Factors Affecting Family Members' Decisions to Reveal Cancer Diagnoses to Patients: A Qualitative Study

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Objective: *To explore the factors affecting the family members' decisions on telling the diagnosis to cancer patients.*
Material and Method: *A qualitative study was conducted using semi-structured, face-to-face interview with 25 close relatives of cancer patients. Content analysis was performed by two independent physicians who then collaborated to reach the conclusions.*
Results: *Relatives primarily preferred the patient not knowing the diagnosis before the disclosure was made, to prevent the patient from getting worse. Factors associated with this preference included personal experience with cancer patients, the patient's personal characteristics, impact of the disease on the patient's future, the prognosis of the disease, and supporting ideas from other relatives. Once the diagnosis had been disclosed, more participants agreed with the disclosure because of the advantages to the patient and themselves. There were only two who found the advantages but still did not agree with the disclosure.*
Conclusion: *Many factors were associated with willingness of relatives to disclose the diagnosis to the cancer patients. However, after disclosure, relatives saw advantages in terms of health care for the patients. Most family members changed their attitudes to a more positive and supportive view of disclosure.*

Keywords: *Conspiracy of silence, Disclosure, Telling the truth, Breaking bad news, Cancer, Surrogate, Family member, Relative, Palliative*

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The diagnosis of cancer is bad news for the patient and family. Many studies have tried to find the relationship between cancer diagnosis disclosure and quality of life for the patient. Earlier studies have found that telling the truth could lead to poor outcomes but more recent studies have found the opposite[1-4]. However, most patients' relatives still believe that telling the truth could worsen the patients' symptoms and quality of life. They commonly ask physicians not to disclose the diagnosis to the patients to protect their loved one from dwelling on negative thoughts of the future[5,6]. On the other hand, nowadays, the patient's right to information about their illness has become an important issue of concern. Patients should have the authority to access their information as much as they want. At the same time, we should not ignore the families' concerns either. Trying to understand the relatives' attitudes about the conspiracy of silence will help doctors to understand and know how to deal with this situation. Even though there have been studies conducted about family members not telling the truth to cancer patients[1,7-9], we know little about why some relatives engage in the conspiracy of silence in cancer diagnosis.

The present study aimed to explore the factors that affect the family members' decisions to reveal diagnoses to the patients diagnosed with cancer, and to elucidate these families' attitudes about disclosure to the patient before and after the disclosure.

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Material and Method

Study design

We used a qualitative study approach with semi-structured, in-depth, face-to-face interviews to meet the objectives of the study. The study was approved by the Ethics Committee of the Faculty of

Medicine, Chiang Mai University (No. 301/2556).

Recruitment and participant selection

We recruited the most involved relatives of advanced-stage cancer patients admitted to Maharaj Nakorn Chiang Mai Hospital (a tertiary care center in Chiang Mai, Thailand) between September and December 2013. We did convenient sampling to select participants until response information was saturated. The inclusion criteria for eligible participants were age at least 20 years old, who along with patient, knew the diagnosis of advanced-stage cancer for at least two months and not more than three years post diagnosis. All participants gave their informed consent to participate in the study after they were informed about the purpose of the study and the interviewer.

Interviews

A trained female physician (KP), who was not involved in the treatment process of the patient, conducted a single interview of each participant. We interviewed each participant individually to let them freely express their views. All interviews took place in a private room at the patients' ward. There were two parts to the interview. The first part was gathering general information on the backgrounds of participants. The second part was focused on examining the participants' attitudes and determining the factors associated with the decision making to reveal the diagnosis (Table 1). We used a topic guide developed by researchers, validated by three non-author physicians, and conducted a pilot test with two cancer patients' relatives. All interviews were audio-taped and transcribed verbatim. Field notes were made and participants provided feedback immediately after each interview to ensure that the information was derived from their perspectives. The average time on the second part of each interview was 46 minutes (33 to 55 minutes).

Data analysis

We analyzed data with content analysis performed by two independent physicians (KP and MP) who then collaborated to reach the conclusions. MP had experience in qualitative study. The themes were identified in advance and some were adjusted regarding to the data. When no new codes emerged, we considered data saturation reached. No more participants were further recruited.

