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Primary family caregivers' reasons for disclosing versus not disclosing a cancer diagnosis in India

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Abstract

Background: Non-disclosure of cancer diagnosis continues to be practiced in India, with many family caregivers concealing it from patients in order to protect them from emotional distress.

Objective: To explore Indian primary family caregivers' reasons for, and experiences of, disclosure versus non-disclosure to patients about their cancer diagnosis.

Methods: Indian disclosing (n=8) and non-disclosing (n=7) primary family caregivers participated in semi-structured interviews exploring their reasons for disclosure versus non-disclosure of cancer diagnosis to their patient. Qualitative content analysis was used to classify the reasons for and for not disclosing. Illustrative quotes were selected to highlight caregivers' motivations for, and experiences of, each reason.

Results: The findings revealed six main reasons for disclosing (emotional well-being, lack of control, preparing the patient, family reasons, patient's personality, and longevity/curability of the disease) and six reasons for not disclosing (emotional well-being, family reasons, patient's personality, longevity/curability of the disease, barriers to communication, and disease severity). Typically, disclosing caregivers considered reasons for as well as against disclosure, whereas non-disclosing caregivers considered reasons against disclosure.

Conclusions: Most of the reasons given for disclosing and not disclosing were the same, although these reasons operated differently for disclosing and non-disclosing caregivers. In addition, justification for these reasons demonstrated cognitive consistency effects that appeared

to reduce any feelings of dissonance regarding caregivers' disclosure, or non-disclosure, decisions.

Implications for Practice: Cancer nurses should provide additional psychological support to non-disclosing caregivers, especially with regard to how they view and engage in their caregiving role.

Keywords: Primary family caregivers; disclosure; nondisclosure; reasons; India; cancer; qualitative

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Introduction

In many Asian cultures, where family embeddedness is an integral feature of the societal structure, the cancer process is a family experience wherein the family automatically becomes the patient's caregivers.¹ Correspondingly, patients often adopt a role of passive acceptance, trusting their family caregivers to entirely handle their medical situation.² This unique attitude of filial piety and compassion towards a cancer patient can extend to medical decision-making when families routinely act as proxies for the patient.^{3,4} Families take these decisions on behalf of the patients as they perceive the latter to be 'vulnerable' and in need of support, comfort, and protection from the stress of the bad news (i.e., cancer diagnosis).² Many Asian families believe it is their responsibility to protect the patient from the distressing news of their cancer diagnosis which may, in part, be due to the cultural attitude and taboo that cancer is tantamount to death.⁵ This protective attitude and family-centered decision-making can result in many family caregivers choosing non-disclosure of cancer diagnosis to patients, to shield the patient from its negative emotional impact.⁶⁻¹⁰ The incidence of families preferring non-disclosure ranges from 23% - 66%¹¹⁻¹³, with 17% - 63% patients not being aware of their cancer diagnosis in Asian cultures.^{8,14-17}

To date, only a few studies have examined reasons for disclosure versus non-disclosure of a cancer diagnosis in Asia. These have shown that the most frequent reasons for disclosure are gaining patients' cooperation with healthcare procedures and staff, helping patients resolve any unfinished business, withholding diagnosis being impossible, confidence in the patient's ability

to fight the disease, and believing that the patient has a right to their diagnosis information.^{18,19}

The reasons most frequently quoted by families for not disclosing are that knowing the diagnosis can make patients feel discouraged and lose the will to fight the disease, can cause emotional and psychological distress, there being no need to inform patients of the truth, that patients may not want to know about their diagnosis, and that cancer diagnosis awareness may affect the treatment and curability unfavourably.^{12,19}

While these studies have documented family caregivers' reasons for and against disclosing, they have not provided a more in-depth exploration of the complexity of the cultural and familial contexts of (non-)disclosure and the experiential aspects of the process of family caregivers' disclosure decision-making. In addition, these studies have not directly compared families who disclosed versus those who did not disclose the cancer diagnosis. Thus, this reduced their ability to differentiate motivations for families' decisions to inform or not inform their patients. Since non-disclosure is prevalent to varying degrees, it is important to understand what leads family caregivers to tell some patients and not to tell some others. To date, there is no research that has explored family caregivers' reasons for *and* for not disclosing a cancer diagnosis to their patient as well as their motivations for, and experiences of, their disclosure decisions. Therefore, the current study will seek to address these gaps in the literature by identifying and then exploring primary family caregivers' reasons for, and their experiences of, disclosure versus non-disclosure in India.

