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Original Article

Why differences exist? an interpretive approach to nurses' perceptions of cancer patients' quality of life

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Abstract

BACKGROUND: Based on the literature review that was conducted, no research study has been found in Australia to provide a detailed understanding of why nurses differ in their perceptions about cancer patients' Quality of Life (QoL) when they communicate with patients in oncology wards.

METHODS: This descriptive exploratory qualitative study was completed in 2007 in two major public hospitals in Adelaide, South Australia. 10 nurses from different inpatient and outpatient oncology services and a palliative setting took part in semi-structured interviews.

RESULTS: After the data collection and analysis six main themes were identified. Differences in nurses' perceptions about cancer patients' QoL were discussed in the light of the sub theme "relationship and rapport".

CONCLUSIONS: In general, participants commented that differences existing between patients' and nurses' perceptions about cancer patients' QoL were due to a poor relationship and rapport between cancer patients and their nurses. Therefore, nurses need to have a genuine interest to make an open relationship with patients in a non-judgmental way. This rapport needs to go beyond the patient and include other health care professionals as well as the patient's family.

KEY WORDS: Cancer, quality of life**,** nurses, patients, qualitative research, perceptions.

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In attempting to give years to the life of cancer patients, the life during these years or their Quality of life (QoL) has frequently been compromised [1]. Research studies which contribute to a greater understanding of the impact of cancer on the individual's QoL and subsequent alleviation of this problem are worthwhile. One important line of inquiry is if nurses can assess patients' QoL on their own behalf or whether they need to assess it directly with patients. There are two main reasons why this inquiry is important.

Firstly, the philosophy of nursing actually invites nurses to nurture people to achieve a holistic health. Focusing on QoL is congruent with the philosophy of a holistic approach in nursing because it also assesses patients' health status across different domains or aspects [2]. So if nurses have a reasonable understanding of cancer patients' QoL they can better identify patients' needs, make decisions and select appropriate actions to be more therapeutic in their supportive roles and to improve patients' QoL [3]. Secondly, there are situations when QoL research studies conducted in the clinical area of cancer patients and some important groups of patients can not take part in the research study due to their poor health status such as those in advanced levels of a cancer or where patients personally do not like to provide QoL information [4]. This might lead to a non-ignorable missing data and can lead to biased findings [5]. Nurses might be selected as patients' proxies for such groups of patients. So it is important to know if nurses' scores can substitute patients' scores or not.

A number of precursor empirical research studies assessed the level of agreement between

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cancer patients and nurses about cancer patients' QoL and explored variables influencing this agreement [6, 7, 8]. However, the outcomes of empirical research studies assessing the level of agreement vary across studies and the variables that have been investigated are very diverse. Moreover, some of the empirical studies that consider variables influencing the level of agreement between patients and proxies are limited because they do not canvass all important variables.

From previous research studies it can be identified that a degree of difference exists between cancer patients' and nurses' perceptions about cancer patients' QoL. However, this is not clear why such differences might occur when nurses communicate with patients. Therefore, the aim of this study was to include an interpretive perspective and explore in depth why cancer patients and nurses might differ in their perceptions of cancer patients' QoL.

Methods

This descriptive exploratory qualitative study was based on the principles of a grounded theory. Annells [9] suggested that researchers might use some aspects of grounded theory, like coding up to a conceptual ordering level, and this is helpful to get a basic understanding of the research area.

This study is a part of a bigger study that was completed in 2007 in two major public hospitals in Adelaide, South Australia. 10 nurses were selected to take part in an interpretive research study using semi-structured interviews. One of the nurses was male and nine were female with clinical experience ranging from only one year to around 30 years. The nurses were working across different inpatient and outpatient services including the palliative system.

Nurses answered to essential questions like "how do you usually assess cancer patients' quality of life?" As well as these questions, it was also necessary to ask some extra questions as the researcher proceeded through the interviews. The interviews were transcribed verbatim, naive read several times, and imported into NVivo version 7 software and analysed using comparative data analysis. In other words, as the concepts and categories emerged through the first interviews, the conceptual sampling was used to identify the next interviewee and questions needed to be asked. Conceptual sensitivity was mainly achieved by relying on the actual data, by conducting a literature review and by entering the field.

The research was approved by two major Clinical Research Ethics Committees. Written information about the research project was provided for nurses and consent was given by participants to take part in the research study. Participants were informed of their right to withdraw from the study at any time if they so desired as well as confidentiality of personal information. In order to deal with nurses' possible emotional distress, supportive care in the form of counselling was negotiated with the Clinical Nurse Consultant of different oncology wards.

