Nurses perceptions and experiences, within the positive health concept, providing care to elderly cancer patients; a qualitative study

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SUMMARY

Title:

Nurses' perceptions and experience with elderly cancer patients

Background:

In 2015, an estimated 105,000 people were diagnosed with cancer. The number of new cancer patients will continue to rise in the coming years. This patient group is vulnerable and often in need of nursing care. There is a discrepancy between the perspective of nurses and elderly patients. This may affect the care provided. The nurses perception and experience of nursing care to elderly cancer patients has not been researched. The concept of positive health will be used to gain insight into their perspectives. Positive health is: "*The ability to adapt and self-manage in the face of social, physical and emotional challenges*".

Aims:

To gain insight into the perceptions and experiences of oncology nurses, within the positive health concept, in the care they provide to cancer patients in the age group 70 years and older.

Study design:

A qualitative descriptive design using semi-structured interviews

Study population:

Oncology nurses caring for elderly cancer patients (≥70) within homecare, hospitals and primary care.

Data collection:

An interview guide and a topic list were used to conduct face-to-face interviews.

Analysis and results:

Thematic analyses with an inductive approach was used. The following themes were found; characteristics of the elderly patient; regular nursing care; accompanying care; the nurse as a coach.

Conclusion:

Oncology nurses provide care based on of the needs they expect the patient to have. Their own perception provides discrepancy between the requested and provided care in some areas. More attention can be devoted to the positive characteristics of elderly patients, to improve quality of life of the patient

Recommendations:

Further research into the differences in perception and experiences of nurses and the elderly cancer patient. Also from the patient perspective.

MeSh Terms:

Cancer patient, elderly, nursing care, perception, positive health

INTRODUCTION

The Comprehensive Cancer Centre of the Netherlands (IKNL) recently reported 105,000 people were diagnosed with cancer in 2015[1]. Two thirds of all cancer patients are older than 60 years, and 25% is over 75 years [2–4]. Cancer is, especially for elderly, a major health challenge. In addition 60% of the cancer patients who are 65 years and older have comorbidities [2,5]. By the year 2040, the number of elderly over 65 years will increase from 2,7 million to 4,6 million[6]. IKNL expects the number of new cancer patients to continue to rise in the coming years [7].

Due to the increasing prevalence of the aging cancer patient population the geriatric importance in cancer patients is becoming more relevant [8]. Considering the chronic nature of cancer and considering the severe physical, psychological, and social consequences of its diagnosis and treatment, the cancer patient is vulnerable and in many cases dependent on nursing care [9,10]. Patients with cancer experience problems with daily functioning, emotional problems and other related issues[11].

Healthcare institutions try to improve quality by focusing on the needs and preferences of the patient. The focus on the patient is an aspect of quality[12]. In 2011, Huber developed a new concept of health from a patient perspective[13]. It takes a wider perspective than the absence of illness. In order to deliver care which puts the patient central it is of importance to follow this approach. This new concept, positive health, is defined as: "*The ability to adapt and self-manage in the face of social, physical and emotional challenges*"[14]. The concept consist of six axes: bodily function, mental functioning and perception, quality of life, social and societal participation, daily functioning and the spiritual/existential dimension. Patients are approached from their strengths and the focus is on enhancing their health. In addition, a person diagnosed with a disease will have other healthy aspects of their lives that may be focused on and strengthened[15]. Looking at nursing care through this perspective, makes it more likely to match patient's need, which could increase quality of care.

At present there is a discrepancy in the way patients and nurses each describe health[13]. This may affect the care provided and the extent to which the patient's needs are met. Oncology patients need this care in different nursing areas. Not all needs of the oncology patients are met, and this deficiency within the nursing care should not be ignored[16]. Another study shows findings about the professional perceptions of healthcare professionals which showed that the reported needs of patients were not always identical to the needs observed by healthcare providers[17].

