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Pivotal role of families in doctor–patient communication in oncology: a qualitative study of patients, their relatives and cancer clinicians

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Families are a unique source of support for many cancer patients. Most advanced communication skills training for oncologists are patient centred and do not cover interactions with family members. The current study used in-depth qualitative interviews of patients, relatives and cancer clinicians with thematic analysis to explore the role of family members in the communication process. Forty-one participants included 10 cancer patients, 10 relatives ensuring proportionate representation of both gender and primary cancer site and 21 doctors representing both medical and surgical oncology. Nineteen of 20 patients and relatives wanted an "open and honest" discussion with their doctors. All patients, relatives and doctors preferred involvement of the family at most stages of cancer treatment. Five themes were identified in relation to communication with family members. The participants highlighted the "importance of family for physical and psychological care," they emphasised the need to "balance patient autonomy and relatives desire to be protective" using varied "negotiating strategies" that are influenced by "socioeconomic circumstances of both patient and family." The doctor–patient-relative communication process was not static with preferences changing over time. The data suggests that communication skills training of cancer clinicians should incorporate modules on better communication with relatives.

KEYWORDS
cancer, communications skills, family, oncology, training

1 | INTRODUCTION

As incidence of cancer rises, oncologists world-wide are confronted with the need to communicate difficult issues with patients and their families. In recognition of the need to balance honesty with pragmatic optimism, many countries have introduced mandatory communication skills training for oncology clinicians so that patients have hope but not unrealistic expectations. A recent review on the key modules for basic communication skills training included "running a family meeting" (Kissane et al., 2012). Despite this, barring a few exceptions (Delvaux et al., 2005; Dumont & Kissane, 2009; Gritti, 2015; Gueguen, Bylund, Brown, Levin & Kissane, 2009), cancer communication skills training and guidelines rarely include family members. The literature is limited to techniques to conduct family

meetings with cancer patients (Dumont & Kissane, 2009; Gueguen et al., 2009). The only randomised trial on communication skills training of cancer physicians that addressed family members concluded that communicating with a patient and a relative requires the acquisition of specific skills which requires appropriate additional training (Delvaux et al., 2005). However, the training continues to be focussed on individual doctor–patient communication.

Families play a key role in support of the patient worldwide. This assumes even greater importance in developing countries where there is limited state-funded cancer care. India with 17% (1.2 billion) of the world's population, has around 1 million new cancer patients every year, with numbers projected to rise more than 1.7 million per year by 2035 (Mallath et al., 2014). Opinion pieces suggest that strong family ties may reduce the personal responsibility of the Indian patient who is undergoing treatment for cancer (Chaturvedi, Strohschein, Saraf & Loiselle, 2014) and that collusion between relatives and doctors and the difficulties associated with that are a key issue (Chaturvedi, Loiselle & Chandra, 2009). Relatives mainly accompany the patient to provide support or to serve as the patient's advocate. Literature from Hong Kong showed family caregivers want to learn about the care giving process (Mok, Chan, Chan & Yeung, 2003). All of this suggests communicating with family members is pivotal. We report on need for inclusion of relatives in cancer communication, as perceived by the cancer patients, their family members and doctors.

2 | METHODS

A qualitative study based on methodological orientation of thematic analyses was conducted at the Tata Medical Center, Kolkata. This is a tertiary care "not-for-profit" cancer hospital with a large catchment area serving eastern India and neighbouring countries. During the study period, 2013–2014, the hospital saw over 12,000 new patients annually. The study was approved by the TMC Institutional Ethical Review Board (EC/TMC/10/13).

2.1 | Research team

The core research team consisted of two consultant psycho oncologists, a psycho oncology fellow, three cancer clinicians and two visiting social science interns. Four (SSD, SC, SG, UM) of the team had previously undergone advanced communication skills course in United Kingdom. The interviews were conducted by the psychology fellow (LT) and the interns (RV, JL) who had limited if any interaction with the study participants prior to the project. This ensured that participants were less inhibited in expressing their views. The lead researcher (SSD) trained all three interviewers in conducting in-depth interviews.

