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Experiences of prognosis disclosure versus nondisclosure among family caregivers of persons with advanced cancer

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ABSTRACT

Caregiving in the South Asian context is often assumed by family automatically for the person with cancer (PWC). In this paper, we applied the disclosure decision-making model (DD-MM) to understand the motives behind cancer prognosis disclosure (or not) by caregivers to the PWC. Fifty caregivers participated in semi-structured interviews; and data were analyzed using Framework Approach. For the disclosing caregivers, some of the themes that emerged were consistent with the DD-MM framework while others were not. In particular, the theme “recipient assessment” was part of the DD-MM framework, while others such as unmet communication needs, caregiver self-reflection, and family support were outside of the framework. In contrast, for the non-disclosing caregivers, the reasons for nondisclosure fit very concisely into the DD-MM framework, particularly with information assessment, recipient assessment, and (non) disclosure efficacy. This study has significant implications for development of communication skills trainings around holding family meetings in India.

Introduction



A cancer diagnosis affects persons with cancer (PWCs), their families, and caregivers. The American Cancer Society (n.d.) defines caregivers as “unpaid loved ones who give the person with cancer physical and emotional care.” Caregivers may be spouses, partners, parents, adult children, other family members, or close friends. In most cases, caregivers take on the role without training or any formal education regarding caring for a PWC. This is particularly true in the South Asian context, where family automatically assumes the role of caregiver for the PWC and often make medical decisions as well as decisions to disclose the cancer diagnosis to the person with cancer (Chittam et al., 2020).

This model of care and medical decision-making is very different in Asia than in the Western countries. Whereas for medical providers, disclosing or informing the PWC about their disease, treatments, tests, and procedures is viewed as a legal and ethical concept in the West (Hall et al., 2012), disclosure in Southern-European and Asian cultures often occurs with family members first, who may deliberate and decide against


disclosure to the PWC, and medical providers usually comply with family wishes (Costantini et al., 2006; Maya et al., 2021; Wang et al., 2013). The caregivers may become the direct point of contact for the medical provider and thus, the decision to disclose important medical information to the PWC lies with the caregiver (Wang et al., 2013).

The conundrum of disclosure versus nondisclosure: the Asian perspective

In Asian cultures, where the sense of filial duty toward an ailing PWC is high (Parveen & Morrison, 2009), many family caregivers believe it is their responsibility to shield PWC from emotionally harmful news, such as a cancer diagnosis and/or poor prognosis (Aljubran, 2010). Therefore, nondisclosure of cancer diagnosis/prognosis is based on the principle of non-maleficence (Hu et al., 2002), which, simply put, is the moral obligation on the part of the family to “do no harm” (Gillon, 1985). Consequently, PWC, families and doctors frequently communicate using euphemisms for cancer such as tumor, fever, and

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lump (Epton et al., 2020), thereby allowing them opportunities to circumvent or avoid direct discussions about diagnosis and prognosis whilst still maintaining a channel of communication.

Past research describing the reasons for and against disclosure of cancer diagnosis and prognosis to the PWC has indicated mixed results. Research from India demonstrates that most frequent reasons for disclosure include desire to improve PWC's emotional well-being, maintaining PWC's hope, family, wanting to prepare the PWC, belief that disclosure can instill a fighting spirit, and to avoid anxiety (Chittem et al., 2020, 2021). Conversely, reasons for not disclosing include desire to protect PWC's emotional well-being, beliefs that disclosure can impede the PWC's longevity/curability of cancer, and not knowing how to reveal the truth (Chittem et al., 2020, 2021). Taken together, these studies suggest that the decision to disclose or not disclose is complex and driven by their concerns for the PWC's well-being coupled with the lack of communication skills in diagnosis/prognosis discussions.

In the current study, we apply the disclosure decision-making model (DD-MM; Greene, 2009) to better understand the motives behind cancer prognosis disclosure (or not) by caregivers to PWC in the Indian context. The DD-MM explicates the relevant factors in the health disclosure decision-making process (Greene, 2009). The current study utilizes the DD-MM with a sample of caregivers who made the decision to disclose or not disclose cancer prognosis information to their loved one with cancer.

Disclosure decision-making model (DD-MM)

The DD-MM provides a framework for understanding the motives behind intentional self-disclosure of health information in interpersonal scenarios (Greene, 2009). Most studies using DD-MM have examined an individual's process of self-disclosure of their health information in dyadic contexts (e.g., Cranmer & LaBelle, 2018; Venetis et al., 2018). The DD-MM describes how disclosers navigate different goals such as seeking support from others and wanting to avoid negative reactions. The model focuses on the comprehensive decision-making process to provide understanding of how individuals make decisions about disclosure and non-disclosure of their own health information. This is the first study, to the best of our knowledge that examines the disclosure of an individual's health information to them by their primary caregiver (rather than from the individual to the

caregiver/loved one, as has been previously examined in DD-MM). As well, most of the research on DD-MM has occurred in the United States, and this study applies the model to the Indian context.