It is important for nurses to understand the needs of the patients they communicate with and to provide sensitive care[18]. These needs and professional support by nurses are a key element[11]. Improving nursing care begins with improving the ones who provide the care[19]. Lynn et al. (2007) observed that the evaluation of quality in care would be incomplete

and ineffective without knowing the perspectives of the nurses[20]. With this in mind it is important to identify the nurse's perception so that it can be adapted to the needs of the patient.

At present, nurses' perspectives on the care they provide to elderly cancer patients have not been researched. Contemporarily that is important given the growing number of elderly cancer patients[7]. Practicing within the positive health concept is at the forefront in health care and this study will be conducted within the aspects of this concept.

AIM

The aim is to gain insight into the perceptions and experiences of oncology nurses (ON) in all settings, within the positive health concept, in the care they provide to cancer patients in the age group 70 years and older.

METHODS

Design

To gain insight into the perspective of ON this study employed a qualitative design with semi-structured interviews guided by an interview protocol.
Qualitative research was used to understand and explore experiences and lived experiences of the ON. This type of research does not illuminate causal explanations [21]. This study was qualitative descriptive because it has as its objective the comprehensive summarization of events specific to individuals or groups of individuals[22]. This design was chosen because it is most appropriate for participants to share their perspective in the care they provide to patients [21,23].

Population and domain

This study includes ON caring for elderly cancer patients. The International Society of Geriatric Oncology (SIOG), who advocated for elderly cancer patients, defined them as 70 years and older[24]. All participants had an additional specialization in oncology and were employed full time or permanent part-time in the hospital, homecare or primary care setting. To ensure maximum variation and heterogeneity in this group the researcher invited participants of different genders, ages, workstations, years of experience and with different employment histories.

Data collection

A total of 12 in-depth-interviews were conducted between 22 March and 12 April, with a duration between 27 and 51 minutes. In the patient letter, the concept of positive health was defined. The six aspects were not described. A topic list was used in which the aspects of the positive health concept were included (table 2). In consultation with the University

Windesheim research group this list was drawn up and the method of application discussed. The interviewer took a workshop at a Dutch University. The interviews took place at the hospital, at the headquarters of home care in general practice and in the participants' homes. All interviews were recorded, transcribed and anonymized.

Data analysis

The qualitative data have been analyzed according to the six phases of thematic analyses of Braun [25]. This has a inductive thematic nature. According to the first step, all interviews have been transcribed, replayed and word-by-word read. This way the researcher became familiar with the data. During the interview memos were recorded to assist in interpreting and categorizing data. In addition, these memos will provide a separation between findings and interpretations[26]. The first interview was individually coded, after which a senior researcher reviewed the quotes and codes. The qualitative data software NVivo was used to code and analyze the data. After coding, looking for patterns started between the labels and possible connections between the perceptions and experiences of the participants[26]. The themes and categories were discussed with a senior researcher. After the initial interviews were transcribed, the concept of the code tree was ready.

Procedures

For recruiting participants, the researchers own network was employed.
Nurses were employed by enrollment from various hospitals, home care institutions and primary care. Maximum variation was pursued within different aspects, to improve the probability of exposure of various views[27]. The participant letter was sent by e-mail and the participant was contacted three days later by the researcher to make an appointment for the interview. Response to the mail identified which ON would become a participant in this study.
At one major academic hospital, the participant's letter with accompanying email was spread throughout the entire cancer center, without response. The email was also distributed among three out of five clinical departments of a specialized oncology hospital, without response.
One floor manager at a top clinical hospital did not want to distribute the email because the department had recently participated in another study.
Two ON responded after the appointed deadline and were placed on a reserve list. Because there were no dropouts, these participants were not included.

Ethical considerations

The principles of the Declaration of Helsinki will be followed during the execution of this study[28]. In the Netherlands this study is exempt from ethical approval, because it does not infringe on the physical and/or psychological integrity of the participant[29]. The participant

was informed of the aim of the study, the modalities of participation and the handling of confidential data within the study. Before the start of the interview, an informed consent was signed. This was then confirmed on the audio recording of the interview. The privacy of respondents will be guaranteed by anonymization of the data. Participation will be voluntary.

