decision-making is taking a significant minority in the west and shared decision-making is the current norm in the west [10].

Undoubtedly, themes that were generated from our work revolved around patient factors, clinician factors, nursing, and psychosocial components. When considering patient factors, some of the components that were considered included cost and affordability, quality of life, patient choice and demand, trust and beliefs, patient knowledge, socio-economic status, educational status, and social support including that of family.

The outcomes generated included a significant shift from the state being a healthcare provider and to a healthcare insurer, raising awareness of health outcome measures, respect patient choice/demand/trust and beliefs, raise patient knowledge, and consider socio-economic/educational status while decision-making.

On the clinician and clinical front communication, risk and consent, patient advocacy, information technology, and clinician knowledge formed the key themes. The outcomes generated include training clinicians in risk communication/consent, encouraging patient groups/voice, direct patients to evidence-based, reliable, specialty-based websites, and raise clinician knowledge.

On the nursing and psycho-social front sharing and support came out as a key theme and the outcome was to increase nursing input in patient care.

When making decisions, it is important that patients' views are taken into account, in addition to their level of knowledge and demands.

It was noted that patients' preferences and decisions are influenced by family members [11]. Patient choice has not developed to any large extent in the developing world. This is due to a number of factors, including cost and affordability, illiteracy, tradition, and lack of awareness [2]. There is also a spiritual aspect in the decision-making process. There does not seem to be much of an emphasis on quality of life.

Internet search engines (www) are also playing a role in decision-making. There has been an enormous amount of discussion about the redundant information available on the internet, especially on search engines such as Google [12]. The consensus is that most of the available information is unreliable, and it is important for the care providing clinicians to direct patients to appropriately reliable specialty websites, and web publications from the relevant medical societies (such as ASCRS, ACPGBI, BASO, ASGBI).

In low- and middle-income country (LMIC) settings, where resources can be limited, oncology clinicians often have to make important decisions quickly using yet unexplored heuristic patterns. "Heuristics" are cognitive shortcuts that are used in situations of high complexity or uncertainty or when the time for individual decision-making is short both of which are common factors in a busy oncology clinic or multidisciplinary team meetings (MDT) [13].

Multidisciplinary teams/tumor boards have a role to play. Evaluation of the quality of multidisciplinary team tumor board decision-making is important. The proportions of decisions implemented are grossly unknown. One such study was from Wood et al., a group in Bristol who evaluated the treatment decisions of the colorectal cancer multidisciplinary team [14]. This study examined multidisciplinary team decision-making by studying whether multidisciplinary team treatment decisions were implemented, and investigated the reasons why some decisions changed after the meeting. The vast majority of colorectal multidisciplinary team decisions were implemented, and when decisions changed, it was mostly because of patient factors that had not been taken into account. This raises the question whether involvement of patients in the multidisciplinary team process would help with better decision-making.

Studies done on physicians who answered a questionnaire about treatment decisions on elderly cardiac patients with multiple comorbidities found that physician while treating this group of elderly patients depended more on their own personal experience and patient preferences than on standardized guidelines [15]. The nature of professional training may impact decision-making and in fact, there is some data to suggest that for non-specific chest pain, cardiologists and internists may differ in terms of investigations requested [16].

Attitudes of clinicians differ towards the nurses with respect to the roles they can undertake in the developing world. In the western world, nurses are in the forefront of patient care. This does not seem to be the case in the developing world. Some of the responsibilities of the specialist nurses are undertaken by the medical social workers. Medical social work is a subdiscipline of social work, also known as hospital social work. Medical social workers typically work in a hospital, skilled nursing facility, or hospice; have a graduate degree in the field; and work with patients and their families in need of psychosocial help. Medical social workers assess the psychosocial functioning of patients and families, and intervene as necessary. Interventions may include connecting patients and families to necessary resources and supports in the community, providing psychotherapy, supportive counseling, or grief counseling, or helping a patient to expand and strengthen their network of social supports. Medical social workers typically work on an interdisciplinary team with professionals of other disciplines (such as medicine, nursing, physical, occupational, speech, and recreational therapy).

In India, trust and beliefs play a significant role in decision-making. The background to this could be because of the role of alternative medicines in India. In Western culture, "alternative medicine" is any healing practice "that does not fall within the realm of conventional medicine." The American National Centre for Complementary and Alternative Medicine (NCCAM) cites examples including naturopathy, chiropractic medicine, herbalism, traditional Chinese medicine, Ayurveda, meditation, yoga, biofeedback, hypnosis, homeopathy, acupuncture, and nutritional-based therapies, in addition to a range of other practices [17]. A 1998 systematic review of studies assessing its prevalence in 13 countries concluded that about 31% of cancer patients use some form of complementary and alternative medicine [18].

Cancer screening has been consistently poor in India. The barriers for population screening seemed to be psychosocial factors [19]. Increasing awareness campaigns, usage of decision-making aids, and changes in government policies are crucial for improving the rate of uptake and successful implementation of national screening programs [19].

Decision-making in oncology is complex, multifactorial, and is influenced by rater and patient-related factors said a study evaluating patient's performance status using the Eastern Cooperative Oncology Group (ECOG) performance scale [13].

Bias Reducing Factors

To overcome bias that may be associated with gathering data, a second moderator was involved in the focus group discussion. The second moderator also took part in thematically analyzing the qualitative data, to help overcome bias. The themes and outcomes from both researchers were compared to derive reoccurring themes and outcomes.

Conclusions

Decision-making in cancer care is a complex physical and cognitive process based on evidence, patient needs, clinician experience, judgment, and patient preference. In India (a developing country), evidence-based patient choice (EBPC) has not developed to a large extent, when compared to the Western world. Decisions seem to be predominantly clinician led. Attitudes of clinicians differ towards the role of nurses. There is not much of an emphasis on quality of life, and there is a clear need for patient groups and a patient voice. In the future, patients should have increased involvement in decisions made about them. The process of decision-making is slowly evolving, and will see metamorphosis in future. It is important for the clinicians and nurses to play a role leading to this change. Decision-making has to be handled delicately and sensitively in cancer care, within the framework of the traditions and culture of the society and financial constraints.

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Declarations

Conflict of Interest The authors declare no competing interests.

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