2.2 | Participants

This study participants comprised adult cancer patients attending outpatient clinics, adult relatives and oncology clinicians. They were selected using purposive sampling to ensure proportionate representation of both gender and primary cancer site. In addition efforts were made to ensure that clinicians recruited represented both medical and surgical oncology specialities and varying levels of experience and seniority. Following informed consent, one to one interviews for patients and relatives were conducted in a standard clinic room and doctors were interviewed at their convenience in their offices.

2.3 | Qualitative interview

Interviews were conducted using a preliminary interview guide. Patients and relatives were probed on their preferences regarding communication of the initial diagnosis and any ensuing bad news. Issues raised included their preferred setting and mode of delivery, and the role of their family members in the care giving process. Patients and relatives were interviewed by LT in English or in Bengali as per their own preference. All interviews were recorded and then transcribed. Following this the interviews that were done in Bengali were translated into English by an independent experienced translator and then again back translated to check for authenticity. All doctors were interviewed in English by RV and JL. English is the language used by the medical profession in India which has several regional languages. Most tertiary cancer centres employ doctors who may speak several different languages at home. Doctors were asked about their views on communication with patients/relatives, especially the manner of breaking bad news, introducing palliative care and areas they faced difficulties with communication. In addition they were asked about past training in communication skills and their preferences with regard to future training. All interviews were audio recorded and once started were completed in the same sitting. During transcription, each section was double checked for accuracy.

2.4 | Data analysis

The interviews were transcribed verbatim and transcripts were anonymised by removing the names and places. Data collection and data analysis ran simultaneously. Interviews were coded by LT and SSD multiple times to ensure that codes related to newer themes were incorporated. UM reviewed the codes and helped to sort out any disagreements between the two coders. Following coding of the data, data synthesis was done by SSD. Basic and global themes were generated in line with the method of thematic analysis (Braun & Clarke, 2006).

3 | RESULTS

The study was conducted between July 2013 and July 2014. Ten patients, 10 relatives and 21 doctors (10 subspecialty trainees and 11 consultants) were interviewed. The median age of patients was 58.5 years (IQR 47.75–63.75). Six were women and four were men. Of the relatives, five were male and five were female. The median age of relatives was 34.5 years (IQR 25.75–54). Three of the 10 relatives recruited in the study were related to a patient who was also a study participant (Table 1).

Median age of doctors was 38.4 years (IQR 31.5–44.5) and 16 were male and 5 were female (Table 2). Only 6 of 21 doctors had received some form of formal communication skills training. All six

TABLE 1 Demographic details of patients and relatives

SN	Individual	Age	Gender	Education	Occupation	Cancer type
P1	Patient	69	Male	Graduate	Business	Carcinoma bladder
P2	Patient	25	Male	Post-graduate	Government employee	Glioblastoma
P3	Patient	62	Male	Post-graduate	Retired	Carcinoma lung
P4	Patient	38	Female	Graduate	House-wife	Carcinoma breast
P5	Patient	57	Female	Post-graduate	Journalist	Carcinoma ovary
P6	Patient	61	Male	Post-graduate	Retired	Carcinoma hypopharynx
P7	Patient	70	Male	Graduate	Retired	Carcinoma prostate
P8	Patient	55	Female	Graduate	House-wife	Carcinoma gallbladder
P9	Patient	51	Female	Post-graduate	House-wife	Non Hodgkin lymphoma
P10	Patient	60	Female	Graduate	House-wife	Primary peritoneal carcinoma
R1	Relative (wife)	57	Female	High school	House-wife	Carcinoma bladder
R2	Relative (son)	34	Male	High school	Manual labourer	Carcinoma lung
R3	Relative (husband)	46	Male	Graduate	Service	Carcinoma breast
R4	Relative (daughter)	20	Female	High school	Student	Carcinoma ovary
R5	Relative (wife)	53	Female	Graduate	House wife	Carcinoma hypopharynx
R6	Relative (son)	27	Male	Graduate	Service	Carcinoma pancreas
R7	Relative (son)	31	Male	Graduate	Business	Carcinoma prostate
R8	Relative (husband)	57	Male	Graduate	Business	Carcinoma gallbladder
R9	Relative (daughter)	22	Female	Graduate	Student	Carcinoma thyroid
R10	Relative (daughter-in-law)	35	Female	Graduate	School teacher	Carcinoma ovary

had prior communication skills training in the UK, USA or Australia. However, no one explicitly mentioned training in communicating with families. The other three mentioned that during their communication skills training the emphasis was always the individual and not families.

