Truth-telling and hematopoietic stem cell transplantation: Iranian nurses’ experiences

Leila Valizadeh, Vahid Zamanzadeh and Leila Sayadi
Tabriz University of Medical Sciences, Iran

Fariba Taleghani
Isfahan University of Medical Sciences, Iran

A Fuchsia Howard
The University of British Columbia, Canada

Alireza Jeddian
Tehran University of Medical Sciences, Iran

Abstract
Background: Hematopoietic stem cell transplantation is a potential cure for a range of life-threatening diseases, but is also associated with a high mortality rate. Nurses encounter a variety of situations wherein they are faced with discussing bad news with hematopoietic stem cell transplantation patients.
Research objective: The aim of this study was to explore the experiences and strategies used by Iranian nurses related to truth-telling and communicating bad news to hematopoietic stem cell transplantation patients.
Research design: A qualitative approach using content analysis of interview data was conducted.
Participants and research context: A total of 18 nurses from the main hematopoietic stem cell transplantation center in Iran participated in semi-structured interviews.
Ethical considerations: The Institutional Review Board of the Tabriz University of Medical Sciences and the Hematology-Oncology and Stem Cell Transplantation Research Center affiliated with the Tehran University of Medical Sciences approved the study.
Findings: In the first main category, not talking about the disease and potential negative outcomes, the nurses described the strategies of not naming the disease, talking about the truth in indirect ways and telling gradually. In the second main category, not disclosing the sad truth, the nurses described the strategies of protecting patients from upsetting information, secrecy, denying the truth and minimizing the importance of the problem. The nurses used these strategies to minimize psychological harm, avoid patient demoralization, and improve the patient’s likelihood of a fast and full recovery.
Discussion: The priority for Iranian hematopoietic stem cell transplantation nurses is to first do no harm and to help patients maintain hope. This reflects the Iranian healthcare environment wherein communicating the truth to hematopoietic stem cell transplantation patients is commonly considered inappropriate and avoided.

Corresponding author: Leila Sayadi, Students’ Research Committee, Nursing and Midwifery Faculty, Tabriz University of Medical Sciences, Tabriz, Postal Code 5138947977, Iran.
Email: sayadi17@hotmail.com
**Conclusion:** Iranian nurses require education and support to engage in therapeutic, culturally appropriate communication that emphasizes effective techniques for telling the truth and breaking bad news, thereby potentially improving patient outcomes and protecting patient rights.

**Keywords**
Breaking bad news, disclosure, hematopoietic stem cell transplantation, Iran, truth-telling

**Introduction**
Hematopoietic stem cell transplantation (HSCT) is the last resort in the treatment of a number of life-threatening diseases, including malignant and nonmalignant hematologic disorders, solid tumors, and autoimmune diseases.\(^1\) With scientific and medical advancements, the number of HSCTs performed worldwide is increasing such that it is now performed in more than 500 centers in 50 different countries.\(^2\) The country of Iran, located in the World Health Organization Eastern Mediterranean region, has an active and growing HSCT program\(^3\) due to the high and increasing incidence of diseases that can be treated using HSCT. Between 1991 and 2010, 3170 patients underwent HSCT in Iran, most commonly for acute myelogenous leukemia, major thalassemia, and acute lymphoblastic leukemia.\(^4\)

HSCT is a time-demanding, invasive procedure, preceded by chemotherapy and related toxicity as well as other side effects.\(^5,6\) HSCT is not always successful and has a high mortality rate.\(^7,8\) Some studies have found HSCT to be one of the most stressful medical procedures because of the associated dangers and risks of complications in physical, psychological, emotional, and social domains.\(^5,6,9\) Patients undergoing HSCT suffer from primary and delayed physical stresses resulting from side effects of chemotherapy and the HSCT procedure itself.\(^7,10\) HSCT patients commonly experience emotional distress, anxiety, depression, disappointment, hopelessness, panic, uncertainty, relationship changes, work and financial challenges, self-image changes, a sense of grief and loss, loss of control of their role in life, and finally, the fear of relapse and death.\(^5,6,9\)

