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**Using  
Teleconsultation  
to Optimize  
Palliative Home  
Care for Patients  
with Advanced  
Cancer**

**Patrick Hoek**



**USING TELECONSULTATION TO  
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# Radboudumc

For reasons of consistency within this thesis, some terms have been standardized throughout the text. As a consequence the text may differ from the articles that have been published.

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# USING TELECONSULTATION TO OPTIMIZE PALLIATIVE HOME CARE FOR PATIENTS WITH ADVANCED CANCER

Proefschrift

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# 1

## GENERAL INTRODUCTION



## INTRODUCTION

*Many patients with advanced disease wish to spend the last stage of their lives at home. As a consequence, the availability of adequate palliative care in the home environment should be guaranteed. There are two forms of palliative home care: general palliative care and specialist palliative care. In the Netherlands, general palliative home care is delivered and coordinated by the patient's general practitioner (GP), mostly in cooperation with home care nurses. If a patient has complex palliative care needs, the input of a specialist palliative care team may be required.*

*Currently, consultation and collaboration between generalist and specialist palliative care providers may be suboptimal, depending largely on (single) phone contacts. The use of teleconsultations may optimize the availability of palliative care expertise in the patient's home environment and facilitate sustainable and proactive care models in palliative home care.*

### Palliative care

Palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness”.<sup>1</sup> Palliative care intends to integrate physical, psychological, social and existential aspects of care. As a result, expertise on a wide range of subjects might be needed and therefore a multidisciplinary team approach is indispensable in palliative care.<sup>1-3</sup>

Palliative care is currently facing essential challenges and requires new and innovative care approaches in order to maintain or improve quality of care and satisfy increasing demand. Two of these challenges form the starting point for this thesis: 1) an increasing need for palliative care in general and 2) an increasing need for community-based palliative care.

### An increasing need for palliative care

The ageing of society is an important demographic trend that has a direct impact on the need for palliative care. The increase in life-expectancy is accompanied by a shift in leading causes of death from communicable toward chronic and degenerative (or: non-communicable) conditions.<sup>4</sup> Globally, chronic conditions are currently the main leading cause of mortality, accounting for up to 68% of deaths worldwide and more than 80% of all deaths in Western societies.<sup>5-8</sup> Every year, cancers account for more than 8 million deaths worldwide and, as a result, are the second most common cause of death in people dying from chronic conditions.<sup>9,10</sup> This is also true in the Netherlands, where chronic conditions such as cancer, dementia, cardiovascular diseases and chronic lung conditions are responsible for the majority of annual deaths.<sup>11,12</sup> Currently, cancer is the main leading cause of mortality in the Netherlands, accounting for almost one-third of all annual deaths.<sup>13</sup>

As a result of these high mortality rates from cancer and other chronic diseases, there is growing need for palliative care. Currently, in Western societies, the need for palliative care is estimated at 50-89.4% of all deaths.<sup>11,14,15</sup>

In addition to these demographic changes, the need for palliative care may also rise as a result of increased attention being paid towards proactive, early palliative care and to an increased base of evidence showing the positive effects of (early) palliative care.<sup>16-18</sup>

### **An increasing need for community-based palliative care**

Internationally, the majority of patients with a life-threatening illness seems to have a preference for dying at home.<sup>19-22</sup> This trend is also found in the Netherlands, where a preference for dying at home ranges between 69% - 83.1% of (hypothetical) patients,<sup>20, 22, 23</sup> and where the actual percentage of patients dying at home ranges from 34% - 50.6% of non-sudden deaths.<sup>23, 24</sup> As a result, a substantial part of palliative care takes place in the community. Moreover, the importance of community-based palliative care is not “just a result” of the patient’s preference to be cared for and eventually die at home. Community-based palliative care may also be a favourable care model in the pursuit of adequate access to palliative care for all patients in need.<sup>25, 26</sup>

However, providing palliative care in the patient’s home-environment requires certain preconditions, such as being able to provide acute treatment and care at home and the availability of nurses who are able to deliver adequate (palliative) home care, in order to avoid unwanted or negative outcomes such as (avoidable) hospitalisations or care transfers at the end of life.<sup>27, 28</sup>

### **Palliative care in the Netherlands**

Unlike other European countries,<sup>29</sup> palliative care is not recognized as a formal medical specialty in the Netherlands. The Dutch government (Ministry of Health, Welfare and Sport) has stated that delivery of palliative care is primarily the responsibility of generalist caregivers.<sup>30</sup> For patients diagnosed with (advanced) cancer, this means that palliative care is usually the responsibility of their oncologist and/ or their GP, depending on where patients are in their illness trajectory. For these caregivers, as well as for other healthcare professionals, additional courses in palliative care are available (e.g. “*Kaderopleiding Palliatieve Zorg*”<sup>31</sup>). Only a minority of healthcare professionals have participated in these courses: less than 1% of all GPs and hospital specialists and around 6% of elderly care specialists.<sup>11</sup> Based on these data, most (generalist) healthcare providers in the Netherlands may be capable of providing general palliative care, however, the majority of healthcare providers are not formally trained to provide specialist palliative care.

As a result, palliative care in the Netherlands largely takes place in non-specialized palliative care settings, such as the patient’s home or (general) hospitals. In addition to these settings, there are relatively few specialized institutions for palliative care, such as hospices, in the Netherlands. These institutions mainly have an inpatient function,<sup>11</sup> while in other countries, such as the United Kingdom, hospices have a more prominent role in both inpatient as well as outpatient and community-based palliative care.<sup>20</sup>

## Palliative care at home

In the context of the Dutch healthcare system, the GP is the main formal caregiver responsible for home-dwelling patients and therefore plays a key role in the delivery and coordination of community-based palliative care. As a coordinator of care, the GP collaborates with other healthcare providers, such as (specialist) home care nurses and healthcare professionals (HCPs) from other settings, like hospitals, nursing homes and hospices.

The central role of the GP in palliative home care is in line with both international literature as well as national (Dutch) viewpoints stating the importance of palliative care to be primarily delivered by the patient's primary treating clinicians.<sup>2, 16, 32, 33</sup> The main reasons for these statements include the scarcity of specialist palliative care providers, the increasing demand for palliative (home)care and the central role and position (both geographically and organisationally) of the GP in the (Dutch) healthcare system for home-dwelling patients. Moreover, GPs regard palliative care as a satisfactory, fulfilling and valuable part of their jobs.<sup>34-36</sup>

However, at the same time, it is acknowledged that GPs experience the delivery of palliative care as burdensome, demanding and time-consuming.<sup>34-37</sup> Furthermore, palliative care can become complex, and consultation or collaboration with a specialist palliative care team may be needed.<sup>2, 16, 32, 33, 37, 38</sup> Quill *et al.* provide examples that require the input of specialist palliative care services: the management of refractory pain and other symptoms, the management of complex psychosocial and existential distress, and conflicts that arise regarding goals or methods of treatment.<sup>16</sup> Others state that whether specialist support is needed largely depends on the personal skills, knowledge, experience and possibilities of the practitioner involved.<sup>33, 37</sup> Based on the literature and on experiences with consultation services available at the start of this thesis,<sup>39</sup> we hypothesize that the need for expert consultation regarding complex palliative care issues among Dutch GPs will be considerable.

## Expert consultation in the Netherlands

In the Netherlands, regional Palliative Care Consultation (PCC) teams are available for professional caregivers in need of specific advice concerning palliative care. These PCC teams are established and supported by the Netherlands Comprehensive Cancer Organisation (IKNL) and receive thousands of requests for consultation per year, reflecting their importance and necessity.<sup>40</sup> The majority of consultations at PCC teams are requested by GPs.<sup>39</sup>

However, there are limitations to PCC teams providing expert consultation: 1) the majority of consultations are requested for patients with a prognosis of <1 month, possibly indicating a reactive care approach; 2) most consultations are requested and answered by phone, while previous research has shown that bedside consultations are more effective in identifying new problems and in addressing the non-physical domains of palliative care; 3) the number of consultations is relatively low compared to the total number of patients in need of palliative care.<sup>39-42</sup> This possible underuse of formal consultation services might indicate that expert consultation in general is not a common procedure among GPs. However, it might

also reflect the use of alternative, informal consultation sources by GPs, such as fellow GPs or (familiar) hospital specialists. To gain a more complete overview on the use of expert consultation in palliative care, more insight in consultation practices from the perspective of the GP is needed.

At the same time, bearing in mind the increasing need for community-based palliative care, we should think about further improving current consultation services. Therefore, more sustainable models, or networks, for collaborations between GPs and specialists in palliative care should be developed. These models should create opportunities for GPs and palliative care specialists to collaborate on an equal basis and provide complementary, proactive, continuous, yet patient-centred palliative home care. At the same time, consultation services should be easily and widely accessible and available to all GPs. The use of telemedicine might be an innovative approach to support these collaborations and improve consultation services.

## Telemedicine

### *Definition*

The use of technology in healthcare is described and defined in several (partly overlapping) ways (Telemedicine, eHealth, telehealth, etc.). In line with Bashur *et al.*,<sup>43</sup> in this thesis, we choose to use the term “telemedicine” to describe the broad concept of the use of information and communication technologies (ICT) in healthcare.

Telemedicine, literally “medicine at a distance” can be defined in various ways. Common aspects in these definitions include 1) bridging geographical distance between two or more people involved in healthcare, 2) by using information and communication technologies (ICT), 3) in order to exchange healthcare information.<sup>43-45</sup> The World Health Organization (WHO) adds a purpose (“to provide clinical support”) and a goal (“to improve health outcomes”) to this definition.<sup>44</sup>

### *Classification*

Craig *et al.* provide a classification system for telemedicine episodes based on: 1) the type of interaction, that can be either real-time (also: synchronous) or pre-recorded (also: asynchronous) and 2) the type of information being transmitted, which can be either “still images” or “moving images”.<sup>45</sup>

In addition, based on both national and international literature, Dohmen classified the use of technology in healthcare in four categories, based on its function:

1. Providing and sharing information, both general (e.g. about a disease or certain treatment) and personal (e.g. about prescribed medication or the use of a digital medical file).
2. Video communication (communication via a screen) between patients and caregivers, between caregivers mutually, or for group education or interventions.

3. Telemonitoring: measuring and monitoring a patient's (physiological) condition from a distance, using certain parameters (e.g. blood pressure or blood glucose) or anamnestic instruments (e.g. a numeric rating scale).
4. Other technologies, such as home automation systems and technologies.<sup>46</sup>

In this thesis, we specially focus on the subtype of telemedicine that can be classified as: synchronous interaction used to transmit audio-visual information for patient assessment. This specialized form of telemedicine is also known as video consultation or teleconsultation.<sup>47</sup>

Furthermore, teleconsultation not only involves communication between healthcare providers mutually; patients are actively involved in the use and evaluation of teleconsultations.

### Teleconsultation

Internationally, video consultation or teleconsultation techniques have been used in different fields of medicine such as psychiatry, diabetes care, and oncology, and have proven to be feasible, acceptable and effective.<sup>47-50</sup>

On a national level, the use of teleconsultation technologies in healthcare (in Dutch: "beeldschermzorg") is assumed to support patients (and elderly) to live independently in their home environment, to stimulate self-reliance and to lead to a more time-efficient provision of care.<sup>51</sup>

Therefore, in 2014, the Dutch government stated that "*within 5 years, everyone who receives care and support at home should have the possibility (if desired) to communicate with a healthcare provider 24 hours a day, via a screen*".<sup>52</sup> However, recent evaluations show that the use of these technologies do not meet this ambition: of all patients receiving care and support at home, only 5% of this group had the possibility to contact a healthcare professional via the use of a screen in 2015.<sup>53</sup> Furthermore, from the perspective of the healthcare providers, 20% of nurses working in the "care sector" (home care, elderly care) indicated that they (or their organisations) use video technologies (e.g. Skype or Facetime) during their daily work, although this percentage was only 7% for nurses working in the "cure sector" (general practice, health centres and hospitals). In homecare, these percentages were the highest: 30% of nurses indicated that they (or their organisations) use video technologies in their daily care.<sup>53</sup> Barriers for a more extensive use of video technologies in daily practice included patient-related factors (unwilling to use video technologies, unfamiliarity with video technologies) and professional-related factors (time, organisational factors, technological issues, financial issues, doubts about potential positive effects).<sup>51, 54</sup> Based on national reports, evaluations and information available on the websites of home care organisations, it seems that video consultation technologies are mainly used in the homecare setting for communication between a patient and a healthcare provider (mostly a nurse) for treatment and support.<sup>53, 55, 56</sup> Mostly, this involves monodisciplinary care. The use and potential of these technologies in and for multidisciplinary care are hardly noticed or reported.