The model proposes that individuals base their decision to disclose on three factors: (a) information assessment (information related to stigma, prognosis, symptoms, preparation, and relevance to others), (b) receiver assessment (assessing factors associated with the person receiving the information), and (c) disclosure efficacy (discloser's confidence and skills needed to share the information). This study used the lens of the DD-MM to examine how caregivers made the decision to disclose (or not) prognosis information to the PWC based on (a) information assessment, (b) recipient assessment, and (c) disclosure efficacy.

Method

Research design

The current research study was a part of a larger study to understand experiences of oncologists, PWC and caregivers regarding disclosure and nondisclosure of an advanced cancer prognosis (see Maya et al., 2021). For the current study, we utilized semi-structured qualitative interviews, using exploratory, open-ended questions with caregivers of PWCs (Blandford, 2014). We used open-ended questions and participants' responses to further probe and direct the flow of the interview (Bernard & Ryan, 1998). Data were analyzed using interpretative phenomenological analysis (Smith & Osborn, 2003).

Participants and procedure

Study participants consisted of primary family caregivers of PWC who were undergoing treatment in Hyderabad, India. Using purposive sampling, interviews were conducted with 50 caregivers (64% men) with a mean age of 49 years. [Supplementary Table 1](#) describes the family caregivers' demographic details. Ethics approval for the study was obtained from the Research Ethics Committees of three individual hospitals as well as from the Institutional Ethics Committee, IIT Hyderabad, Hyderabad, India (IITH-IEC-2017-04-05).

The research site was a trust hospital located in Hyderabad, India that provides only cancer care. This hospital treats PWCs from diverse socio-economic and cultural backgrounds ranging from PWCs who receive government health insurance (e.g., Aarogyashree) to those who are self-financing their healthcare. We chose

this research site because it includes PWC-caregivers from a variety of demographic and cultural backgrounds.

Data for this study was collected over seven months. The first author approached family caregivers during the PWC's treatment appointment and explained the general study details (i.e., a study exploring cancer communication experiences). Inclusion criteria for family caregivers were the PWC identified them as crucial to their cancer-related caretaking and decision-making; they were aware of the PWC's diagnosis and prognosis; and they spoke Hindi, Telugu, or English. Of the 70 caregivers who were approached, 5 caregivers declined participation due to PWC related factors (PWC was fatigued, experiencing treatment-related distress, and felt uncomfortable to talk), 5 caregivers declined participation as the family caregivers were uncomfortable with being interviewed, and 10 caregivers became ineligible for the study (for miscellaneous reasons). After obtaining informed consent, caregivers' demographic details were noted, and the interview was conducted. The interview questions are included in [Supplementary Table 2](#).

Interviews

Interviews were held in private rooms. Semi-structured, audio-recorded interviews with open-ended questions were used to focus on caregivers' experiences of the illness and their reasons for disclosure or nondisclosure to the PWC. In particular, the questions centered around the following topics: illness history and experiences of PWC, family's attitude toward disclosure versus nondisclosure of cancer prognosis to the PWC, disclosure and nondisclosure experience - (in the case of disclosing families): details about disclosing (i.e., when, how, who), and reasons for disclosing (versus nondisclosing), (in the case of nondisclosing families): reasons for not disclosing (versus disclosing), who makes this decision, how they ensure nondisclosure - and advantages versus disadvantages of (non)disclosure.

Interviews took approximately 29 minutes (range = 10 to 55 minutes). Interviews were conducted in Telugu (caregiver: $n = 28$), Hindi (caregiver: $n = 6$), and English (caregiver: $n = 16$). All Telugu and Hindi interviews were translated and transcribed in English. Pseudonyms were assigned for each participant.

Data analysis

The approach used to analyze the data was the framework approach, which is a version of thematic analysis

or qualitative content analysis (Ritchie & Spencer, 1994). This method identifies commonalities along with differences in the data and then focuses on the relationship between various subjective parts of the data, eventually drawing descriptive/explanatory understanding around the themes in the data (Gale et al., 2013). Framework approach works through a detailed and systematic six-step process (i.e., familiarizing, coding, working analytical framework, applying the analytical framework, charting the data, and mapping and interpretations) which are interconnected and help the researchers to arrive at a conclusive outcome.

In the present study, the coding team read the transcripts (familiarization); systematically coded the data into themes (data coding); read and deliberated about using DD-MM as the theoretical foundation (working analytical framework); re-read the themes developed in the prior step, and applied the DD-MM framework to code all transcripts, including setting aside themes that did not fit within the DD-MM framework (applying the analytical framework); summarized relevant themes into categories to get themes and sub-themes (charting the data and mapping into the framework matrix); and finally, interpreting and mapping the data to understand the results (data interpretation).

Results

This study qualitatively examined the process of disclosure ($n = 28$) and nondisclosure ($n = 22$) of cancer prognostic information from caregiver to the PWC, using the lens of DD-MM and focusing on (a) information assessment, (b) receiver assessment, and (c) disclosure efficacy. The caregivers were divided into two broad groups (disclosing and nondisclosing) and the results are presented for each of the sub-groups separately. [Supplementary Tables 3 and 4](#) include the quotes for each theme.

Disclosing caregivers (when prognostic information was disclosed to the PWC)

For the disclosing caregivers' group, because the disclosure (of diagnosis and prognosis) had already happened, some of the themes that emerged were consistent with the DD-MM framework and others were not. In particular, the theme 'recipient assessment' was part of the DD-MM framework, while other themes such as unmet communication needs, caregiver self-

reflection, and family support were outside of the framework.