3.1 | Importance of doctor–patient communication

The majority (19/20) of the patients and relatives highlighted the pivotal role of doctor-patient communications - "The patient will get to know about the problem only when the doctor speaks to them." (R2); "Doctors should communicate properly alongside doing medical treatment and more explanations will help patients adhere to medical treatment" (R8) and the need for an open and honest discussion - "When the doctors explained every single detail about the treatment she will be doing, I was less worried" (P4). This was also echoed by clinicians "I think they all want information" (Consultant Medical Oncologist); "So you would just tell the patient on day one that, no, you're not a magician and you can't work miracles. You have to be honest with your patients" (Consultant Clinical Oncologist).

While there were no explicit statements about poor doctor patient communication, the patients alluded to it by putting forward reasons for limited information sharing by their doctors – time pressures - "Doctors play a major role in communicating with patients. But due to time constraints they can't talk properly to patients. They are so busy that it appears a bit scary to ask questions (P1)"; and underestimating patient's ability "They think patients will not understand anything. So (they feel) 'what's the point in discussing with the patient?'"(P7).

Clinicians perceived breaking bad news to be a difficult task. One of them said "I think this is one of the big challenges." (Consultant Gastroenterologist). Doctors valued proper communication with patients, and one of the surgeons concluded "When Communication stops everything stops." (Consultant Surgical Oncologist). Communication skills influence patient satisfaction. A patient explained "If the patient is going to lose everything it's not fair if the doctors are not going to tell him straight…. the doctor didn't ask me to go out from the room, and tell my wife, or something like that; and I think I felt good about that" (P6).

Key themes highlighted during interviews on the role of communication with family members were the following:

3.1.1 | Importance of family for physical and psychological care

Patients and their family members discussed the importance of families in providing support and care throughout the cancer journey from diagnosis, through active curative treatment and eventually during palliation. Patients expressed their dependence on their family members – "I think my son will help me recover and do whatever is necessary" (P1). A family member expressed in similar lines that she is not only very involved in the physical aspects of caring but also at an emotional level – "I have to handle him very carefully explaining and making him understand the importance of medicines and treatment and support him" (R6). The

TABLE 2 Demographic details of doctors who were interviewed

SN	Age	Sub-speciality	Gender	Designation	Years of experience
1	43	Head & Neck Surgical Oncology	Male	Consultant	14
2	40	GI Oncology	Male	Consultant	15
3	40	Clinical Oncology	Male	Consultant[a]	16
4	50	Breast Oncology	Female	Consultant	27
5	53	Medical Oncology	Female	Consultant	30
6	55	GI Oncology	Male	Consultant	32
7	41	Respiratory Medicine	Female	Consultant[a]	20
8	46	GI Oncology	Male	Consultant[a]	26
9	33	Medical oncology	Male	Consultant	9
10	50	Gynaecological Oncology	Male	Consultant[a]	26
11	30	Surgical Oncology	Male	Fellow	7
12	33	GI Oncology	Male	Fellow	9
13	29	Breast Oncology	Female	Fellow	4
14	34	Surgical Oncology	Male	Fellow	9
15	33	Surgical Oncology	Male	Fellow	7
16	35	Surgical Oncology	Male	Fellow[a]	12
17	32	General Medicine	Male	Consultant	9
18	32	Radiation Oncology	Male	Fellow	8
19	31	Clinical Haematology	Male	Fellow	7
20	41	Gynaecological Oncology	Female	Fellow[a]	10
21	31	Radiation Oncology	Male	Fellow	4

[a]Past communication skills training.

value of such support provided by family members was highlighted by several doctors - "families become useful in the absence of community nurses and other sources of support" (Consultant Radiation Oncologist). Hence, many would involve relatives in discussions about treatment - "I prefer that both patient and the family members stay together in the room." (Consultant GI Oncologist). Involving the family members in treatment and cancer care was perceived to improve adherence and outcome – "I think it's better that the family gets involved. We are able to send them home quicker." (Consultant Head & Neck Surgeon); "I try to rationalise with my husband and tell him the advantages of sticking to the treatment plan as advised and try to convince him" (R1). It was viewed as especially important as cancer progressed from a curable to an incurable stage – "The family becomes even more important when it is about palliation." (Fellow, Gynaecological Oncology)