Although there is no definitive evidence of a direct relationship between psychological factors and survival among patients undergoing HSCT, psychological factors might adversely affect the outcome of this procedure. A relationship between mortality and depression among HSCT patients was found in two studies,\(^11,12\) and suggests that the provision of adequate psychological care must be a priority.\(^6\)

Healthcare professionals care for HSCT patients for a prolonged period of time wherein they witness patient suffering resulting from the transplant procedure itself, related complications, irreversible long-term side effects, disease relapse, treatment failure, and death.\(^7,13\) One challenge in the provision of psychological care to HSCT patients is telling patients the truth and breaking the bad news. The patient’s experience of receiving bad news might result in significant negative consequences, including worsening of their condition, losing hope for the future, and shattering their hopes and dreams.\(^14,15\) Therefore, sensitive and effective communication is crucial when caring for patients undergoing HSCT.

Caring for HSCT patients is a process that demands teamwork, but nurses tend to provide the preponderance of caring work,\(^13,16\) and thus, nursing care plays a vital role in the quality of care among these patients. Although nurses encounter a variety of situations wherein they are faced with discussing bad news with HSCT patients, the bulk of the previous research has focused on the role and experiences of physicians in communicating difficult information.\(^17\) The few studies related to HSCT nursing care have primarily focused on nursing management strategies for physical problems and the toxicity caused by medical procedures\(^13,18\) and have suggested some broad recommendations for providing psychological care.\(^6,9\) Thus, there is a current need for more detailed investigations into nurses’ experiences of telling HSCT patients
difficult truths and communicating bad news. Communication in general, and more specifically the imparting of bad news to patients, is greatly influenced by cultural norms and values. Noting a significant lack of related nursing guidelines in Iran, this study was conducted to explore and understand strategies used by Iranian nurses related to truth-telling and communicating bad news to HSCT patients.

The findings of this study will shed light on the vital nursing work performed in the communication of difficult information to HSCT patients in particular, but will also provide insight into the caring nature of nurse–patient communication in general. This research is also essential for highlighting aspects of nursing care that require change.

Methods
We used a qualitative design, with content analysis methods in this study. Content analysis methods result in a clear description of the categories and concepts that describe the phenomenon under study. In accordance with conventional qualitative content analysis methods, coding categories in this study were derived directly and inductively from the interview data.

Participants and research context
This study was conducted in the main HSCT center in Iran. This center consists of three adult HSCT wards with 25 beds in total, one pediatric ward with 11 beds, and two hematology-oncology wards with 24 beds in total. Patients are first admitted to the hematology-oncology wards where they undergo diagnostic procedures and receive chemotherapy before HSCT. Patients who develop complications after HSCT are often readmitted in these wards. Patients are then admitted to the HSCT wards to undergo transplant. Acute myelogenous leukemia, thalassemia major, and acute lymphoblastic leukemia are the most common transplanted disorders in this center. The median age of HSCT patients is 23 years. In these wards, 67 graduate (BSc) clinical nurses work full time (minimum of 35 h per week), all of whom are women.

A purposive sample of 18 nurses took part in this study. Nurses were included who had at least 1 year of work experience with HSCT patients, and were willing and able to describe detailed information on the subject. The participants included 10 nurses from the adult HSCT wards, 2 from the pediatrics HSCT ward, and 6 from the hematology-oncology wards. All were women, aged 25–53 years, and their work experience in HSCT patient care ranged from 1 to 21 years.

Data collection
The data was collected by one researcher (L.S.) between December 2011 and May 2012 via semi-structured interviews. The interviews were conducted in the Persian language in the hospital, on a date and time of the participant’s choice, and lasted from 30 to 90 min. The main focus of the interview questions was on nurses’ experiences of breaking bad news to HSCT patients. Each interview began by asking the participant to describe the strategies they use when uncomfortable events occur for HSCT patients, and they are faced with breaking bad news. Examples of interview questions are as follows:

1. What do you do when uncomfortable events occur that may influence the emotional state of your HSCT patients?
2. How do you break the bad news to your HSCT patients?
3. Describe a situation of how you managed telling the truth and breaking the bad news to one of your HSCT patients.
All interviews were recorded and transcribed verbatim. Interviews were conducted until data saturation occurred, that is, obtaining further data provided no new information or insight into the emerging findings.