Results

During the process of comparative data analysis it was found that participants are addressing a number of concepts like openness, enthusiasm, rapport and communication that facilitate nurses' understanding of patients' QoL. These concepts were then connected together under the sub theme 'relationship and rapport'. The most important characteristics of this sub theme which were found in this research study are considered in following sections.

Enthusiasm

Participants explained that enthusiasm or interest in health care professionals facilitates the process of establishing a good rapport with patients to assess their QoL. Consider, for example, the following extract:

> If you've got a genuine interest in the person you're looking after [that might allow you to have a better understanding of the patient's quality of life]. Willingness to engage and spend time voluntarily.It's the emotional and psychic energy to be involved with another person and possibly with a person who is going through something painful (Nurse 10).

Interest in health care professionals to develop a good relationship with patients is very important because they need to engage with patients who are suffering from pain or other physical and psychological issues. Such experiences are not pleasant, so nurses need to have a high motivation and psychological energy for such an engagement. In the following quota, the nurse described an unpleasant experience:

> If you have a young mother with two young children admitted who is going to die with us, that in itself can be quite traumatic. The staff can identify with this. They may have two young children, what if that was me? And that can actually get in the way of a good therapeutic relationship (Nurse 8).

In these situations, more interested nurses make a therapeutic relationship with patients to help them.

More enthusiastic nurses might search for a common interest in order to communicate with patients:

> Just chatting with patients about what you learn, what are you do, are you knitting or sewing or have a dog. Once you have a common interest, you can talk about (Nurse 4).

It is also possible that a more interested nurse even spends voluntary times with the patient in and outside of the hospital to communicate with patients:

> As most nurses do I have been guilty of after hours, I go around and walk the dogs or clean for them (Nurse 4).

In contrast, less interested nurses might only respond to the surface issues to make their jobs easier:

> Sometimes there are days when I just want to do the work and [I am not interested] to be bothered by the complexities of quality of life…If this person [patient] looks bright and fairly happy, then I think that is OK, that is good. This is a little bonus. This person does not seem to have problems. I won't go looking for trouble here. I'll just accept this as one of the easy patients (Nurse 10).

To facilitate nurses' relationship with patients', nurses need to explore in what areas of nursing they are more interested to work:

> The beauty of being a nurse is that you can find your special niche for your personality type. The theatre if you're more of a production line type. If you have a great ability and interest to relate to people then you are drawn to places like palliative care, medical units where you have the opportunity to develop relationships with people. It's about your natural sense of which you are (Nurse 8).

In the medical wards like oncology and palliative care areas, in which research study was conducted, often patients are hospitalised for a longer time and the situation is not critical. Here, nurses need to be more therapeutic in their relationships so that they can relate to patients, understand their situation and improve their level of comfort and QoL. Conversely, in acute areas such as surgical and emergency wards, there is not much time for a detailed relationship with patients but rather nurses need to have an ability to make quick decisions to manage sudden problems.

Openness

Openness is also very important during the relationship and rapport with patients. Openness is the quality of being able to think, accept or listen to different ideas or people. Participants stated:

> You need to be aware of what information [patients] got and discuss with them openly (Nurse 4).
>
> That's why I keep coming back to communication through this entire interview. It's the key. Not being restricted but being ready for whatever might come up (Nurse 8).
>
> I think having an inquisitive mind and seeking new knowledge and being open to new ideas and new thoughts [is a factor to better understand patients' quality of life] (Nurse 9).

Here participants expressed the idea that nurses need to be prepared to enquire, listen and discuss issues with their patients if they are to have a better picture of patient QoL. An open-minded nurse is ready to hear and/or discuss about everything that might happen during the course of a relationship and communication with patients. Nurses cannot restrict themselves to hear specific things they want to, rather they need to be prepared to listen to a variety of thoughts and opinions. Moreover, nurses need to encourage patients to talk about all issues even if they think these ideas would be unpleasant and/or contrasting with them and their ideas.

Be fit and well

It is important that nurses who are looking after patients are at a high level of wellness otherwise this will affect their ability to communicate with patients:

> Things like stress and so on would decrease the amount of listening power they [nurses] have (Nurse 6).
>
> If I [nurse] have poor quality of life, that is going to colour my perception against the people that I am looking after...I suppose you can look at the issue in this way. If I come to work and I have got head ache that is impacting on my quality of life. Is not it? on that point of time, and yes I would be more grouchy than usual, I might not feel like opening up to the people, and encouraging me to talk and build up a rapport, therefore I think in that way so every one knows it is a bad day (Nurse 2).
>
> You have to make sure you are fit and well and ready to listen (Nurse 6).

