

Perspectives of nurse specialists on moving follow-up oncology care closer to home

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English abstract

Title: Perspectives of nurse specialists on moving follow-up oncology care closer to home.

Background: There is a continued rise of cancer patients who receive follow-up care. To maintain good quality care, it is necessary to explore other possibilities of providing this kind of care. In this study, the possibility of moving follow-up care of the nurse specialists will be explored. Patients will benefit if the follow-up care of nurse specialists could be moved in facilities closer to the patients' home or when patients can stay at home while receiving follow-up care. Unfortunately, little is known on the possibilities of moving follow-up care of nurse specialists closer to home.

Aim: To gain insight in nurse specialists' perspectives, working in the outpatient clinic, on follow-up care of adult cancer patients closer to home.

Method: A qualitative study using semi-structured interviews was conducted. The thematic analysis framework of Braun and Clarke was used for analysis.

Results: Four themes emerged from the data on the perspectives of nurse specialists on follow-up care closer to home: 1) the needs of patients as the starting point, 2) the perceived preconditions for moving follow-up care, 3) the perceived own role of the nurse specialist, and 4) the perceived possibilities of moving follow-up care.

Conclusion: This study provides insight in the perspectives of nurse specialists on follow-up care of adult cancer patients closer to home. Nurse specialists believe that moving follow-up care by placing the hospital-based consultations within patients' homes using technology, is a realistic and preferable manner to adapt to the future of out-of-hospital follow-up care.

Recommendations: For further research it is of great importance to gain insight on patients' perspectives and in the concept of meaningful care.

Keywords: Perspectives, nurse specialist, follow-up care, cancer patients.

Nederlandse samenvatting

Titel: Het perspectief van verpleegkundig specialisten op het verplaatsen van follow-up zorg voor oncologiepatiënten dichterbij huis.

Achtergrond: Er is een continue toename van kankerpatiënten die follow-up zorg ontvangen. Voor het behouden van kwalitatief goede zorg is het nodig om andere mogelijkheden te exploreren. In deze studie, wordt de mogelijkheid van het verplaatsen van de follow-up zorg van de verpleegkundig specialist onderzocht. Het zou patiënten ten goede komen wanneer deze zorg verplaatst zou worden naar faciliteiten dichterbij huis of wanneer de patiënt thuis kan blijven terwijl hij follow-up zorg ontvangt. Helaas is er nog weinig bekend over de mogelijkheden om follow-up zorg te verplaatsen.

Doel: Om inzicht te verkrijgen in het perspectief van de verpleegkundige specialist, werkzaam op de poli van een ziekenhuis, op follow-up zorg van kankerpatiënten dichterbij huis.

Methode: Een kwalitatieve studie met behulp van semi-gestructureerde interviews. Het framework van Braun en Clarke is gebruikt voor de thematische analyse.

Resultaten: Vier thema's geven het perspectief van de verpleegkundig specialist op follow-up zorg dichterbij huis weer: 1) de behoefte van de patiënt als beginpunt, 2) de randvoorwaarden voor het verplaatsen van follow-up zorg, 3) de eigen rol van de verpleegkundig specialist en 4) de mogelijkheden van het verplaatsen van follow-up zorg.

Conclusie: Deze studie geeft inzicht in het perspectief van verpleegkundig specialisten op het verplaatsten van follow-up zorg voor volwassen oncologiepatiënten dichterbij huis. Verpleegkundig specialisten zijn van mening dat het verplaatsen van ziekenhuisconsultaties naar bij patiënten thuis, met behulp van technologie, een realistische en wenselijke manier is om de toekomstige follow-up zorg buiten het ziekenhuis te realiseren.

Aanbevelingen: Het is van groot belang om eerst inzicht te verkrijgen in het perspectief van de patiënt en daarnaast ook in het begrip zinvolle zorg.

Kernwoorden: Perspectief, verpleegkundig specialist, follow-up zorg, kankerpatiënten.