Data analysis

Content analysis began with the first interview and continued until the last. Data analysis was conducted in the Persian language and the findings were then translated into English. Each interview was reviewed several times to obtain a sense of the whole and was coded line by line to identify the subcategories. The subcategories were categorized into larger categories based on similarities and differences, and after several alterations, a label was chosen for each category. The analysis was finalized by identifying two categories under which all subcategories were subsumed.

To maintain rigor, the researchers discussed and compared the codes and findings as a group until minor disagreements were revised and consensus was reached. To strengthen the credibility of the findings, the codes were extracted and results taken back and shared with the participants to validate the congruency of the codes with their experiences. To enhance the dependability of the research, one of the researchers collected and analyzed the data and the others discussed and verified the findings. The transferability of research findings was addressed through purposive sampling based on a maximum variation in participant characteristics in terms of age, nursing experience, and the HSCT hospital wards.

Ethical considerations

The Institutional Review Board of the Tabriz University of Medical Sciences and the Hematology-Oncology and Stem Cell Transplantation Research Center affiliated with the Tehran University of Medical Sciences approved the study. All participants provided informed consent and were assured of anonymity. They were also informed that they could stop the interview or withdraw from the research at any time, although this did not happen.

Findings

The two main categories, not talking about the disease and potential negative outcomes, and not disclosing the sad truth, with seven subcategories, describe Iranian nurses’ experiences of truth-telling and communicating bad news to HSCT patients and strategies they used in these difficult situations.

Not talking about the disease and potential negative outcomes

The HSCT nurses had devised ways to not talk about the grave nature of the patient’s condition and their high risk of a poor outcome and possible death as a way to avoid contributing to the psychological distress common among these patients. This category consisted of three subcategories, including not naming the disease, talking about the truth in indirect ways, and telling gradually.

Not naming the disease. In Iran, patients are referred to a legal medicine center where they are informed of the nature of their disease, their prognosis, and the chance of a successful transplant prior to undergoing a HSCT. As such, the nurses in this study assumed that the patients were aware, to some degree, of their disease and prognosis before being hospitalized for a transplant. One nurse stated:

The transplant patients go to see a legal medicine consultant before coming here. That consultant physician has a duty to talk to them about their disease prognosis and the chance of recurrence.
Although the legal medicine physician told the patients their diagnosis and provided information about their prognosis, the nurses avoided using related terms, particularly “cancer” when communicating with these patients. One of the nurses from a HSCT ward explained:

Patients undergoing HSCT have a weak psychological condition. We never name their disease; we never tell them you know, you have cancer! Not because we are obliged by anyone not to use the term cancer, but we don’t use the term anyway. I ask them, when did your disease start? When did you know you are sick? When did you need care? When did you become a patient? When did you start your treatment? Where did you start your treatment?

Talking about the truth in indirect ways. There were situations throughout the treatment process that required the communication of information to the patient to ensure their cooperation with the healthcare team. In these situations, negative information was relayed to patients in an indirect manner, as explained by one nurse:

Sometimes you have to give the patient some truths. If the patient does not know anything he/she might not be cooperative. To do this we use some special words. Like we say, you have a blood disease, you have a lymphatic disease, your treatment is like this. When we use these words, most of the patients understand what we are talking about. Most patients are clever enough to put things together and understand what we are referring to.

Telling gradually. The nurses told their patients bad news gradually as a strategy to avoid fully discussing difficult and distressing information with the patient. The nurses controlled the bad news as a way to mitigate the related emotional impact. One nurse said:

Sometimes there is no way to tell the patients the whole bitter truth. We have to consider how much bad news and truth the patient can tolerate. We have to give them the truth little by little. So we give them this kind of news gradually and consider the patient’s tolerance when telling them.

However, the nurses indicated that the patients often wanted to know more about their condition when information had been withheld. Even in these cases, the nurses would convey bad news gradually based on the nurses’ monitoring of the patient’s reaction and emotional state:

There have been instances when the patient insisted on knowing about their condition or heard some information and wanted to know more. We would consider their mood and whether or not they could tolerate the bad news, and would then gradually tell them some of the bad news with the help of their family members.