Participants expressed that nurses who are not happy or with lower levels of QoL might be too engaged with themselves and cannot focus on the patients and listen to them appropriately. Nurses' feeling might colour their perceptions of what other people may be feeling.

Consider patients' characteristics

Participants in this study pointed out that some patients' characteristics are very important when nurses want to develop rapport with patients. One of them is the issue of gender:

> My opinion is that females have been more open about the issue and they also want to know about their condition whereas I sometimes found that males are just, do it I do not want to know about it, but it is not for every one because there are some people that want to know. But I do find in general females are more open in the discussion (Nurse 5).
>
> Sometimes female patients are more comfortable with female nurses and sometimes male patients with male nurses (Nurse 2).

So, female patients are seen to be more interested about detailed discussions with nurses compared with male patients. Patients also may feel better to talk with a nurse from their same gender. If these issues can be taken into account by nurses, they may better communicate with patients.

Another issue is the age of patients when nurses communicate with patients:

> Younger people seem more frightened and older patients may be more accepting (Nurse 5).
>
> May be a older person who has come to the realisation that accept the process that I have this disease, I am 80, 90, and I am tired, and I am ready to go, such acknowledgement makes it easy compared to a 22 year old who has leukaemia and is dying, that is more challenging, confronting and emotional for nurses compared to a older person who is ready to go to the heaven (Nurse 7).

Here it can be seen that dealing with older cancer patients might be generally easier compared with younger ones because the older ones might have accepted and acknowledged their diagnosis. Nurses need to be aware that communication with a younger cancer patient might be more challenging.

Nurses also need to be aware of patients' language and culture:

> I suppose it is not only the better language skills to communicate with but you might have more cultural background for example when the person comes from the similar culture you have a few more cues as to what person thinking but when the person comes from different culture or background you can find yourself thinking maybe I should not have said that. You have to be sort of mindful of the culture (Nurse 2).

Nurses need to be mindful that Australian language might be considered as a difficult one to understand for those who have different first language:

> Specifically Australians have a lot of funny words. We have an awful lot of funny words for different things, for example, down in the dumps means feeling low, and a lot of people, we have now a Chinese girl, she just looked at me a couple of times. It has a big impact; this is the way that Australian people say things (Nurse 4)

Accordingly, nurses must be very careful in their communication with second language patients and arrange an interpreter as necessary:

Non English language patients, they are a bit harder, but most people when they are having treatment, they have still the same reactions to the treatment, and you can pick up, and if I cannot understand, I get some one who can, so involving a family member if I can because they can discuss openly. Sometimes they prefer to have an outsider to come in and do some translations and someone who gives them better understanding (Nurse 4).

Nurses also need to be aware of the stage of cancer if they want to be more in tune in their communication:

> Understanding the cycle of cancer, understanding the type of cancer they have, understanding the impact these cancers have on their quality of life, knowing the full cycle, what really gets to you because you know the cycle of the cancer and you know, all right at the best you have three years, you can be much more in tune or aware of the stages they are at, because you are aware of the stages of the cancer and how it works and its impact on the patients (Nurse 4).

Altogether, nurses in their communication with patients need to consider demographic and clinical characteristics of patients such as age, gender, language, culture, treatment and stage of cancer.

Be non-judgmental

When nurses communicate with patients, they need to be aware of differences that exist between their perceptions about patients' QoL with that of patients' perceptions. Nurses need to approach patients in a non-judgmental way. Participants stated:

> That is part of nursing try not to put your own. Remember that is your patients' view that you are considering and to understand that they do have different views to you...aware of differences between patients and yourself (Nurse 1).
>
> You might have your own assumptions about what that person may be feeling, just looking at from your own point of view, but at the same time you need to be mindful of trying to see how that person would see things from their perspective (Nurse 2).

Here it can be concluded that in order to better understand patients' QoL, nurses need to put aside their own assumptions and try not to be judgmental about patients' QoL. Nurses with a non-judgmental approach toward patients are often more supportive in their roles:

> I have to be just there and provide supportive capacity to try to listen, at least he found some one to communicate his feeling with in non judgmental way, some body not to turn around and push his feeling aside, just got to go with it (Nurse 2).