Introduction

Worldwide the number of patients with cancer is increasing.^{1,2} In 2018 there was an estimated number of 17 million new cases of cancer.³ Although the prevalence of cancer is rising, in the period between 1990 and 2016 the death rates have declined with 17 percent. Due to improved treatments, patients' survival rates have increased.^{1,4-6} In the Netherlands, over 800.000 people are treated or have been treated for cancer, and this number is expanding.⁷

After primary treatment of cancer in a hospital, patients receive follow-up care. Follow-up care is defined by the National cancer institute as; *“Care given to a patient over time after finishing treatment for a disease. Follow-up care involves regular medical checkups, which may include a physical exam, blood tests, and imaging tests. Follow-up care checks for health problems that may occur months or years after treatment ends, including the development of other types of cancer.”*⁸ Nowadays, treatment can be continued during follow-up. Stabilizing cancer and treating side effects of medication, improves patients' quality of life and their life expectancy is prolonged.⁹ This treatment after primary treatment is also seen as follow-up care. After primary cancer treatment, patients often experience physical and mental complaints^{1,10}, such as fatigue and psychological distress.^{1,11} In comparison to adults without cancer who are similar in age and sex, cancer survivors experience more health complaints for many years after cancer treatment.^{1,12} The follow-up care is of great importance for making sure these patients experience as little inconvenience as possible and to improve quality of life.

Over the past few years, the follow-up care of cancer patients is primarily delivered by nurse specialists (NS). These professionals are master educated nurses specialized in oncology health care. They assess medical imaging and blood tests to capture recurrences and during the whole process they guide their patients on how to cope with the consequences of cancer and the following treatment in daily life.¹³ NS are mainly positioned in a hospital. As a consequence, patients have to travel to the hospital for follow-up appointments. This often takes a lot of their time and energy, while they should be focused on the best quality of life or recovery when possible. Patients will benefit if the follow-up care of NS would be moved to facilities closer to the patients' home or when patients can stay at home while receiving follow-up care. Consequently, patients no longer have to go to the hospital as often, they can receive care in the comfort of their own home or closer to home and care can be more personalized.^{14,15} These changes in the follow-up care lead to a better experienced quality of care.^{15,16}

In the Netherlands there is an ongoing trend to migrate care from the hospital closer to patients' homes or even at home.^{14,17} To make this movement possible for the follow-up

care of cancer patients, changes are needed.^{17,18} Unfortunately, little is known about the possibilities of moving follow-up care of NS closer to home. To ensure good quality of care for oncology patients when moving this care closer to patients' homes, it is essential to gain an insight on how NS portray their role and their perspectives on the future of out-of-hospital follow-up care. This insight will support policy makers to capture the possibilities and impossibilities of follow-up care closer to home to benefit the quality of care.

Aim

To gain insight in nurse specialists' perspectives, working in the outpatient clinic, on follow-up care of adult cancer patients closer to home.

Method

Design

An explorative descriptive qualitative study was performed to discover and understand the perspectives of the NS.¹⁹⁻²¹ This approach suits the objective, as it was important to get a deeper understanding on how NS portray the future of follow-up care.

Population and domain

The population included NS working in oncology care in a Dutch hospital setting and were eligible if they cared for adult cancer patients, in the outpatient clinic, during the follow-up of their treatment. The respondents were recruited in secondary and tertiary hospitals in the Netherlands. The NS were purposively selected, because a specific group of people was approached for the knowledge they could provide on this subject.²² Maximum variation was strived for by selecting respondents with a diversity in certain characteristics, such as; age, gender, working experience as a NS, specialization and place of work.²² Different characteristics could influence the perspective of the NS, therefore maximum variation was important to achieve a complete and representable insight of the whole population.²³ Sixteen NS were approached, fifteen agreed to participate. One NS changed his mind because of the added work pressure due to the COVID-19 pandemic.

Data collection

Data collection took place from January until April of 2020. At the beginning of the study all respondents were contacted through e-mail or in person by the supervisor (SV). When they agreed to participate they were contacted by the first researcher (MJ) through e-mail or phone.