Method

Participants

Participants were primary family caregivers of patients with cancer. Individual interviews were conducted with a total of 15 caregivers (male $n = 12$, female $n = 3$) aged between 21 to 75 years (Table 1). Eight caregivers were disclosing and seven caregivers were non-disclosing. All of the disclosing caregivers had known about the cancer diagnosis before the patient. Ethics approval for the study was obtained from the Research Ethics Committee at the Department of Psychology, University of Sheffield, UK. Approval for the study was also granted by Basavatarakam Indo-American Cancer Hospital (BIACH), Hyderabad, India.

Procedure

Primary family caregivers were approached in the hospital during their patient's treatment appointment and asked if they would be interested in participating in the study. The inclusion criteria were that the caregiver (i) was the primary individual who made the decision about whether or not to reveal the cancer diagnosis to the patient), (ii) did not have any psychiatric condition (as reported by the participant), and (iii) could speak English, Hindi or Telugu. If a caregiver expressed an interest in participating, then the researcher explained the study to them in detail in their preferred language.

After any questions had been answered, the informed consent form was explained to them. Verbal consent was taken from caregivers who did not know how to sign. Upon obtaining informed consent, the researcher noted the caregiver's demographic details and the patient's demographic and medical details as shared by the caregiver. Following this, the researcher commenced the interview with the caregiver.

Interviews

Semi-structured interviews with open-ended questions were used to focus on primary family caregivers' reasons for disclosure versus non-disclosure of the cancer diagnosis to their patient. The interview also sought to explore participants' motivations for, and experiences of, their disclosure decision. Table 2 describes the interview topic and sample questions. The interviews were held in private in the deputy medical officers' rooms that are on each wing/floor of the hospital. Each interview took approximately 25 minutes and was recorded on a digital audio recorder. All interviews were conducted in Telugu (as this was the regional language and the one the participants were most comfortable with as compared to Hindi or English) and were transcribed into English. All transcripts followed forward- and back-translation to ensure accuracy and that no cultural nuances and tones were missed in the process.

Analysis

The data underwent two stages of analysis. The goal of the first stage was to document reasons for and against disclosing. In order to achieve this, the first author produced a list of all the reasons for and against disclosing the cancer diagnosis cited by the caregivers through a content analysis of the interviews.²⁰ Participants cited a total of 44 individual reasons for disclosing and 70 reasons for not disclosing. The first and second authors then independently reviewed the reasons for disclosing and not disclosing to generate a coding scheme to categorize the reasons using appropriate labels (e.g., emotional well-being, lack of control, patient's personality). The first and second authors then met to discuss and agree on the coding scheme before independently categorizing the individual reasons. Upon the completion of the categorization, a Kappa score was calculated to assess agreement between the raters. A Kappa score of .76 was

achieved for the reasons for disclosure and .77 for the reasons for non-disclosure, both considered acceptable scores.²⁰ Any disagreements were resolved through discussion.

The goal of the second stage of the analysis was to select illustrative quotes to highlight each reason and to more fully understand caregivers' underlying motivations and experiences. The transcripts were carefully read by the first author to gain a deeper understanding of the caregivers' accounts. The author marked quotes which best highlighted these motivations and experiences. The second author then independently audited the transcripts containing these quotes. A final set of illustrative quotes for each reason was then agreed by both the authors. In this way, the authors attempted to capture caregivers' motivations for, and experiences of, cancer diagnosis disclosure versus nondisclosure.

Results

The number of disclosing and non-disclosing caregivers who cited each of the final reasons for, and for not, disclosing are presented in Tables 3 and 4. A cut-off point of at least one-third of participants was used to help identify the modal reasons for, and for not, disclosing. Six reasons for disclosing were cited by at least one-third (i.e., 3 out of 8) of the disclosing caregivers, whereas no reasons for disclosing were cited by at least one-third (i.e., 3 out of 7) of the non-disclosing caregivers (Table 3). Six reasons for not disclosing were cited by at least one-third of the non-disclosing caregivers, whereas only two reasons for disclosing were cited by at least one-third of the non-disclosing caregivers (Table 4).