The same nurse explained the gradual process through which she would communicate the news of a transplant rejection and relapse of the disease to the patient:

I have a patient with hemorrhage; the hemorrhage is due to transplant rejection. The patient is worried and is so tired. I am not going to tell the patient that the transplant has failed. I tell the family members but not the patient. I first tell the patient this might be because of post-transplant complications. Then I try to gradually ready the patient for the fact that the transplant has failed with the help of family. I say the doctor has taken a Chimerism test and will tell you about the results tomorrow. Most patients know what the Chimerism test is. When the results come, myself and the other nurses tell the patient that the Chimerism results are low and they might need to have their transplant repeated. Then we tell them they should not worry since there will be another transplant performed for them.
Not disclosing the sad truth

The main category of not disclosing the sad truth consisted of four subcategories: protecting patients from upsetting information, secrecy, denying the truth, and minimizing the importance of the problem.

Protecting patients from upsetting information. This subcategory included the ways nurses protect HSCT patients by keeping sad and upsetting information from them. This upsetting news could pertain to the patient themselves, other patients, financial problems, or the patient’s family. The nurses did not give their patients medical information to avoid worsening their condition. One nurse described:

I never give patients any medical information. When their cell count is low I do not tell them your platelets are low, your white blood cells are low, and we want to start this treatment for you.

The nurses hid the bad news about other HSCT patients who had complications, poor outcomes, or had died, as exemplified by one nurse from a hematology, oncology, and transplant ward that admits patients before or after HSCT:

We have two beds in each room. When a patient’s condition becomes critical and there is no hope to keep them alive, we transfer them to an isolated room with one bed so other patients don’t know about their condition. So, if they die others won’t notice. HSCT is the only hope these patients have and we should avoid discouraging them by letting them know about these bad outcomes. We try to dilute these bitter truths.

The nurses also discouraged, and in some cases prevented, relatives from communicating upsetting information to the patient. The nurses described experiences wherein they thought the patient’s condition would deteriorate if family members conveyed disconcerting news. One nurse described her experience:

One patient’s problem was her husband, calling again and again saying: there is no money; the drugs are expensive; I don’t know how I’ll be able to find the money. And the patient was so afraid that she might not be able to finish her transplant. I called her family and told them not to talk to her about their financial problems since it will hurt her.

The nurses also avoided giving the patients bad news about their family members as much as possible. One nurse provided this example:

We had a patient. In her third or fourth day of hospitalization her husband had an accident and went into a coma. The patient was in a critical state and was taking chemotherapy. We saw her daughters were nervous so we did not let them visit the patient. We told them not to say anything to their mother about the bad news. We also told the patient that since she was getting chemotherapy and a transplant, we did not let anybody visit her. The patient would call her family so when one of her daughters was more stable we let her to come and stay with her mother, but we told her not to say anything about her father’s condition. We did not let her know anything while she was hospitalized.

Another nurse described a similar incident where she protected the patient from upsetting information:

I had a patient whose brother died. And the visitors came to visit the patient wearing black because of the brother’s death but I did not let them visit the patient. I told them to go and change their clothes. I told them the patient will know something is wrong when she sees your clothes.
Secrecy. The HSCT nurses hid distressing news from their patients, including information about the treatment they were undergoing and the death of another patient. This secrecy was intended to reduce the patient’s anxiety and avoid demoralization. For example, in some situations the fact that a patient was undergoing chemotherapy was completely concealed. One nurse explained:

Some patients are too sensitive, like they start having nausea even by knowing that their serum contains chemotherapy drugs. We know that we should tell patients when they are getting chemotherapy, but we do not tell this to some patients since it causes them a lot of anxiety. So we do not tell them.

Going through HSCT and experiencing complications prolonged the patient’s hospital stay, and as a result, the patients on the wards formed close friendships with each other. There were many times when a patient had died from complications but their death was hidden from other patients. Even when patients would ask the nurses about another patient, the nurses would avoid disclosing the truth. One of the nurses in the study stated:

When other patients ask us about the condition of a patient in critical condition we never tell them that they are in a bad state or have died. I tell the other patients that we sent the patient to the intensive care unit and tell the other staff to say the same. The patients care a lot about each other.