Quite often more experienced nurses who observed different patients and situations might be less judgmental in their approaches:

> I suppose you see enormous range of people of all walks of life, a lot of diversity and it probably teaches you to be very accepting and non judgmental and tolerant and not to be biased but we still measure quality of life to a degree from our own experiences and so going through the process of caring for people (Nurse 7).

Altogether, for an effective communication and rapport nurses need to approach patients in a non-judgmental way. This is an approach which allows nurses to be more supportive in their roles.

Involve the family and other health care professionals

Participants in this research study also commented that relationship and rapport with patients needs to go beyond the patient and include the family:

> If you establish a very close rapport with the person you are caring for and their family in a very accelerated manner and I think that you have an opportunity to be witness to very private and deep and important relationship issues that maybe give you a sense of what is important for that person. So, there are opportunities that they are made available to facilitate, opportunities to explore quality of life (Nurse 7).

This is a good example of how the family is important and health care professionals need to recognise, through their communication, if patients have a supportive family or not. This is particularly important when patients are in advanced levels or when they are dying because at these stages patients are more dependent on their families.

Participants in this research study also recognised the family as an important source of information when patients cannot communicate or are in the palliative care area:

> I guess a lot of time they are in the palliative situation and are not able to comprehend the questions or if they are they are not able to verbalise their feeling. I guess quality of life can be determined by speaking to their family (Nurse 1).
>
> We had an interesting situation only a few days ago...We actually spoke to the family about using a drug that we hadn't used before...They said, "We know our mother would want to receive that."...That woman stopped twitching the minute that infusion started. And that family was delighted because she looked a whole lot more comfortable and peaceful. They became the voice for their mother. They kept saying, "I know this is what my mother would want." We'd had these conversations so we do use the family in that way (Nurse 8).

The patient's family can be used as a good source of QoL information particularly when patients cannot communicate well.

In order to better understand patients' situation, communication with other health care professionals is also important:

> When something comes up that you [nurse] don't have the skills to manage and that's where having a multi disciplinary team is so vital. You might have to say to your patient, this is an issue that I can't help you with, but I have a colleague who can, a social worker. Would you like me to get them to speak with you? It all adds to a greater understanding and why they behave the way they do, why they react as they do, why they put the coping mechanisms in place that they do (Nurse 8)
>
> I think discussing the patient in a multidisciplinary group would be useful as well to bring out issues and I think it would be useful overall to bring out issues that need to be discussed about the patient care (Nurse 9).

Altogether the relationship and rapport needs to be established not only with patients but also by patients' family and other health care professionals. Relationship with the family is especially very important because they have a

supportive role for patients and they can work as a proxy in some situations.

A holistic approach

An effective rapport is also one that attempts to understand all aspects of individuals' QoL such as physical, psychological, and social relationships. Participants, however, identified what a holistic approach means for them:

> I think holistic is very over rated and I think it locks people in. We all strive for the ideal, that Utopian way of life. If we say that it's holistic care, therefore we are doing the right thing. Unless you get in and really understand your patient on a deep level of communication, holistic care is just a concept (Nurse 8).

A holistic approach in fact is a relationship and rapport with the patient which is deep enough to understand all aspects that might impinge on patients' QoL:

> Make sure that you care for all parts of patients…Make sure you listen to what is happening, you look after the spiritual, emotional needs as well…I think it needs more intensive evaluation than evaluating physical capacity (Nurse 6).
>
> Unless you've interviewed them [patients] at length and done a thorough psycho-social assessment, I don't think any nurse would advocate for them (Nurse 8).
>
> So often it is physical care and emotional support that it is the first response of what the patient needs. The bigger picture of spiritual life or meaning does not come into it until I got a relationship with the patient (Nurse 10).

In a comprehensive approach all aspects of patients need to be taken into consideration. Although the physical issues are an important aspect of individuals' Qol, the psychological and spiritual aspects of QoL cannot be overlooked.

In a comprehensive approach, personal issues such as sexual aspects need to be taken into consideration:

> It wouldn't be common that patients talk about those personal aspects. But yes, it could be beneficial. Even just expression of these issues with somebody else is useful. The only ways that those discussions come about with a patient are when a relationship has been well established involving trust (Nurse 10).
>
> We do not really do any sexual assessment, urology patients, we do not tend to. Even though they have a need for sexual assessment, and it is an area that nursing staff find particularly difficult to deal with because they do not know how to talk about it with patients. But because we are working in haematology/oncology there is a need to address that because the patients are under chemotherapy (Nurse 3).

Without considering all aspects of QoL including the private aspects like sex life or financial issues, it is very difficult to have a holistic and comprehensive picture of individuals' QoL. These areas are difficult for nurses to deal with unless a close relationship and rapport is established between patients and nurses.