Reasons for disclosing given by disclosing caregivers

1. *Emotional well-being.* The most frequently cited reason given by disclosing caregivers for revealing the cancer diagnosis to their patient was to ensure the patient's emotional well-being. Caregivers believed that if their patient was unaware of the illness, then they would become suspicious, which could lead to feelings of panic, fear, and worry. Before disclosing, caregivers considered several scenarios that had the potential to increase their patients' levels of emotional "trauma" or lead them to be in a "bad state". The most frequently cited situations were when family members would have to talk in whispers about the illness in the presence of the patient and that the side-effects of the treatment could alarm the patient. Thus, caregivers felt that knowing earlier on in the cancer trajectory could prevent future distress.

If the patient doesn't know, everyone will be whispering and she will be suspicious. This will have a psychological affect. (DC 1)

Patient might get highly suspicious which will increase their tension, they might over think. (DC 3)

2. *Lack of control.* Given that the participants were recruited from a tertiary cancer center, caregivers were aware that they would not have been able to conceal that they were at a 'cancer' hospital. The waiting time at the hospital as well as the layout of the treatment spaces allowed for an increased likelihood for patients to converse with each other. Hence, caregivers were conscious of the possibility that someone would "inadvertently" disclose the diagnosis to their patient.

Once we came here (BIACH) I knew that the patient can read the signs and is educated enough to guess it's cancer. (DC 4)

Somehow, inadvertently...in an encounter with someone, she will get to know its cancer...that's why we told her. (DC 2)

3. *Preparation.* Caregivers believed that patients who were aware of and ready for the consequences of cancer and its treatment fared better and were more resilient. Further, caregivers acknowledged that in the center of the cancer trajectory was the patient who was experiencing and facing the illness directly. Therefore, the caregivers felt it was necessary for patients to be prepared to “physically and mentally fight” the illness.

Telling her the diagnosis was better for her as it is she who has to go through all the treatment. (DC 5)

She has to accept it (cancer) and fight it. She is in a strong position now as she is prepared for the cancer journey. (DC 9)

4. *Family reasons.* Some caregivers felt they could grow together and as a family through the cancer experience. Caregivers also felt they were able to engage in their caretaking efforts effectively because once the patient was aware of their diagnosis they were able to talk freely about the illness, thus allowing for opportunities to keep the channels of communication and family bonding open.

Family gains from informing. It is easier to handle the situation now because we speak openly about it (cancer). But for one month our whole family was depressed. We kept thinking, “Why did we get this disease?” Now, we don’t have that depression – we can face anything together, we have become very attached (to each other). (DC 2)

We (the patient and family) mature from the experience. (DC 3)

5. *Patients’ personality.* Some disclosing caregivers exhibited high levels of confidence about their patient’s ability to handle the impact of the diagnosis. Further, the caregivers felt that the patient may persistently ask questions about their illness, mainly because they perceived the patient as “extremely intelligent” thus making it impossible to “hide” the diagnosis.

She’s a brave person. I knew she could handle it (cancer diagnosis). (DC 8)

If she does not know why she is having to go through cancer treatment, then she will keep asking me questions. I will be stuck. So I told her. (DC 5)

6. *Longevity and Curability.* Caregivers reported a positive connection between disclosure, the patient’s state of mind, their emotions and its impact on their body (i.e., health outcomes), which could improve their longevity and/or increase their chances of disease curability. Thus, caregivers were able to envision the benefits of disclosure, rather than framing their reasons based on the potential negative outcomes of non-disclosure.

If my patient knows, she will be confident and then the recovery will be much better and quicker. (DC 1)

My logic was simple: if they (their patient) know the truth, they won't be scared. If they are not scared, they will live longer. (DC 2)

Reasons for not disclosing given by non-disclosing caregivers

1. *Emotional well-being.* The most frequently cited reason by non-disclosing caregivers for non-disclosure was to protect their patient's emotional well-being. The caregivers believed that their patients may react negatively to the cancer diagnosis which would result in the latter becoming "emotionally and mentally disturbed". They felt that patients would be more "stable and encouraged", less fearful and tensed, and would not be depressed as they were unaware of their diagnosis.

If he knows, then he will feel disheartened, he will become weakened and upset. (NDC 2)

The patient is already fearful of the operation (surgery). On top of which if they also know that it is cancer, it will only increase their fear. (NDC 7)

2. *Patient's personality.* Non-disclosing caregivers reported that the patient's personality was another key reason for non-disclosure. This reason was frequently justified on the basis of previous experiences in which the patient had reacted negatively to a "scary" diagnosis and

situations in which they had not exhibited resilience or a positive outlook. Caregivers felt that their patient was not “rough and tough” enough to handle the diagnosis and that they did not know enough about cancer to understand that there may be a cure to the illness.