Semi-structured face-to-face interviews were conducted with the use of an interview guide. This contributed to gather similar information from each respondent.²² The interview guide supported the researcher to achieve the aim of the study and to explore the research topics.²² The interview guide contained questions that focused on how follow-up can be moved closer to home, what are the possibilities and the impossibilities and how NS view their role in this kind of care. The interview guide was based on literature¹⁴ and expert opinion. During interviews probing, prompting and summarizing questions were used to stimulate the respondent to elaborate on a topic and search for reasoning and meaning.²² Additionally, during and after the interviews, memos were written to capture the first thoughts and ideas, this supported the researchers' interpretation of the interviews.^{22,23}

The first two interviews were pilot interviews. Both interviews were listened by the supervisor (SV) and discussed with the first researcher (MJ). Little changes were applied to strengthen the interview technique. After the first interview one question was added to the interview guide: Where does the follow-up care consist of within your specialization? Due to COVID-19 pandemic the last two interviews were conducted by telephone. All interviews were conducted by the first researcher (MJ). Fifteen interviews were completed. All interviews were audiotaped and took place at the working place of the respondents. The characteristics were collected after the interview through questionnaires. The duration of the interviews ranged from 20 to 46 minutes with a mean of 36 minutes.

Data analysis

The thematic analysis framework of Braun and Clarke was used for analysis.²⁴ This is a generic approach for qualitative analysis that provides theoretical flexibility within a clear structured framework.^{22,24} The analysis was an iterative and non-linear process. During the analysis, data collection and analysis were alternated and initial impressions and thoughts were noted.²² This ensured the researchers' understanding of the data and validate findings which led to a better interpretation of the data. Throughout the whole process constant comparison was applied until saturation was reached.^{23,25,26}

All interviews were transcribed verbatim and anonymized. Data analysis started after the first two interviews. The research team consisted of two nurse scientists in training (MJ, MW) and the supervisor (SV), who is an experienced researcher. The six phases of the framework of Braun and Clarke were followed.²⁴ Within the first phase, the transcripts were individually read out in full to get an overall picture and re-read for grasping the details. During this process initial thoughts were noted. The second phase existed of systematically and independently generating initial codes. These codes were assigned to meaningful paragraphs within the interview text, representing the essence of the paragraphs.

During multiple sessions the researcher discussed the codes and reached consensus

(MJ, MW). The supervisor (SV) then reviewed the codes. Subsequently, within the third phase, the initial codes were collated into potential themes. These potential themes were discussed (MJ, MW) and all relevant data was structured to each theme. During the fourth phase, the potential themes were reviewed (MJ, SV) on consistency to make sure they represented the codes and the entire data set. A thematic map of the analysis was generated (figure 1). Within the fifth phase, inconsistencies were discussed, as well as further development and defining of themes within the research team (MJ, MW, SV) until consensus was reached. To complete the analysis, within the sixth phase, the final relation between literature, the research question, the data and the themes were presented in this article.²⁴

To validate the results a member check was conducted. Eight NS responded, two were no longer attainable, and five did not respond. The results were confirmed, not leading to any changes. The NS agreed on the content of the results. Data saturation was reached after 11 interviews, because no new information could be added and the perspectives of NS were thoroughly described.^{22,23,25} Data analysis process was supported by using Nvivo (QSR International).²⁷ IBM-SPSS Statistics version 24 was used for analyzing respondent characteristics.²⁸

Ethical considerations

This study was conducted according to the principles of the Declaration of Helsinki (version 64, october 2013)²⁹ and in accordance with the Medical Research Involving Human Subject Act (WMO).³⁰ The study was approved by the Medical Ethics Research Committee of the University Medical Center Utrecht (20-050/C). The data was handled according to the European Union General Data Protection Regulation and the Dutch Act on Implementation of the General Data Protection Regulation.³¹ The university policy framework for research data Utrecht University were applied.³² Informed consent was obtained from all respondents.

Results

Of the 15 NS who participated in the study 86.7% (13) worked in a tertiary hospital, 73.3% (11) was female, and the mean age was 50 (32-64). All NS had one of the following specializations in oncology; gastroenterology (colorectal, stomach, esophagus, hepato-pancreato-biliary), breast, head and neck, lung, hematology, urology (testicular, prostate, bladder), or gynecology (vulvar, cervical). For further information, see table 1.

