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Responding to family requests for nondisclosure: The impact of oncologists' cultural background

ABSTRACT

Context: Nondisclosure of cancer diagnosis is common in many Eastern countries. Consequently, immigrant families often approach oncologists with requests for nondisclosure in Western countries.

Aims: To explore differences in the attitudes and practices of Western-born and nonWestern born oncologists in Australia when faced with a nondisclosure request.

Settings and Design: Using a cross-sectional design, oncologists were interviewed over the telephone.

Methods: Using the snowball method, 14 Australian (Western = 9, non-Western = 5) oncologists were recruited. Oncologists participated in a semi-structured interview exploring their experiences of, and response to, a request for nondisclosure, and their perceptions of how their cultural background influenced these attitudes and responses.

Analysis: The interviews were transcribed and analyzed using interpretative phenomenological analysis.

Results: Six main themes emerged from the study: (1) Barriers to truthful communication, (2) an ethical and moral dilemma, (3) high costs of nondisclosure, (4) cultural influences on interpretation and understanding of requests for nondisclosure, (5) emotional impact of bad news on patients, families and oncologists, and (6) truthful disclosure as a gentle balancing act.

Conclusions: All oncologists felt that the family request for nondisclosure was difficult, with many cultural and emotional nuances to take into consideration. Some immigrant Australian oncologists who had a similar cultural background as the patient/family, felt they could better understand the desire for nondisclosure. Irrespective of their cultural background, all oncologists acknowledged that breaking bad news had to be done in a gentle, gradual manner. The study suggests a need to develop a culturally sensitive cancer communication model.

KEY WORDS: Australia, cancer, communication, culture, immigrant, nondisclosure, oncologists

INTRODUCTION

Full disclosure, patient autonomy and informed consent are the fulcrum of medical ethics in the West.^[1-4] Consequently, Western medical practice promotes open and free communication with patients such that they are fully aware of their illness and treatment, their queries are addressed and patients are encouraged and supported to be involved in medical decision-making. However, variations in patient-doctor preferences, especially in multicultural societies, suggest a discrepancy between doctors' and patients' attitudes towards cancer disclosure, communication styles and medical decision-making.^[5,6] Patients from Eastern cultures seeking cancer treatment in Western countries may prefer nondirect communication, and sometimes nondisclosure.^[6] The role of family in medical decision-making is also more pronounced and acceptable among patients from

Eastern cultures,^[7,8] with patients sometimes expecting the family to supersede them in terms of receiving information and being involved in decision-making.^[9]

Contrasting to Western medical practice, oncologists in Eastern countries comply with this family-centered approach by routinely communicating diagnosis and prognosis information to families, allowing them to make disclosure and other medical decisions for the patient.^[9-11] However, while a number of studies have explored oncologists' responses to nondisclosure requests, there is no published research that has explored the role of oncologists' own culture on these responses within a multicultural Western environment. Therefore, the current study explored differences between Western and non-Western-born oncologists in the way they interpreted and dealt with the family request for nondisclosure in Australia.

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METHODS

Participants and procedure

Eligible participants were oncologists (medical, surgical, and radiation) practicing in Australia. Participants were recruited using snowball and purposive sampling. Three E-mails were initially sent by the Medical Oncology Group of Australia (the peak representative body for medical oncologists in Australia) to their membership, detailing the study and requesting interested oncologists to E-mail the lead researcher.

Following their interview, participants were asked to nominate other oncologists, inform them about the study and if they were interested, provide them the researcher's E-mail address to contact. The researcher then contacted these oncologists to obtain informed consent. The researcher particularly sought to balance the sample with Western and non-Western-born oncologists. Recruitment continued until informational redundancy (saturation of themes) was achieved, with three consecutive interviews yielding no new themes.