The patient is too sensitive, isn't 'rough and tough'. (NDC 2)

Depends on patient's personality. She was adamant about not even going to a hospital as she was scared of the cancer tests the first time we did them. (NDC 3)

3. *Longevity and Curability.* The caregivers felt that patients' *longevity* and *disease curability* was associated with how patients' mental well-being influenced their body's ability to respond to the illness and its treatment. Further, non-disclosing caregivers believed that if patients were told of their diagnosis, then they would become too upset to engage in self-care behaviours, which could compromise their lifespan.

The more she thinks about it (cancer), the more she will get depressed, and the more her body will not respond (to treatment). (NDC 1)

The disease may not get cured if the patient is fearful. (NDC 7)

4. *Barriers to communication.* Some non-disclosing caregivers cited barriers to communication as a reason for not disclosing, with key issues being their own lack of knowledge and their inability to provide patients with a justifiable explanation for their cancer. Additionally, primary

family caregivers were unsure about how to disclose the diagnosis to the patient and how to handle the patient's subsequent reactions to the diagnosis.

If the patient had a bad habit (e.g., smoking, alcohol abuse), you can mentally prepare them by telling that their cancer came due to the habit. But he (their patient) is a person who is very healthy, who never even had a bad fever...there's no valid reason for him getting this disease. So what am I going to tell him when he asks me why he got this (cancer)? (NDC 4)

Frankly, we are scared that she'll get very scared. How am I supposed to tell her when I am myself so scared? (NDC 5)

5. *Disease severity.* The major determining factors for citing disease severity as a reason for non-disclosure were patients' level of pain and the stage of the disease. The caregivers felt that empathic non-disclosure would at least reduce the negative impact of the cancer experience on the patient.

The patient is already unstable due to pain. Why should I worsen it for them? (NDC 6)

6. *Family reasons.* Some caregivers felt that disclosing to their patient would have a ripple effect such that other family members would also become aware of the diagnosis. Visiting or contacting a sick/dying relative, irrespective of how distant one's relationship is to them, to offer one's sympathies is a social custom in India.²¹ Non-disclosing caregivers reported that they were not confident that their extended family's reaction would be conducive to the patient's well-

being and they were certain that their negative reactions would create opportunities for increased emotional “drama”.

If she doesn't know, then we can make sure that our relatives don't know also.... You see, if the news (of the cancer diagnosis) will spread to relatives who will call her (the patient) to share their sorrow. They will aggravate her trauma and grief by reminding her of her young children. People will bring her down. (NDC 6)

If you tell the patient, then you have to tell everyone. Telling no one is beneficial. If too many know....especially ladies....they will appear sad in front of the patient. This will make the patient depressed even further. (NDC 4)

Discussion

The current study explored Indian primary family caregivers' reasons for disclosure versus non-disclosure to patients about their cancer diagnosis. The findings revealed six main reasons for disclosing: emotional well-being, lack of control, preparing the patient, family reasons, patient's personality, and longevity/curability of the disease. The reasons of lack of control, preparing the patient, and patient's personality are in line with previous research examining families' reasons for disclosing, whereas the reasons of emotional well-being, family reasons, and longevity/curability of the disease add to the existing literature.^{12,13} The findings also revealed six main reasons for not disclosing: emotional well-being, family reasons, patient's personality, longevity/curability of the disease, barriers to communication, and disease severity. The reasons of emotional well-being, patient's personality, and longevity/curability of the disease are in line

with previous research examining families' reasons for non-disclosing, whereas family reasons, barriers to communication, and disease severity add to the existing literature.^{12,18,19}

