Title

Health literacy in communication, decision-making and outcomes among cancer patients, their families and clinicians in India: A multicentre cross-sectional qualitative study.

Health literacy in communication, decision-making and outcomes among cancer patients, their families and clinicians in India: A multicentre cross-sectional qualitative study

Richard Harding[1], **Naveen Salins**[2], **Krishna Sharan**[3], **Maria L. Ekstrand**[4,5]

[1]Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, Florence Nightingale School of Nursing, Midwifery and Palliative Care, King's College London, London, UK

[2]Department of Palliative Medicine and Supportive Care, Kasturba Medical College Manipal, Manipal Academy of Higher Education, Manipal, Karnataka, India

[3]Department of Radiotherapy & Oncology, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, Karnataka, India

[4]Division of Prevention Science, Center for AIDS Prevention Studies, University of California, San Francisco, California, USA

[5]St John's Research Institute, St John's National Academy of Health Sciences, Bengaluru, Karnataka, India

Abstract

Objective: Cancer patients in India prefer full information regarding diagnosis and prognosis, but evidence suggests poor insight. This study aimed to identify the role of health literacy among adult patients living with cancer, their families and health professionals in decision-making and treatment outcomes in India.

Methods: This cross-sectional in-depth study recruited patients, families and clinicians from three centers. Inductive thematic analysis informed a novel conceptual model.

Results: We recruited $n = 34$ cancer patients, $n = 33$ family members, $n = 11$ doctors and $n = 14$ nurses ($N = 92$). Principle emergent themes were the following: (1) Preferences and dynamics of diagnosis and prognosis disclosure, for example, the dominant preference was for families who held hope for cure to discourage disclosure; clinicians sometimes disclosed in line with perceived ability to pay for treatment. (2) Understanding of disease and its treatment options (etiology, potential trajectory, treatment options), for example, lay understandings of cancer etiology as contamination from outside the home, and reluctance of patients to ask questions of clinicians. (3) Priorities in decision-making, for example, not engaging patients due to fear of patient distress, patients initiated on anticancer treatments without knowledge or consent,

Correspondence Richard Harding, Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, Florence Nightingale School of Nursing, Midwifery and Palliative Care, King's College London, London SE5 9PJ, UK. Richard.harding@kcl.ac.uk.

Author Manuscript

pursuing futile treatments. (4) Anxieties over finances and outcomes (disclosure, decision-making, care pathways), for example, clinicians attempting to reduce families pursuing expensive and inappropriate treatment options with patients who have poor insight, catastrophic spending based on poor decisions.

Conclusion: The novel evidence-based health literacy model offers potential for feasible and acceptable intervention to support families in communication, disclosure and decision-making. This may improve patients' access to informed, appropriate care pathways.

1 | BACKGROUND

In 2018, there were 1,157,294 incident cancer cases in India, and 784,821 deaths.[1] By 2060, cancer will be the main driver of serious health-related suffering in low-income countries, with an estimated 1.65 million decedents experiencing significant suffering in the last year of life (a 407% increase from 2016).[2,3]

Indian cancer patients would prefer full knowledge regarding diagnosis and prognosis,[4] while their family caregivers prefer the opposite.[4] Patients believed that knowledge of diagnosis and prognosis might enable them to be prepared, know treatment options, anticipate complications, and plan for future and family. The family caregivers thought that patients knowing a diagnosis and prognosis may negatively affect the future course of illness and cause patients to experience stress, depression, loss of hope, and confidence. These findings were corroborated in a further Indian study, with most patients preferring to know their diagnosis, prognosis, treatment options and adverse effects of cancer directed therapies.[5]

Patients require health literacy to make informed decisions. Health literacy is "*the degree to which individuals have the capacity to obtain, process and understand basic health information and services to make appropriate health decisions*",[6] and is key to global health systems strengthening.[7] Greater health literacy would support the WHO's "Strategy on Person-Centred Care" in which "all people have access to health services that are provided in a way that responds to their preferences".