[Table 1]

Four main themes emerged during analysis; 1) 'the needs of patients as the starting point', 2) 'the perceived preconditions for moving follow-up care' 3) 'the perceived own role of the NS' and 4) 'the perceived possibilities of moving follow-up care'. There is a separation between the first two themes and the following themes. The first two themes, represent what should be considered before follow-up care can be moved closer to home. The following themes show the perspectives of NS on how they portray follow-up care when moved closer to home. The themes are described below and illustrated in Figure 1.

The needs of patients as the starting point

The majority of the NS indicated that, before follow-up care is moved closer to home it is of utmost importance to gain insight in patients' perspective on necessities. They said that it is always important to determine first what the needs of patients entail and then alter the care to these needs. As one NS said that, for example, older patients feel the need for more guidance during their follow-up as where the care for younger patients is focused on returning to a 'normal' life as it was before cancer.

'The question is, what are the needs of the patients. I find this very difficult. I do not really know what the needs of the patients are.' (R4)

'It consists of talking to the patient, exploring what kind of problems he experiences, not my problems, but of the patient. And discovering what the best way is to help this patient.' (R5)

'I think it is very important to first ask patient associations how they portray the optimal care for this patient group.' (R6)

The perceived preconditions for moving follow-up care

The NS stated that before follow-up care can be moved it is essential that certain preconditions are met to ensure that implemented changes will be sustainable.

Most of the NS indicated that treatment guidelines are currently adjusted based on new research outcomes. They feel that, before altering these guidelines it is essential to establish first what kind of care is meaningful to provide and what the necessary duration of follow-up care should be. The NS explained that for some types of cancer, the follow-up care is five to ten years after the discovery of the illness. For other types of cancer, the procedure is only to react when there are complaints. A few NS wondered whether some of the current care is still necessary to provide when following this procedure.

'Well, I believe it is important to first research whether we provide meaningful care (...). (R9)

'For example, colon cancer patients have a ten year follow-up, why?' (R5)

Some NS expressed another addition to treatment guidelines is needed. They emphasized that letting the patient take the lead in their own health should be part of care as usual. NS experienced a certain unwritten standard in the hospital to take care for the patient and arrange everything for them. Patients are used to this standard, especially older patients, and in the NS' opinion, this makes it harder to motivate patients to take control over their own health.

'Whoever, where ever we should give the lead back to the patient.' (R5)

NS also expressed that many practical issues need to be arranged before the current follow-up care can be organized closer to home. One of these issues is the financial compensation, which needs to be structured for NS as either professional independent entrepreneurs or in paid employment by a hospital. Furthermore, NS indicated that electronic devices (e.g. computers) used for patient consultation need to be easy to use, reliable and privacy protected for both the patient and the NS.

In general, when follow-up care will be moved from the hospital by placing NS in a facility closer to the patients' homes, all respondents said there is a strong need to have a clear demarcation of the disciplines involved. It needs to be clear who has the overall responsibility for a patient.

The perceived own role of the NS

When moving follow-up care closer to home most NS said that they think their role will not change. They believe that coordination and continuity within the follow-up care remains the core of their role. To achieve this, they said it is vital that a NS has easily accessible contacts with colleagues, has substantive knowledge about the clinical practice, knows what treatment the patient has had, is able to acknowledge re-occurrences of cancer, can refer to other professionals and is a point of contact for patients and colleagues.

A few NS reported that there can be a difference in the content of their profession depending on the specialization of the NS. For some NS, the emphasis lies more on the psychosocial guidance, although for others there is a larger emphasis on identifying re-occurrence of cancer. This influenced their perspective on moving follow-up care closer to home. For example, when all control appointments are combined with imaging, the patient has to visit the hospital. However, when the follow-up solely exists of conversations, then it is

easier to relocate these appointments to another facility closer to home. Only when imaging devices would be available closer to home, it would be possible to relocate this kind of care in his entirety.