Recipient assessment

Key themes under recipient assessment included: PWC has the right to know, benefits of disclosure, and harms of disclosure.

Most disclosing caregivers revealed that their PWC knew of the prognosis at the very outset and sometimes simultaneously (i.e., both the PWC and caregiver became aware of the prognosis at the same time). However, while some of the caregivers spoke of PWCs having access to this information because it was their “right to know,” many caregivers expressed displeasure about not having control over how and when the PWC “got to know everything about the cancer.” The former group of caregivers believed that their PWC “should know everything – there is nothing that we hide from her and nothing we ever thought of hiding from her” and that they “couldn’t find a reason not to tell” the PWC. These caregivers made active efforts to include the PWC in all the medical decision-making both with the oncologist and in family discussions. On the other hand, the latter group did not like that the PWC was informed the truth without consulting the caregiver. These caregivers were upset not because the PWC was told about the poor prognosis, but that it was told in a “sudden” way and without the caregiver to “cushion the blow.” Despite these reservations on the method of disclosing the prognosis, all caregivers were confident that their PWC will be “able to handle anything, even bad news.” Every caregiver recalled instances of the PWC’s “bravery” which were usually references to how the PWC provided courage to other family members, the primary caregiver and even the healthcare team.

Nearly half ($n = 12$) of the disclosing caregivers were able to identify benefits of their PWC knowing about the prognosis. The central and most frequently cited advantage was that PWCs cooperated with the caregivers’ efforts for taking curative treatment. Caregivers were relieved that the PWC was being adherent to treatment protocols, willing to engage in discussion of treatment options, and remained strong when facing the side-effects of the treatment. They were appreciative when PWCs were “realistic” about cancer treatment (e.g., postponed any “unnecessary” commitments/travels, did not attend many family functions as this may tire them and jeopardize their health) and maintained their focus on “giving everything a go.”

The other half of the caregivers ($n = 13$) believed that prognosis disclosure did more harm than good, exacerbated their PWC’s worries and worsened their emotional well-being. They attributed these poor PWC outcomes to “wanting to know everything without hiding any information,” “constantly” reading up on their illness and amassing “too much” information and being an “overthinker.” Caregivers felt especially distraught as they were helpless and relegated to being “mere spectators of his anguish,” i.e., having to watch the PWC struggle with intrusive thoughts and putting up a strong front for the sake of the family. Consequently, the caregivers tried multiple methods to mitigate these negative effects of being aware of one’s poor prognosis such as trying to “comfort and motivate” the PWC, advising the healthcare professionals about how to “temper the information they share,” and confront the PWC about “looking for information too much” and “taking too much stress.”

Unmet communication needs

Caregivers frequently cited gaps in communication from the oncologist. Key themes included: unapproachable/inaccessible oncologist, lack of information from the oncologist, and lack of time.

According to caregivers, the essential quality of an accessible oncologist was their approachability, especially in terms of clarifying PWC’s queries. That is, an oncologist with whom the PWC felt “comfortable to talk to and ask doubts” and “when you asked them [doctors] for any kind of help, they are always ready to do that.” Language was another major communication barrier that caregivers experienced which, they felt, distanced the oncologist from them. This was observed mainly among older caregivers who were usually the spouse of the PWC. In these instances, caregivers reported that they arranged a phone call between their (educated) child and the oncologist or narrated what the oncologist said whilst sharing pictures of any medical reports as way of seeking clarifications from their children.

Caregivers believed it was the oncologists’ duty to provide correct and timely medical information. When the right information was not given to the PWC/caregiver, it resulted in PWC’s being “greatly” discomfited which made caregivers, sometimes, disappointed with the oncologist. A more common occurrence was that caregivers engaged in guesswork about what the oncologist may have meant to communicate during the medical consultation, especially regarding treatment efficacy and strategy. After a consult (both in-patient and out-patient), caregivers

muller over the content of the interaction for hours and sometimes days – they recounted the entire consultation, analyzed the intent behind the oncologists' words and gestures, pondered over “every little detail,” and discussed the conversation repeatedly with close relatives and PWC. One caregiver even wished they could record these interactions, however brief, for posterity's sake. Since the consultations tended to be short and caregivers were not sure what they can and cannot ask the oncologist, they inevitably attempted to “figure out a link between what the doctor said and how the PWC is feeling.” As the main concern and focus was on extended the PWC's life, they attempted this guesswork in relation to the treatment outcomes.

Lack of time was the prime cause of caregivers' frustration and disappointment in their oncologist, noting that the PWC often lost “interest in asking any questions” after several attempts of “trying to catch the doctor's attention.” Caregivers were able to understand that the oncologist has a “huge” PWC load and, therefore, cannot “spend the kind of time I want him to.” Consequently, caregivers felt that “we should have someone who can explain to us” and were pleased when other members of the healthcare team (e.g., nurses, social workers) cleared their doubts.

Caregiver self-reflection

Caregivers engaged in a reflection of their duties, fears, helplessness, distress, and guilt leading to the following themes: caregiver duties, caregiver fear and stress, caregiver helplessness, caregiver distress, and caregiver guilt.