## Teleconsultation in palliative care

The evidence for the use of telemedicine in palliative care is largely based on small studies with mixed scientific rigor. Reviews on the use of eHealth or telehealth interventions in palliative care (which involves a broader concept than teleconsultations or video consultations) state that telehealth interventions are considered useable, acceptable, feasible and potentially effective and beneficial in terms of symptom management, quality of life, and cost effectiveness. However, these reviews emphasize that there is a lack of evidence based on studies with a robust research design (RCTs) describing patient-relevant clinical outcomes.<sup>57-60</sup> Therefore, performing an RCT on the use of teleconsultations in palliative care will significantly contribute to the existing base of knowledge regarding the use of telemedicine in palliative care .

In more detail, several studies have specifically described the use of teleconsultations in different palliative care settings for different purposes. Whitten *et al.* described a telehospice project in Michigan, in which almost 200 patients participated. Most patients felt that the telehospice service contributed positively to their overall end-of-life care. Furthermore, patients were highly satisfied with the services in its current form and mainly appreciated the immediate access they had to their care providers.<sup>61</sup> Hebert *et al.* compared conventional palliative homecare visits to a combination of conventional visits and “video-visits” among patients from rural areas in Canada receiving palliative homecare. They found no differences between groups regarding symptom management (ESAS), quality of life (MQOL) and level of care (PPS). Although the study was underpowered due to recruitment difficulties, the authors concluded that care of a similar quality can be delivered via videophones compared to conventional care.<sup>62</sup> Furthermore, Bensink *et al.* and Bradford *et al.* described the use of videoservices in the context of paediatric palliative care in Australia. These small studies revealed that the use of video techniques was an acceptable and feasible means for providing palliative care, led to satisfaction among users and had the potential to be an effective, cost-efficient means for providing palliative care.<sup>63-65</sup> Regarding the cost-effectiveness in the study by Bradford *et al.*, a large part of the cost savings were related to reduced travel costs, as the distance between the patient’s home and a specialist paediatric service can be considerable in a country the size of Australia.<sup>64</sup> In addition to potentially beneficial effects, some studies also reported difficulties in patients recruitment.<sup>62,65</sup> Bensink *et al.* even described that they had to switch study design from an RCT to an acceptability study as a result of delays in recruitment.<sup>65</sup>

Finally, Watanabe *et al.* described how a virtual clinic was initiated to organize patient consultations and multidisciplinary meetings between local telehealth facilities and a specialized cancer institute. These consultations proved to be feasible, cost-effective and were satisfactory to the users. Furthermore, these consultations showed potential in optimizing symptom palliation, as mean symptom scores (ESAS) for anxiety and appetite significantly improved in patients who had at least one follow-up visit in the virtual clinic.<sup>66</sup>

## The teleconsultation project in Nijmegen

Central to this thesis is the NWO-project<sup>a</sup> 'Optimization of complex palliative care at home by means of teleconsultations', that was developed and initiated in Nijmegen in 2009 by the Department of Anaesthesiology, Pain Medicine and Palliative Care at the Radboudumc, in collaboration with regional partners (ZZG Zorggroep en Focuscura).

With this teleconsultation project, we aimed to provide an interdisciplinary palliative care consultation service in order to develop sustainable, high-quality collaborations or networks between home-dwelling patients with advanced cancer and complex palliative care needs, their GP and the hospital-based specialist palliative care consultation team (SPCT). We designed a care model in which patients had weekly contact with the SPCT, at a prescheduled moment, using teleconsultations. These teleconsultations between the patient and the SPCT would form the basis of telephone consultations between the SPCT and the patient's GP with regard to the patient's palliative care trajectory, including current and future challenges, problems, needs, and treatment policy. The patient's GP remained the patient's central caregiver with regard to palliative care.

Initially, teleconsultation devices consisted of a PAL-4-desktop computer, with a touch screen, a separate microphone/ speaker and a separate camera. These computers were replaced at a later stage by tablet computers (iPad 2 and iPad mini), mainly for reasons of user friendliness.

## OBJECTIVES AND RESEARCH QUESTIONS

This teleconsultation project consists of both an empirical-ethical analysis as well as an evaluation of the effectiveness of teleconsultations. In his thesis "*Teleconsultation: enhancing personalized palliative care at home. An empirical-ethical analysis*",<sup>67</sup> Van Gorp used qualitative research methods to focus on the ethical and philosophical issues regarding the use of teleconsultation in palliative home care.

The objective of this thesis is to evaluate whether and how the use of teleconsultation affects the quality of palliative home care for patients with advanced cancer and complex palliative care needs. This objective led to in the following research questions:

1. What is the current practice regarding (expert) consultation in palliative care for home-dwelling patients with complex palliative care needs?
2. How do weekly teleconsultations between patients receiving palliative home care and a hospital-based specialist palliative care consultation team affect the quality and outcome of palliative home care?
3. What is the potential of an innovative interdisciplinary care model using teleconsultation techniques to affect the quality and outcome of palliative home care for adolescents and young adults with advanced cancer?

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<sup>a</sup> Netherlands Organisation for Scientific Research (NWO)

## OUTLINE OF THIS THESIS

In **Chapter 2** we describe the consultation practices of GPs within the context of palliative homecare. A digital questionnaire was sent to all GPs in the region of Nijmegen to gain insights into: the sources (both formal and informal) used for consultation, the timing and content of consultations and the GP's satisfaction with the current situation regarding consultation services.

In **Chapter 3** we retrospectively describe the practice of (formal) expert consultation by Dutch Palliative Care Consultation Teams in the period 2004-2011. We specifically focus on consultations in which palliative sedation was discussed to gain more insights in the practice of palliative care consultations with regard to complex palliative care needs.

**Chapter 4** describes a randomized clinical trial on the use of weekly, prescheduled teleconsultations between a hospital-based specialist palliative care team and home-dwelling patients with advanced cancer. In this RCT, we evaluated the effect of these weekly teleconsultations on patient-experienced symptom burden, unmet palliative care needs, experienced continuity of medical care, hospital admissions, and satisfaction with teleconsultations. Furthermore, the effect of teleconsultations on the burden experienced by informal caregivers, as well as healthcare professionals' satisfaction with teleconsultations, were evaluated.

In **Chapter 5** we report on a qualitative multiple case study on the use of teleconsultations in palliative care for adolescents and young adults (AYA's) with advanced cancer. Teleconsultations in this study, simultaneously involved both the patient, the patient's GP and the patient's hospital caregiver(s). Furthermore, teleconsultations were not strictly prescheduled at the start of the study. We interviewed all participants (patients and caregivers) to gain more insights in whether and how these teleconsultations might be of added value in the palliative care for young patients with complex palliative care needs.

In **Chapter 6** we conclude this thesis with a general discussion, conclusions and recommendations.

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# 2

## PALLIATIVE CARE CONSULTATIONS IN PRIMARY CARE: A CROSS-SECTIONAL SURVEY AMONG DUTCH GENERAL PRACTITIONERS

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## ABSTRACT

### Background

Expert consultation supports general practitioners (GPs) in delivering adequate palliative homecare. Insight into consultation practices from a GP's perspective is needed in order to shape consultation services to their wishes and needs.

### Aim

To explore palliative care consultation practices from a GP's perspective.

### Design and setting

Cross-sectional web-based survey among all GPs (n=235) in the region of Nijmegen, the Netherlands.

### Methods

Our questionnaire contained questions about the delivery of palliative care by GPs, their consultation practices and satisfaction with current services. Questions consisted mainly of 5-point Likert scales. We transformed these scales into numerical values to calculate mean scores. Linear mixed models for repeated measurements were used to study differences in scores.

### Results

GPs most often consulted informal caregivers (mean score 3.6) or fellow GPs (mean score 3.3). Physical problems were discussed the most (mean score 3.5), while social and existential issues were discussed least (mean score 1.9 for both). In their choice of a particular consultation service, GPs considered the quality of the provided advice to be the most important factor. GPs were satisfied with current consultation services, with fellow GPs receiving the highest satisfaction scores (mean score 4.6). Finally, when recalling their last palliative patient, most GPs started requesting consultation during this patient's last month of life.

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**Conclusions**

Next to informal caregivers, GPs preferably seek advice from fellow GPs. Physical issues receive much attention during consultations; however, other vital aspects of palliative care seem to remain relatively neglected, such as social and existential issues and a proactive care approach.

## BACKGROUND

The need for palliative care is rising in most Western countries due to an increased life expectancy, an ageing population and an increase in the number of people dying of chronic conditions.<sup>1-3</sup> Depending on the methods and definitions used, the need for palliative care in Western countries is estimated at 50–89.4% of all deaths.<sup>4-6</sup>

An important part of palliative care takes place in the community. In a recent resolution on palliative care as formulated in 2014, the WHO emphasized the role of primary and community/home-based care in improving adequate access to palliative care.<sup>7</sup> Furthermore, most people suffering from chronic, life-limiting conditions prefer to stay at home until death.<sup>8-12</sup> For these home-dwelling patients, general practitioners (GPs) play a pivotal role in the delivery and coordination of palliative homecare.<sup>13-16</sup>

However, although GPs regard palliative care as an essential, fulfilling and satisfactory part of their job, the delivery of palliative care is also considered time-consuming, demanding and burdensome, as palliative care can be rather complex.<sup>13-17</sup>

Additionally, GPs can experience a feeling of discomfort about their own competences, as they are regularly confronted with conditions they are not familiar with and for which they did not receive adequate training.<sup>13, 15-17</sup>

The aforementioned issues regarding complexity of palliative care and feelings of discomfort about one's competences might be overcome by consultation of, or collaboration with, healthcare professionals specialized in palliative care.<sup>14, 15, 18</sup> Ideally, these experts support GPs by giving advice on complex issues, thereby complementing the palliative care as delivered by GPs.<sup>15</sup> Mitchell<sup>16</sup> stated that with adequate specialist help and support, GPs are able to deliver 'satisfactory symptom control' and 'adequate palliative care'.

Regarding the importance of expert consultation in palliative homecare, insight into the GP's perspective on this matter is of vital importance. This insight supports consultation services and sources to adapt to the wishes and needs of GPs and will support policymaking. Current insights into consultation practices are mostly drawn from national palliative care consultation services, such as the Netherlands Comprehensive Cancer Organisation (IKNL)<sup>19-22</sup> or focused mainly on formal consultation services, such as established palliative care units or services.<sup>23</sup> However, these formal services do not cover possible informal sources of consultation, such as other GPs or district nurses.<sup>24</sup>

Therefore, the aim of this study is to explore palliative care consultation practices, from the GP's perspective, also taking into account consultation requests to caregivers other than those related to established or formal consultation services.

## METHODS

### Design

We performed a cross-sectional study, using a web-based digital survey that was sent to all GPs in the region of Nijmegen, the Netherlands. Data were collected during May and June 2014.