3.1.2 | Balancing patient autonomy and relatives protectiveness

All accepted that breaking bad news in the presence of family members was good practice. In this context, one of the oncologists said - "Patients actually never come to the hospital alone. They often come with their family." (Consultant Breast Surgeon). A senior oncologist justified this as – "When it is done in the presence of such people, a lot of the bad news is shared. So, the patient actually doesn't need to deal with it himself or herself in entirety… they act as a buffer between the patient, the news and the doctor…." (Consultant Radiation Oncologist). The buffering role of relatives was also emphasised by a patient - "Doctors often do not want to hurt the patient and so they give the bad news to the family members and automatically the patient gets the news from the family members." (P7).Concerns raised included the need to determine relative's relationship to the patient – "If we are delivering news to a family member, then we make sure that the person is actually family, not any relative, neighbour or bystander. We always ask 'how are you related to (the patient)?' If it is a close relation, only then we disclose the news. Otherwise we prefer not to" (Fellow, GI Oncology).

However, majority of patients (7/10) and relatives (8/10) stated that they would prefer bad news to be first discussed with family members - "doctors should break the news to the relatives first" (R11). This was also supported by 19 of 21 doctors, 14 of whom stated that they shared bad news with the family first with only four stating that they spoke to both the family members and the patient together. Only two doctors told their patient first but even they went on to add that they would be willing to share the diagnosis with family members. Patient confidentiality and related concerns were only explicitly mentioned by one clinician. On similar lines one of the patients said that "the patient may become nervous if the bad news was given to him first" and went on to say that "the news should come from the relatives." (P7).

At times the family would request that information be withheld from the patient. In these situations, some doctors would ask the patient - "'what do you want to know about your disease?' And, if a patient says: 'I want to know everything,' it really doesn't matter what the relatives say. I say this to the relatives, as well and discuss with the patient and try to answer his questions" (Consultant GI Oncologist). Patients may clearly state that they do not wish to know the details "'no, I don't want to know the details. I'm going to go out of the room. You tell my son everything that you want to and I'll do whatever he says,' well, that's the patient's choice" (Consultant GI Oncologist). However, establishing the patient's explicit views is important as it cannot be assumed that all are comfortable with a dialogue that is limited to the clinical team and the family – "If doctors discuss with my family members only, then I may not be able to understand the treatment and possible outcomes. This would keep me worried about my future" (P9).

3.1.3 | Negotiating with family members

Doctors engage with patient relatives in their own unique ways from the very first consultation - "I usually get the history from the patient regarding the symptoms' and (ask) families what tests have been done" (Fellow, Surgical Oncology). This builds the basis for negotiations on the manner of breaking bad news "I usually tell the relatives that somebody has to tell the patient what's wrong and it is much easier for me to tell them rather than for them." (Consultant Respiratory Physician). The negotiating style varied among individual clinicians - "If the relatives come in first and say 'don't tell my mother that she has a malignancy'. I first sit and reason out with them that this being a cancer hospital, there is no way that she is not going to know that she has cancer."(Consultant Medical Oncologist); "First, I try to convince the relatives that they must start talking to the patient." (Consultant Radiation Oncologist). "Usually families are convinced and when the patient returns" (Fellow, Surgical Oncology). A consultant surgeon said that he often chooses the most receptive relative amongst a group and tries to engage him/her to take a lead role – "That is what I look for among the relatives. If there is one person most receptive, I build on him. Unconsciously I give him the role of counsellor. I say: 'It is your job to make him (the patient) feel good. He shouldn't be feeling down before surgery, he should be up…' this is a big responsibility that I have entrusted on him. He takes it on with a lot of pride and he comes back and says: 'my father did this and that' and I say 'Great, you did a good job.'"(Consultant Head & Neck Surgeon). A caregiver suggested that "if there are many relatives in the room, the doctor should not talk to everyone together in the room as this may lead to confusion. He should choose one person to be in the room and discuss with him" (R3).

Communication also played a role when patients and family members have differing views on treatments, including those that have impact on body image - "Even when you tell them there is a small tumour, the family members often say just remove the breast. Once you start talking to the woman about it, she will, not always but often say that she would prefer if it wasn't removed" (Consultant Breast Surgeon). Providing more information often helps the clinician negotiate with family members.