First, disclosing caregivers believed it was their duty to take care of their PWC and described their caregiving responsibilities in the words of “shoulds,” “musts,” and “hads.” Second, caregivers were afraid for their PWC, the way in which the cancer compromises the body, and about what would happen after the PWC's death. Third, caregivers felt helpless in the face of the “constant, uncontrollable” pain and other side-effects such as nausea, lack of hunger, and difficulty breathing. Bearing witness to the PWC's pain was the most evocative experience for the caregiver as they attempted to reconcile with their desire to prolong their PWC's life through aggressive, curative treatment and the “heart breaking reality” of the pain brought on by the treatment. In addition, caregivers revealed that having to watch the PWC's struggle with the side-effects, especially the “embarrassing” ones such vomiting, hair loss, skin discoloration, was a demanding experience.

Fourth, consistent in the disclosing caregivers' accounts were high levels of distress which emerged from feelings of grief, sadness, and insufficiency. Most disclosing caregivers were extremely shaken when they began talking about their PWC's impending death. The grief led way to feelings of distress since the caregivers felt that the PWC did not have a chance to “live their life to the fullest.” This distress was particularly strong among caregivers who were either the child or parent of the PWC. If the PWC was the child, the parent caregiver was saddened that they (i.e., both PWC and caregiver) would not be able to “see how her life panned out.” If the PWC was the parent, the child caregiver was distressed that they could not help to fulfill their family responsibilities (e.g., marry off their child who was also the caregiver). Finally, some caregivers revealed they were “filled with regret” that they were not able to help detect the cancer early, do “anything and everything to save their life” and berated themselves for thinking the PWC's initial health complaint was “just a simple, general problem.”

Family support

Caregivers described their families coming together to help the PWC and experiences of the family as a unit. This was evident in three themes: family comes together, family providing informational support, and role of the daughter-in-law.

All disclosing caregivers identified and valued the core family members coming together to provide support to the PWC. Family members had multiple, sometimes overlapping, supportive care roles such as providing financial, logistical, informational, emotional and at-home (e.g., cooking, paying bills) support. Owing to the multiple supportive roles shared among family members, caregivers said that “PWCs and caregivers got better with their communication” regarding medical decision-making quite early into the care trajectory.

Families came together to provide multiple types of care of which informational support was the most valued by the caregiver. While caregivers were “proud of how we all became very strong mentally and very supportive,” they were especially happy that every member of the family was doing their best to procure whatever information was needed for and by the PWC. In the beginning, informational support took the form of identifying the “best hospital, best doctor, best care,” this support morphed into information-gathering and provision about self-care practices (e.g., reading up on and purchasing whey protein in order

to “boost their capacity to manage the side-effects”), and symptom identification and reporting (e.g., “I taught her the basic signs that she needs to be aware about the differences in her body system and when she needs to ask for a doctor’s help”). In this way, caregivers approached information support through a practical lens, especially as the PWC was approaching the end-of-life.

Interestingly, of all the family members, the daughter-in-law of the PWC was the most scrutinized in her ability and willingness to perform a supportive care role. Older, male, and married caregivers who were dependent on their children to provide certain forms of care (e.g., cooking, cleaning, emotional) were the only group who shared their views and experiences regarding their daughter-in-law. Some caregivers had “unhappy” experiences because they perceived their daughter-in-law as “unhelpful,” not empathic, and uncooperative. They blamed their daughter-in-law for “poisoning my son ... that’s why even he doesn’t see or talk to my wife that much even when she asks him to visit her.” On the other hand, a daughter-in-law who was perceived to be docile, “proactively helping the PWC,” and fulfilled their role obligations as defined by the wider family network elevated the caregiver’s experiences and improved PWC’s mental health outcomes.

Nondisclosing caregivers (when prognostic information was not disclosed to the PWC)

The reasons for nondisclosure of prognostic information to the PWC fit very concisely into the DD-MM framework, particularly with information assessment, recipient assessment, and (non) disclosure efficacy.

Information assessment

Key themes under information assessment included i) finding a causal attribute, ii) awareness of “poor” prognosis, iii) awareness of treatment being palliative, not curative, and iv) planning to disclose.

First, many caregivers (n = 15) shared their thoughts about how and why their family member got diagnosed with cancer and got to this stage (i.e., causal attribute). Tobacco chewing was cited frequently followed by alcohol, stress, and unknown reasons. In some cases, the search for causal attributes also led to some existential queries such as “he was a good person and never hurt anyone.”

Some caregivers (n = 7) shared their awareness of PWC’s poor prognosis, which was usually delivered to them by the oncologist. All caregivers were able to

clearly make sense of the prognosis and accepted that “some types of cancers just don’t get cured.” While most caregivers were unable to articulate the stage and prognosis using medical jargon, they were all able to coherently convey what their oncologist and their own observations suggested, i.e., “the cancer is only getting worse and worse.” Caregivers assessed the deteriorating “situation” based on a variety of factors such as the cancer type, stage, symptoms, number of treatment side-effects, how the PWC is handling these side-effects, frequency of hospital visits, age of the PWC, and “where the PWC started and where they are now.”