RESULTS

Sample

Purposive sampling was used to obtain maximum knowledge[30]. An unknown number of ON were approached in an oncological hospital, academic hospital, top clinical hospital, two region hospital, home care organizations and one general practice. The final sample consisted of 12 ON of which two were men and ten were women. The age of the nurses varied between 32 and 64.

The positive health aspects are described throughout the themes. The following themes are indicated: the elderly cancer patient, nursing care and experiences, the coaching nurse.

The elderly cancer patient

A majority of the nurses maintained that all patients are different. They have a different history, have experienced other events in life and deal with those events uniquely. Physical vitality also differs. This theme is divided into the strengths and weaknesses.

Strengths

A strength of elderly is they are better able to comprehend and cope with the course of their illness. The elderly can resign themselves to what happens to them. Some nurses indicate that elderly people give reciprocity by expressing gratitude.

(That's different, I think that's very different. Yes, what kind of person you are and how you deal with your illness (B))

(I think that, the elderly, are able to say: I have had a good life (H))

The elderly are often accustomed to being self-sufficient and taking care of themselves. The nurses indicated that asking for help is difficult within this group. This is as true for their relatives as for their other caregivers. The perseverance of the elderly stands out. There is a strong mentality of not complaining and fighting on present.

(I think many people, especially the elderly, find it hard to ask for help (J))

(But before, the people had the mentality of ..okay.. I have to.. I have to go on, just keep going even though you cannot. Do not complain and keep going. In the older generation that is shown more than nowadays (L))

Weaknesses

This is in contrast with taking care of their choices. Choices are largely based on what the doctor says, or what loved ones prefer. There is difficulty making choices and investigating possibilities. Elderly are more often informed passively.

(But often the elderly people look up to the doctor, and therefore do what the doctor says (I))

Also the social network is often smaller and the informal caregiver is older. The nurses are mainly focused on what can go wrong because of the smaller network. There is a correlation between a smaller social network, a more vulnerable informal caregiver and the resilience of the elderly cancer patient to withstand the treatment and/or illness.

(This occurs more often with the elderly patient. That their social network is smaller, you need to be aware of that. (A)).

(And that people are already weaker, and sometimes the informal caregiver is weaker, yes, then you decline faster (E))

The elderly may have difficulty expressing feelings to nurses. Nurses in turn may have the idea the elderly do not always know what they feel and what their perspective is.

(*I think elderly regularly discount their complaints or keep themselves from asking questions such as "could we reschedule my chemotherapy so I can go out with my siblings for a day", elderly would never ask something like that (A))*

Nursing care

Nursing care in the oncological setting is mainly giving the patient insight into their own needs and wants. This theme is divided between compassionate care and an alerting role. By listening and asking questions nurses attempt to uncover the elderly's wants and needs. Within homecare it is emphasized that elderly will indicate the tempo and the nurse tries to match this.

Compassionate Care

Nurses offer time and attention to the patients. They want to provide care where the elderly

feels heard and seen. Listening and actively engaging the elderly by asking questions is seen as an essential part of care.
(It is good to wonder what is important for the elderly patient, especially listening carefully and try to come to terms by asking questions (H)).

(Just listening to what's happening and sometimes asking some enlightening questions and then, of course, observing what you see, what do you hear? What do you really hear (G)).

Additionally, the focus is primarily on the patient, what kind of cancer somebody has, does not matter anymore. Nurses also try to empathize the stage of life and where in the disease process the elderly is. And thereby they seek to raise awareness about the near future and prospects.

(People who received bad news and are on that crossroads in their lives asking themselves what am I going to do now. How does my future, shorter than I thought, look and how should I shape it? Yes.. what would I like to do, where do I want to be when I get sick, who do I want to help or how can I organize it? (E))

(You cannot just focus on someone's disease. It is no longer important what kind of cancer someone has (F))

Alerting role

The alerting role is described by the ON as a skill of observation, feedback to the patient and asking in depth how they are doing. In the hospital the Distress Thermometer (DT) is used to measure how patients manage.

(Frequently alerting, looking at how and what and discussing quality of life and that they can, have and could take control over that part of their lives (D)).