Discussion

The major aim of the study was to explore why nurses' perceptions about cancer patients' QoL might be different from those of cancer patients' own perceptions. This matter was explored in the light of how nurses communicate with cancer patients.

Participants believed that the main reason for differences that exist between patients' and nurses' perceptions about cancer patients' QoL is poor relationship and rapport. A poor relationship and rapport can lead to ineffective communication [10]. Therefore, this supports a need for nurses to develop a more holistic relationship and stronger rapport with patients which underpins the assessment of cancer patients' QoL. In this study participants commented on how nurses can develop such a relationship and rapport with patients.

It was discussed by participants that what makes nurses have a stronger relationship and

rapport with patients is a genuine interest and their love to nurture people. Enthusiasm directly or indirectly influences nurses, relationship with patients [11, 12]. Participants believed that this genuine interest might encourage nurses to spend more time with patients and communicate with patients in an open, receiving and non-judgmental way. More importantly, many of nurse-patient communications are not pleasant, so nurses need to have a high motivation and psychological energy for such an engagement [13]. An effective rapport is also one that attempts to understand all aspects of individuals' QoL such as physical, psychological, and social relationships. This is what sometimes named in the relevant literature as a holistic approach [14, 15].

Findings of the study are similar to a research study conducted by King et al [2] in which the main aim was to explore QoL of cancer patients from the perspective of oncology nurses. In this research study a focus group was used involving 24 oncology nurses in the United States of America (USA). When the interviews were transcribed and after coding, five main themes and a conceptual model were identified. The main important outcome of the research study was that nurses' assessments of patients' QoL were dependent on the strength of their relationships and nurses with a better relationship with patients could better assess cancer patients' QoL.

This research study found that patients and nurses differ in their perceptions of cancer patients' QoL. However, this research study did not have enough time and resources available to completely understand, from both patients' and nurses' perspectives, how such differences might impact on patients, particularly their QoL. Therefore, it would be very useful in an interpretive study to explore how differences in patients' and nurses' perceptions of patients' QoL influenced patients' QoL and other related issues, like patients' coping styles, in more depth.

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References

1. Isikhan V, Guner P, Komurcu S, Ozet A, Arpaci F, Ozturk B. The relationship between disease features and quality of life in patients with cancer--I. Cancer Nurs 2001; 24(6): 490-5.
2. King CR, Hinds P, Dow KH, Schum L, Lee C. The nurse's relationship-based perceptions of patient quality of life. Oncol Nurs Forum 2002; 29(10): E118-26.
3. King CR. Introduction: improving oncology nursing through advances in quality-of-life issues. Oncol Nurs Forum 2006; 33(1 Suppl): 3.
4. Addington-Hall J, Kalra L. Who should measure quality of life? BMJ 2001; 322(7299): 1417-20.
5. Sneeuw KC, Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. J Clin Epidemiol 2002; 55(11): 1130-43.
6. Horton R. Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting. Palliat Med 2002; 16(6): 488-94.
7. Fisch MJ, Titzer ML, Kristeller JL, Shen J, Loehrer PJ, Jung SH, et al. Assessment of quality of life in outpatients with advanced cancer: the accuracy of clinician estimations and the relevance of spiritual well-being a Hoosier Oncology Group Study. J Clin Oncol 2003; 21(14): 2754-9.
8. von Essen L. Proxy ratings of patient quality of life factors related to patient-proxy agreement. Acta Oncol 2004; 43(3): 229-34.
9. Annells M. Grounded theory. In: Schneider Z, Elliott D, LoBiondo-Wood G, Haber J, editors. Nursing research : methods, critical appraisal and utilisation. Sydney: Mosby Publishers, 2003.
10. Corner J. Nurses' experiences of cancer. Eur J Cancer Care (Engl) 2002; 11(3): 193-9.
11. Hedstrom CH. Job satisfaction among critical care nurses (Burnout). 1991.
12. Sadovich JM. Work excitement in nursing: an examination of the relationship between work excitement and burnout. Nurs Econ 2005; 23(2): 91-6, 55.
13. Finfgeld-Connett D. Meta-synthesis of caring in nursing. J Clin Nurs 2008; 17(2): 196-204.
14. Bishop LP, Griffin C. Holistic healing methods positively advance patient care. Nurs Manage 2006; 37(7): 30-35.
15. Saylor C. The circle of health: a health definition model. J Holist Nurs 2004; 22(2): 97-115.