Of particular interest is the finding that patients' emotional well-being, personality, beliefs about the longevity and curability of cancer, and family reasons were cited by both disclosing and non-disclosing caregivers as their reasons for and for not disclosing, respectively. However, it is important to note that while these reasons were cited by both the groups, they operated differently for each of them. Since all the caregivers were an immediate family member of the patient, the patient's reactions to cancer were both foreseeable and important to them. In view of the many demands cancer places on caregivers,^{22,23} it is not surprising that each group of caregivers took into consideration how manageable a patient would be if they became aware versus remained unaware of their diagnosis. Interestingly, caregivers perceived there to be a link between an optimistic/pessimistic personality, response to cancer, and subsequent health outcomes, such that a patient with a positive personality will be better able to cope with the cancer diagnosis thus impacting their health outcome positively and vice-versa. Indeed, previous research has indicated an association between optimism and fighting spirit,²⁴ and pessimism and poorer adjustment among cancer patients.²⁵

The study revealed some reasons for and against disclosing that were unique to each caregiver group. Disclosing caregivers gave two additional reasons for revealing the diagnosis to their patient: preparation and lack of control. Consistent with previous quantitative research, disclosing caregivers in the current study reported that their decision was made in order to prepare the patient and due to their inability to control the external environment.^{18,19} Thus, there

may be higher levels of cancer awareness among disclosing caregivers than their non-disclosing counterparts as the former exhibited knowledge about the side-effects of cancer treatment and its lengthy trajectory. In addition, disclosing caregivers may make a pragmatic decision to disclose as they recognise the likelihood that patients might become aware of their cancer diagnosis through external cues, such as being in a cancer hospital and talking to other patients, over which they have little control. Non-disclosing caregivers gave two additional reasons for concealing the diagnosis from their patient: barriers to communication and disease severity. In line with previous research, non-disclosing caregivers in this study reported preferring to not reveal the true diagnosis because they did not know how to inform, did not know how to handle the patient after disclosing, and felt ill-equipped to answer the patient's questions about the causes for their cancer.²⁶ This was particularly the case when caregivers preferred empathic non-disclosure, that is they felt that telling the truth would exacerbate the severity of the patients' disease or its side-effects (e.g., pain).

It is striking to note that in this study disclosing and non-disclosing caregivers perceived their families in different ways, which influenced their disclosure decisions. Disclosing caregivers believed that the patient would be able to adjust to their diagnosis and that they (i.e., caregiver and patient) could grow together through the cancer experience. This highlights the caregivers' ability to view their care-taking role as an opportunity to mature with their patient rather than as a burden, indicating an optimistic and/or resilient approach towards cancer. This finding supports existing psycho-oncology research in India which has found that many family caregivers made positive appraisals of their altered, more demanding role and that caregivers experienced cancer-related posttraumatic growth.^{27,28} However, contrasting this "fight it together" attitude, non-

disclosing caregivers reported that their extended family was a barrier to truthful disclosure because they would react in a negative, overtly sympathetic manner that could make the patient feel worse. This emphasizes non-disclosing caregivers' negative approach to their changed role as well as their relationship with their patient, i.e., they felt that it would be difficult to manage and/or monitor their relatives' interactions with the patient alongside their other caregiving tasks, thus placing a huge demand on their limited resources (i.e., physical and emotional). Thus, disclosing and non-disclosing caregivers were observed to view their responsibilities towards their patient and their ability to carry out their duties differently, such that the former used an assets-based approach (i.e., focussing on the strengths and potentials) while the latter used a deficit-based approach (i.e., focussing on the difficulties and limitations) to their role as a caregiver.^{29,30}

Non-disclosing caregivers were less likely to cite reasons for disclosing than disclosing caregivers were to cite reasons for not disclosing. This finding is in line with previous research that has found this form of high endorsement from disclosing caregivers and vice versa.^{12,19} Indeed, as was observed in the disclosing participant profiles, although all were aware of the true diagnosis before their patient was, and most withheld the information at the outset, they subsequently disclosed the diagnosis. Therefore, it is possible that in the process of disclosure decision-making, these caregivers considered the benefits and issues regarding disclosing versus not disclosing the diagnosis to their patient. On the other hand, non-disclosing caregivers may have firmly made up their mind about their decision, thus not allowing themselves to consider the benefits of disclosure. This form of decision-making may have helped them to function productively in their caregiving role without any lingering doubts. These findings are also in line

with cognitive dissonance theory as,³¹ having made a decision, caregivers endorsed reasons that supported their decision and disagreed with (or did not even mention) reasons for the alternative course of action.