3.1.4 | Influence of socioeconomic circumstances of both patient and family

Patients themselves identified that information sharing and discussions should be personalised - "The doctor should check the educational background of the patient and family members and then disclose information accordingly. Sharing too much information may make them confused" (P2). A caregiver went on to say that the discussions should be with "someone who is mature enough to handle the information" (R7).

Doctors also said that they often tailor information to match understanding of the patient and family "If I get a very good positive vibe from the patient that he understands what is going on I explain the whole thing to them… the stages of illness and type of treatment needed. But many patients don't understand. Then I just show them the pictures of the original cancer and how they are likely to look at the end. I skip the steps in between." (Fellow, Surgical Oncology); "I use (web based resources) for people who I think have access to the internet. Sometimes family members will look up a website rather than the patient themselves. But there are plenty of patients as well who would spend time looking at websites." (Consultant Breast Surgeon).

Treatment related decisions are often made jointly by the clinicians, patients and family members - "Usually the family and the patient decide together." (Fellow, Clinical Haematology). However, when the treatment is financed by family instead of the patient, this introduces another layer of complexity – "For educated and financially independent patients, I would give the patient all available treatment choices (Consultant Medical Oncologist)." However, when a patient is financially dependent on somebody else, clinicians make a judgement call – "One option is to tell the patient: 'oh, this is available,' but it might mean that they receive the second or third best treatment and, if things go wrong, the patient will always live and die with the feeling that there was something better that could have been done. That, I think, is not really fair (Consultant Medical Oncologist)." The second option is to limit the information on treatment options so as not to "put pressure on that other person to actually finance the 'best'. I mean, the guy might have to sell off everything, lose the patient and then have nothing left for him and his own family. So you have to play it a little carefully over here. It's a judgement call." (Consultant Medical Oncologist).

3.1.5 | Shifting responsibility from family to patient

As the disease progresses, the preference of the patients, relatives and clinicians about who should be in charge of decision making, seems to shift from family to patient – "What we have seen is that after breaking the news (of transition from curative to palliative options) there is a sort of 'shock and denial' period. Finally the patient comes to accept what has been said and after that they tend to sort of make the decisions needed. Before that decisions are made by the family members. After they get to know they make the decisions." (Fellow, Radiation Oncology); "the patient should be informed first (of the transition) but with enough care so that they can prepare for any subsequent

bad news. This should be done in the presence of the family members" (R6). At this juncture it maybe the relatives who need support - "Patients usually accept, it is the family who starts breaking down" (Fellow, Clinical Haematology). However, not all are convinced about the shifting of all responsibility to the patient- one relative said that "If the patient is given all the responsibility, he may become hopeless and start thinking that 'I am going to die soon'. This is not in the best interest of the patient" (R10).

3.1.6 | Family and communication skills training

Doctors valued proper communications with patients and families. Many modelled their clinical interactions based on observing senior colleagues. Clinicians agreed that formal communication skills training can be beneficial - "Yes, training can definitely help in communication. I feel training in communication would help in making difficult information more palatable for the patient. It makes a huge difference in the way you talk to your patient." (Fellow, Surgical Oncology). With regard to communication with relatives, one doctor said that, "When five people ask me questions at the same time I sort of get overwhelmed and I think I could do a bit better." (Consultant Clinical Oncologist). Doctors emphasised need to be trained in dealing with multiple family members. Perceived training needs varied depending on experience. One doctor commented that "One-size-fits-all training is not going to work." (Consultant Head Neck Surgeon). A senior consultant commented on possible training methods "small courses and a little guidance from a trainer. Trainers can quietly come in and observe what I am doing and then give me feedback – this is right, this is wrong" (Consultant GI Surgeon).

4 | DISCUSSION

Our study on views of patients, their relatives and clinicians regarding family's role and importance in the communication process found that majority, if not all, consultations involve family members. Clinicians use a variety of communication techniques to negotiate and balance patient autonomy and relatives' desire to withhold "bad news." With disease progression, families seem to become more accepting of sharing information and making decisions with the patient. This intense interaction between family members, patients and clinicians is inadequately addressed in most cancer communication skills training for doctors. There is an urgent need to bridge this gap.