Low levels of patient health literacy are associated with avoidance of care seeking, increased hospitalization and emergency care, poor medication adherence, higher mortality, and decreased uptake of cancer screening.[8-15] Indian studies have documented low levels of health literacy among patients in tertiary care, breast cancer, tuberculosis care, and dental care.[16-20] Low health literacy in India has been associated with lack of vaccination uptake, difficulty understanding medical regimens and missed medical appointments.[19,21]

Health literacy is crucial in the context of cancer, which carries clinical uncertainty, high mortality risk, financial burden, and negatively impacts quality of life.[22] Cancer patients and

families are expected to process information and make complex, informed decisions while facing overwhelming psychological, social, economic, physical and spiritual burden.[23]

While prior health literacy studies have focused on patients and described their preference for full information regarding cancer diagnosis and prognosis, families in many non-Western cultures are often decision-makers.[24-26] A review of the evidence for non-disclosure of a cancer diagnosis and prognosis found that non-disclosure is higher in "family-centric" Asian cultures compared to the rest of the world.[27] The findings suggest that while physician non-disclosure remains common practice in collectivist cultures (such as India), there appears to be a shift in attitudes towards disclosure may occurring. The review reports data from India that family-centeredness leads to collusion between family and oncologist, but concludes that research around disclosure of prognosis in under-researched in India. This is of specific concern given the relatively high mortality rates.

Development of health literacy-promoting interventions in the context of cancer requires an understanding of patients' and families' cultural preferences and practices in information sharing, how health literacy is created and utilized in interactions with health professionals, and the mechanisms by which it affects outcomes.

This study aimed to identify the role of health literacy among adult patients living with cancer their families and health professionals in decision-making and treatment outcomes in India.

2 | METHODS

2.1 | Setting

This qualitative cross-sectional study was undertaken at three hospitals in southern India. These are not for profit, admitting patients under government health schemes that pay patient fees. Ethical review and approval were provided by University California San Francisco (ref: 288665) and Kasturba Medical College and Hospital (ref: 380/2018). The Clinical Trials Registry India reference was CTRI/2019/03/018073.

2.2 | Participants

Inclusion criteria (patients, family members and oncology staff): 18 years of age, able to speak English, Malayalam or Kannada, and to provide informed consent.

Patients must have an established malignancy and attending a cancer center. The family member was nominated by the patient as the person most involved in their care. Purposive sampling criteria (patients and families): age, sex, primary malignancy and stage, family member relationship to the patient, patient HIV status (given the high prevalence of cancer among people with HIV in India, i.e., 10–17 times proportional risk increase for non-Hodgkin lymphoma, 10 for anal cancers in men, 8 for vulva/vaginal malignancies, and 4 for cervical cancer).[28]

Criteria for staff were profession (medicine or nursing), experience with treating cancer patients with HIV infection, and length of clinical experience. Nurses in the oncology

centers are largely trained through experience within their job. We aimed to recruit until data saturation, estimated at around 30 patients and 30 family members.

2.3 | Procedure

Patients were referred by oncology and HIV colleagues, staff were recruited from oncologists (including trainees) and oncology nurses at the recruitment sites. Following screening, patients were asked to nominate a family member. Recruitment continued until thematic saturation with respect to study objectives.[29] Patients, family members and staff gave written informed consent prior to data collection.

Interviews were conducted by Indian researchers with a Masters degree in Psychology or Psychiatric social work and had never worked as hospital clinical staff. Data collection took place face-to-face in a private room. Patient interviews were conducted separately from their family members. The interview topic guide (addressed insight and understanding of diagnosis and its implications and expectations for the future, decision-making and information practices processes and preferences, social, psychological and economic implications of decisions.

2.4 | Data management and analysis

Verbatim transcriptions were translated by an independent professional translator within 48 h. Original and back-translated versions were then compared and discrepancies resolved by consensus with the research team. Data were imported into NVIVO V12 for inductive thematic analysis,[30] drawing on social constructivism to understanding how participants create their understanding. We built a single coding frame from all three samples (patients, families, professionals) without a priori themes. The initial coding frame was presented to the cross-national research team, and refined and revised before being applied to the entire dataset by two researchers. The team members involved in analysis were an Indian oncologist, an academic from the United States with over 25 years' experience in research in Indian, and an United Kingdom academic The themes are presented with illustrative quotes with participant ID numbers to demonstrate use of the sample breadth. Reporting is in line with COREQ.