Within oncological care, the spiritual/existential component, quality of life and aspect of treatment are subjects of discussion. ON provide support in the final phase of life and ask critical questions during the final moments. They try to improve quality of life by reducing physical complaints where possible. Life goals such as the birthday of a grandchild give meaning to life and could be a reason to make the choice for treatment. When hampered by complaints it is difficult to open up for existential reflections. ON recognize the patient's convictions are paramount and they strive to seek these out and use them in their care. It is repeatedly emphasized that the patient himself determines the quality of life.

(So, indeed, the quality of life is just very important... I also think that it's very important for them to keep control over this themselves (D))

The coaching nurse

ON help patients make choices during the disease process, including treatment options, taking patient desires and needs into account. They support the patient with education, decision making and creating a safe environment.

Patient education

ON provide patients information about the treatment and the course of illness. In the hospital, patient education is provided about the cancer treatment and the disease. If it is not possible to cognitively process all the received information, the ON adapts the explanations to match the patient's level of knowledge.

(Well, of course, you can always tell them.. you can always give advice but they have to do it themself. But you can give them some substance to think about, what would happen if we stop treatment and how are you doing then? (D)

(Of course, at the hospital, they get a lot of information at once. And then they are thinking about it and then you actually notice that there are just not many things left or they actually forget things .. and in the hospital you only have limited time (J))

(...people can not make an informed choice, based on individual knowledge because that knowledge is not there (E))

Decision making

The ON identifies the influence of loved ones and the doctors plan. If the doctor proposes a plan of action, the elderly cancer patient tends to follow this advice. In addition, they tend to accept treatment if asked to by a loved one and let their own opinion count less.

Also, support is given to decisions and behaviors of elderly patients that affect their health.

Elderly tend to neglect their own opinions in this way. The ON attempts to help the elderly to discover their own preferences and to accept the responsibility of their choices by asking directed questions. Even when that choice may be made for a loved one.

(But ultimately, the most important thing is that choice remains with them. That is the most important thing (J))

(I do not want the doctor to decide for me, I do not want to hurt, I want to .. stay home or .. I do not want to go to a hospice, I do not want to go to a hospital anymore. If you can identify all you do not want then you know at some point what you do want (H))

Create safety

Finally, the ON offer safety and structure by discussing complaint management with the patient and by just being there.

(You want that.. despite being sick and in spite of the fact that you are going to die, that you can feel safe and get the help you need without unnecessary complaints, or when they occur that you can do something about it (E))

DISCUSSION

In this study, the perceptions and experiences of ON on the care they provide to elderly cancer patients within the positive health concept were investigated.

Positive health is: "*The ability to adapt and self-manage in the face of social, physical and emotional challenges*". The different components within the definition of positive health are applied in varying degrees within nursing care. The results of this study show that ON adapt their care to the individual patient. In general, the focus is more on the patient and less on the disease. In oncology care the ON are focusing on weaknesses and complaints rather than the strengths and facilitators. The ON perception of patients as unique persons is in line with the mindset of positive health.

Self-management is supported by interviewing the elderly in order to identify their needs and desires. This insight is crucial to improve self-management[31]. Also delivering information and patient education will help make choices leading to improved self-management[32] which is part of the positive health concept. One of the main roles of the ON is to empower the elderly to choose[33].

Results in this study show that elderly have difficulty in opening up psychologically and in expressing what they feel or asking for help. Research on oncology patients show ON can provide support emotionally by listening to what gives meaning and giving good feedback[38]. Controlling physical suffering increases the coping capacity in patients. It is important in this way to address all aspects[38].

To measure distress in elderly patient's, DT is applied. This is a valid measuring instrument developed for cancer patient and measures the degree of distress experienced by the patient on a physical, social, emotional and practical level [34]. in the broadest sense it is equivalent to positive health but the perspective is contrary to the positive health concept. This measures the distress instead of focusing on the strengths as pursued in positive

health[14]. Within psychosocial care in general it is unusual for caregivers to focus on positive aspects[35].