The study has several strengths. A three-way investigation of the themes involving cancer patients, their relatives and clinicians ensured exploring different perspectives to capture a holistic picture. The study adhered to COREC guidelines for qualitative research (Tong, Sainsbury & Craig, 2007) for its design and implementation. Interviewers were all non-medical and not part of the team treating the patients allowing study participants to speak more freely. The doctors had varying degree of experience and represented most oncology specialities.

We found that the family played an integral part in communication between clinicians and cancer patients. Relatives are often present during difficult times of the journey of a cancer patient and actively participate in the care process (Merckaert, Libert, Delvaux & Razavi, 2005; Zaider & Kissane, 2010). Although perceived to be more important in countries with limited publically funded cancer care, the role of families is equally crucial in high income countries (Rhondali et al., 2014). Even in the west, regular routine family meetings are not uncommon in cancer care but only sparse literature is available about how to engage and utilise this excellent resource (Albrecht, Eggy & Ruckdeschel, 2010; Coyle & Kissane, 2010).

We found that patients preferred to know their cancer diagnosis and be involved in decision making. This is the norm in western cultures (Seifart et al., 2014) and is reflected around the world through an increasing trend towards full patient disclosure (Chaturvedi et al., 2014; Ichikura et al., 2015). Our findings are in contrast with recent reports from Canada (Oliffe, Thorne, Hislop & Armstrong, 2007) and Australia (Chittem & Butow, 2015) that suggest that cancer patients from non-Western cultures may prefer less information and do not desire full disclosure. Like Gautam and Nijhawan (1987) two decades ago, we found that majority of Indian patients want to be told the truth. This together with the recent report from India that patients unaware of their cancer diagnosis have more depressive symptoms (Chittem, Norman & Harris, 2015), lends support to adopting full patient disclosure in the LMIC setting.

However, majority of patients and relatives preferred bad news to be first disclosed to family members. The findings highlight the importance of developing communication skills to be able to handle these two seemingly opposing dilemmas – the patient's wish to know details versus their desire that most issues be first discussed with close family members. With disease progression, families are less reluctant to share difficult decision making with patients. This was also noted by Muckaden, Marathe, Tulshan, Carvalho and Pinto (2005) who found that while two-thirds of women with cervical cancer had their diagnosis concealed by their family members, collusion only persisted in about 15% towards end of life. Clinicians need to be aware of these changing dynamics and address them in family meetings appropriately. The communication needs of patients are centred on being able to ask questions and handle bad news in the company of another trusted adult. In our current understanding of the communication process, we feel doctors often modulate the information they share based on their own appraisal of the patients' socio-cultural background and explicit preferences of the patient to meet the expected outcome of balancing the autonomy of the patient and at the same time build a caring therapeutic relationship.

Communication skills training is mandatory for cancer clinicians in many countries. Checklists are available for family meetings in an oncology setting that includes ways to declare goals, explore agendas, clarify issues and conclude the meeting (Kissane et al., 2012). These techniques, however, are not included in mainstream communication skills courses for oncologists. Specific modules need to be developed to help oncologists learn these skills. These modules should include

exploring patient preferences with regards to family involvement in disclosure and decision making, negotiating techniques with relatives and an understanding that these preferences evolve over time. The patients' desire to eventually know the 'truth' is universal.

A key limitation was that the interviews were conducted at a single not-for-profit cancer centre in India. This may not have captured all aspects of involvement of families in information sharing and decision making as this may vary across cultures and countries. However, it is likely that the central finding of the study that cancer clinicians need to interact and negotiate with relatives is universal. Another issue was that patient and family quotes were limited in comparison to those from clinicians. This was to a certain extent mitigated by ensuring that all interviews were conducted in private with systematic use of prompts and no involvement of medical staff.

5 | CONCLUSION

Families are a unique source of support for many cancer patients. Most advanced communication skills training for oncologists do not cover interactions with family members. Our study found that all patients, relatives and doctors preferred involvement of the family during cancer treatment. Five themes were identified in relation to communication with family members. The participants highlighted the "importance of family for physical and psychological care," they emphasised the need to "balance patient autonomy and relatives desire to be protective" using varied "negotiating strategies" that are influenced by "socioeconomic circumstances of both patient and family." The doctor–patient-relative communication process was not static with preferences changing over time. The data suggests that communication skills training of cancer clinicians should incorporate modules on better communication with relatives.

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