3 | RESULTS

3.1 | Sample characteristics

We recruited $n = 34$ cancer patients (primary cancer diagnoses were mainly gynecological $n = 9$ and breast $n = 6$; Table 1); $n = 33$ family members; $n = 11$ doctors and $n = 14$ nurses (Table 2). Interview duration was 25–69 min. Interviews were conducted in Kannada ($n = 66$), English ($n = 24$) and Malayalam ($n = 2$).

3.2 | Main findings

Four main themes relating to health literacy were identified: (1) Preferences and dynamics of diagnosis and prognosis disclosure, (2) Understanding of disease (etiology, potential trajectory, treatment options, (3) Decision-making, (4) Cost-drivers and outcomes (disclosure, decision-making, care pathways). A model of the data is presented in Figure 1.

3.2.1 | Preferences and dynamics of disclosure—Families overwhelmingly preferred to manage information regarding diagnosis and prognosis, reducing the risk of patient psychological distress,

> "We don't do any such things in front of her, do not talk anything. We live happy. She talks to us happily we also do the same. Actually, she does not know that she has this disease we also stay with her like that only."

> (Family 405)

Even if a patient asks questions, the family choose to "protect" the patient,

> "We haven't told her that it is not curable because she worries a lot. ….. She gets tensed soon. So, we don't share anything with her, be it about the money or her disease. We just talk something else and change the topic."

> (Family 403)

Information was withheld with the expectation of cure,

> "So, I decided at that time itself and told the doctor also that 'I don't like to inform him now and I will inform him when he gets cured and comes out of the hospital. At that time, I would patiently explain to him Sir. I request you also not to tell him anything from your side."

> (Family 402)

A minority of patients used language of "power" "courage" and rights to full, direct disclosure,

> "P: No, no. It should be told to the patient…. We cannot cheat the patient because everybody will have the right in their life. Everyone finds out himself and everybody go on their own. So, when they have that right, it should not be hidden from them… It amounts to cheating, like killing someone by cheating" (Patient 312)

Clinicians also reported that their professional view on patient disclosure was at odds with cultural gender-based processes,

> "As a physician, each and every patient has a right to know what they have. Because eventually it will be the patient who will be getting cured or who will go through all the side effects, might not get cured. But again in our part of the world if you see the socio economic status of the patients which we deal with, the man of the family has a final say in everything."

> (Staff 913)

3.2.2 | Understanding of disease—Patients and families identified tobacco/beedi and alcohol to be the main cancer risks. Common beliefs were also consumption of "outside food" (particularly oily food), pollution and heredity,

> "So, according to what I have read, it occurs because of the plastic consumption. For example, it occurs because of having food and beverages outside."

> (Family 408).

HIV acquisition was rarely associated with unprotected sex,

"**P:** Someone told that the disease comes sometimes, from the blood… and it comes my stepping onto the urine, comes from mosquito bite. …but sometimes it comes in those who urinate, sometimes when people with such disease (HIV) spit, from that it comes, if people step on to the dust of the nose, likewise if we come into the contact with their breath then also it comes like this he told." (Family 214)

Patients and families reported a passive approach to information acquisition from their care providers,

"**I:** Have you spoken to the doctor?

P: The participant nods her head to indicate 'no'…

I: You did not speak to the doctor at all, have you spoken to the sister?

P: No…

I: Why did you not speak?

P: They did not ask… That's why we did not speak about it…" (Patient 319)

Concerns were expressed that clinician time should not be wasted,

> "I did not talk to the doctor about these things, because if we start talking more, there will be many patients behind us. Poor things, they will be disturbed. So, I thought that if I start speaking about it, it may amount to speaking unnecessarily. So, he is one doctor handling hundred patients, as such I cannot speak more about myself."
>
> (Patient 313)

Both medical and nursing staff reported only sharing positive information,

> "But we will always give a positive attitude. Whatever stage it is in 2nd, 3rd stage, we will give positive attitude only. To everyone we say, everything will be alright, everything will be alright…like that only."
>
> (Staff 915)

3.2.3 | Decision-making—Clinicians reported patients and families wanting to hand decisions to the doctor,

> "If you look at the Indian patients, most of the times they generally most of our patients want us to take the decision. That's how it is. You know our patients are not as aware and as educated as the patients in the west. So our patients mostly want us to make the decisions."
>
> (Staff 903)

In terms of multiprofessional care, nurses were clear that they had no role in decision-making and information sharing,

> "I never done. So mainly diagnosis, treatment options everything will be discussed by doctors only. So we do only orders. We don't have any…when they ask us also we don't have any right to explain them."