I believe that the role stays the same, where ever you perform it.' (R6)

'When you do follow-up care here, we are more prone to consider a re-occurrence or something similar much faster.' (R3)

'Yes, but I am not only a point of contact for the patient. I am a point of contact for everything. (...) So, I am a point of contact for the whole process.' (R6)

The perceived possibilities of moving follow-up care

One of the possibilities to move the follow-up care closer to home is by relocating the NS in a facility closer to the patients' home. The majority of the NS expressed that this is undesirable, especially for rare types of cancer (e.g. pancreatic cancer). They stated that NS in such a setting would only provide follow-up care for a few of these patients a year. They mentioned that this are not enough patients to build and retain the needed expertise when treatment is not centralized as it is in a hospital. Although some NS did mention that it might be possible to relocate the NS for follow-up care for the more common types of cancer (e.g. breast cancer). For these types of cancer the patient numbers are much higher, and therefore easier to maintain the needed expertise.

A few NS thought that all care could be relocated, but others emphasized on moving only the more universal guidance for complaints that almost all cancer patients experience, such as fatigue and psychological distress.

However, if you would only see five patients I wonder how much you are able to detect.' (R4)

'I can imagine that for more common types this could be possible, such as breast or colon cancer. (...) However, for these rare tumors it is not desirable when it comes to centralizing care and building expertise.' (R8)

Based on the continued involvement of NS during the whole process, some of the NS expressed they want to stay involved after treatment. Because they see it as their role to provide follow-up care at the patients' homes. However, it is difficult to achieve because the region where patients live is too widespread, taking too much time to travel.

As an achievable alternative NS cited to replace the hospital-based consultation by telephone or video consultation. A number of NS expressed they were already replacing hospital-based consultation by telephone follow-up. Most of the NS agreed that telephone or video consultations is a suitable alternative. This saves the patients' time, energy and traveling costs. Most NS preferred video consultation, because they could see the patient and assess the situation.

'One patient said, why do we not use video consultation? (...) Especially for these people that are in a vulnerable situation, (...) it would be a good solution. You can look them in the eye, without them having to come to the hospital.' (R12)

When exploring the possibilities, transferring follow-up care to the general practitioner (GP) was mentioned. Some NS are convinced that a GP could play an important role in follow-up care, especially for patients with a less complex clinical picture. For rare types of cancer most of the NS clearly stated that it is not possible to move this kind of care because of the low patient numbers. The GP would be missing the needed expertise, specifically on identifying re-occurrences.

When it concerns assessing the skin, that is far more difficult. I just know, that there are GP's that will only see a patient with vulvar cancer in their practice once in their life. So, it is not possible to get the needed expertise. (R4)

NS reinforced that they are trained to integrate both medical nursing care, combined with their experience in the different types of cancer, makes their knowledge and expertise very specific. This makes it more difficult to transfer their tasks to other healthcare professionals.

[Figure 1]

Discussion

This study gave insight on the perspectives of NS on follow-up care moved closer to home. Our results showed that NS found it necessary that before follow-up care can be moved the needs of patients should be explored and certain preconditions should be met. NS expect that their role in follow-up care would not change. Relocating the NS to a facility closer to home, such as in a GP practice, was only seen as doable for the more common types of cancer. Moving the consultations into the patients' home, while NS still work from the

hospital, is seen as a fitting option for moving the follow-up care of NS closer to home. This can be achieved by replacing hospital-based consultation by telephone or video consultation.

There are no prior studies found regarding the relocation of follow-up care by NS closer to the patients' homes. Most studies focus on transferring follow-up care to a different discipline, such as to the GP³³ or to community care³⁴. Furthermore, the content of the profession of the NS in the Netherlands is difficult to compare with similar professions in other countries, because the content of their profession can differ or the description of the content is missing.^{35,36} This makes it more difficult to compare the literature to the Dutch healthcare system.

Other options for moving follow-up care closer to home are examined. Such as outpatient clinics within a GP practice led by medical specialists^{37,38} or nurse-led follow-up care at home.^{39,40} Outpatient clinics led by specialists showed a higher patient satisfaction, better collaboration between GP's and specialists and fewer patients that missed an appointment.³⁷ A systematic review on the benefits of outpatient clinics within primary care, also shows that more patients prefer an outpatient clinic instead of a hospital-based clinic.³⁸ Nurse-led follow-up at home is just as effective compared to conventional follow-up care in hospitals.^{39,40} Although patient satisfaction was higher during the home-based follow-up.³⁹ This suggests that moving the NS to a facility closer to home, such as a general practice, or at home, could have positive outcomes when patient numbers are efficient.