Semi-structured interviews with open-ended questions were developed to focus on oncologists' experiences of a request for nondisclosure, how their cultural background influenced their attitudes, and how they handled the issue of nondisclosure [Table 1]. Interviews were conducted by a psychologist trained in qualitative methods, recorded over the telephone, and subsequently transcribed and analyzed. Each interview took approximately 40 minutes. Ethical approval for the study was obtained from the Human Research Ethics Committee at the University of Sydney.

Analysis

The study used interpretative phenomenological analysis,^[12] a qualitative research methodology that is primarily interested in understanding a homogenous group of individuals' subjective accounts or perceptions of certain events or experiences they commonly experience.^[13] Emergent themes based on the authors' interpretations of the recorded interviews were noted for each transcript, and characteristic quotes were identified to exemplify each theme. Themes were then checked for emerging patterns, differences and consistency, similarities across participants and the role of specific accounts. From these, super-ordinate themes were iteratively developed, which were used as a basis for clustering sub-ordinate themes when analyzing subsequent transcripts. Pseudonyms have been used for all quotes. Whole or part quotes presented in the

Table 1: Interview topics

Preference for disclosure/nondisclosure with reasons for preference
Barriers or constraints when communicating with patients, role of family
How do they go about dealing with the family, role of own cultural background
How do they break the bad news to the patient, role of own cultural background
Managing of feelings of patient, family and self when breaking bad news

text are italicized. Full quotes for each theme and subordinate theme are presented in Table 2.

RESULTS

Fourteen oncologists (12 males, 2 females), aged 34-57 years, participated in the study, of whom nine were Western and five were non-Western-born [Table 3]. Six themes were identified.

Barriers to truthful communication

All oncologists commented that there were several barriers to truthful communication, when they saw an immigrant patient. A family request for nondisclosure was the first and "biggest" barrier to truthful communication, which challenged their ability to talk honestly to patients at the outset. Oncologists observed that family interference was due to many reasons: Firstly a belief that a cancer diagnosis was tantamount to a death sentence, stemming from immigrancy at an early age, which left families without access to the information they could understand and marooned them in the medical world of their childhood. As a consequence family members feared that cancer disclosure could result in poor psychological outcomes for the patient, that they may refuse treatment, lose hope, die immediately after disclosure or not be able to cope with the news.

Five Western-born oncologists reported that another barrier to truthful communication was not sharing a common language with the patient, as this led to a "superficial," nondirect relationship with the patient conducted through family or professional interpreters. With such patients they often found it challenging to understand their level of awareness of their illness or desire for additional information. Further, oncologists noticed that while patients were comforted by having an interpreter who could speak their language, professional interpreters were also impersonal, as "it's not their job to be involved in the human interaction". Consequently, they felt distanced from their patients and unable to offer them a personalized relationship and emotional support. While the family did add value in terms of creating an emotionally supportive consultation, five Western oncologists and one non-Western-born oncologist (Chung) observed that the language barrier was made more difficult when families were interpreters. They suspected that family members did not always translate what they were really saying, thus interfering with the doctor-patient relationship and breeding mistrust in the relative as an "unreliable" interpreter.

An ethical and moral dilemma

All participant oncologists recognized that the family's request for nondisclosure posed an ethical and moral dilemma. Administering patients "toxic", "poisonous" and "aggressive" medication without them being fully informed of their condition and the reason for this treatment, made oncologists very "uncomfortable." The oncologists believed relatives were