It is also apparent from the results that patient quality of life for ON is seen as important within the care. This is an axis within the positive health concept. What is striking about this is that just emphasizing the qualities of the elderly and applying them in positive terms in care can contribute to the quality of life. Research shows that the experienced inner strength ensures the quality of life and the capacity to apply self-management[31]. At present, healthcare systems do not apply this knowledge sufficiently making this an area of potential improvement.

ON care for the elderly, providing security and structure. This is in line with other research showing that patients feel more secure when complaints management is applied[36]. For in-depth conversations, ON indicated that older people would rather have a somewhat older nurse[16] and also reducing physical complaints is experienced by patients as important to feel safe[36]. The importance of providing information, and complaints management is highlighted by the ON participating in this research and within other research[16]. Satisfaction with information provided is slightly different between the elderly and younger patients. The elderly tend to prefer the doctors make decisions regarding treatment[37]. A result also evident in this study.

Strengths and limitations

Participants were drawn from a variety of health settings and regions, are both men and women and vary in age from 32 to 64 years. This heterogeneity corresponds to the entire group of ON and is a strength within this research. Also, the gender ratio within this study, listed in table 1, is in accordance with Dutch statistics. There were 119.000 specialized ON employed in the Netherlands of which 102.000 were women and 17.000 men[39].
The response within several hospitals was moderate, meaning academic hospitals and oncology hospitals were not included which is a limitation. It is possible that a difference in the type of ON working in a specialized or academic hospital may affect the range of the results. In order to achieve face validity, a senior researcher was involved during the process.

Practical implications

Most ON have corresponding perceptions about the care they provide to elderly patients. First of all, it is important for ON to emphasize the positive characteristics of the elderly in their care as described by the positive health concept. This awareness must take place within the ON attitude. Secondly, It is important that ON realize there is a discrepancy between patient needs and the ON perceived patient needs.

CONCLUSION

The results of this study show that care for elderly cancer patients is seen by the ON as alternating. The positive health concept is applied in different levels, and at different levels within nursing care. The ON tailor the care to best fit the needs they expect the elderly patients have. A discrepancy, of what the needs of elderly patients are, is still present. Several components of the current care in these studies correspond to previous studies. There is potential for significant improvement within nursing by approaching the patient from their strengths. This concept is not yet well known and the focus of the typical ON is providing assistance for weaknesses and not in supporting strengths.

Recommendations

Further research is recommended for the concept of positive health, so this method can be substantiated, adapted or assessed as unuseful. In addition, further research is needed regarding how the nurse can focus more on the positive characteristics of the elderly and tailor the care to achieve positive effects. In this way, it is possible to improve tailored care.

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ATTACHMENTS

Table 1

	Gender	Age in years	Setting	Education	Nursing experience in years Regular	Oncology	Oncology patients
Mean		48	-	-	25	10	-
	Male	34	Ambulatory care Hospital	Oncology Hematology	7	1,5	All
	Female	55	Ambulatory care Hospital	Oncology	38	16	All
	Female	53	Ambulatory care Hospital	Oncology	18	5	Lungcancer
	Female	50	Ambulatory care Hospital	Oncology Farmacology Heamtology	28	2	All
	Male	58	Homecare	Oncology	34	10	All
	Female	48	Homecare	Oncology Terminal Care	25	18	All
	Female	36	Primary care	Oncology Nurse practicioner	12	7	All
	Female	64	Homecare	Oncology	47	17	All
	Female	51	Homecare	Oncology	31	7	All
	Female	32	Homecare	Oncology	13	8	All
	Female	48	Chemotherapy unit Hospital	Oncology Hematology	30	20	All
	Female	48	Chemotherapy unit/ oncology ward Hospital	Oncology	15	9	All

Table 1 Characteristic of participants

Table 2

Broad and open introduction question
Can you tell me more about the care you give to elderly cancer patient, aged 70 and older?

Topics (positive health)
Bodily function
Mental function and perception
Spiritual/existential dimension
Quality of life
Social and societal participation
Daily functioning

Tablel 2 Topics in interviewguide