It is noteworthy that caregivers substantiated some of their disclosure decisions by imagining the opposite scenario. For example, disclosing caregivers felt that if they were to withhold the diagnosis from the patient he or she would get more curious about their illness, and that caregivers would not be able to continue with non-disclosure as the patient may find out about the illness once they arrived at a 'cancer' hospital. As for non-disclosing caregivers, they believed that disclosure would upset patients to the point of jeopardizing lifespan, and that if caregivers were to reveal the diagnosis then their extended family's response to this news would be too difficult to handle. These findings underline the cognitive processes involved in disclosure decision-making in which the family attempts to picture various consequences of disclosing versus non-disclosing before making the decision based on what they believe to be the best outcome for the patient. These findings are consistent with previous quantitative research in which reasons for (non)disclosure were phrased in the context of the opposite scenario.¹⁸

Limitations

A number of limitations that should be noted. First, due to the small sample size, the generalizability of the findings remains to be established. In addition, the sample predominately, but not exclusively, comprised well-educated, male caregivers. This may reflect the patriarchal system in India in which men frequently take dominant decisional roles, a phenomenon that is particularly apparent in care taking.^{32,33} This person (male) will typically be a close family

member, but can also be a more distant relative, such as a cousin or brother-in-law, if they are the most qualified (or educated) person in the extended family. As a result, in the current study, it was often a male caregiver who accompanied the patient to their hospital appointment as the key family member making decisions about the patient's care (including the decision to disclose the cancer diagnosis or not). Second, the present study focused on caregivers' attitudes toward disclosure of cancer diagnosis but not cancer prognosis. Future research could examine Indian caregivers' attitudes and preferences for disclosure versus non-disclosure of cancer prognosis to cancer patients who are at different stages of their illness. Finally, the study cannot determine whether the reasons given for and for not disclosing change over time and/or the extent to which they are important when caregivers are about to decide to disclose. Future studies should therefore use longitudinal designs to explore these issues.

Implications for Research and Practice

Notwithstanding these limitations, the current findings have a number of implications for research and practice. In particular, the findings suggest a need to unpack how the decision to disclose versus non-disclose unfolds over time to track the psychological underpinnings and changes in this decision, and gain a deeper understanding of how these decisions interact with caregivers' experiences of their role over a period of time. A major implication for practice arises from the finding that non-disclosing caregivers approached their role through a deficit-based style and, as a result, feelings of cognitive dissonance may be experienced by this group. Therefore, non-disclosing caregivers may require additional psychological support such as discussing their experiences in terms of caregiving, focussing on the positive aspects of their role as a caregiver. This support may be best delivered through cancer nurses since they interact more

personally with the patient and their families (than physicians),³⁴ thus affording them a better understanding of the internal family dynamics as well as developing a relationship with the patients and their primary caregivers.

One of the key roles of an oncologist as the principal medical care provider is to disclose a cancer diagnosis to a patient. While this is an accepted practice in Western cultures, oncologists practicing in Asian cultures or in multicultural countries may be approached by family members to not reveal the true diagnosis to the patient.³⁵ Oncologists may therefore be faced with the need to strike a delicate balance between their professional responsibility towards the patient and respecting the family's wishes as the key informal caregivers. Recent research has called for a collaborative communication method in such situations to include the oncologist, family members and the patient in cancer communication and decision-making.^{36, 37} To foster this more collaborative approach, oncologists may require additional training in dealing with patients' and caregivers' reactions to a cancer diagnosis.

Conclusions

This study highlighted the importance of using a qualitative methodology to explore a complex, cultural phenomenon such as cancer non-disclosure. Further, the study brings to the fore three key findings. First, most of the reasons for disclosing and not disclosing were the same, although these reasons operated differently for disclosing and non-disclosing caregivers. Second, families perceived their patient differently which reflected on how they undertook their caregiving responsibilities such that disclosing families used an assets-based approach and non-disclosing used a deficit-based approach to their role. Finally, there were cognitive consistency effects

which, we propose, worked to reduce dissonance regarding the disclosure decision among both the caregiver groups. The findings also have important implications for cancer care both in India (and other Asian countries) as well as Western multicultural countries, where oncologists and cancer nurses may encounter requests for the non-disclosure of a cancer diagnosis from family members.