Results

Twenty-five close relatives of cancer patients were interviewed to reach the data saturation point. No participant was excluded and none refused to enroll in the study. There were 15 men and 10 women, mean age was 55.3 years old (21 to 81 years old), most were of Thai ethnicity. Only one participant's mother was hill tribe but she was born in Thailand, held Thai nationality, and spoke Thai fluently. All were Buddhists. Demographic data were summarized in Table 2.

During the analysis, three categories were identified: family members' attitudes about disclosing cancer diagnosis, the conspiracy of silence, and changes in attitude after the disclosure.

Family members' attitudes about disclosing cancer diagnosis

In the present study, we found that, prior to the disclosure of the diagnosis, there were three different attitudes toward disclosing cancer diagnosis: "do not want" the patient to know (n = 10), "want" the patient to know (n = 8), and "no idea" (n = 7).

Most participants did not want the patients to know their cancer diagnoses because they worried that knowing it could worsen the patients' conditions, both emotionally and physically. For this reason, some tried to conceal the diagnoses, which led to the conspiracy of silence for a while. Factors that relatives

Table 1. Interview guide

Main topic	Guide questions
Attitude towards cancer diagnosis disclosure to the patient	Before the diagnosis was disclosed to the patient, do you prefer the patient to know or not to know the diagnosis? Why?
The conspiracy of silence	Agree or disagree and why? Have you done that to the patient? If yes, for how long and how did you feel? Why it was revealed and how did you feel afterwards?
Changing in attitude after diagnosis disclosure	Does your attitude after the diagnosis was disclosed remain the same or not? Explain why?

Table 2. Demographic characteristic of participants and cancer patients

Characteristic	Close relatives (participants) n = 25 (%)	Cancer patients n = 25 (%)
Gender		
Male	10 (40)	15 (60)
Female	15 (60)	10 (40)
Age range		
20-35	2 (8)	3 (12)
36-60	20 (80)	13 (52)
>60	3 (12)	9 (36)
Relation to patient		
Spouse	12 (48)	
Child	7 (28)	
Parent	4 (16)	
Daughter-in-law	1 (4)	
Sibling	1 (4)	
Primary cancer		
Lung		9 (36)
Cervix		5 (20)
Bone		2 (8)
Liver		2 (8)
Uterus		2 (8)
Ovary		2 (8)
Base of tongue		1 (4)
Leukemia		1 (4)
Kidney		1 (4)
Period since having symptom until diagnosis was disclosed		
Less than 1 month		5 (20)
1 month to 1 year		19 (76)
More than 1 year		1 (4)
Period since diagnosis was disclosed until time of interview		
2 months to 1 year	17 (68)	
More than 1 year to 3 years	8 (32)	
Disclosing diagnosis		
Participants know first	6 (24)	
Together	11 (44)	
Patients know first	8 (32)	
Attitude		
Initially		
“Do not want” the patient to know	10 (40)	
“Want” the patient to know	8 (32)	
No idea	7 (28)	
Currently		
“Want” the patient to know	23 (92)	
“Do not want” the patient to know	2 (8)	

used to determine whether patients could handle the bad news were:

Previous experience with cancer outcome
Seeing or knowing someone who had cancer with a poor outcome after disclosure could lead the patients and relatives to have negative attitudes about having cancer. In accordance with that prior attitude, they assumed that the patient would never want to know. “My neighbor, after she knew she got cancer,

her symptoms worsened rapidly. She couldn't eat, lost weight and no longer wanted to live".

Patient characteristics

Those who always had negative thoughts about having disease (especially cancer) or were easily concerned about things happening around them have a greater chance of getting worse. "Normally, he doesn't want to go to any hospital. He always thinks that going to the hospital is to catch disease. He is afraid that the doctor will find some disease in him. Everyone knows that cancer is incurable so it's better for him not to know the diagnosis".

In addition, there would be a greater chance to have a negative impact on advanced-age patients. "According to what I know, the elderly always got worse after they knew that they have cancer".

Impact of the disease on patients' futures

With patients who were starting a new job, getting a better one, or being promoted to a higher position, relatives tended to hesitate to disclose the diagnosis. They believed that knowing the diagnosis could cause the patient to feel down about him/herself. "He only finished primary school, is not highly educated. But now he has a chance to join the army, which he always dreamed of. It's like his dream is shattered".