Similarly, many caregivers (n = 7) understood that treatment is palliative, not curative, and maintained realistic expectations of the treatment efficacy, preferred not to insist on curative treatment, and accepted palliative treatment. Although caregivers shared that they were hesitant to stop pursuing treatment with a curative intent, they were aware and accepting of “putting” their PWC on palliative treatment. None of the caregivers used the word ‘palliative’ explicitly (either because the word is alien to them as Telugu-speakers or they preferred not to use the word) but were able to coherently describe the central intention behind palliative treatment, i.e., it is not life prolonging but focused on ensuring the PWC is comfortable. Further, the caregivers did not like to admit that they actively chose palliative treatment for their PWC and focused the conversation on their desire to “ensure she’s not in pain, not uncomfortable ... isn’t going to suffer ... that’s what is important now, ma’am.”

Finally, several nondisclosing caregivers (n = 18) were considering informing the PWC about the poor prognosis at the time of the interview. Whereas some caregivers just mentioned that they were considering informing the PWC, others described their planning in greater detail. They admitted to replaying scenarios in their mind about how they would disclose, what the PWC’s reactions would be, and what they will need to do in order to support the PWC. There were also some caregivers who were more comfortable sharing their thoughts, although fleetingly, said they had “figured out clear and specific way in which a PWC should be told something terrible like this.” Among these methods were revealing the truth gently, assessing how much information the PWC can take and who should disclose, and revealing the prognosis as a family.

Recipient assessment

Key themes under recipient assessment included: oncologist suggested “wait and watch,” protect the

PWC, PWC will understand caregiver's perspective in not disclosing, PWC's "difficult" personality, PWC will not understand and/or hasn't asked, and extended family's reaction toward the PWC.

First, most of the caregivers ($n=20$) reported not disclosing the prognosis because their oncologist suggested it would be best to "wait and watch." These caregivers appreciated the advantages of truthful disclosure, thought that the PWC was "courageous" enough to handle the news, and believed that "a PWC should never be cheated." Yet caregivers were told by their oncologist to "wait and see how the treatment turns out" and "if the cancer does not reduce, then... maybe we should go ahead and tell." Thus, caregivers were in a state of uncertainty, fear, and nervousness (e.g., "it's a little scary because we really do not know how it is going to be in a few days"). They reported that the "hardest part of all this" was that they had to "limit what we reveal or how we behave with the PWC" whilst "worrying what's going to happen in the near future."

Second, many nondisclosing caregivers ($n=14$) wanted to "protect" their PWC from the bad news and thought nondisclosure was the "kindest thing to do at times like these." They were concerned that the PWC might not be able to handle "such terrible news," it would be unfair to burden the PWC with this information, and that this would only worsen their already existing state of "constant worry."

Third, many nondisclosing caregivers were sure that the PWC will understand and accept that they "had" to withhold the truth. They admitted it was a "tricky situation" as their "conversations have to be careful - none of us should over talk or under talk" and regretted keeping their PWC in the dark. Most caregivers reasoned with themselves that not disclosing was the "need of the hour." Caregivers justified their nondisclosure as "doing good" for the PWC. As the PWC's cancer worsened and caregivers questioned their nondisclosure decision, they enlisted the support of the family members who knew the truth to "subtly reinforce my choices," i.e., they relied on these family members to "occasionally take over fielding all the questions," reassure them, and give them courage that they "know how to deal with this, whatever happens, we will deal with it."

Fourth, some non-disclosing caregivers ($n=8$) cited their PWC's personality as the reason for not revealing the truth about their prognosis. PWCs were described as "obstinate," "noncooperative" and "lacking any ability to think ahead." Caregivers displayed signs of anger (e.g., nose flaring, eyes

reddening) and exasperation (e.g., high pitched tone, pursing their lips and raising their eyebrows which is a culturally rooted nonverbal expression) when recounting situations when their PWC refused treatment due to "silly reasons like the needle is hurting too much." Since they wanted the PWC to cooperate with their treatment decisions and "absolutely do not want her to give up at this point in time," they felt it was best not to tell them about the poor prognosis.

Fifth, a small group of caregivers ($n=4$) reported that their PWC had never directly or indirectly indicated to them that they wanted to know the illness prognosis or did not exhibit an ability to comprehend the prognosis even if they were told, therefore they had not disclosed the information. Caregivers felt that there was "no need to make the effort to tell them everything" when they did not communicate or comprehend their prognosis. When probed, the caregiver revealed that they ascertained PWC's illness comprehension through "casual conversations" about what the cancer diagnosis meant and entailed. In this way, the caregiver was able to assess that the PWC "doesn't think it is something very big, but she knows that it is serious, and it requires treatment."

Finally, a deterrent for disclosure among a few caregivers ($n=3$) was the extended family's reactions and behavior toward the PWC. For these caregivers, the family (immediate and extended) was one unit from whom information cannot be "easily" shared. They believed that if the truth "were to get out," then their relatives would either be devastated, or they would "unnecessarily make a fuss" about the PWC. Caregivers were certain that "this will become a highly unmanageable" situation both from the perspectives of the PWC as well as the extended family.