References

1. Simpson P. Hong Kong families and breast cancer: Beliefs and adaptation strategies. *Psycho-Oncology*. 2005;14:671-683.
2. Aljubran AH. The attitude towards disclosure of bad news to cancer patients in Saudi Arabia. *Annals of Saudi Medicine*. 2010;3:141-144.
3. Mok E, Chan F, Chan V, et al. Family experience of caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing*. 2003;26:267-275.
4. Wong M-S, & Chan SW-C. The experiences of Chinese family members of terminally ill patients – A qualitative study. *Journal of Cancer Nursing*. 2007;16:2357-2364.
5. Lee A, Wu HY. Diagnosis disclosure in cancer patients – When the family says “No!” *Singapore Medical Journal*. 2002;43:533-538.
6. Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: Communication in palliative care. *Palliative Medicine*. 2002;16:297-303.
7. Ozono S, Saeki T, Inoue S, et al. Family functioning and psychological distress among Japanese breast cancer patients and families. *Supportive Care in Cancer*. 2005;13(12):1044-1050.
8. Back MF, Huak, CY. Family centred decision making and non-disclosure of diagnosis in a South East Asian oncology practice. *Psycho-Oncology*. 2005;14(12):1052-1059.
9. Gonçalves JF, Castro S. Diagnosis disclosure in a Portuguese oncological centre. *Palliative Medicine*. 2001;15(1):35-41.
10. Horikawa N, Yamazaki T, Sagawa M, et al. The disclosure of information to cancer patients and its relationship to their mental state in a consultation-liaison psychiatry setting in Japan. *General Hospital Psychiatry*. 1999;21(5):368-373.

11. Mizuno M, Onishi C, Ouishi F. Truth disclosure of cancer diagnoses and its influence on bereaved Japanese families. *Cancer Nursing*. 2002;25(5):396-403.
12. Ozdogan M, Samur M, Bozcuk HS, et al. "Do not tell": what factors affect relatives' attitudes to honest disclosure of diagnosis to cancer patients?. *Supportive Care in Cancer*. 2004;12(7):497-502.
13. Sun Y, Sun B, Li X, et al. Study of Cancer Diagnosis Based on Families Attitudes' Analysis. In: *Proceedings of the International Conference on Information Engineering and Applications (IEA) 2012*. London: Springer; 2013:261-268.
14. Atesci FC, Baltalarli B, Oguzhanoglu NK, et al. Psychiatric morbidity among cancer patients and awareness of illness. *Supportive Care in Cancer*. 2004;12(3):161-167.
15. Chittem M, Norman P, Harris PR. Relationships between perceived diagnostic disclosure, patient characteristics, psychological distress and illness perceptions in Indian cancer patients. *Psycho-Oncology*. 2013;22(6):1375-1380.
16. Gongal R, Vaidya P, Jha R, et al. Informing patients about cancer in Nepal: what do people prefer?. *Palliative Medicine*. 2006;20(4):471-476.
17. Phungrassami T, Sriplung H, Roka A, et al. Disclosure of a cancer diagnosis in Thai patients treated with radiotherapy. *Social Science & Medicine*. 2003;57(9):1675-1682.
18. Wang DC, Peng X, Guo CB, et al. 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*. 2013;21(4):1089-1095.
19. Yun YH, Lee CG, Kim SY, et al. The attitudes of cancer patients and their families toward the disclosure of terminal illness. *Journal of Clinical Oncology*. 2004;22(2):307-314.

20. Burla L, Knierim B, Barth J, et al. From text to codings: intercoder reliability assessment in qualitative content analysis. *Nursing research*. 2008;57(2):113-117.
21. Laungani P. Culture and identity: implications for counselling. In: Palmer & Laungani, eds. *Counselling in a Multicultural Society*. London: Sage; 1999:35-70.
22. Chan CW, Chang AM. Stress associated with tasks for family caregivers of patients with cancer in Hong Kong. *Cancer nursing*. 1999;22(4):260-265.
23. Yun YH, Rhee YS, Kang IO, et al. Economic burdens and quality of life of family caregivers of cancer patients. *Oncology*. 2005;68(2-3):107-114.
24. Schou I, Ekeberg Ø, Ruland CM. The mediating role of appraisal and coping in the relationship between optimism-pessimism and quality of life. *Psycho-Oncology*. 2005;14(9):718-727.
25. Carver CS, Pozo-Kaderman C, Harris SD, et al. Optimism versus pessimism predicts the quality of women's adjustment to early stage breast cancer. *Cancer*. 1994;73(4):1213-1220.
26. Hu WY, Chiu TY, Chuang RB, et al. Solving family-related barriers to truthfulness in cases of terminal cancer in Taiwan: a professional perspective. *Cancer Nursing*. 2002;25(6):486-492.
27. Mehrotra S, Sukumar P. Sources of strength perceived by females caring for relatives diagnosed with cancer: an exploratory study from India. *Supportive Care in Cancer*. 2007;115(12):1357-1366.
28. Thombre A, Sherman AC, Simonton S. Religious coping and posttraumatic growth among family caregivers of cancer patients in India. *Journal of Psychosocial Oncology*. 2010;28(2):173-188.
29. Carr A. Positive psychology. *Clinical Psychology*. 2005;45:5-6.