A review on the use and effectiveness in palliative cancer patients shows that telephone follow-up is a feasible alternative to hospital-based consultations. Overall patients' experiences were positive.⁴¹ Using telephone follow-up also met the needs of patients with colorectal cancer.⁴² A video consultation leads to a similar perceived quality of care by patients⁴³ and is also seen as a viable alternative for hospital-based consultations.⁴⁴

Our finding that preconditions need to be met corresponds with other studies, especially an established financial structure and optimal collaboration between involved disciplines.^{35,36,45-47} The necessity of secure telephone and video consultation is confirmed.⁴⁷

Strengths and limitations

The main strength of this study was the use of different strategies to enhance the quality of the study. To assess the researcher understanding and interpretation of the interviews a member check was applied. Member checking enlarges the trustworthiness of the study^{22,23,26}, as well as the use of the consolidated criteria (COREQ).⁴⁹ To establish the validity the analysis was performed by multiple researchers.²² Multiple joint meetings of the research team took place to discuss the coding process and reach consensus. Within the sample there was maximum variation within most characteristics, leading to a diverse sample.

Due to the COVID-19 outbreak, the last two interviews could not be conducted face-to-face. Telephone interviews were conducted instead. Interviews by telephone tend to be shorter and more dominated by the interviewer⁵⁰, although for some subjects it can provide similar results and it can replace face-to-face contact.⁵¹ The telephone interviews could have slightly different outcomes as there was no non-verbal communication. This makes it more difficult to interpret the given answers and possibly influenced the manner of questioning. Furthermore, a consequence of the COVID-19 pandemic was that all joint meetings between the research team were by telephone or video conference, which could have influenced the interaction between the team members and therefore the depth of the results.

Implications for clinical practice and further research

Before follow-up care can be moved it is essential to gain more insight in patients' perspective on necessities. There are also certain preconditions that have to be met, such as establishing what meaningful care is, up-to-date guidelines and reliable devices. When exploring the possibilities, it was clear that rare and more common types of cancer need a different approach when discussing the movement of follow-up care by the NS closer to home, due to the large difference in patient numbers. Consultations in other forms, such as by telephone or video are seen as suitable alternatives for hospital-based consultations.

For further research it is of great importance to gain insight on patients' perspectives on follow-up care. More understanding of how patients experience follow-up care and what they perceive as good quality care when follow-up care is moved closer to home is needed. Furthermore, when researching this subject there should be more attention on the concept of meaningful care. This ensures that the changes that will be implemented in the healthcare system will have an added value for patient care.

Conclusion

Our study provides insight in the perspectives of NS on moving follow-up care of adult cancer patients closer to home. The NS' perceptions of moving follow-up care showed that in their opinion, moving NS closer to the patients' homes by relocating NS is not the answer. However, NS believe that moving follow-up care by placing the hospital-based consultations within patients' homes, using technology, is a realistic and preferable manner to adapt to the future of out-of-hospital follow-up care. The findings of our study contribute to the understanding of policy makers on the possibilities and impossibilities of moving follow-up care closer to home. Moreover, our findings support policy makers to implement sustainable changes to benefit the quality of care for cancer patients.

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Tables and figures

Table 1: Characteristics of respondents

	Respondents n (%) or mean (range) (N=15)
Age*	
Mean	50 (32-64)
30-39	3 (20%)
40-49	3 (20%)
50-59	5 (33.3%)
60-69	4 (26.7%)
Gender	
Male	4 (26.7%)
Female	11 (73.3%)
Working experience*	
Mean	8 (2-24)
0-9	10 (66.7%)
10-19	4 (26.7%)
20-29	1 (6.6%)
Hospital	
Secondary	2 (13.3%)
Tertiary	13 (86.7%)

* In years

Figure 1: Thematic map of analysis