Table 2: Quotes

Super-ordinate themes	Sub-ordinate themes	Quote
Barriers to truthful communication	Family interference	"... Basically the family members will usually pull us aside before the consultation and they will indicate ... their preference for nondisclosure of a malignant diagnosis as they are concerned that their parents or family member will not be able to cope with the diagnosis" (Chris, Malaysia)
	Historical pessimism	"... The main reason why is that, you know, cancer was basically a commitment to die ... As soon as they use the word cancer before, people said "Oh they they're definitely going to die"" (Tariq, Iran)
	Language barrier	"... Even though you try not to speak in scientific or too medical terms I think sometimes that their understanding of words, and of how the body works maybe is a barrier and then I find it hard to talk." (Sylvia, UK)
	Lack of trust in family as interpreter	"... Especially even worse, if the family is being used as the interpreter. So you don't know exactly how much the patient understands and how much they (family) actually interpret (what I say)" (Chung, HK)
An ethical and moral dilemma	Patient autonomy	"... I think that it's wrong to deny people the opportunity to hear that they've got cancer or the opportunity to hear that the prognosis might be good or bad or that they may or may not be treatment options " (James, UK)
	Desire to respect family's wishes and ensuring a straightforward consultation to the patient	"I'd say to him "Okay I'm going to try and understand where you're coming from but you have to understand where I'm coming from. He needs to know that he's got cancer because otherwise he might understand only that it's a treatment of death, he'll get more scared you know, he'll have a tougher time is you know is that what you want?" ... say to him you know "Can you- I'm very happy if you explain that to this patient. You know so you are in charge"" (Stan, Australia)
High costs of nondisclosure	Duty as oncologist to patient, not family	"So often I get around it sometimes by saying, "Do you realize that my duty as a carer is not to you but it's to them?"" (Joe, Australia)
	Counter-productive for both family and patient	"... I think nondisclosure often leads to a lot of conflict because ... it makes the patient much more difficult to manage because the family will have unrealistic expectations as well as the patient themselves might have very unrealistic expectations" (Chris, Malaysia)
Culture influences interpretation and understanding of requests for nondisclosure	Personal sense of regret	"... You may never resolve it; you may never get the chance to ... have that discussion. Sometimes there's other relatives... they may never allow you the privacy to do it. ... they always leave you with a lingering feeling that this could have been done better" (Joe, Australia)
	Own cultures helps understand and communicate with family	"My culture offers me a very good opportunity to understand what it (cancer) means and why they (family) are asking for that (nondisclosure) and... because of that understanding I can then speak to them and explain to them about the problems about that kind of request" (Surya, Sri Lanka)
	Hard to understand culture different to your own	"I consider myself Western, in my cultural perspective whatever that means ... I would say that I recognize that people have different attitudes and different cultures and I guess one of the difficulties I have is that although we like to be what you might call 'culturally sensitive' it is it is awkward to have to deal with multiple different cultures-that is, exactly what one particular culture wants versus another" (Jordan, Australia)
	Own culture may influence attitudes	"... Middle class educated Western background so. I have those sort of values of. you know at least in theory um. full and open kind of disclosure and discussion and... kind of a shared decision-making model for the treatment options. so you know I think that's probably pretty, you know, pretty profound influence" (Tom, UK)
Emotional impact of bad news on patients, families and oncologists	Integrate experience of other cultures as part of own culture and attitudes	"... Once you start to recognize that there is more than one world view about how to communicate within the culture of the family – that can have a striking change in how you come to be slightly more open-minded than before " (Mark, Australia)
	On patient	"... This is going to be a life changing event, you know, for them and for their family..... everything is now going to change, destroyed their family, you know, their hopes for future, their employment their lifestyle, everything is going to change and ... it's a very big thing for them" (Tariq, Iran)
Truthful disclosure is a gentle balancing act	On oncologist	"I think all of us in oncology must develop something that we do to depersonalize that so that we do not get distracted every day that we come to work..." (Sylvia, UK)
	Gradual disclosure	"Sometimes you just need to decide how much disclosure you want to give to the patient on the first consult. Some patient might not be able to accept all the information on the on the first ... you know, you might have to disclose the information gradually." (Mai, China)
	Discussing with the family first	"... Meet with the family members first to the exclusion of the patient ah and I do have a patient discussion with the family... I do explore with the... ah family members why they are wanting to protect the patient" (Stephen, Australia)
	Euphemisms	"I mean it depends on how bad they want the euphemism to be, if the euphemism is "tumor" or "serious disease" I sometimes go along with them at first. But if the euphemisms I've been asked to say they have got a bad cold I think... oh that's just silly! If the euphemism is close enough for them to understand that it is serious I sometimes let it go for the first visit or two until I've got to know them better" (Bob, UK)