Prognosis of disease

If the cancer is in an early stage, it is better to tell the patient compared to an advanced stage. In this case, earlier stage could give the patient hope of being cured. "I wouldn't let her know if she was terminally ill. It seems to be hopeless".

Support from other relatives

Discussions among the relatives were sometimes held in order to come up with the best disclosure decision for the family and patient. "Before I told her about her cancer diagnosis, I talked to all of the family members to help me make the decision. They said it was up to me. At that time, I thought I had to tell her. She had the right to know and she needed to know in order to get the treatment too. Most of them agreed with this idea so that's why I told her".

The conspiracy of silence

Six out of ten participants in the "do not want" group had been concealing the diagnosis for a period of time to prevent the patient from getting worse. However, they all felt uncomfortable due to:

1) Being afraid to lose the patient's trust. "I'm afraid that she will get angry when she finds out that I lied to her".

2) Unusual behavior making the patient suspicious. "I was trying to let her do something that was good for her health. She was a bit surprised because I had never done this".

3) Being unable to discuss the disease directly with the patient. "I didn't want her to know, but it was hard to discuss the treatment plan with her if she didn't know she had cancer".

Eventually, however, the diagnoses were disclosed. All six cases were done so in different ways: intentionally by the specialist after referred for specific management, due to patient's request, relatives' discomfort hiding the information, and for benefit of engaging in treatment. The relatives felt much better after disclosure.

Changes in attitude

Once the cancer diagnoses were disclosed to all patients, 23 of the participants agreed with the disclosure because of the advantages to the patient and themselves. These included the patient's self-awareness regarding their health, ease of caring for the patient and assessing the patient's needs once the truth is known, and decreased stress felt by the family members.

In the two groups that "did not want" the patient to know the diagnosis and had "no idea", it was found that the patient did not get as bad as family members thought. Patients did get worse and had negative emotional responses such as getting depressed, losing their appetite, crying, and being stressed. However, this only lasted for a short period, varying from a week to three months. Their emotional states improved afterwards.

There were two participants who still did not want the patients to know their diagnoses. They did not feel that the advantages outweighed the disadvantages. One of them found that the patient's emotional response was too furious. "Taking medicine is not a big deal, but sometimes when I give him a small pill, he gets angry and scolds me. I think if he didn't know the diagnosis, he wouldn't have been like this".

Another said she was afraid to tell her husband the diagnosis. "I didn't want to tell my husband that he had cancer. I wanted him to know by himself. I would feel bad to say that word myself. I will never be the one who says that word".

Discussion

Before the disclosure was made, most of the relatives preferred to keep the diagnoses away from the patients. Similar to previous studies, they believed that knowing the diagnoses could have negative impacts on the patient's emotional and physical well-being[3,9]. Factors found to be associated with this belief were patient's characteristics, impact of the disease to the patient's future, previous experience about cancer, disease prognosis, and supportive ideas from other relatives. In contrast to prior studies, age was found to have no impact on relatives' attitudes[9], but might have impact on patients' demand[10-12]. Younger patients prefer to know the diagnosis and progress to the acceptance stage sooner.

Relatives would face discomfort and conflict while they kept the diagnoses away from patient. This would have been expected, but some of the relatives chose to do so anyway thinking that disclosing the truth would worsen the patient's situation. Relatives did not want the patients to know the diagnoses; however, they did not know what to do when they were with the patient.

Once the diagnosis had been disclosed to the patient, most of the family members tended to change their attitudes to agree with the disclosure because they found more advantages to the patient and themselves. The advantages included patient's self-awareness regarding their health, ease on caring and assessing patient's needs, and decreased their own stress. Such results were also found in some previous studies[13,14]. On the other hand, a few relatives still did not want the diagnosis to be disclosed.

One of the two participants who did not want to tell the truth, said that her husband became more aggressive after the diagnosis was revealed. All patients need time for adaptation and they become in some or all stages of grief as described in Elisabeth Kubler-Ross' five stages of grief model[15]. This patient could still be in the anger stage. We need to educate families about the grievous stages so they can deal with patients' emotions appropriately.

The other participant who was against disclosure was afraid to tell her husband. She herself did not want him to be told the diagnosis. She wanted him to find out by himself from the symptoms and the progression of the disease. She was afraid to say the word cancer. This family member's characteristics could be one factor affecting her beliefs about disclosure. This could indicate that the physicians need to evaluate family members' attitudes more closely. "Does not want" might not always mean he or she does not want the patient to know, but rather that he or she does not want to be the one who discloses the diagnosis. We, as physicians, could help families deal with this situation.