(Non) disclosure efficacy

Key themes under (non) disclosure efficacy included: caregiver's conundrum and key strategies for maintaining nondisclosure.

Almost all the caregivers ($n=23$) shared the back-and-forth thoughts about disclosing versus not. Caregivers' main reasons for thinking about disclosure were that they felt "bad" or "guilty" for the PWC who was "kept in the dark" and the PWC was asking "every single person about what's going on with her - except us." When their conscience was not able to "take it anymore," caregivers started "toying with the idea of just telling her." Even though considering disclosure may have been precipitated by moral or in some cases, religious obligations, caregivers were not yet sure of

how to disclose and showed no urgency to divulge the truth.

Several caregivers ($n = 14$) used the same methods of maintaining nondisclosure which included informing only a select group of family members, warning healthcare staff in advance to not reveal the prognosis, provide the PWC with some minimal amount of medical information, and keeping the PWC distracted. Caregivers used all, some, or a combination of these methods in order to ensure that the bad news was concealed from the PWC. Interestingly, one caregiver described that the PWCs asked “absolutely anyone, even the lab technician, whether they are hiding something from her.” Still, caregivers were able to ensure nondisclosure because they were always “ahead of the PWC” by “staying on top of who he talks with” and never giving a “definitive statement” to the PWC about their health status. To create a semblance of speaking the truth and to assuage the PWC, caregivers gave them a little information whenever the PWC appeared agitated or suspicious.

Discussion

This study qualitatively examined the process of disclosure and nondisclosure of cancer prognostic information from caregiver to the PWC, using the lens of DD-MM and focusing on (a) information assessment, (b) receiver assessment, and (c) disclosure efficacy for two broad groups of caregivers (disclosing and nondisclosing). The themes for the disclosing caregiver group did not map as well on the DD-MM because the disclosure had already occurred, and caregivers focused more on their experiences. However, for the nondisclosing caregiver group, the themes mapped perfectly on the DD-MM. [Supplementary Table 5](#) presents a comparison of themes related to the process of disclosure and nondisclosure of cancer prognostic information from caregivers to the PWC.

The key themes for the disclosing caregiver group focused on receiver assessment where the caregivers agreed that PWC had a “right to know” their prognosis, but the caregivers were divided in terms of whether knowledge of prognosis was helpful/unhelpful for the PWC. Whereas having knowledge can equip PWCs to take charge of their own health, manage their symptoms, be more pro-active in their care, it can also lead to hopelessness and a desire to just “give up.” A study on effect of prognosis information disclosure to the PWC indicated that recall of prognostic disclosure was associated with more realistic and accurate perceptions of prognosis, which was in turn

associated with higher rates of advance care planning and preference for comfort-oriented end-of-life care (Enzinger et al., 2015). Western studies frequently suggest that prognostic discussions are welcomed by most PWC’s and could have substantial benefits without harming PWC’s emotional well-being or the PWC-physician relationship. However, the results from Asian countries is mixed (Maya et al., 2021).

The cultural lens through which end-of-life discussions are framed in the Indian context do not focus on the “act of dying” but whether the PWC has fulfilled their responsibilities in the world (Chittem et al., 2021). The “fighting spirit” is ascribed to be positively correlated with the responsibilities left for the PWC. In other words, if the PWC perceives that they have responsibilities left (e.g., getting their son/daughter married, financial security for the family), they will have a stronger fighting spirit and may want to know information about disclosure and prognosis to better prepare for fulfilling their responsibilities (Chittem et al., 2021). There are gender-related differences in these narratives (e.g., Indian men tend to feel more responsible toward the financial security of the family whereas Indian women considered dying before their husband auspicious thus reported acceptance of death – see Chittem et al., 2021), but need to be explored in future research in the contexts of (non)disclosure of the prognosis.

This is the first study to date that uses DD-MM to focus on the process of disclosure when the information is in the hands of the caregiver of the PWC (and not the PWC themselves). The findings revealed that caregivers assessed the information in terms of causality, prognosis, and preparation. Overall, caregivers were aware of the cancer prognosis and accepting of the palliative route that the oncologist had recommended for treatment. Many caregivers thought about gentle ways of planning for disclosing prognostic information to the PWC, but there was no imminent rush to divulge the information to the PWC. To better understand this finding, it is important to recognize that the role(s) an Indian caregiver may play was dependent on the family structure and role ascription made by patients, with each family member taking on different care responsibilities (such as emotional, logistical, financial) (see Chawak et al., 2020). Therefore, it is possible that Indian caregivers need to acquire and consolidate multiple aspects of the prognosis information (e.g., emotional valence, financial strain of a particular treatment plan) before sharing it with the patient.

Clearly, for the nondisclosing caregivers, assessment of the recipient was an important factor in disclosure decision making and mapped well on the DD-MM. Caregivers wanted to “protect” the PWC, relied on guidance from the oncologist about when to share information with the PWC, and also considered the extended family’s response if the prognostic information was shared with the PWC. Similarly, for (non) disclosure efficacy, caregivers struggled with the should I/should I not disclose to the PWC and had extensive strategies for maintaining nondisclosure. This is not surprising because, past studies from Asia and our previous work on diagnosis nondisclosure from the perspectives of Indian caregivers, show that family caregivers consider a range of aspects and consequences of telling the truth (see Chittem et al., 2020). Similarly, Kim et al. (2014) reported that caregivers’ attitudes toward disclosure were linked to their PWC’s functional status and severity of the symptoms, with them becoming disinclined toward disclosure when they perceived their PWC to be doing poorly in their emotional and cognitive wellbeing, and noted increased symptoms of nausea, vomiting, pain, and insomnia. Taken together, it can be understood that the decision to maintain nondisclosure is based on a variety of factors and involves significant cognitive effort on the part of the caregiver.