## Setting

In the Netherlands, GPs coordinate care for patients staying at home, including palliative care. Within the Dutch healthcare system, GPs function as 'gatekeepers'. Therefore, non-emergency specialist or hospital care is only available for patients after referral by their GPs. This also applies to specialist palliative care, which is usually provided by a hospital specialist (e.g. anaesthesiologist or oncologist). When in need of expert advice concerning palliative care, GPs can consult several (regional) palliative care services, such as the IKNL. In general, the vast majority of these consultations are requested and answered by phone, whereas only in a small minority of cases bedside consultations occur.<sup>25</sup> Next to these formal consultation services, GPs can consult other caregivers for advice or to discuss complex issues. These consultations might have a more informal character.

## Participants

We sent email invitations, containing a hyperlink to our digital survey, to all 235 GPs, affiliated with a large GP cooperative in the region of Nijmegen (CIHN). This cooperative covers a region of ~430 000 inhabitants in the eastern part of the Netherlands. Invitations were sent in May 2014. Reminders were sent after 2 and 5 weeks, respectively. The survey was filled in anonymously.

## Questionnaire

### *Development*

We searched for relevant topics concerning (expert) consultation in palliative care in the national and international literature. On the basis of these topics, we developed a concept questionnaire. Different stakeholders (two individual GPs and two associations of GPs involved in regional policymaking concerning consultation in palliative care) were requested to assess this concept questionnaire on its relevance and its appropriateness to answer the research questions.

On the basis of their comments, a revised questionnaire was developed. This questionnaire was piloted under five individual GPs, who were requested to assess the survey on its relevance, clarity, content validity, unequivocality and length. After this pilot, a final version of the questionnaire was developed. A web-based version of the questionnaire was developed using LimeSurvey (LimeSurvey Project Hamburg, Germany, <http://www.limesurvey.org>).

### *Content*

For this questionnaire, the following definition of palliative care was used: 'care for patients suffering from life-threatening illnesses, that do not lead to a sudden death, but as a result of which the patient will likely die within the near future (approximately within 1 year)'.<sup>26</sup> The final version of the questionnaire consisted of two parts. Part 1 consisted of mandatory questions concerning: (1) demographics of the GPs, (2) the delivery of palliative care, (3) consultation practices (number of consultations per year, sources used for consultation,

topics of consultation, sources used per topic), (4) considerations for choosing a particular consultation source, (5) satisfaction with current consultation services, (6) preferences for the location of a central consultation institute and (7) suggestions for improvement. Regarding the question on consultation sources used, 13 common sources of consultation were predefined in the questionnaire. For all these sources, respondents were asked to indicate their relative use of these sources on a five-point Likert scale. This method was also used for the questions concerning topics of consultation (13 items predefined; five-point Likert scales to indicate relative frequency), considerations for choosing a particular consultation source (5 items predefined; five-point Likert scales to indicate relative importance) and satisfaction with current consultation services (5 items predefined, four services predefined; five-point Likert scales were used to indicate relative satisfaction). Part 2 consisted of optional questions concerning: (1) additional demographics, (2) additional activities in palliative care and (3) a recall of the last patient to whom respondents delivered palliative care. If applicable, respondents could freely add one or more answer options to the predefined items.

### Statistical methods

Questionnaires were completed online using LimeSurvey. Since the question regarding the extent to which respondents use different consultation sources was considered the first main question of our questionnaire, only questionnaires in which this question was completed were included for analysis. The demographic characteristics of the participants are described as median and range in case of continuous variables, and number and percentage in case of categorical data. The Likert scales were transformed into numerical values.

Linear mixed models for repeated measurements were used to study differences on (1) the use of consultation sources, (2) topics of consultation, (3) considerations in the choice of a particular consultation source and (4) scores for satisfaction, separately. The dependent variable was the outcome of the Likert scale. The independent variables were (1) consultation sources (13 sources), (2) topics of consultation (13 topics), (3) considerations in the choice of a particular consultation source (five considerations) and (4) satisfaction about consultation sources (four sources), respectively. In each model, the intercept of the participant was treated as a random variable. The estimated mean Likert scale with the 95% CI of each source (topic, consideration, respectively) of the independent variable is presented. The appropriate contrast test was used to test differences between the levels for statistical significance.

Statistical analyses were performed using SAS V.9.1 for Windows (SAS, Cary, North Carolina, USA) and IBM SPSS Statistics V.20 for Windows (IBM Corp., Armonk, New York, USA).

A  $p < 0.05$  was considered statistically significant.

### Ethical considerations

The Committee on Research Involving Human Subjects (CMO) Region Arnhem-Nijmegen stated that no further ethical assessment was needed for this research (registration number 2014/160).

## RESULTS

A total of 119 questionnaires were included for analysis (valid response rate: 119/235=50.6%). Of the respondents, 67 were male (56.3%), and the median age was 52 years (range 32–67 years; *table 1*).

**Table 1.** Characteristics of respondents (GPs)

	Median	(range)	n
<b>Age (years)</b>	52	(32 – 67)	119
<b>Experience as a GP (years)</b>	19.5	(2 – 40)	118
	<b>n</b>	<b>(%)</b>	<b>n</b>
<b>Sex</b>			119
Male	67	(56.3)	
Female	52	(43.7)	
<b>Provision of palliative care (patients/year)</b>			118
0 – 1	5	(4.2)	
2 – 3	14	(11.9)	
4 – 5	33	(28.0)	
6 – 10	37	(31.4)	
> 10	29	(24.6)	
<b>Requested palliative care consultations by GP (patients/year)</b>			118
0 – 1	34	(28.8)	
2 – 3	58	(49.2)	
4 – 5	17	(14.4)	
6 – 10	7	(5.9)	
> 10	2	(1.7)	
<b>Out of office availability for palliative patients GPs<sup>1</sup> (% of patients)</b>			119
0 – 20%	19	(16.0)	
20 – 40%	16	(13.4)	
40 – 60%	16	(13.4)	
60 – 80%	25	(21.0)	
80 – 100%	43	(36.1)	
<b>Part 2 additional questions concerning GP practice (optional)</b>			
<b>Practicing as a GP (average days/week)</b>			91
2	1	(1.1)	
3	33	(36.3)	
4	44	(48.4)	
5	13	(14.3)	
<b>Type of GP practice</b>			93
Group practice	31	(34.1)	
Health centre	11	(12.1)	
HOED-construction <sup>2</sup>	22	(24.2)	
Duo practice	22	(24.2)	



Table 1. (continued)

	n	(%)	n
Solo practice	5	(5.5)	
Other	2	(1.6)	
<b>Location of GP practice</b>			92
Country side/ small village	33	(35.9)	
Slightly urbanized area (>20,000 inhabitants)	25	(27.2)	
Urbanized area (> 50,000 inhabitants)	3	(3.3)	
Large city (> 100,000 inhabitants)	31	(33.7)	
<b>Specialist training in palliative care</b>			93
Yes	3	(3.2)	
No	90	(96.8)	
<b>Additional activities in palliative care</b>			92
No	83	(90.2)	
Yes, consultant in palliative care	3	(3.3)	
Yes, other (e.g. administration, SCEN-physician)	6	(6.5)	

<sup>1</sup> During the last 3 months of life.

<sup>2</sup> **HOED-construction:** two or more GPs having their own practice, but working at the same geographical location. **GP,** general practitioner; **HOED,** Huisartsen onder één Dak; **SCEN,** Support and Consultation regarding Euthanasia in the Netherlands.

### Delivery of palliative care and consultation practices

Most GPs (66; 56.0%) provided palliative care to at least six patients per year. Furthermore, the majority of the GPs (92; 78.0%) requested consultations for  $\leq 3$  patients per year (*table 1*). GPs most frequently consult informal caregivers (3.6; 95% CI 3.4 to 3.7) and fellow GPs (3.3; 95% CI 3.2 to 3.5), compared with all other listed consultation sources (linear mixed model appropriate contrast test; *table 2*). Respondents added the following sources: patients themselves (two respondents), fellow GPs from a 'peer group' (one), theologian (one), brochures from the Royal Dutch Medical Association (one) and a specialized institute for psycho-oncology care (one).

Physical symptoms were most frequently discussed during consultations (mean score 3.5; 95% CI 3.4 to 3.7), compared with all other listed topics (linear mixed model appropriate contrast test; *table 3*). The topics that were least discussed during consultation mainly covered psychological, social and existential issues. Among these, social and existential issues received the lowest scores (mean score 1.9; 95% CI 1.8 to 2.1 and 1.9; 95% CI 1.7 to 2.0, respectively; linear mixed model appropriate contrast test; *table 3*). Respondents added the following topics: aftercare after euthanasia (one respondent) and advice about palliative treatment options (one).

In their choice of a particular consultation source, respondents considered quality of provided advice (mean score 4.6; 95% CI 4.4 to 4.7) the most important consideration. Clarity concerning responsibilities in patient care was considered least important (mean score 3.8; 95% CI 3.7 to 3.9; linear mixed model appropriate contrast test; *table 4*).

**Table 2.** Sources used for consultation

	n	Estimated		Significance <sup>a</sup>
		Mean	(95% CI)	
<b>Consultation sources</b>				
Informal caregiver	119	3.6	(3.4-3.7)	A
Fellow GP	119	3.3	(3.2-3.5)	B
Homecare nurse	119	2.8	(2.6-2.9)	C
Regional PCC team	119	2.6	(2.5-2.8)	C,D
Hospital specialist in attendance	119	2.5	(2.4-2.7)	D
Pharmacist	118	2.1	(1.9-2.2)	E
Hospital-based consultation team	117	2.0	(1.9-2.2)	E
SCEN-physician	118	1.9	(1.8-2.1)	E
Existential worker	118	1.6	(1.5-1.8)	F
Physical/ occupational therapist	117	1.5	(1.4-1.7)	F,G
Psychological worker	117	1.5	(1.4-1.7)	F,G
Hospice-based or nursing home –based consultation team or physician	119	1.4	(1.2-1.5)	G,H
Social worker	117	1.3	(1.1-1.4)	H

Scores are based on a 5-point Likert scale: 1 = never; 5= always.

n = observed numbers.

<sup>a</sup> Sources that share the same letter, do not have statistically significant different mean scores, using a linear mixed model and the appropriate contrast test.

GP, general practitioner; SCEN, Support and Consultation regarding Euthanasia in the Netherlands.

Additional considerations brought up by respondents were: former experiences/trust (three respondents), knowing each other (three), substantive knowledge of a patient (two) meddling (one), level of complexity (one), the presence of a treating hospital specialist (one) and administrative concerns (one).

Within the region of Nijmegen, respondents were largely satisfied with all consultation services that were currently available (mean scores for all services >4.0). However, GPs were most satisfied with consultations provided by fellow GPs (mean score 4.6; 95% CI 4.5 to 4.7) and the regional Palliative Care Consultation (PCC) team (mean score 4.4; 95% CI 4.3 to 4.5; linear mixed model appropriate contrast test; *table 5*).

### Recall of last palliative patient

The additional questions concerning the last palliative patient were completed by 92/119 respondents (77.3%). For most respondents, this was <3 months ago (83.7%) and concerned a patient aged between 60 and 80 years (54.3%). The vast majority of these patients had a diagnosis of cancer (79.3%). Approximately 9 out of 10 patients eventually died at home (87.0%). Almost 3 out of 4 respondents (72.8%) stated that they consulted at least one person or institute during the palliative care trajectory, mostly a fellow GP (68.7%), the hospital

**Table 3.** Topics of consultation

	n	Estimated		Significance <sup>a</sup>
		Mean	(95%CI)	
<b>Topics of consultation</b>				
Physical symptoms	114	3.5	(3.4-3.7)	A
Pharmacological problems	115	2.9	(2.8-3.1)	B
Medical-technical procedures	112	2.9	(2.7-3.0)	B
Euthanasia	113	2.6	(2.5-2.8)	C
Organisation of care	113	2.6	(2.4-2.8)	C
Need for second opinion	113	2.6	(2.4-2.7)	C
Palliative sedation	115	2.6	(2.4-2.7)	C
Need for moral support	112	2.6	(2.4-2.7)	C
Informal care-related problems	113	2.3	(2.1-2.5)	D
Psychological symptoms	115	2.2	(2.1-2.4)	D,E
Discontinuing treatment	114	2.1	(1.9-2.2)	E,F
Social problems	115	1.9	(1.8-2.1)	F
Existential problems	115	1.9	(1.7-2.0)	F

Scores are based on a 5-point Likert scale: 1 = never; 5 = very often

n = observed numbers.