Table 3: Participant details

Name	Age	Gender	Specialty	Country of birth	Country of parents' birth	Country where medical education was completed
Joe	42	Male	Medical oncology	Australia	Greece	Australia
Jordan	39	Male	Medical oncology	Australia	Borneo (father) and Australia (mother)	Australia
Mark	57	Male	Medical oncology	Australia	Poland	Australia, UK and USA
Stan	44	Male	Surgical oncology	Australia	Australia	Australia
Stephen	34	Male	Medical oncology	Australia	Australia	Australia
Sylvia	51	Female	Medical oncology	UK	UK (father) and Canada (mother)	UK and Australia
James	42	Male	Medical oncology	UK	UK	Australia
Tom	49	Male	Medical oncology	UK	UK (father) and Australia (mother)	Australia
Bob	56	Male	Radiation oncology	UK	UK	UK and Australia
Tariq	42	Male	Medical oncology	Iran	Iran	Tehran and Australia
Surya	53	Male	Radiation oncology	Sri Lanka	Sri Lanka	Sri Lanka
Chung	41	Male	Medical oncology	Hong Kong	China	Australia
Mai	36	Female	Medical oncology	China	China	China and Australia
Chris	34	Male	Medical oncology	Malaysia	Malaysia (father) and Singapore (mother)	Australia

thus denying patients their “natural right” to make their own treatment decisions.

However, most Western (6) and two non-Western-born (2) oncologists also acknowledged the importance of respecting the family’s wishes. Thus, they felt caught in a moral dilemma between respecting family wishes and ensuring patient autonomy. These oncologists observed that there was “art” in how they tackled this dilemma, which included being empathic, reassuring, inclusive yet firm when explaining to nondisclosing families the need for disclosing necessary information to patients.

A small number of oncologists (Western = 3, non-Western = 2) felt their duty was towards the patient and not the family, since it was the patient who was receiving their treatment. These oncologists felt that nondisclosure to any degree was an act of deception they strongly opposed. Therefore, they confronted the family by telling them they would not partake in any dishonesty surrounding diagnosis disclosure. This attitude toward nondisclosure was supported by the belief that patients already knew they had cancer by virtue of the name of the cancer center, having seen previous oncologists or having gone through a long treatment or diagnostic process. Patient’s awareness was deduced by the oncologist either by observing the patients’ body language or by simply asking prompting questions such as, “What do you understand about what the tests have shown?” (James).

High costs of nondisclosure

Five Western and one non-Western oncologists reported that the costs of the nondisclosure are multipronged and high. The most common concern was the potential impact of constrained family communication on the patient, due to their inability to freely discuss the disease leading to “unrealistic expectations,” “unanswered questions” and patients being unable to express their fears. Unfulfilled communication was viewed as especially problematical at the end of life, as patients were not given the chance to put their affairs in order and “communicate with the important people in their life.” This sense of unfulfilled communication was heightened

when families used various strategies to request nondisclosure even before the oncologist met the patient, ranging from calling in advance, speaking in English if the patient was not English-speaking, to leaving the oncologist a note or message, or “catching” or “ambushing” the oncologist in the hospital corridor before they entered the consulting room. One oncologist, Joe, reported that nondisclosure resulted in a personal and “lingering” sense of regret that he could have done things better. Indeed, oncologists Stan and Jordan observed that another cost of nondisclosure was inferior supportive and potentially medical care for the patient.

Cultural influences on interpretation and understanding of requests for nondisclosure

Oncologists (Western = 4, non-Western = 4) reported that nondisclosure was more commonly requested by families from collectivist/family-centered cultures such as Chinese, Korean, Greek, Italian, Arabian than those from Western cultures such as Australian, UK, US.