(Staff 912)

Clinicians provide options relative to the perceived wealth of the patient and family,

> "After seeing the patients, after talking with them, I get an idea about their financial status. So, if a patient is in the low poor socioeconomic state, I don't tell them all those expensive treatments you know. Which will again take them down, because they will agonise that if I had money, I could have been saved. So I don't tell them."

(Staff 910)

Anticipation of distress was the common driver for not involving the patient,

> "She might feel more shocked hearing that the treatment given here is not working out….So they should inform the husband and they could start the treatment in some other way. If the lady gets to know it, her heart would be broken, and she would be in complete shock."

(Family 207)

As a result, the decision-making responsibility does not generally lie with the patient,

> "Actually, as a son, I should only take the decision. We don't have anybody to guide us. We should only take him to the doctors. So, I should only take the decision."

(Family member interview 205)

Therefore, cancer treatment could be initiated without the patient knowing their diagnosis,

> "So, if we tell her about this matter right now, she takes it to her mind which may have side effects during her treatment time… So, like this, there is no problem for her. We have told her that we are getting this treatment as it is necessary to prevent any possible problem in future… So, that treatment has been started… Even at this moment, she does not know that she has the first stage cancer"

(Family 402)

However, treatment initiation was also a route to disclosure,

"Patient: He did not say anything. He did not say that I had the disease. It appears the doctor told my son, and he also did not tell me.

Interviewer: When did you come to know?

Patient: What is there to know? When we see the board, we will know." (Patient 314)

There are serious implications from poor health literacy, including death when alternative treatments are sought,

> "too many patient bystanders are involved in a patient care and they force us, not to impart the information to the patient that they have cancer. This puts us in, you

know, because you see at the end of the day it is the patient who will be tolerating the terrible side effects of the treatment, not the patient relatives. So they have a right and it is our moral duty to inform them. What they are about to go through. The thing that holds us back at times is that, if we actually tell the patient against the patient relative's desire for the same, they can go to another centre. That is not our problem. The problem is potentially curable cancer patients, may be taken away from here (hmm) given some nonsense bull shit Babaji ki bhooti (hmm) and they will lose their lives."

(Staff 906)

In the scenario of disease not responding to treatment, patients would prefer to be told, invoking their rights to information and decision-making,

"Every person will have that much right in their life. We cannot snatch it. It should be told. When you know the truth now, you should tell him, because we come here with a lot of trust in you. If the matter is hidden from the patient and tomorrow if something happens it amounts to a greater crime than a murder. Since you don't intend to take away my life, you will surely inform me. So, even in case of a murder, it will be known that murder has been committed. So, if such a matter is concealed, it becomes a serious crime. It should not be hidden."

(Patient 311)

3.2.4 | Cost-drivers and outcomes—The cost implications for treatment (drugs, travel and accommodation) as well as opportunity cost (family travel with patients, lost employment) exert strong influence on information-giving and decision-making processes.

Patients were able to articulate the trade-off between cost and potential effectiveness,

"In this case, both should decide about that. Since it is expensive, they might have to think about it before choosing it, because if it doesn't work out then it would be a waste of money. So, it is better they both decide about that."

(Patient 311)

There were limits to the sources of finance

"They may get it done once [treatment] by taking the loan with great difficulty, they cannot do it repeatedly Sir. It becomes a major problem for them. Now, the family will face great amount of financial problem Sir."

(Family 419)

The impact of choosing cancer treatment is family-wide and across generations,

"We sold our agricultural land… Now we raised the load for his check-up, followed by this we sold the land… After selling it, he cleared the debt and about 3 lakh rupees [\$US 4,000] were left with us. … We have done everything by taking the loan……It has made lot of effect on our family. Few persons have even supported us thinking that my husband should become all-right… We were bringing money from them, but we should return it also you know Sir… Then we sold our

agricultural land and returned their money. Now, we don't have money, that's why we stopped coming here."