<sup>a</sup> Topics that share the same letter, do not have statistically significant different mean scores, using a linear mixed model and the appropriate contrast test.

**Table 4.** Considerations in the choice for a particular consultation source

	n	Estimated		Significance <sup>a</sup>
		Mean	(95% CI)	
<b>Considerations</b>				
Quality of provided advice	108	4.6	(4.4-4.7)	A
Fastness of provided advice	108	4.3	(4.2-4.5)	B
Accessibility and availability	108	4.3	(4.2-4.5)	B
Equality in cooperation and communication	108	4.0	(3.9-4.2)	C
Clarity concerning responsibilities	108	3.8	(3.7-3.9)	D

Scores are based on a 5-point Likert-scale: 1 = very unimportant; 5 = very important

n = observed numbers.

<sup>a</sup> Considerations that share the same letter, do not have statistically significant different mean scores, using a linear mixed model and the appropriate contrast test.

specialist in attendance of the patient (53.7%) and/or homecare organisations (58.2%). On average, 3.6 different persons or institutes were consulted. The most common topics for consultation were: physical symptoms (70.1%), pharmacotherapy (43.3%), palliative sedation (32.8%) and the organisation of care (32.8%). On average, respondents consulted for 3.7 different topics for this patient. The large majority of respondents found that consultation fitted their needs totally (61.2%) or for a large part (35.8%). Most consultations occurred for

**Table 5.** Satisfaction with main consultation services available in the region Nijmegen

	n	Estimated		Significance <sup>a</sup>
		Mean	(95%CI)	
<b>Consultation sources</b>				
Fellow GP	103	4.6	(4.5-4.7)	A
Regional PCC team	96	4.4	(4.3-4.5)	B
Homecare nurses	98	4.3	(4.1-4.4)	C
Hospital-based consultation team	62	4.1	(3.9-4.2)	D

Scores are based on a 5-point Likert-scale: 1 = very unsatisfied; 5 = very satisfied.

n = observed numbers.

<sup>a</sup> Sources that share the same letter, do not have statistically significant different mean scores, using a linear mixed model and the appropriate contrast test.

GP, general practitioner.

the first time within the patient's last month of life (58.2%). The vast majority of respondents (92.5%) considered this moment the appropriate time for consultation.

## DISCUSSION

### Main results

This study aimed to provide insight into palliative care consultation practices from a GP's perspective. We found that the majority of GPs provided palliative care to at least six patients per year, while most GPs requested consultation for a maximum of three patients per year. Next to informal caregivers, GPs mainly consult fellow GPs. Consultations most often concerned the physical domain of palliative care, while social and existential issues were rarely discussed. Finally, requests for consultation often occur during the patient's last month of life.

### Strengths and weaknesses

To the best of our knowledge, this is the first study that comprehensively describes palliative care consultation practices in primary care based on the GP's own perspective. The main strength of this study is that we have taken into account a wide range of possible and available consultation sources in our region. In addition, respondents could freely add other consultation sources in open text. This also applied to the topics discussed during consultation and the considerations determining the choice of a particular consultation source. Although the options that were freely added could not be taken into account in the statistical tests, they provided useful extra information concerning consultation sources and topics relevant to GPs.

Additionally, several stakeholders involved in primary palliative care were involved in the developmental process of the questionnaire to warrant the relevance of questions. Moreover, all GPs in our region were invited to complete this questionnaire.

Furthermore, the response rate in this study was 50.6%. This is relatively high and comparable to other survey-based or questionnaire-based research among GPs, concerning topics in the field of palliative care.<sup>27–29</sup>

This study has some limitations. First, since the questionnaires were filled in anonymously, we could not perform a non-responder analysis. Although we achieved a relatively high response rate, a non-responder analysis could have provided useful additional information about the generalizability of our results.<sup>30</sup> This information was, however, not available. Second, recall bias may have occurred as we asked respondents for past consulting behaviour, whereas GPs annually provide palliative care to a relatively low number of patients. Third, although the questionnaire was face validated for its content, we did not formally test the questionnaire for its validity and reliability. Fourth, in our questionnaire, we have not specified nor specifically asked whether consultations were requested and answered by phone or if bedside consultations occurred as well.

### Comparison with the literature

We found that in palliative care, GPs mainly consult fellow GPs. The value of consulting fellow GPs concerning palliative care has been described earlier.<sup>24,31</sup> This might be a result of fellow GPs being easily approachable and consultation being more informal. The latter was also highly valued in the study conducted by Wilson and Cox.<sup>32</sup> GPs in our study highly valued the advice provided by their fellow GPs. However, we have no information about how these consultations eventually influenced the quality of patient care.

Furthermore, GPs frequently consulted informal caregivers. Strictly, they cannot be considered experts in palliative care; however, they play an important role in the delivery of care for palliative patients.<sup>33,34</sup> Therefore, cooperation with informal caregivers is considered important and occurs frequently.<sup>24</sup> Pype *et al.*<sup>14</sup> underlined the importance of good understanding with family members, in order to deliver adequate palliative homecare.

Consultation mainly covered physical problems. This is consistent with earlier research that focused on consultation services that were solely or mainly consulted by GPs.<sup>19, 21, 22, 31</sup> Contrary to this, consultation for social and existential issues occurred infrequently. This might indicate that these issues receive too little attention in palliative care, as suggested by Abarshi *et al.*<sup>35</sup> and Evans *et al.*<sup>36</sup> It could also be explained by how palliative care consultation is organized in the Netherlands. Consultations are mainly requested and answered by phone, and follow-up consultations to explore additional problems are often absent. As a result, social and existential problems may remain neglected during ‘stick-to-the-point’ telephone consultations.<sup>20, 22</sup>

In addition, we found that some complex issues within palliative care (eg, euthanasia, palliative sedation and the need for a second opinion) scored relatively high among the topics discussed during consultation. These scores do not necessarily reflect the actual practice of palliative sedation or euthanasia. An explanation for these relatively high scores could be that GPs consider consultations as an opportunity to reflect, together with other healthcare

professionals, on their own practice. This might particularly be the case if palliative care is complex or if ethical issues are involved.

Furthermore, we found that the first moment of consultation often occurred relatively late, that is, within the last month of a patient's life. On the one hand, this could be explained by an increasing symptom burden during the last weeks of life, thereby increasing the complexity of palliative care.<sup>37</sup> As a result of this increased complexity, additional expertise might be needed. On the other hand, this may also reflect a rather reactive approach towards palliative care, while the importance of a proactive palliative care approach is increasingly emphasized.<sup>38, 39</sup>

Finally, the results of our questionnaire describe the practice of consultation within the field of palliative care in a Dutch context. There might be several context-related and concept-related differences that make it difficult to extrapolate our results to other countries. First, on the basis of figures of formal consultation services in the Netherlands, the majority of consultations are requested and answered by phone, while bedside consultations occur rarely.<sup>25</sup> This concept of consultation might differ from the concept of consultation in other countries. Second, in our study, consultation with hospice-based teams or physicians occurred rarely. This might differ from practices in other countries, such as the UK, where hospices play a more prominent role in the delivery of community-based palliative care and palliative care consultations.<sup>40</sup> Third, in the Netherlands, GPs play a pivotal role in the delivery of palliative care for home-dwelling patients, and therefore Dutch GPs provide palliative care relatively frequently. In other countries, for example, the UK or Australia, palliative care is recognized as a separate medical specialty and, as a result, GPs in general might be less involved in the provision of palliative care.<sup>26,41</sup>

## CONCLUSIONS

In the Netherlands, consultation concerning palliative care in general practice mainly occurs within the community. Although GPs are largely satisfied with how palliative care consultation is currently organized, some vital aspects of palliative care threaten to remain neglected: the social and existential domains of palliative care and a proactive care approach. Future research should explore the underlying reasons why the aforementioned topics receive relatively little attention during consultations. Since these are clinically relevant topics within palliative care, adequate attention during consultation is of vital importance.

Therefore, raising additional awareness on these topics could be particularly relevant within: (1) the further development of palliative care consultation in primary care and (2) training and educational programmes in primary palliative care.

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# 3

## ADDRESSING PALLIATIVE SEDATION DURING EXPERT CONSULTATION: A DESCRIPTIVE ANALYSIS OF THE PRACTICE OF DUTCH PALLIATIVE CARE CONSULTATION TEAMS

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## ABSTRACT

### Main Objective

Since palliative sedation is considered a complex intervention, consultation teams are increasingly established to support general practice. This study aims to offer insight into the frequency and characteristics of expert consultations regarding palliative sedation.

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### Methods

We performed a retrospective analysis of a longitudinal database. This database contained all patient-related consultations by Dutch Palliative Care Consultation teams, that were requested between 2004 and 2011. We described the frequency and characteristics of these consultations, in particular of the subgroup of consultations in which palliative sedation was addressed (i.e. PSa consultations). We used multivariate regression analysis to explore consultation characteristics associated with a higher likelihood of PSa consultations.

### Main Results and Their Significance

Of the 44,443 initial consultations, most were requested by general practitioners (73%) and most concerned patients with cancer (86%). Palliative sedation was addressed in 18.1% of all consultations. Palliative sedation was relatively more often discussed during consultations for patients with a neurologic disease (OR 1.79; 95% CI: 1.51–2.12) or COPD (OR 1.39; 95% CI: 1.15–1.69) than for patients with cancer. We observed a higher likelihood of PSa consultations if the following topics were also addressed during consultation: dyspnoea (OR 1.30; 95% CI: 1.22–1.40), agitation/delirium (OR 1.57; 95% CI: 1.47–1.68), exhaustion (OR 2.89; 95% CI: 2.61–3.20), euthanasia-related questions (OR 2.65; 95% CI: 2.37–2.96) or existential issues (OR 1.55; 95% CI: 1.31–1.83).

### Conclusion

In conclusion, PSa consultations accounted for almost one-fifth of all expert consultations and were associated with several case-related characteristics. These characteristics may help clinicians in identifying patients at risk for a more complex disease trajectory at the end of life.

## BACKGROUND

Palliative sedation (PS) is commonly applied in end-of-life care, but its frequency and characteristics vary between care settings and countries.<sup>1-8</sup> Palliative sedation involves the deliberate lowering of consciousness in patients nearing death to relieve the burden of refractory symptoms.<sup>9</sup> Refractory symptoms are “symptoms for which all possible treatment has failed, or it is estimated that no methods are available for palliation within the time frame and the risk-benefit ratio that the patient can tolerate”.<sup>10</sup> Because of the far-reaching consequences of palliative sedation, it is considered a treatment option of last resort.<sup>11</sup>

To guide medical practice concerning palliative sedation, several guidelines and frameworks have been published. Expert consultation is one of the topics addressed in these guidelines. For example, the Dutch national guideline on palliative sedation advises consultation with an “appropriate expert” when the attending physician lacks sufficient expertise and experience in the field of palliative sedation.<sup>12</sup> Expert consultation in the context of palliative sedation is also advocated by other frameworks and guidelines on palliative sedation, and some recommend mandatory consultation.<sup>13-19</sup>

Previous research conducted in the Netherlands shows that guideline recommendations on palliative sedation were increasingly applied in daily practice by Dutch physicians.<sup>20</sup> However, in the Netherlands, as well as in other countries, shortcomings were reported regarding the intention to use palliative sedation, the adequate usage of medication and communication with patients, informal caregivers and mutually between formal caregivers.<sup>19-23</sup> Furthermore, Swart *et al.* demonstrated that 41% of physicians believed that administering palliative sedation had a life-shortening effect and that 14% had experienced pressure to commence sedation, mainly from patients and their relatives.<sup>24</sup> Finally, it has been argued that individual general practitioners typically have little experience with palliative sedation in their caseload.<sup>12,25</sup> Altogether, these findings suggest that there is a substantial need for expert support concerning palliative sedation.