All non-Western oncologists reported that their own culture helped them to understand cancer nondisclosure, while all Western oncologists reported that they found it difficult to understand cultures different from their own. Non-Western oncologists felt they could be more sensitive to patients from a similar background at the outset, choosing a more “nondirect” communication style and being “cautious” in their use of the word “cancer”. They also felt they better understood and could more easily accommodate the family-centered approach to medical decision-making. However, due to their medical training in the Western system, they still maintained a positive attitude towards full disclosure.

On the other hand, Western oncologists reported that they struggled with understanding a “different way of thinking,” feeling “affronted” by nondisclosure. Western oncologists also felt “uncertain” about how to interpret nonverbal cues (e.g. smiles, gestures) as each culture might have a different meaning for these. Four Western oncologists noted that their “dominant, middle class, educated” background that followed a “strong medical legal flavor, which is about

giving people information, making sure that they've got the choices" (James), had a "profound influence" on their attitude toward nondisclosure. However, they also felt that they had to "adapt" their style of communication to suit the patient's background by choosing "culturally sensitive language" and diverse ways to share medical information. A few Western oncologists (Mark, Stan and Tom) consciously tried to be more open to and respectful of a "different world view".

Emotional impact of bad news on patients, families and oncologists

Some oncologists (Western = 2, non-Western = 2) noted that breaking bad news can have an emotional impact not only on patients, families but also oncologists. They understood that a cancer diagnosis has the potential to permanently change a person's and their families' life in many dimensions such as their occupation, lifestyle, dreams and hopes. These oncologists viewed emotional support as an integral part of their role. This was achieved by being attentive to patients' emotional needs, listening to and being "tuned into" their "emotional requests" and normalizing their responses. This required oncologists to guide patients through this emotional journey, while assisting families to overcome their personal fears and anxieties in order to care for their ailing patient.

Three oncologists, Sylvia, Stan and Surya, felt their personal experience of losing their parent to cancer sensitized them to the "receiving end" of bad news, better equipping them to provide support. Indeed, all four oncologists admitted that a cancer diagnosis disclosure had an emotional impact on them as well, making breaking bad news "quite hard". They reported that coping by "depersonalizing" and distancing themselves protected them from getting "distracted" during work, a skill which came with time and exposure to breaking bad news.

Truthful disclosure as a gentle balancing act

All oncologists agreed that cancer disclosure should be approached within a growing relationship in a gradual and "systematic" manner where patients had the opportunity to steer the communication. This step-by-step approach was described as an "art," which aimed at ensuring patients and families feel secure and reassured. Consequently, oncologists observed, disclosure took place slowly over several meetings, wherein they gauged patients' and families' levels of acceptance of the information that was discussed in each meeting. First understanding families' concerns regarding truthful disclosure and then empathically convincing the family about the benefits of disclosure was preferred by most oncologists (Western = 5, non-Western = 4). Giving families the time to share their reasons for nondisclosure helped oncologists to understand their knowledge and perspective. This allowed oncologists to customize their explanations or "appeals" for the need for disclosure in a way that addressed these concerns whilst describing their own ethical obligation to the patient.

Further, a small group of oncologists were also inclined to consult families about their disclosure plan; discussing how and to what extent they should break the news, how the patient would receive news, and how they as a family could offer support at the time of cancer disclosure. The driving force for this approach was the oncologist's desire to develop a "very good relationship" between all parties, by ensuring clarity in cancer communication and "keeping the peace" between family and patient. These oncologists believed there was no one way to break the bad news to patients, instead being sensitive and building patient trust was a key feature of being honest. This meant they had to gently balance open communication (with the help of the family), such that they were neither "sugar-coating" vital medical information, nor "shocking" the patient with too much information.