(Family 206).

Clinicians reported a responsibility for honesty to avoid inappropriate catastrophic spending,

"It is no use telling a lie today, 3 months later the patient is dead and the whole family is in a state of denial, the kids are not school, all the property has been sold off. Chasing of fruitless treatment. So it is required to be very truthful. It hurts for a few days. But our psychosocial eh… assistants, they do a tremendous job by helping the patient out of that (hmm)."

(Staff 906)

4 | DISCUSSION

The model derived from our original data identifies the processes in communication, disclosure and decision-making that lead to potentially poor outcomes in serious illness. Health care providers are driven by professional values to disclose (though influenced by perception of ability to pay for treatment). This is countered by family pressure to conceal, driven by fear of invoking patient anxiety. Decisions are commonly taken by male family members. Patients hesitate to ask questions and are often not invited to ask, and nurses do not play a part in information sharing. The sequalae of these processes is that patients may have poor insight into their disease. They often lack agency in decision-making, lack consent to treatment, access potentially futile treatment, and suffer treatment poverty. Within the oncology team these processes are led by the oncologist, with nurses not holding any role in information sharing.

Prior studies have shown that 37% of advanced cancer patients in India had their prognosis withheld by family caregivers with resulting poorer QoL, and that those with poorer education were more likely to have prognosis withheld.[31] Collusion between professionals and families in India leads to prognosis being initially concealed for 40% of advanced cancer patients.[32] Our model illustrates the mechanisms and sequalae of these prior findings. Due to the well-recognized common challenges of late cancer presentation in India, the model addresses health literacy in relation to both diagnosis and prognosis.[33] In our study cancer was the index diagnosis, but comorbidity (such as those in our sample dually diagnosed with HIV and cancer) will expose the patient to other clinical teams with potentially different practices and preferences in disclosure and decision-making.

4.1 | Clinical and research implications

To achieve health literacy, the individual must obtain, process and understand information.[6] Our data suggest that current processes do not enable health literacy among patients with cancer and suggest potentially feasible ways to improve health literacy. Firstly, clinicians are motivated towards disclosure, and families are empowered to hold information. Given that cancer patients prefer diagnostic and prognostic information, interventions to support families to share information and engage patients in decision-making may be appropriate. This is supported by the existing literature.[27] In order for patients to follow

Leventhal's model for self-regulation and disease self-management (awareness of health threat, navigation of effective responses, formulate potential treatment actions, integrate feedback on efficacy an progression),[34] appropriate interventions to meet the first stage (awareness) are crucial.

However, poverty will still mitigate against ability to achieve some treatment-related decisions. The majority of the Indian population (64.5%) spend out-of-pocket for health-related expenses.[35,36] Health-related spending is a major driver of poverty, and is greater for these with advanced disease.[37] Moreover, low socioeconomic status was associated with greater suffering at the end of life in Indian patients with advanced cancer.[38]

With respect to the further research necessary to improve care and outcomes, prior evidence suggests that stigma regarding cancer and death may play a strong role in this process.[39] The data from our study suggest that causes of cancer, the diagnosis and poor prognosis may all be stigmatizing.

4.2 | Study limitations

Firstly, we recruited from three centers geographically co-located or within an hour's drive, therefore we cannot extrapolate to other Indian regions. However, it is noteworthy that our model explains findings from prior studies across India. Second, the interviewers were careful to not disclose information related to their disease, but it cannot be ruled out that the patients had more information than they were prepared to reveal and were colluding themselves. Third, we do not have information on education and socioeconomic status of patients or on disease stage and a larger study would be needed to identify the impact of these characteristics on health literacy. Lastly, further research may reveal additional challenges to health literacy among cancer patients with comorbid diseases other than HIV.