However, if expert consultation services are available, they seem to be used by health care professionals in only a minority of palliative sedation cases.<sup>26-29</sup> Koper *et al.* investigated considerations of Dutch physicians regarding expert consultations about palliative sedation. Main reasons for physicians to consult specialist palliative care services for palliative sedation are a lack of expertise and that consultation is considered supportive. Reasons not to use these consultation services were as follows: physicians having sufficient expertise themselves; consideration of palliative sedation as a normal medical procedure; time pressure; fear of disagreement with the consultant; and considering consultation as having little added value.<sup>30</sup> An alternative approach to gain additional insight in consultation practices concerning palliative sedation is to study, nationwide, the documentation of requested consultations at expert consultation services.

Therefore, the aims of this study are to investigate the following over a period of 8 years: 1) the frequency and characteristics of palliative care consultations given by Dutch Palliative Care Consultation (PCC) teams, 2) the frequency and characteristics of consultations in which

PS was addressed, and 3) the consultation characteristics associated with a higher likelihood of PS being addressed during consultation. These characteristic might help clinicians in identifying patients at risk for a more complex disease trajectory at the end of life, for whom timely consultation with an expert might be appropriate.

## 3

## METHODS

### Design

We performed a retrospective analysis of a national database consisting of the registration of all consultations by Dutch PCC teams that were requested between 2004 and 2011.

### Setting

In 1998, the Dutch government installed a national program for the development and improvement of palliative care. As a result of this program, regional PCC teams were established to ensure the availability of specific advice concerning palliative care for all professional caregivers. In 2011, 23 PCC teams were available for expert consultation, covering the whole country. PCC teams generally consist of general practitioners, medical specialists and specialized nurses who are recruited from regional health centers and hospitals. PCC team members are practicing healthcare professionals who have a special interest in palliative care and are trained in such. Some PCC teams offer a 24/7-consultation service, while others are available for consultation only during weekdays and to a limited extent during out-of-office hours. Most consultations were requested and answered by phone (approximately 90% in 2011).<sup>31</sup> Often, advice given by consultants is previously discussed with one or more fellow consultants.<sup>31,32</sup> Recommendations are mainly communicated by phone and, as much as possible, confirmed in writing. Only in a small minority of cases bedside consultations occur.<sup>31</sup> For each individual consultation, consultants themselves registered their specific clinical findings, diagnosis, treatment advice and other appointments in a national, standardized, web-based, consultation database (*PRADO, IKNL, Ecommany, the Netherlands*).

### Participants

In PRADO, a number of characteristics were systematically recorded for every consultation, mainly using tick boxes: date of consultation, region of consultation, patient demographics (date of birth, age, gender), diagnosis, estimated prognosis, listed symptoms and problems, place of residence and the specialty or training of the professional caregiver requesting the consultation. With regard to the listed problems, within PRADO the following sentence is displayed: "the consultation concerns the following problems...". Subsequently, the consultant lists one or more problems that have been addressed during consultation, using tick boxes. "Palliative sedation", is one of the options available in this list.

We grouped consultations based on whether or not "palliative sedation" was selected by the consultant. As a result, two groups were defined: 1) consultations in which palliative sedation was addressed by the consulting caregiver and/or the consultant and registered

as such in PRADO (PS addressed, abbreviated as PSa consultations), 2) other consultations (PS not addressed, abbreviated as PSna consultations). To prevent duplication of cases, we included only the first consultation for every patient.

### Statistical analysis and main outcome measures

Data were exported from the PRADO system into a Comma-Separated Value (CSV) file. Data were anonymized and de-identified and were subsequently imported and analyzed in Stata, Version 12.0 (StataCorp. 2011. *Stata Statistical Software: Release 12*. StataCorp LP, College Station, Texas, United States).

The number of annual consultations for PCC teams was described and displayed as a percentage of the annual mortality rates as registered by Statistics Netherlands (CBS). Proportions and 95% confidence intervals (95% CIs) were used to describe differences in characteristics between PSa consultations and PSna consultations. Differences in characteristics were analyzed for statistical significance using uni- and multivariate regression analysis. A p-level < 0.05 was considered statistically significant.

### Ethical considerations

The Committee on Research Involving Human Subjects (CMO) Region Arnhem-Nijmegen stated that no further ethical assessment was required for this research. (Reg. 2013/423). Informed consent was not obtained, since we only used data from an existing, clinical database, that was anonymized and de-identified prior to analysis.

## RESULTS

### General description of all palliative care consultations

During the study period, 44,443 first consultations were registered and included for analysis. The vast majority of these consultations were requested by general practitioners (GPs) (72.7%) and concerned patients residing at home (74.7%). Most patients enlisted for consultation were diagnosed with cancer (86.1%). The most frequently listed symptoms were pain (45.0%), agitation/ delirium (15.4%), dyspnoea (15.4%), and nausea/vomiting (15.0%). Other topics frequently addressed during consultation related to pharmacological questions (51.2%), moral support for the professional caregivers themselves (33.7%) and issues about the organization of care (23.7%). More than half of the consultations (56.8%) concerned patients with an estimated prognosis of less than 4 weeks. The vast majority of consultations were requested during office hours (85.0%) (Table 1). The annual consultation rate, in relation to the annual mortality number, rose during the first years of the study, from 3.6% (95% CI: 3.5%- 3.7%) in 2004 to 4.8% (95% CI: 4.7%-4.9%) in 2006. After 2006, annual consultation rates declined until 2008 and remained rather stable at approximately 4% afterwards (Table 2).



### PSa consultations

Palliative sedation was addressed in 8,038 (18.1%) of the consultations. PSa consultations were most often requested by GPs (87.4% of all PSa consultations, 7,023 PSa consultations) and most often concerned patients diagnosed with cancer (82.1%, 6,597 PSa consultations). Since 86.1% (38,248 consultations) of all consultations concerned patients diagnosed with cancer, the proportion of PSa consultations for this group of patients was relatively low (17.2%; 95% CI: 16.9%-17.6%). Relatively high proportions of PSa consultations were found for patients diagnosed with heart failure (25.0%; 95% CI: 22.5%-27.5%), neurologic diseases (22.9%; 95% CI: 20.4%-25.4%), chronic obstructive pulmonary disease (COPD) (26.4%; 95% CI: 23.1%-29.6%), and other diagnoses (23.8%; 95% CI: 22.1%-25.5%). Furthermore, palliative sedation was relatively often addressed in consultations in which the following symptoms or issues were also raised: exhaustion (proportion of PSa consultations: 28.7%; 95% CI: 27.1%-30.4%), agitation/delirium (28.2%; 95% CI: 27.2%-29.3%), dyspnoea (25.2%; 95% CI: 24.2%-26.2%), euthanasia-related (34.4%; 95% CI: 32.3%-36.5%), and existential issues (21.6%; 95% CI: 19.3%-24.0%). Also, a relatively high proportion of PSa consultations was found for patients with an estimated prognosis of less than 4 weeks (27.3%; 95% CI: 26.8%-27.9%). Finally, palliative sedation was addressed relatively often in consultations outside of office hours (23.5%; 95% CI: 22.4%-24.5%) (Table 1). Over the years, palliative sedation was increasingly addressed during PCC consultations, from 10.5% of cases in 2004 (95% CI: 9.6%-11.4%) to 21.6% of cases in 2011 (95% CI: 20.5%-22.8%). PSa consultation rates as a percentage of

**Table 1.** Characteristics of all consultations by Dutch PCC teams (2004 – 2011)

Variable	All consultations		PSa consultations		Proportion of PSa consultations <sup>a</sup>	
	n	%	n	%	%	(95% CI)
<b>Year of consultation</b>						
2004	4,851	10.9	509	6.3	10.5	(9.6-11.4)
2005	5,508	12.4	735	9.1	13.3	(12.4-14.2)
2006	6,465	14.6	1,178	14.6	18.2	(17.3-19.2)
2007	6,044	13.6	1,145	14.2	18.9	(18.0-19.9)
2008	5,283	11.9	1,127	14.0	21.3	(20.2-22.4)
2009	5,532	12.5	1,111	13.8	20.1	(19.0-21.1)
2010	5,638	12.7	1,125	14.0	20.0	(18.9-21.0)
2011	5,122	11.5	1,108	13.8	21.6	(20.5-22.8)
<b>Consultation region</b>						
North	5,728	12.9	924	11.5	16.1	(15.2-17.1)
East	11,536	26.0	1,577	19.6	13.7	(13.0-14.3)
South	8,591	19.3	1,460	18.2	17.0	(16.2-17.8)
West	10,760	24.2	2,011	25.0	18.7	(18.0-19.4)
Middle	7,828	17.6	2,066	25.7	26.4	(25.4-27.4)

Table 1. (continued)

	All consultations		PSa consultations		Proportion of PSa consultations <sup>a</sup>	
	n	%	n	%	%	(95% CI)
<b>Consulting Professional Caregiver</b>						
General practitioner	32,319	72.7	7,023	87.4	21.7	(21.3-22.2)
Hospital specialist	2,666	6.0	196	2.4	7.4	(6.4-8.3)
Nurse	5,183	11.7	331	4.1	6.4	(5.7-7.1)
Elderly care physician	1,674	3.8	244	3.0	14.6	(12.9-16.3)
Other	2,586	5.8	242	3.0	9.4	(8.2-10.5)
Unknown	15	0.03	2	0.02	13.3	(-3.9-30.5)
<b>Place of residence</b>						
Home	33,190	74.7	6,435	80.1	19.4	(19.0-19.8)
Hospice	2,874	6.5	516	6.4	18.0	(16.6-19.4)
Nursing/Residential Home	3,328	7.5	683	8.5	20.5	(19.2-21.9)
Hospital	4,008	9.0	271	3.4	6.8	(6.0-7.5)
Other	928	2.1	121	1.5	13.0	(10.9-15.2)
Unknown	115	0.3	12	0.2	10.4	(4.8-16.0)
<b>Gender</b>						
Male	22,593	50.8	4,218	52.5	18.7	(18.2-19.2)
Female	21,804	49.1	3,813	47.4	17.5	(17.0-18.0)
Unknown	46	0.1	7	0.1	15.2	(4.8-25.6)
<b>Age (years)</b>						
0- 39	1,473	3.3	258	3.2	17.5	(15.6-19.5)
40- 64	16,189	36.4	2,749	34.2	17.0	(16.4-17.6)
65- 79	16,655	37.5	2,947	36.7	17.7	(17.1-18.3)
≥80	9,435	21.2	1,969	24.5	20.9	(20.0-21.7)
Unknown	691	1.6	115	1.4	16.6	(13.9-19.4)
<b>Diagnosis</b>						
Cancer	38,248	86.1	6,597	82.1	17.2	(16.9-17.6)
Heart failure	1,135	2.6	284	3.5	25.0	(22.5-27.5)
Neurologic disease	1,065	2.4	244	3.0	22.9	(20.4-25.4)
Chronic obstructive pulmonary disease (COPD)	694	1.6	183	2.3	26.4	(23.1-29.6)
Other	2,477	5.6	590	7.3	23.8	(22.1-25.5)
Unknown	824	1.9	140	1.7	17.0	(14.4-19.6)
<b>Symptoms<sup>b</sup></b>						
Anorexia	1,842	4.1	273	3.4	14.8	(13.2-16.4)
Dyspnoea	6,858	15.4	1,728	21.5	25.2	(24.2-26.2)
Agitation/delirium	6,857	15.4	1,937	24.1	28.2	(27.2-29.3)
Decubitus/ulcus	1,024	2.3	121	1.5	11.8	(9.8-13.8)
Depressed mood	3,268	7.4	370	4.6	11.3	(10.2-12.4)
Nausea/vomiting	6,680	15.0	899	11.2	13.5	(12.6-14.3)
Mouth problems	1,149	2.6	156	1.9	13.6	(11.6-15.6)
Constipation/diarrhea	2,168	4.9	206	2.6	9.5	(8.3-10.7)