Appreciating the cultural connotation of the word "cancer" played a key role in the way bad news was broken to patients. Almost all (Western = 7, non-Western = 4) oncologists were not opposed to using euphemisms, as long as the patient was able to understand its implications. Using words such as "tumor," "growth" or "lump" was most favored by oncologists as an acceptable approach to communicate "what's going on" to patients, without threatening them or their families. However, although they did arrive at this compromise in consultation with the family, oncologists clarified that the choice of euphemism had to be a "close enough" description of the seriousness of the real disease. Sometimes, this meant they had to eventually find a way to use the word "cancer" in their consultations. Only two oncologists (Jordan and Tariq) disagreed with this approach as they believed that by "diluting the message" they were, in effect, lying to the patient.

DISCUSSION

The current study explored differences between Western and non-Western-born oncologists in the way they interpreted and dealt with the family request for nondisclosure in Australia. The findings revealed that oncologists reported family and language were barriers to truthful communication, the family request for nondisclosure posed an ethical and moral dilemma to them, oncologists felt there were high costs of nondisclosure to patients and their families, they agreed that there were cultural influences on interpretation and understanding of requests for nondisclosure, they observed an emotional impact of bad news on patients, families and oncologists, and they believed that truthful disclosure was a gentle balancing act.

The study highlighted that oncologists experienced a tug-of-war between their desire to be culturally sensitive and their Western medical ethics. They accommodated the central role of families in patients' lives by using euphemisms, eliciting the family's fears of disclosure, focusing on family comfort, and by a willingness to consult with the family on how to break the news. However, oncologists also did not want to disregard their medical ethics. For example, some were willing

to use a euphemism for “cancer,” but only if it did not stray far from the truth, thereby misleading the patient. Consequently, oncologists felt caught in a moral and ethical dilemma, as they struggled to balance their Western need to promote patient autonomy and informed consent with their recognition of the importance of respecting and accommodating family wishes.

The study findings highlight a need for embedding doctor-patient communication within cultural sensitivity training,^[14,15] especially in a multicultural society such as Australia and when disclosing bad news.^[16] Building on the results of this study, cultural sensitivity training might emphasize including and engaging the family in communication and decision-making,^[16-18] nonverbal communication, indirect speech, the cultural connotations of specific words and sentences, taking cues and tailoring the consultation based on family and patient reactions, allowing the patient to steer the conversation, and asking the patient what they would like to know. Overall, all oncologists in the current study felt that the optimal culturally sensitive form of disclosure is the gradual, step-by-step, consultative approach, which is probably optimal for all cultures.^[19,20]

A unique and key finding in this study was that non-Western-born oncologists felt better equipped to understand and communicate with both families and patients. Perhaps, these oncologists can provide the necessary bridge between the need to adhere to Western medical ethics and the desire to respect the cultural contexts of cancer communication. Hence, it may be important to include non-Western-born oncologists when developing and delivering cultural sensitivity training programs.

In this study, oncologists felt nondisclosure carried high costs for the patient and family, who may receive sub-optimal supportive and medical care and be robbed of the chance to finalize affairs and say their goodbyes. Previous research has reported a relationship between nondisclosure and negative patient outcomes (e.g. increased distress, unfulfilled communication, hopelessness),^[21-24] the avoidance of which were, interestingly, some of the reasons for nondisclosure for some Eastern families.^[25-28] Further, oncologists reported feeling themselves, a sense of lost opportunity and poor communication due to nondisclosure, suggesting that cultural training could improve their own outcomes. Further, it may be beneficial to include health psychologists/counselors in the communication process to facilitate culturally empathic communication between patients, families and physicians.

This study has several strengths and limitations that should be taken into account when interpreting the findings. Its strengths include the inclusion of oncologists who were and were not born in Australia, bringing different cultural perspectives to the question of nondisclosure, and highlighting the contribution that nonnative-born health professionals can make to this discourse. While an in-depth qualitative approach

was appropriate in gaining the perspectives of oncologists, and the data reached saturation suggesting that all relevant themes had been elicited, the results may not be generalizable to the wider oncology population, and quantitative research to build on this study would be helpful.

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