Denying the truth. The nurses denied the truth to HSCT patients when they thought it would compromise the patient’s condition. For example, the nurses hid the chemotherapy from the patients and, when questioned by the patients, denied that they were in fact giving them chemotherapy. One nurse stated:

When we are giving the chemotherapy some patients ask us if they are getting chemotherapy drugs. We say it’s a drug. Sometimes we give them 5 to 6 days of chemotherapy and the patient only finds out when it is done. This way the patient will have less anxiety and experience fewer side effects.

Another nurse, with 1 year of experience caring for HSCT patients, explained that it was common practice for nurses to deny the truth to patients when they inquired about another patient’s death:

Patients undergoing transplant who come to the clinic sometimes hear about another patient’s death. They hear that a patient has died after HSCT, and then they come to the ward and ask us if we have heard about that patient’s death. But we tell them: no, no, that patient had a different condition, had a different disease, it was different from your disease.

Not only did the nurses deny the difficult truth, but in some cases they would give patients false information thinking this would have a psychological benefit and bolster their spirits. One HSCT nurse described her experience of telling a patient the truth, after which the patient’s condition rapidly deteriorated and, as a result, she decided not to tell the truth from then on:

I tell them whatever will make their condition better. I do not give them the right information. When I first started working I told a patient the truth about their cell count or platelet counts two or three times. Then I saw how anxious they were when the count was low. The patient kept saying: oh, my platelets are low, what should I do? Then I saw that the patient needing a ventilator and then died. So I never give them the right information anymore. I only tell them what I think will satisfy them. This way, I will be more relaxed myself.
Minimizing the importance of patient problems. The HSCT patients commonly faced multiple physical and psychological difficulties, which the nurses considered intolerable for any human being. Thus, the nurses attempted to minimize the importance of these difficulties for the patient. One nurse explained:

The patients are suffering so much, they have so many problems. But when they are anxious about their condition, we tell them it’s nothing, it’s normal, this stage will pass.

Another nurse described the circumstances of a patient who was hospitalized after undergoing HSCT and was not expected to survive. Yet, even in the last days of the patient’s life, the nurse tried to minimize the gravity of the situation. She explained that “The doctor says there is nothing we can do. But I still kept telling her there is nothing to worry about.”

Discussion
This study described the experiences and strategies Iranian HSCT nurses used in truth-telling and communicating bad news to patients. The first main category, not talking about the disease and potential negative outcomes, consisted of three subcategories, including not naming the disease, talking about the truth in indirect ways, and telling gradually. The second main category, not disclosing the sad truth, consisted of four subcategories: protecting patients from upsetting information, secrecy, denying the truth, and minimizing the importance of the problem. The nurses used these strategies with HSCT patients to minimize psychological harm, to avoid demoralization, and to improve patient’s likelihood of a fast and full recovery.

The strategies used to avoid talking about the truth and communicating bad news described by the nurses in this study are in contrast to strategies used in other, primarily Western countries. For example, American and Western researches indicate that the truth is directly communicated to cancer patients.23,24 Our study findings that nurses do not directly communicate the truth to patients and withhold breaking bad news are in line with previous Iranian research that indicates that physicians do not communicate bad news directly to their patients either.25

The nurses in our research avoided using the term “cancer” in their daily communications with patients, despite the fact that the patients had been informed of the nature of their disease when counseled by a legal medicine physician prior to HSCT. Furthermore, the nurses avoided talking to their palliative patients about their imminent death. These findings are in line with research that indicates that in Iran the word “cancer” is taboo and very rarely used in daily communications,26 while discussions about death and dying are taboo in some Asian countries.27–29 This is in stark contrast to Western healthcare norms,30,31 where patients are provided with information about their prognosis even when there is no hope for a cure.