Table 1. (continued)

	All consultations		PSa consultations		Proportion of PSa consultations <sup>a</sup>	
	n	%	n	%	%	(95% CI)
Pain	19,977	45.0	2,924	36.4	14.6	(14.1-15.1)
Exhaustion	2,981	6.7	857	10.7	28.7	(27.1-30.4)
Other	8,412	18.9	1,463	18.2	17.4	(16.6-18.2)
<b>Issues<sup>b</sup></b>						
Daily functioning	5,005	11.3	534	6.6	10.7	(9.8-11.5)
Euthanasia-related	1,981	4.4	682	8.5	34.4	(32.3-36.5)
Pharmacological	22,739	51.2	3,514	43.7	15.5	(15.0-15.9)
Informal care	3,501	7.9	429	5.3	12.3	(11.2-13.3)
Moral support professional caregiver	14,992	33.7	2,386	29.7	15.9	(15.3-16.5)
Organization of care	10,529	23.7	1,409	17.5	13.4	(12.7-14.0)
Social	2,593	5.8	249	3.1	9.6	(8.5-10.7)
Existential	1,175	2.6	254	3.2	21.6	(19.3-24.0)
Other	2,428	5.5	204	2.5	8.4	(7.3-9.5)
<b>Estimated Prognosis</b>						
Less than 4 weeks	25,231	56.8	6,898	85.8	27.3	(26.8-27.9)
Between 4 weeks and 3 months	7,600	17.1	333	4.1	4.4	(3.9-4.8)
More than 3 months	3,394	7.6	82	1.0	2.4	(1.9-2.9)
Unknown	8,218	18.5	725	9.0	8.8	(8.2-9.4)
<b>Time of consultation</b>						
Out-of-office hours	6,377	14.4	1,497	18.6	23.5	(22.4-24.5)
Office hours	37,763	85.0	6,509	80.1	17.2	(16.9-17.6)
Unknown	303	0.7	32	0.4	10.6	(7.1-14.0)

**PCC teams:** Palliative Care Consultation Teams; **PS:** palliative sedation; **PSa consultation:** palliative sedation addressed during consultation; **95% CI:** 95% confidence interval.

<sup>a</sup>Proportion = (PSa consultations / total consultations)\*100%, per single variable.

<sup>b</sup>Total of variables for "Symptoms" and "Issues" exceeds 100% due to more than one symptom / issue registered per consultation.

annual mortality numbers varied between 0.4% in 2004 (95% CI: 0.3%-0.4%) to 0.9% in 2006 and 2007 (95% CI: 0.8%-0.9% for both years) (Table 2).

### Multivariate regression analysis – characteristics associated with PSa consultations

The following characteristics were associated with a higher likelihood of palliative sedation being addressed during palliative care consultations: 1) patients being diagnosed with a neurologic disease (OR 1.79, 95% CI: 1.51–2.12) or COPD (OR 1.39, 95% CI: 1.15–1.69) compared to cancer (reference variable) and 2) the presence of dyspnoea (OR 1.30, 95% CI: 1.22–1.40), agitation/delirium (OR 1.57, 95% CI: 1.47–1.68), exhaustion (OR 2.89, 95% CI: 2.61–3.20), euthanasia-related issues (OR 2.65, 95% CI: 2.37–2.96) or

existential issues (OR 1.55, 95% CI: 1.31–1.83). The following characteristics were associated with a lower likelihood of palliative sedation being addressed during consultations: 1) patients having a prognosis of more than 4 weeks (OR 0.15 (95% CI: 0.13–0.16)) for an estimated prognosis of “between 4 weeks and 3 months” and OR 0.08 (95% CI: 0.06–0.10) for “more than 3 months,” respectively), 2) professional caregivers other than the GP being the caregivers requesting consultation (OR varying from 0.36 for nurses (95% CI: 0.32–0.41) to 0.61 for elderly care physicians (95% CI: 0.51–0.72)) and 3) the timing of the consultation characterized as “during office hours” (OR 0.88; 95% CI: 0.82–0.95) compared to “out-of-office hours” (reference variable) (Table 3).

**Table 2.** Number of all consultations by Dutch PCC teams over the period 2004–2011

	AMN n	All consultations			PSa consultations		
		n	% of AMN	(95% CI)	n	% of AMN	(95% CI)
<b>Year of consultation</b>							
2004	136,553	4,851	3.6	(3.5-3.7)	509	0.4	(0.3-0.4)
2005	136,402	5,508	4.0	(3.9-4.1)	735	0.5	(0.5-0.6)
2006	135,372	6,465	4.8	(4.7-4.9)	1,178	0.9	(0.8-0.9)
2007	133,022	6,044	4.5	(4.4-4.7)	1,145	0.9	(0.8-0.9)
2008	135,136	5,283	3.9	(3.8-4.0)	1,127	0.8	(0.8-0.9)
2009	134,235	5,532	4.1	(4.0-4.2)	1,111	0.8	(0.8-0.9)
2010	136,058	5,638	4.1	(4.0-4.3)	1,125	0.8	(0.8-0.9)
2011	135,741	5,122	3.8	(3.7-3.9)	1,108	0.8	(0.8-0.9)

**PCC teams:** Palliative Care Consultation Teams; **AMN:** Annual Mortality Number;

**PS:** palliative sedation; **PSa consultation:** palliative sedation addressed during consultation; **95% CI:** 95% confidence interval.

**Table 3.** Univariate and multivariate analysis of all consultations by Dutch PCC teams (2004 – 2011) – Characteristics associated with PSa consultations.

	Univariate analysis Odds ratio (95% CI)	Multivariate analysis Odds ratio (95% CI)
<b>Year of consultation</b>		
2004	1 (reference)	1 (reference)
2005	1.31 (1.16-1.48)	1.41 (1.24-1.61)
2006	1.90 (1.70-2.12)	1.69 (1.49-1.91)
2007	1.99 (1.78-2.23)	1.66 (1.47-1.88)
2008	2.31 (2.07-2.59)	2.26 (1.99-2.57)
2009	2.14 (1.91-2.40)	2.11 (1.86-2.40)
2010	2.13 (1.90-2.38)	1.98 (1.74-2.24)
2011	2.35 (2.10-2.64)	2.17 (1.91-2.47)

Table 3. (continued)

	Univariate analysis Odds ratio (95% CI)	Multivariate analysis Odds ratio (95% CI)
<b>Consultation region</b>		
North	1 (reference)	1 (reference)
East	0.82 (0.75-0.90)	0.90 (0.81-0.99)
South	1.06 (0.97-1.16)	1.28 (1.15-1.41)
West	1.20 (1.09-1.30)	1.19 (1.08-1.31)
Middle	1.86 (1.71-2.03)	1.42 (1.29-1.57)
<b>Consulting professional caregiver</b>		
General practitioner	1 (reference)	1 (reference)
Hospital specialist	0.29 (0.25-0.33)	0.52 (0.42-0.64)
Nurse	0.25 (0.22-0.28)	0.36 (0.32-0.41)
Elderly care physician	0.61 (0.54-0.71)	0.61 (0.51-0.72)
Other	0.37 (0.32-0.43)	0.52 (0.45-0.61)
Unknown	0.55 (0.13-2.46)	0.78 (0.17-3.70)
<b>Place of residence</b>		
Home	1 (reference)	1 (reference)
Hospice	0.91 (0.82-1.00)	1.09 (0.97-1.22)
Nursing/Residential home	1.07 (0.98-1.17)	1.02 (0.91-1.14)
Hospital	0.30 (0.27-0.34)	0.70 (0.59-0.84)
Other	0.62 (0.51-0.76)	0.85 (0.69-1.05)
Unknown	0.48 (0.27-0.88)	0.83 (0.43-1.58)
<b>Gender</b>		
Male	1 (reference)	1 (reference)
Female	0.92 (0.88-0.97)	0.98 (0.93-1.03)
Unknown	0.78 (0.35-1.75)	1.11 (0.44-2.78)
<b>Age (years)</b>		
0- 39	1 (reference)	1 (reference)
40- 64	0.96 (0.84-1.11)	0.93 (0.80-1.09)
65- 79	1.01 (0.88-1.16)	0.93 (0.79-1.08)
≥ 80	1.24 (1.07-1.43)	0.93 (0.80-1.10)
Unknown	0.94 (0.74-1.20)	1.09 (0.83-1.43)
<b>Diagnosis</b>		
Cancer	1 (reference)	1 (reference)
Heart failure	1.60 (1.40-1.84)	1.15 (0.98-1.34)
Neurologic disease	1.43 (1.23-1.65)	1.79 (1.51-2.12)
Chronic obstructive pulmonary disease (COPD)	1.72 (1.45-2.04)	1.39 (1.15-1.69)
Other	1.50 (1.36-1.65)	1.53 (1.37-1.72)
Unknown	0.98 (0.82-1.18)	1.06 (0.87-1.31)

Table 3. (continued)

	Univariate analysis Odds ratio (95% CI)	Multivariate analysis Odds ratio (95% CI)
<b>Symptoms (present)</b>		
Anorexia	0.78 (0.68-0.89)	1.13 (0.97-1.32)
Dyspnoea	1.67 (1.57-1.77)	1.30 (1.22-1.40)
Agitation/delirium	2.03 (1.91-2.16)	1.57 (1.47-1.68)
Decubitus/ulcus	0.60 (0.50-0.73)	0.87 (0.70-1.08)
Depressed mood	0.56 (0.50-0.62)	0.96 (0.84-1.09)
Nausea/vomiting	0.67 (0.62-0.72)	0.72 (0.67-0.79)
Mouth problems	0.71 (0.60-0.84)	0.92 (0.76-1.11)
Constipation/diarrhea	0.46 (0.40-0.53)	0.66 (0.56-0.77)
Pain	0.65 (0.62-0.68)	0.74 (0.70-0.78)
Exhaustion	1.93 (1.77-2.09)	2.89 (2.61-3.20)
Other	0.94 (0.89-1.00)	1.00 (0.93-1.08)
<b>Issues (present)</b>		
Daily functioning	0.51 (0.46-0.56)	0.76 (0.69-0.85)
Euthanasia-related	2.51 (2.28-2.76)	2.65 (2.37-2.96)
Pharmacological	0.69 (0.66-0.73)	0.54 (0.51-0.58)
Informal care	0.61 (0.55-0.68)	1.09 (0.97-1.24)
Moral support professional caregiver	0.80 (0.76-0.84)	0.84 (0.79-0.90)
Organization of care	0.64 (0.60-0.68)	0.84 (0.78-0.90)
Social	0.46 (0.41-0.53)	0.87 (0.74-1.02)
Existential	1.26 (1.09-1.45)	1.55 (1.31-1.83)
Other	0.40 (0.35-0.46)	0.46 (0.39-0.53)
<b>Prognosis</b>		
Less than 4 weeks	1 (reference)	1 (reference)
Between 4 weeks and 3 months	0.12 (0.11-0.14)	0.15 (0.13-0.16)
More than 3 months	0.07 (0.05-0.08)	0.08 (0.06-0.10)
Unknown	0.26 (0.24-0.28)	0.26 (0.24-0.28)
<b>Time of consultation</b>		
Out-of-office hours	1 (reference)	1 (reference)
Office Hours	0.68 (0.64-0.72)	0.88 (0.82-0.95)
Unknown	0.38 (0.27-0.56)	1.02 (0.68-1.53)

PCC teams: Palliative Care Consultation Teams; PS: palliative sedation; PSa consultation: palliative sedation addressed during consultation; 95% CI: 95% confidence interval.