5 | CONCLUSION

Universal Health Coverage requires access to essential health services, that is, prevention, treatment, rehabilitation, and palliative care.[40] This will require improved health literacy to ensure appropriate access and decision-making, especially in light of the projections for cancer mortality and suffering in low- and middle-income countries.[3] Good communication and informed decision-making are the hallmark of quality, person-centered care,[41] and the methods to achieve that must be feasible and acceptable for Indian clinical settings. Our data suggest that families should play a central role in information sharing and that patient preference must be established.

ACKNOWLEDGMENTS

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

REFERENCES

1. GLOBOCAN. GLOBOCAN 2012: Estimated Global Cancer Incidence, Prevalence and Mortality 2012. Lyon, France: IARC; 2014.

2. Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. Lancet Glob Health. 2019;7(7):e883–e892. [PubMed: 31129125]

3. Sleeman KE, Gomes B, de Brito M, Shamieh O, Harding R. The burden of serious health-related suffering among cancer decedents: global projections study to 2060. Palliat Med. 2020;35(1):231– 235. [PubMed: 32945226]

4. Ghoshal A, Salins N, Damani A, et al. To tell or not to tell: exploring the preferences and attitudes of patients and family caregivers on disclosure of a cancer-related diagnosis and prognosis. J Glob Oncol. 2019;5:1–12.

5. Sankar SD, Dhanapal B, Krishnaraj B, Karra S, Natesan V, Gomathi Shankar V. Desire for information and preference for participation in treatment decisions in patients with cancer presenting to the Department of General Surgery in a tertiary care hospital in India. J Glob Oncol. 2018;2018(4):1–10.

6. Institute of Medicine. Health Literacy: A Prescription to End Confusion. Committee on Health Literacy, Board on Neuroscience and Behavioral Health. Washington, DC: National Academies Press; 2004.

7. Dodson S, Good D, Osborne R. Health Literacy Toolkit for Low- and Middle-Income Countries: A Series of Information Sheets to Empower Communities and Strengthen Health Sytsems. New Delhi, India: World Health Organization, Regional Office for South-East Asia; 2015.

8. Cartwright LA, Dumenci L, Cassel JB, Thomson MD, Matsuyama R. Health literacy is an independent predictor of cancer patients' hospitalizations. Health Lit Res Pract. 2017;1(4):e153– e162. [PubMed: 31294261]

9. Zhang NJ, Terry A, McHorney CA. Impact of health literacy on medication adherence: a systematic review and meta-analysis. Ann Pharmacother. 2014;48(6):741–751. [PubMed: 24619949]

10. Bostock S, Steptoe A. Association between low functional health literacy and mortality in older adults: longitudinal cohort study. BMJ. 2012;344.

11. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011;155(2):97–107. [PubMed: 21768583]

12. Morris NS, Field TS, Wagner JL, et al. The association between health literacy and cancer-related attitudes, behaviors, and knowledge. J health Commun. 2013;18(Suppl 1):223–241.

13. Peterson NB, Dwyer KA, Mulvaney SA, Dietrich MS, Rothman RL. The influence of health literacy on colorectal cancer screening knowledge, beliefs and behavior. J Natl Med Assoc. 2007;99(10):1105–1112. [PubMed: 17987913]

14. Ojinnaka CO, Bolin JN, McClellan DA, Helduser JW, Nash P, Ory MG. The role of health literacy and communication habits on previous colorectal cancer screening among low-income and uninsured patients. Prev Med Rep. 2015;2:158–163. [PubMed: 26844065]

15. Sentell T, Braun KL, Davis J, Davis T. Health literacy and meeting breast and cervical cancer screening guidelines among Asians and whites in California. SpringerPlus. 2015;4:432. [PubMed: 26306294]

16. Sreedevi A, Quereshi MA, Kurian B, Kamalamma L. Screening for breast cancer in a low middle income country: predictors in a rural area of Kerala, India. Asian Pac J Cancer Prev. 2014;15(5):1919–1924. [PubMed: 24716912]

17. Muniyandi M, Rao VG, Bhat J, Yadav R, Sharma RK, Bhondeley MK. Health literacy on tuberculosis amongst vulnerable segment of population: special reference to Saharia tribe in central India. Indian J Med Res. 2015;141(5):640–647. [PubMed: 26139783]

18. Rathnakar U, Belman M, Kamath A, Unnikrishnan B, Shenoy A, Udupa A. Evaluation of health literacy status among patients in a tertiary care hospital in coastal Karnataka, India. J Clin Diagnost Res. 2013;7(11):2551–2554.