Study implications

This study has theoretical, research, and practical implications. Theoretically, this study indicates that DD-MM can be used to study the process of disclosure when the cancer-related information is controlled by the caregiver of the PWC. Previous studies had only focused on disclosure of one’s own information to others. Examining the utility of DD-MM to study both diagnosis and prognosis disclosure by the caregiver to the PWC may lead to a greater applicability of the theory in the Asian cancer caregiving context. This is an important area for future research.

Practically, the study highlighted a clear need for information by the disclosing caregiver group and dissatisfaction with oncologist communication. Patient and family preferences regarding disclosure must be established in the beginning of the treatment, as well as during treatment, so that clear expectations are communicated. Designing communication skills training for oncologists in holding family meetings and involving caregivers in cancer care may improve the communication gap between oncologists and PWCs/caregivers (Rosa et al., 2022). Additionally, developing

caregiver training to better prepare cancer caregivers to provide care to the PWCs may help in reducing caregiver distress (Applebaum et al., 2023).

Study limitations

We recognize that this study has some limitations. First, there were geographic limitation - this study was carried out at various cancer hospitals in Hyderabad, India, a city in Southern India. As such, the results may not be generalizable to other cancer centers or hospital settings in other parts of the country. Medicine in India is practiced in a wide variety of ways and includes regional and urban/rural contexts. Besides Western medicine (or Allopathy) which was the context in this study, India has the unique distinction of having six additional recognized systems of medicine: Ayurveda, Siddha, Unani, Yoga, Naturopathy and Homoeopathy (Ravishankar & Shukla, 2007) which we did not explore in this study. Second, we interviewed one caregiver per PWC for this study. Given that many PWCs have more than one caregiver, a more comprehensive understanding of prognosis disclosure decision making that seeks perspectives of all the family members involved is warranted. Finally, a dyadic study of caregiver and PWC may provide a better understanding of how much information is truly “hidden” versus “not discussed.”

Conclusions

This study describes the process of disclosure and nondisclosure of cancer prognostic information from caregiver to the PWC, using the lens of DD-MM. Results described key considerations of the caregivers, particularly around receiver assessment and disclosure efficacy where the caregivers had disclosed prognostic information to the PWCs. For the non-disclosing group, assessment of the receiver was a key consideration in caregivers’ decision to not disclose. This study has significant implications for development of communication skills trainings around holding family meetings in India, where diagnosis and prognosis is discussed in detail both with patients and their caregiving families. As well, caregiver focused programs in hospitals will not only prepare caregivers to better deal with caregiving issues, but to also provide supportive care to patients and their caregiving families.