## DISCUSSION

### Main results

Palliative sedation was addressed in approximately one out of five palliative care consultations in the Netherlands during the period 2004–2011. The likelihood of palliative sedation being addressed during consultations was higher if the consultations were requested by GPs and during “out of office” hours. Additionally, palliative sedation was relatively more often addressed for patients with a non-cancer diagnosis, for patients with an estimated prognosis of less than 4 weeks, and for patients with dyspnoea, agitation/delirium, exhaustion, euthanasia-related or existential issues.

### Strengths and weaknesses

A main strength of this study is the use of a national, standardized database containing all consultations for Dutch PCC teams in the Netherlands that were provided and registered in the period 2004 to 2011. By using this database, we were able to give a detailed overview of the practice of palliative care consultations during this period. The number of missing values is low (<2% of all cases per variable) for most variables. However, Schrijnemakers *et al.* demonstrated that during telephone consultation a substantial share of the present problems may not be discussed and subsequently not be registered.<sup>32</sup>

Furthermore, to prevent duplication of patients with multiple consultations in our study sample, we decided to include only the first consultation per patient. Consequently, follow-up consultations in which palliative sedation may have been addressed were not included. Nevertheless, our final sample included 89.3% of all PSa consultations (8,038 out of 9,005 PSa consultations) by Dutch PCC teams, which warrants the representativeness of our results. Another consequence of the study methods used is that we were not able to study which percentage of PSa consultations eventually led to the actual application of palliative sedation. Furthermore, palliative sedation was defined in a general way, therefore no distinction could be made between continuous and intermittent sedation. These factors hamper a comparison of our study to the international literature concerning the practice and incidence of palliative sedation. Also, since palliative sedation could only be registered by checking the tick-box “palliative sedation”, no additional information was available on this topic (e.g. who initiated discussion about palliative sedation?). Therefore PSa consultations may form a heterogeneous group of consultations.

Finally, consultation rates from this study must be interpreted with caution because we have studied only consultations delivered by PCC teams. Consequently, we did not take into account alternative sources for palliative care consultations (e.g., hospital specialists or colleagues specialized in palliative care). Rietjens *et al.* showed that physicians, particularly clinical specialists, but also 29% of the GPs, discuss sedation with other physicians rather than with a consultation service.<sup>29</sup> These “unofficial” consultations are not taken into account in our study. This may have led to an underestimation of consultation rates.

### Comparison with the literature

We found an increase in PSa consultations over the period from 2004 to 2011. This appears to be in line with previous research describing the incidence of palliative sedation in the Netherlands and Belgium.<sup>3,4,33</sup> The sharpest increase can be observed between 2005 and 2006. This finding may be related to the publication of the guidelines on palliative sedation by the Royal Dutch Medical Association (RDMA) in 2005, most likely leading towards an increased awareness among practitioners.<sup>20</sup> In the Netherlands, the estimated incidence of (continuous) palliative sedation in 2010 was 12.3% of all deaths.<sup>3</sup> Similar or higher percentages were found in Belgium (14.5% in 2007) and the United Kingdom (18.7% in 2007/2008).<sup>4,23,33</sup> In our study, the PSa consultation rate (PSa consultations as a percentage of the annual number of deaths) in 2010 was 0.8%. This suggests one PSa consultation by PCC teams for every 15 cases of palliative sedation in the Netherlands (12.3%/0.8%). This rate is lower than the consultation rate of 22% found by Swart *et al.*<sup>24</sup> One explanation for this different consultation rate, could be that Swart *et al.* asked physicians whether they consulted any palliative care team, whereas we only studied consultations requested at PCC teams. Anyhow, our finding demonstrates that the use of PCC teams for palliative sedation seems not a common practice. This rate is probably higher for general practitioners, as PSa consultations in our study were mainly requested by general practitioners (87.4% of all PSa consultations), while, according to the literature, general practitioners only perform almost half of all sedations.<sup>34</sup>

Our study raised three further topics that warrant discussion. First, dyspnoea, agitation/delirium and exhaustion were significantly associated with a higher likelihood of palliative sedation being addressed during consultation compared to other listed symptoms. A systematic review by Maltoni *et al.* showed that the most common indication for palliative sedation is delirium (54%) followed by dyspnoea (30%).<sup>35</sup> The complex management of these symptoms in end of life care is acknowledged in literature.<sup>36,37</sup> The finding that exhaustion is associated with a higher likelihood of PSa consultations is in line with other research conducted in the Netherlands, stating that exhaustion is a common indication to start palliative sedation.<sup>20,24</sup> However, it is not mentioned as a common indication for palliative sedation in recent international literature.<sup>35</sup> Furthermore, although pain is a commonly mentioned symptom during PSa consultations (2,924 PSa consultations; 36.4%), resonating with the literature,<sup>20,24,25</sup> it is not independently associated with a higher likelihood of PSa consultations. This might be a result of the overall high incidence of pain in all consultations requested at PCC teams (19,977 consultations; 45.0%). As a result of this high denominator, the proportion of PSa consultations is relatively low for pain.

Second, apart from symptoms, the underlying diagnosis appears relevant. Although cancer accounts for the vast majority of palliative care consultations,<sup>38</sup> palliative sedation was discussed relatively more often for patients diagnosed with COPD and neurologic diseases. This might be explained by the fact that patients with these diagnoses experience a relatively unpredictable disease trajectory.<sup>39,40</sup> On the one hand, this may result in an increased risk of a complex terminal trajectory with a higher chance at refractory symptoms and PSa



consultation. On the other hand, this may result in uncertainty regarding the estimated prognosis of patients and the suitability of palliative sedation. It is therefore important that clinicians confronted with patients with an end-stage COPD or neurologic disease prepare advanced care planning for palliative care in time, including expert involvement.

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Third, consultations in which existential issues were discussed were associated with a higher likelihood of palliative sedation being addressed during consultation. The RDMA guideline on palliative sedation recognizes that existential suffering may be among the refractory symptoms that lead to unbearable suffering and state that expert consultations for these problems are strongly recommended.<sup>12</sup> However, existential suffering as an indication for palliative sedation remains controversial.<sup>41</sup> Previous research has shown that euthanasia, rather than palliative sedation, is related to existential problems relatively often.<sup>42</sup> In this regard, it is also important to notice that addressing “euthanasia-related issues” and palliative sedation were highly interrelated in this study. PCC teams appear to have a role in supporting physicians to explore palliative care options for patient cases in which questions concerning euthanasia, existential issues and palliative sedation intermingle. Clinicians confronted with existential suffering in end-of-life care are therefore encouraged to seek support from expert teams to prevent palliative sedation being applied for controversial indications.

## CONCLUSIONS

Expert consultation in the field of palliative sedation is advocated when physicians lack sufficient knowledge or expertise in the field of palliative sedation. However, mandatory consultation for palliative sedation, as argued by some, remains an ongoing debate in the recent literature.<sup>30,43</sup> From our study, the use of expert consultation services for palliative sedation does not appear to be a common practice. This might indicate a limited need for expert consultation as a result of physicians being sufficiently skilled in this area. It might also point to an already covered need for expert consultation provided by other healthcare professionals beyond regular consultation services. Finally, there might be a neglected need for expert consultations due to physicians being unaware of their limited expertise concerning palliative sedation. Further research is needed here.

Consultation rates for palliative sedation appear to be rather low. To verify the accuracy of these consultation rates, future research must reveal the use of expert consultation services other than established PCC teams. In addition, future research should yield more insight into the needs of general practitioners concerning palliative sedation, which could guide current palliative care consultation teams in adapting their services to these needs. This might lead to an increase in consultation rates and eventually improve the practice of palliative sedation.

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# 4

## THE EFFECT OF WEEKLY SPECIALIST PALLIATIVE CARE TELECONSULTATIONS IN PATIENTS WITH ADVANCED CANCER – A RANDOMIZED CLINICAL TRIAL

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## ABSTRACT

### Background

Teleconsultation seems to be a promising intervention for providing palliative care to home-dwelling patients; however, its effect on clinically relevant outcome measures remains largely unexplored. Therefore, the purpose of this study was to determine whether weekly teleconsultations from a hospital-based specialist palliative care consultation team (SPCT) improved patient-experienced symptom burden compared to “care as usual”. Secondary objectives were to determine the effects of these teleconsultations on unmet palliative care needs, continuity of care, hospital admissions, satisfaction with teleconsultations, and the burden experienced by informal caregivers.

### Methods

Seventy-four home-dwelling patients diagnosed with advanced cancer were recruited from outpatient clinics of a tertiary university hospital and from regional home care organizations between May 2011 and January 2015. Participants were randomized to receive weekly, prescheduled teleconsultations with an SPCT-member (intervention group), or to receive “care as usual” (control group), for a period of 12 weeks. The primary outcome of this study was: patient-experienced symptom burden indicated by the following: (1) Total Distress Score (defined as the sum of all nine subscales of the Edmonton Symptom Assessment System) and (2) the Hospital Anxiety and Depression Scale. Mixed models were used to test for differences between the two groups.

### Results

The Total Distress Score became significantly higher in the intervention group than in the control group, reaching significance at week 12 (adjusted difference at week 12: 6.90 points, 95% CI, 0.17 to 13.63;  $P = 0.04$ ). The adjusted anxiety scores were higher in the intervention group than in the control group (estimate effect: 1.40; 95% CI, 0.14 to 2.66;  $P = 0.03$ ). No difference was found between the groups in adjusted depression scores (estimate effect: 0.30; 95% CI,  $-1.39$  to 1.99;  $P = 0.73$ ) or in secondary outcome measures.

### Acknowledgments

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## **Conclusions**

Adding weekly teleconsultations to usual palliative care leads to worse reported symptom scores among home-dwelling patients with advanced cancer. Possible explanations for these findings include excess attention on symptoms and (potential) suffering, the supply-driven care model for teleconsultations used in this trial, and the already high level of specialist palliative care provided to the control group in this study.

## **Trial registration**

“The Netherlands National Trial Register”, NTR2817, prospectively registered: March 21, 2011.

## **Keywords**

Telemedicine, Teleconsultations, Advanced cancer, Palliative care, Symptom burden



## BACKGROUND

Palliative care intends to improve the quality of life of patients facing life-threatening illnesses and that of their families.<sup>1</sup> Due to an increase in the number of patients dying from chronic, life-threatening conditions, the need for palliative care is expected to rise.<sup>2,3</sup> In the Netherlands, as well as in other Western countries, the majority of these patients prefer to be cared for at home until death.<sup>4,5</sup> An important condition for dying at home is the availability of easily accessible, community-based palliative home care.<sup>6-9</sup> Consequently, general practitioners (GPs) play a vital role in the delivery of palliative care to home-dwelling patients.<sup>8,10</sup>

However, when a patient's condition deteriorates, palliative care can become increasingly complex.<sup>11</sup> As a result, GPs may require additional expertise.<sup>12-14</sup> Sustainable models for collaboration between GPs and expert palliative care teams should therefore be developed to guarantee proactive, continuous, yet patient-centered palliative home care. Telemedicine might be an innovative approach to supporting these collaborations.<sup>15</sup>

One of the applications of telemedicine is videoconferencing (also video- or teleconsultations), which involves the use of real-time (synchronous) audio-visual communication technology.<sup>16</sup> Videoconferencing has been proven to be feasible, acceptable, and effective in different fields of medicine, including psychiatry, diabetes care, and oncology.<sup>17-20</sup> Within palliative care, videoconferencing techniques have been used to establish multidisciplinary meetings between (rural) health centers and specialized institutes, to support patients and their families in their home-environment, and to deliver hospice care to patients living at a distance.<sup>21-26</sup> The results regarding the use of these techniques in palliative care are promising in terms of feasibility, acceptance and satisfaction among its users, cost-efficacy, and quality of care.<sup>22-27</sup>

Although these results are promising, studies describing the use of videoconferencing techniques to improve the quality of palliative care for patients residing at home are generally small or have methodological limitations.<sup>16</sup> Recent reviews on this topic emphasize the need for randomized clinical trials (RCTs) with clinically relevant outcomes that are measured with validated instruments.<sup>16, 28-30</sup>

Therefore, the primary objective of this study was to evaluate whether weekly teleconsultations between patients receiving palliative home care and a hospital-based specialist palliative care consultation team (SPCT) improves patient-experienced symptom burden when compared to "care as usual".