In conclusion, the family members of cancer patients in the present study changed their attitudes from the "Conspiracy of Silence" prior to diagnosis disclosure to a more positive and supportive attitude after the diagnosis was revealed. The main factors that changed their attitudes were the benefits to the patients and families, and the fact that the patient's conditions did not deteriorate as they had expected. Evaluating patient and family attitudes towards the "Conspiracy of Silence" in cancer diagnoses is important. The results of the present study could be used to discuss the pros and cons of disclosure with the families. Patients have the authority to decide "How much they want to know about their disease". If the families understood this point, this could open up the opportunities for physicians to discuss the issue with the patients directly and allow them to assess the patients' need for information.

The first limitation of the present study was the participants. We included only Northern Thai Buddhists that may have different attitudes from other areas. Secondly, results in other settings, such as the intensive care unit or emergency department, might be different from this study. Lastly, in the present study we focused only on family members' view. Correlating family members' view with patients' attitudes needs to be studied further.

What is already known on this topic?

We have known that many relatives try to prevent the cancer patient from diagnosis disclosure because they believe that this might worsen the patients' condition.

What this study adds?

We found the factors that affected family members' decisions to reveal cancer diagnoses to patients which include personal experience with cancer patients, the patient's personal characteristics, impact on the patient's future, the prognosis of the disease and supporting ideas from other relatives.

We found that most patients did not get worse as the relative were primarily concerned. Moreover, they found many advantages after patients were told the diagnosis. These lead the relative to be more positive about telling the truth.

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Potential conflicts of interest

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ปัจจัยที่มีผลต่อญาติในการตัดสินใจเปิดเผยการวินิจฉัยโรคมะเร็งแก่ผู้ป่วย: การวิจัยเชิงคุณภาพ

กนกพร ภิญโญพรพาณิชย์, ชัยสิริ อังกุระวรานนท์, ปัทมา โกมุทบุตร, มณี ภิญโญพรพาณิชย์

วัตถุประสงค์: ศึกษาปัจจัยที่ส่งผลต่อการตัดสินใจของญาติผู้ป่วยในการเปิดเผยการวินิจฉัยโรคมะเร็งแก่ผู้ป่วย

วัสดุและวิธีการ: สัมภาษณ์ญาติผู้ป่วยมะเร็ง 25 ราย ด้วยคำถามกึ่งมีโครงสร้างและนำข้อมูลที่ได้มาวิเคราะห์เนื้อหา

ผลการศึกษา: *ญาติผู้ป่วยส่วนมากอยากปิดบังการวินิจฉัยโรคมะเร็งแก่ผู้ป่วย เพราะเกรงว่าผู้ป่วยจะรับไม่ได้และอาจส่งผลทำให้ผู้ป่วยมีอาการแย่ลง ปัจจัยที่ส่งผลต่อความคิดดังกล่าวได้แก่ ประสบการณ์เดิมของญาติเกี่ยวกับโรคมะเร็ง ลักษณะและนิสัยของผู้ป่วยที่ญาติคาดว่ามีแนวโน้มจะรับไม่ได้ ผลของโรคต่อการทำงาน พยากรณ์โรค และความเห็นจากคนรอบข้าง แต่หลังจากผู้ป่วยได้ทราบว่าเป็นมะเร็งแล้วญาติ 23 ราย เห็นด้วยว่าผู้ป่วยควรทราบการวินิจฉัยโรคเพราะส่วนใหญ่ผู้ป่วยจะปรับตัวได้มีเพียง 2 รายที่ยังคงอยากให้ปิดบัง*

สรุป: *มีหลายปัจจัยที่ส่งผลต่อความต้องการของญาติผู้ป่วยในการปิดบังการวินิจฉัยโรคมะเร็งแก่ผู้ป่วย แต่เมื่อญาติผู้ป่วยพบว่าการที่ผู้ป่วยทราบผลการวินิจฉัยโรคเป็นประโยชน์ต่อการดูแลผู้ป่วย ญาติผู้ป่วยส่วนใหญ่เปลี่ยนทัศนคติว่าควรเปิดเผยการวินิจฉัยโรค*