19. D'Cruz AM, Shankar Aradhya MR. Health literacy among Indian adults seeking dental care. Dent Res J. 2013;10(1):20–24.

20. Ramandeep G, Arshdeep S, Vinod K, Parampreet P. Oral health literacy among clients visiting a rural dental college in North India—a cross-sectional study. Ethiop J Health Sci. 2014;24(3):261–268. [PubMed: 25183933]

21. Johri M, Subramanian SV, Sylvestre M-P, et al. Association between maternal health literacy and child vaccination in India: a cross-sectional study. J Epidemiol Community Health. 2015;69(9):849–857. [PubMed: 25827469]

22. Kelley AS, Covinsky KE, Gorges RJ, et al. Identifying older adults with serious illness: a critical step toward improving the value of health care. Health Serv Res. 2016;52(1):113–131. [PubMed: 26990009]

23. Moens K, Higginson IJ, Harding R, IMPACT E. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? a systematic review. J Pain Symptom Manag. 2014;48(4):660–677.

24. Rao A, Ekstrand M, Heylen E, Raju G, Shet A, Shet A. Breaking bad news: patient preferences and the role of family members when delivering a cancer diagnosis. Asian Pac J Cancer Prev. 2016;17(4):1779–1784. [PubMed: 27221852]

25. Macaden SC. Integrated care plan for the dying: facilitating effective and compassionate care as an urgent process needed in India. Indian J Palliat Care. 2017;23(1):1–2. [PubMed: 28216855]

26. Stanford J, Sandberg DM, Gwyther L, Harding R. Conversations worth having: the perceived relevance of advance care planning among teachers, hospice staff, and pastors in Knysna, South Africa. J Palliat Med. 2013;16(7):762–767. [PubMed: 23701035]

27. Chittem M, Maya S, Chawak S. Nondisclosure of a cancer diagnosis and prognosis: recommendations for future research and practice. Indian J Cancer. 2021;58(2):158–164. [PubMed: 32594077]

28. Dhir AA, Sawant S, Dikshit RP, et al. Spectrum of HIV/AIDS related cancers in India. Cancer Causes Control. 2008;19(2):147–153. [PubMed: 17992576]

29. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 2018;52(4):1893–1907. [PubMed: 29937585]

30. Braun V, Clarke V. What can "thematic analysis" offer health and wellbeing researchers? Int J Qual Stud Health Well-being. 2014;9:26152. [PubMed: 25326092]

31. Victor A, George CE, Inbaraj LR, Norman G. Benefit or harm? a study on impact of collusion on the quality of life among palliative care patients. Indian J Palliat Care. 2018;24(1):61–66. [PubMed: 29440809]

32. Jeba J, Jacob A, Kandasamy R, George R. The patient who 'must not be told': demographic factors associated with collusion in a retrospective study in South India. Postgrad Med J. 2016;92(1093):659–662. [PubMed: 27099298]

33. Thakur NA, Humne AY, Godale LB. Delay in presentation to the hospital and factors affecting it in breast cancer patients attending tertiary care center in Central India. Indian J Cancer. 2015;52(1):102–105. [PubMed: 26837990]

34. Leventhal H, Phillips LA, Burns E. The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. J Behav Med. 2016;39(6):935–946. [PubMed: 27515801]

35. World Health Organization Global Health Expenditure database. Current health expenditure (% of GDP) - India: World Bank 2016. https://data.worldbank.org/indicator/SH.XPD.CHEX.GD.ZS?locations=IN

36. World Health Organization Global Health Expenditure database. Out-of-pocket expenditure (% of current health expenditure): World Bank 2016. https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS?locations=IN

37. Berman P, Ahuja R, Bhandari L. The impoverishing effect of healthcare payments in India: new methodology and findings. Econ Political Wkly. 2010;45(16):65–71.

38. Malhotra C, Krishnan A, Yong JR, et al. Socio-economic inequalities in suffering at the end of life among advanced cancer patients: results from the APPROACH study in five Asian countries. Int J Equity Health. 2020;19(1):1–13.