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References

- Aljubran, A. H. (2010). The attitude towards disclosure of bad news to cancer patients in Saudi Arabia. *Annals of Saudi Medicine*, 30(2), 141–144. <https://doi.org/10.4103/0256-4947.60520>
- American Cancer Society. (n.d.). *What a cancer caregiver does. Caregiver and family*. <https://www.cancer.org/treatment/caregivers/what-a-caregiver-does.html>
- Applebaum, A., Gebert, R., Behrens, M., Loschiavo, M., Parker, P., Shaffer, K., Carver, A., & Diamond, E. (2023). Development and feasibility of a communication training to assist caregivers with advanced care planning. *Palliative & Supportive Care*, 21(2), 1–8. <https://doi.org/10.1017/S1478951522001080>
- Bernard, H. R., & Ryan, G. W. (1998). Qualitative and quantitative methods of text analysis. In H. R. Bernard (Ed.), *Handbook of research methods in cultural anthropology* (pp. 595–646). Rowman & Littlefield.
- Blandford, A. E. (2014). Semi-structured qualitative studies. Interaction Design Foundation- IxDF. <https://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/semi-structured-qualitative-studies>
- Chawak, S., Chittam, M., Butow, P., & Huilgol, N. (2020). Indian cancer patients' needs, perceptions of and expectations from their support network: A qualitative study. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 35(3), 462–469. <https://doi.org/10.1007/s13187-019-1483-4>
- Chittam, M., Elliott, J., & Olver, I. (2021). Demonstrating the importance of cultural considerations at end-of-life utilising the perspective of Indian patients with cancer. *Supportive Care in Cancer: official Journal of the Multinational Association of Supportive Care in Cancer*, 30(3), 2515–2525. <https://doi.org/10.1007/s00520-021-06656-1>
- Chittam, M., Maya, S., & Chawak, S. (2021). Nondisclosure of a cancer diagnosis and prognosis: Recommendations for future research and practice. *Indian Journal of Cancer*, 58(2), 158–164. https://doi.org/10.4103/ijc.IJC_740_19
- Chittam, M., Norman, P., & Harris, P. (2020). Primary family caregivers' reasons for disclosing versus not disclosing a cancer diagnosis in India. *Cancer Nursing*, 43(2), 126–133. <https://doi.org/10.1097/NCC.0000000000000669>
- Costantini, M., Morasso, G., Montella, M., Borgia, P., Cecioni, R., Beccaro, M., Sguazzotti, E., & Bruzzi, P. (2006). Diagnosis and prognosis disclosure among cancer patients. Results from an Italian mortality follow-back survey. *Annals of Oncology: official Journal of the European Society for Medical Oncology*, 17(5), 853–859. <https://doi.org/10.1093/annonc/mdl028>
- Cranmer, G. A., & LaBelle, S. (2018). Using the disclosure decision-making model to understand high school football players' disclosures of concussion symptoms. *International Journal of Sport Communication*, 11(2), 241–260. <https://doi.org/10.1123/ijsc.2017-0120>
- Enzinger, A. C., Zhang, B., Schrag, D., & Prigerson, H. G. (2015). Outcomes of prognostic disclosure: associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer. *Journal of Clinical Oncology: official Journal of the American Society of Clinical Oncology*, 33(32), 3809–3816. <https://doi.org/10.1200/JCO.2015.61.9239>
- Epton, T., Chittam, M., Tanikella, R., Rajappa, S., Sinha, S., & Harris, P. R. (2020). Indian patient use of cancer euphemisms: Association with psychological outcomes and health behaviours. *Psycho-oncology*, 29(7), 1193–1200. <https://doi.org/10.1002/pon.5408>
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1), 117. <https://doi.org/10.1186/1471-2288-13-117>
- Gillon, R. (1985). "Primum non nocere" and the principle of non-maleficence. *British Medical Journal (Clinical Research ed.)*, 291(6488), 130–131. <https://doi.org/10.1136/bmj.291.6488.130>
- Greene, K. (2009). An integrated model of health disclosure decision-making. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty, information management, and disclosure decisions: Theories and applications* (pp. 226–253). Routledge/Taylor & Francis Group.
- Hall, D. E., Prochazka, A. V., & Fink, A. S. (2012). Informed consent for clinical treatment. *CMAJ: Canadian Medical Association Journal = Journal de L'Association Medicale Canadienne*, 184(5), 533–540. <https://doi.org/10.1503/cmaj.112120>
- Hu, W. Y., Chiu, T. Y., Chuang, R. B., & Chen, C. Y. (2002). Solving family-related barriers to truthfulness in cases of terminal cancer in Taiwan: a professional perspective. *Cancer Nursing*, 25(6), 486–492. <https://doi.org/10.1097/00002820-200212000-00014>
- Kim, S., Ko, Y., Kwon, S., Shin, D. Y., Kim, C. H., Yang, S. H., Cho, S. J., & Na, I. I. (2014). Family caregivers' awareness of illness and attitude toward disclosure during chemotherapy for advanced cancer. *Psycho-oncology*, 23(11), 1300–1306. <https://doi.org/10.1002/pon.3565>
- Maya, S., Banerjee, S., Chawak, S., Parker, P., Kandikattu, S., & Chittam, M. (2021). Oncologists' experiences with discussing cancer prognosis with patients and families: Perspectives from India. *Translational Behavioral Medicine*, 11(10), 1896–1904. <https://doi.org/10.1093/tbm/ibab070>
- Parveen, S., & Morrison, V. (2009). Predictors of familism in the caregiver role: A pilot study. *Journal of Health Psychology*, 14(8), 1135–1143. <https://doi.org/10.1177/1359105309343020>
- Ravishankar, B., & Shukla, V. J. (2007). Indian systems of medicine: a brief profile. *African Journal of Traditional, Complementary, and Alternative Medicines: AJTCAM*, 4(3), 319–337. <https://doi.org/10.4314/ajtcam.v4i3.31226>

- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (Eds.), *Analyzing qualitative data* (1st ed., pp. 173–194). Routledge.
- Rosa, W. E., Cannity, K., Moreno, A., Cardillo, C., Schofield, E. A., Korc-Grodzicki, B., Parker, P. A., Manna, R., Alici, Y., Nelson, C., Alexander, K., & Banerjee, S. C. (2022). Geriatrics communication skills training program for oncology healthcare providers to improve management of care for older adults with cancer. *Pec Innovation*, 1, 100066. <https://doi.org/10.1016/j.pecinn.2022.100066>
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Sage Publications Inc.
- Venetis, M. K., Chernichky-Karcher, S., & Gettings, P. E. (2018). Disclosing mental illness information to a friend: Exploring how the disclosure decision-making model informs strategy selection. *Health Communication*, 33(6), 653–663. <https://doi.org/10.1080/10410236.2017.1294231>
- Wang, D. C., Peng, X., Guo, C. B., & Su, Y. J. (2013). When clinicians telling the truth is de facto discouraged, what is the family's attitude towards disclosing to a relative their cancer diagnosis? *Supportive Care in Cancer: official Journal of the Multinational Association of Supportive Care in Cancer*, 21(4), 1089–1095. <https://doi.org/10.1007/s00520-012-1629-y>