A substantial and growing body of research indicates that the ways in which healthcare teams communicate with patients are greatly influenced by cultural norms and beliefs.20,32,33 In Western countries, the direct communication of information to patients is grounded in the ethics of protecting and upholding individual patient rights and autonomy. Protecting and promoting patient autonomy is greatly valued as a means to provide patients the necessary tools to make their own informed medical decisions.24 Yet, in other parts of the world,34,35 decisions about what and how much information is given to patients are made by physicians and family members.24 In Iran, there is an environment of nondisclosure, wherein physicians and nurses are commonly of the opinion that communicating the truth about cancer to patients is a mistake that ought to be avoided.25,36

Previous studies have described the experience of undergoing HSCT to be extremely difficult, physically and psychologically,5 and particularly distressing owing to the high associated mortality rate. Nurses who
care for these patients are well aware of the suffering they endure and pay special attention to easing this suffering in the daily care they provide. The Iranian nurses in this study did not communicate honestly with their patients, but rather, protected patients from upsetting information, kept information secret, denied the truth, and minimized the importance of problems.

These findings are similar to studies that describe strategies nurses use to avoid telling the truth to patients, including deceiving patients, denying the truth, telling half-truths, giving partial information, omitting details, giving vague or euphemistic responses, giving misleading information, avoiding instances of communication, concealing facts, and simply not disclosing. Telling patients the truth is a moral and legal obligation of healthcare professionals in some countries, and is viewed as an essential element of respecting patient rights, enhancing patients’ trust in their healthcare professional, and reducing uncertainty. However, for the nurses in this study, and similar to other research, these benefits were outweighed by the danger of causing fear and psychological distress, patients being unprepared and incapable of coping with bad news, and shattering patients’ hopes and dreams for the future. Although telling the truth is recognized as a nurse’s duty, it seems that the priority for Iranian nurses is to first do no harm and to help patients maintain hope, and the only remaining hope for survival is a successful transplant. Indeed, the nurses in this study described the withholding of information and hiding of the truth as a norm in patient care in certain contexts that are described as closed awareness context. Despite these findings, research in Iran, and elsewhere, provides evidence that patients prefer to be told the truth about their condition, even when it is bad news.

The nurses in this study also indicated that they did not disclose sad or upsetting information to patients as a way of maintaining their own peace of mind. Similarly, other researchers have indicated that nurses avoid communicating the truth and giving bad news to patients because of heavy workloads and insufficient time to adequately discuss information, fear of unexpected questions, disruption of the nursing ward, and fear of being unable to control the fallout of such discussions.

While this research provides important insights into truth-telling practices among Iranian HSCT nurses, further research is needed that explores additional conditions and situations wherein nurses use strategies to avoid telling patients the truth. These findings would also be complemented by investigations of HSCT patients’ opinions of truth-telling in this cultural context. Furthermore, there is a need to describe strategies that other healthcare professionals utilize when handling sad, upsetting, and difficult information, and to see how the approaches and strategies compare.

Limitations

This study was limited to descriptions and experiences of female nurses.

Conclusion

The findings of this study provide evidence that nurses caring for HSCT patients in Iran use several strategies to not talk with patients about their disease and potential negative outcomes, and to not disclose the sad truth. These strategies were used intentionally to minimize psychological harm, avoid patient demoralization, and improve the patient’s likelihood of a fast and full recovery.

The nurses in this study appeared to consider avoiding the communication of bad news and the specific strategies this entails, to be a standard and necessary aspect of caring and their nursing practice. Since this is in sharp contrast to a patient’s right to accurate and truthful information, these nursing practices deserve greater attention and consideration from health educators, managers, and policymakers. Specifically, practice guidelines will need to be developed to guide HSCT nurses. Moreover, having a team consisting of psychologists and psychiatrists in HSCT wards might help both patients and staff to cope with difficult and often...
sad news. It is of utmost importance that nurses are taught and supported by healthcare managers and policymakers to engage in therapeutic, culturally appropriate communication that emphasizes effective techniques for telling the truth and breaking bad news. Improving nurses’ knowledge of effective communication through the development and implementation of training programs and integration with nursing school curriculum has the potential to improve patient care and outcomes.

Acknowledgments
Much gratitude to the Hematology and Oncology Research Center related to Tehran University of Medical Sciences for generous assistance to perform this research. The researchers are very grateful to the participants for their genuine cooperation and their time and trust.

Declaration of conflicting interests
None.

Funding
This study was part of a doctoral dissertation of L.S. supported by Tabriz University of Medical Sciences. Dr. Fuchsia Howard holds a Michael Smith Foundation for Health Research (MSFHR) Post Doctoral Research Trainee Award.

References