39. Harding R, Nair S, Ekstrand M. Multilevel model of stigma and barriers to cancer palliative care in India: a qualitative study. BMJ Open. 2019;9(3):e024248.

40. World Health Organisation. Universal health coverage. http://www.who.int/mediacentre/factsheets/fs395/en/

41. Giusti A, Nkhoma K, Petrus R, et al. The empirical evidence under-pinning the concept and practice of person-centred care for serious illness: a systematic review. BMJ Glob Health. 2020;5(12):e003330.
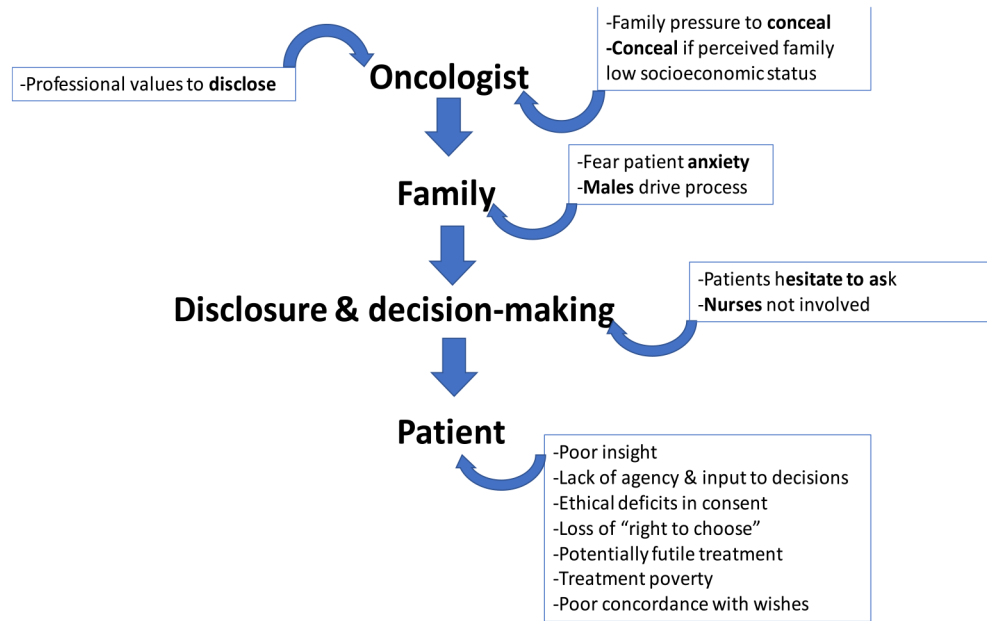
FIGURE 1.

Model of health literacy and its impact on disclosure, decision-making and outcomes among Indian patients and families living with cancer or cancer with HIV

TABLE 1

Staff sample characteristics ($n = 25$)

	N
Professional designation	
Doctor	11
Nurse	14
Gender	
Male	9
Female	16
Institution	
Kasturba Medical College[a]	18
Gov't Medical College Kerala	3
Father Muller Mangalore	4
Medical specialty	($n = 11$, doctors only)
Oncologist	2
Radiation oncologist	8
Oncology surgeon	1
Age	median = 35, range = 22–61
20–29	6
30–39	11
40	8
Years of clinical experience: *nurses*	
5	3
5.1–10	2
10.1–15	1
>15	8
Years of clinical experience: *doctors*	
5	2
5.1–10	3
10.1–15	4
>15	2

[a]One in Mangalore and 17 in Manipal.

TABLE 2

Patient (n = 34) and family (n = 33) sample characteristics

	Patients (n = 34)	Family members (n = 33)
Type of patient		
Cancer	20	18
Cancer + HIV	14	15
Gender		
Male	12	19
Female	22	14
Type of family member		
Spouse		10
Child		15
Sibling		6
Mother		2
Time since cancer diagnosis		
<6 months	17	
6–11 months	4	
12–23 months	5	
24 months	8	
Age	Median = 52, range = 18–68	Median = 36, range = 18–66
18–39	7	18
40–59	17	12
60	10	3