30. Friedli L. 'What we've tried, hasn't worked': the politics of assets based public health 1. *Critical Public Health*. 2013;23(2):131-145.
31. Festinger L. *A theory of cognitive dissonance*. Stanford, CA: Stanford University Press; 1957.
32. Singh S, Badaya S. Factors influencing uptake of cervical cancer screening among women in India: A hospital based pilot study. *J Community Med Health Educ*. 2012;2(157):2161-0711.
33. Gupta R, Rowe N, Pillai VK. Perceived caregiver burden in India: Implications for social services. *Affilia*. 2009;24(1):69-79.
34. Hupcey JE. Establishing the nurse-family relationship in the intensive care unit. *Western Journal of Nursing Research*. 1998;20(2):180-194.
35. Chittem M, Butow P. Responding to family requests for non-disclosure: The impact of oncologists' cultural background. *Journal of Cancer Research and Therapeutics*. 2015;11(1):174.
36. Butow P. Communicating with culturally and linguistically diverse patients in cancer care. *Communicating Qual Saf Health Care*. 2015;11:245.
37. Laidsaar-Powell R, Butow P, Charles C, et al. The TRIO Framework: Conceptual insights into family caregiver involvement and influence throughout cancer treatment decision-making. *Patient education and counseling*. 2017;100(11):2035-46.

Table 1. *Caregivers' and Patients' Characteristics*

		Disclosing caregivers (n = 8)	Non-disclosing caregivers (n = 7)
<u>Caregivers:</u>			
Mean age (years)		39	35
Gender	Male	5	7
	Female	3	0
Education	10 th standard	0	1
	12 th standard	0	0
	Undergraduate	2	1
	Postgraduate	6	5
Relation to the patient	Spouse	5	3
	Child	3	2
	Sibling	0	1
	Brother-in-law	0	1
<u>Patients:</u>			
Mean age (years)		50	44
Gender	Male	4	2
	Female	4	5
Cancer type	Ovarian	3	2
	Breast	2	2

Lung	1	
Thyroid	1	
NHL	1	
Liver		1
Rectum		1
Cervical		1

Table 2. *Interview Topics and Sample Questions*

Interview topic	Sample questions
Reasons for choosing disclosure versus non-disclosure	Have you told or not told the patient about their cancer diagnosis? Why did you decide to tell them or not tell them? Did you think about telling them versus not telling them? If yes, what were the reasons you had for telling them versus not telling them?
Motivations for their disclosure decision	What made you decide to tell your patient or not tell your patient?
Experiences of their disclosure decision	How do you feel about disclosing or not disclosing the diagnosis? How has disclosing or not disclosing impacted you?

Table 3. *Frequency of Reasons for Disclosing by Group*

Reason	Disclosing caregivers (<i>n</i> = 8)	Non-disclosing caregivers (<i>n</i> = 7)
Emotional well-being	6	0
Lack of control	6	0
Preparation	4	1
Family reasons	3	1
Patient's personality	3	0
Longevity and curability	3	0
Disease severity	2	0
Barriers to communication	2	0
Moral reasons	2	0
Trust in hospital	1	0

Note. Reasons cited by at least one-third of participants in each group are highlighted in bold font.

Table 4. *Frequency of Reasons for Not Disclosing by Group*

Reason	Disclosing caregivers (<i>n</i> = 8)	Non-disclosing caregivers (<i>n</i> = 7)
Emotional well-being	4	7
Patient's personality	4	7
Family reasons	2	4
Longevity and curability	0	4
Barriers to communication	1	4
Disease severity	1	4
No benefit in disclosing	1	2
Patient's age	0	1
Own responsibilities	1	1

Note. Reasons cited by at least one-third of participants in each group are highlighted in bold font.