The secondary objectives were to evaluate the effect of these teleconsultations on (1) unmet palliative care needs, (2) experienced continuity of medical care, (3) hospital admissions, and (4) satisfaction with teleconsultations. Furthermore, the effect of teleconsultations on the burden experienced by informal caregivers, as well as healthcare professionals' satisfaction with teleconsultations, were evaluated.

## METHODS

### Design

We conducted a two-armed, non-blinded randomized clinical trial. The study protocol (Reg 2010/382) was approved by the Committee on Research Involving Human Subjects Region Arnhem-Nijmegen and has been previously published.<sup>15</sup> The study was prospectively registered at The Netherlands National Trial Register (NTR2817). During the study period, two amendments were approved by the Committee on Research Involving Human Subjects. Written informed consent was obtained from all participants.

### Participants

#### *Setting and location*

Initially, the inclusion period for this trial was 18 months. However, mainly as a result of recruitment delay, the inclusion period was extended to 45 months (May 2011–January 2015). Patients were recruited from the outpatient clinics of the Radboud university medical center, Nijmegen, the Netherlands, mainly at the Department of Palliative Medicine as well as from regional home care organizations.

#### *Inclusion criteria*

Participants had to be aged 18 years or above, Dutch speaking, and able to give informed consent. Furthermore, they initially had to meet the following criteria: (1) be diagnosed with a progressive oncological condition, (2) reside at home, (3) have a GP who agrees to participate, (4) have a Karnofsky Performance Status score (KPS) of 60 or below, and (5) have a life-expectancy of 3 months or less.

Because of recruitment problems, the first amendment was implemented in February 2013, after 24 participants had been included. The criteria of a KPS of 60 or below and life expectancy of 3 months or less were replaced by a new criterion, namely that patients should not be receiving any disease-modifying treatment at the time of inclusion nor would do so in the future. However, as recruitment did not improve sufficiently, a second amendment was implemented in July 2013, after 35 participants had been included, whereby the latter criterion was removed and was not replaced with new inclusion criteria.

### Randomization

After completing the baseline measurements, the participants were randomized into two groups: intervention or control. We used block randomization with different size blocks (4 and 6) to maintain an equal balance between groups. Randomization occurred at the level of individual patients, with an allocation ratio of 1:1. The author involved in the process of approaching, informing and visiting participants (PH) was not informed about the outcome of the randomization process before baseline measurements had taken place. Initially, it was expected that patients would be recruited by their GPs and therefore, to prevent bias, a cluster randomization procedure at the level of the GP was described in the original study

protocol.<sup>15</sup> However, the vast majority of patients were eventually recruited via the SPCT and GPs did not recruit individual participants for this study. Consequently, there were no clusters of participants with the same GP. Therefore, in the first amendment, we decided that there was no further need for cluster randomization. As a result, randomization took place at the level of the individual participant.

## 4

### Care as usual

Participants in both groups received palliative home care provided by their GP, supported by the SPCT according to the standard referral procedures, i.e., patients could be referred to the SPCT by their GP or by the attending hospital specialist or were not referred at all. If applicable, follow-up by the SPCT occurred by phone or by patients visiting the outpatient clinic, depending on the patient's preference, the complexity of their problems, and/or the stage of their disease.

### Intervention group

#### *Procedure*

Participants in the intervention group had weekly teleconsultations for a period of 13 weeks in addition to their usual care. First, a teleconsultation device was installed at the patient's home. Patients who had not visited the SPCT before were evaluated at the outpatient clinic or during a home visit by one of the SPCT members (a nurse or physician). Then, teleconsultations were scheduled on a weekly basis for a period of 13 weeks. At the agreed time, a member of the SPCT (mostly the nurse practitioner) initiated the teleconsultation. In between these scheduled appointments, the participants could not directly contact the SPCT members through teleconsultation. When in need of medical advice, the patients were encouraged to contact their GP; however, if necessary, the SPCT could be reached by phone.

A predefined consultation schedule was available to the SPCT members to ensure that all domains of palliative care were sufficiently covered during the teleconsultations. Problems and needs of participants were identified and discussed with other team members if necessary. The participant's GP was invited to visit and join the patient during the teleconsultation appointments. If this was not possible, after the first teleconsultation, a member of the SPCT contacted the patient's GP by phone to discuss the patient's current problems and needs, possible treatment policies, and the GP's involvement during the following study period. After the first and the last scheduled teleconsultation, the SPCT was encouraged to send a letter to the participant's GP, outlining the patient's current problems and needs and advised treatment policies.

#### *Teleconsultation device*

Initially, in 2011, teleconsultation devices consisted of a Pal4-desktop computer ("*Bidibox*", *Focusscura Inc., the Netherlands*) with a touch screen, a separate microphone/ speaker, and

a separate camera. During the study period, tablet computers became available. These devices seemed more user-friendly, and therefore the “Bidibox” computers were replaced by tablet computers (*iPad 2® and iPad mini®; Apple Inc., United States*). The Pal4 application was replaced by FaceTime® (*Apple Inc., United States*).

### Outcome measures

The primary outcome was patient-experienced symptom burden, based on the Edmonton Symptom Assessment System (ESAS) and the Hospital Anxiety and Depression Scale (HADS). The secondary and other study outcomes have been described in our study protocol.<sup>15</sup>

4

### Data collection

Data collection ended after 12 weeks. During the 13th week of the study period a closing teleconsultation was scheduled for participants from the intervention group. During this 13th week participants did not complete any questionnaires.

Questionnaires for baseline measurements were handed over by one of the researchers (PH) or sent through postal mail. After completion, participants handed over the questionnaires to the researchers or sent them back through postal mail. During the study period, participants received and returned the required questionnaires through postal mail and sent them back every 4 weeks. If necessary, one of the researchers (PH) reminded the participants by phone, SMS, or e-mail to return the required questionnaires.

Participants completed the following questionnaires: the ESAS (at baseline, weekly follow-up), HADS, Problems and Needs in Palliative Care-short version, and a modified version of the Nijmegen Continuity Questionnaire (NCQ) (all three: at baseline, four-weekly follow-up). Informal caregivers completed one questionnaire: Self-Perceived Burden from Informal Care (EDIZ) (at baseline, two-weekly follow-up).

Additionally, participants in the intervention group completed a Patient Satisfaction Questionnaire (PSQ) after the first two teleconsultations. If applicable, the SPCT members involved in the teleconsultations and the participant’s GPs also completed a PSQ after the first two teleconsultations.

Finally, demographic information was collected at baseline. Information on other study outcomes (GP contacts, complex interventions, and hospital admissions<sup>15</sup>) was requested from the patient’s GP after the study period.

### Questionnaires

The ESAS is a self-reporting scale consisting of nine symptoms that are common in patients diagnosed with cancer.<sup>31</sup> Items can be scored on a 0–10 visual numerical scale (with 0 indicating the absence of a symptom and 10 indicating the worst imaginable intensity of a symptom). The ESAS is widely used, and its psychometric properties are considered good in our study population.<sup>32–35</sup> The Total Distress Score (TDS) is defined as the sum of the nine subscales. The HADS is a 14-item self-report screening scale that provides an indication of

the possible presence of anxiety and depressive symptoms.<sup>36</sup> Each item is scored on a 4-point Likert scale. The questions assess symptoms in the preceding week. Its psychometric properties are considered moderate to good.<sup>35, 37</sup>

The secondary outcomes of this study were measured by the following questionnaires: (1) the Problems and Needs in Palliative Care-short version (patient-experienced problems and needs),<sup>38, 39</sup> (2) the NCQ (patient-experienced continuity of care),<sup>40, 41</sup> (3) the PSQ (satisfaction with teleconsultations),<sup>42-44</sup> and (4) the Self-Perceived Burden from Informal Care.<sup>45</sup>

## 4

### Sample size

For the original calculation of sample size, we refer to our study protocol.<sup>15</sup> As a result of the aforementioned changes in the randomization procedure, we removed the correction factor to adjust for a cluster effect, yielding an aimed total sample size of 84 patients.

### Statistical analysis

Data were stored and analyzed in the Radboud university medical center, Nijmegen, the Netherlands, using SPSS Software (IBM Corp. Released 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp).

Observed values were reported as the mean and standard deviation (SD) for continuous variables, and the number and percentage for categorical variables.

The null hypothesis for this study was that there would be no difference in patient-experienced symptom burden between the intervention and control groups. To test this hypothesis, for all outcomes, a mixed model with a random intercept for "Patient" was used to accommodate the repeated measurements over time. The dependent variable was the relevant outcome, at any time after T0. For scale variables, a linear mixed model was used, while for dichotomous outcomes, a generalized mixed model with a logit-link function was used. To identify the best model, a series of models was tested. Starting from the simplest model, each subsequent model was extended step by step until further extensions showed non-significant improvement.

The simplest model had only the Experimental condition (i.e., "group": intervention or control) and the measurement of the outcome variable at T0 ("score at baseline") as the independent variables. The next step added Time as an independent variable. After that, the interaction between Experimental condition and Time ("group\*time") was considered.

By using mixed models, every available observation contributes to the modeling of the relation between outcome and variables. As a result of this approach, missing data did not result in exclusion of participants from analyses.

Statistical software R, version 3.0.1, was used in combination with the *lmer* procedure from the *lme4* library for the mixed modeling analyses.

## RESULTS

A total of 957 patients were screened. We excluded patients who (1) did not meet the inclusion criteria ( $n = 511$ ); (2) were not approached for participation for other reasons ( $n = 202$ ); or (3) were not willing to participate ( $n = 167$ ). Thus, a total of 77 participants gave informed consent and were enrolled in the study. Of these participants, three did not complete the baseline measurement. Consequently, 74 participants were randomized to either the intervention group ( $n = 38$ ) or the control group ( $n = 36$ ). A total of 32 participants (42%) completed the study. All other participants prematurely ended this study for several reasons, mostly related to death or deteriorating condition (*Fig. 1*). The attrition rates were relatively high in both groups; 61% and 53% of participants in the intervention and control group, respectively, stopped contributing data during the course of the study. These rates did not differ between groups ( $P = 0.64$ ). Sensitivity analyses on the attrition rates in relation to baseline measurements of participants showed a significant correlation between baseline scores on TDS, HADS-anxiety, and HADS-depression and attrition rates for participants from the control group. The effect of this on the study outcomes was mitigated by including baseline scores as independent variables in the regression models.

Demographic baseline characteristics are shown in *Table 1*. All 74 participants were analyzed for the primary outcome. Furthermore, 71 participants had an informal caregiver who gave informed consent and was enrolled in the study.

Due to financial and time constraints this study was ended after 45 months before the calculated sample size was reached.

### Symptom burden

At baseline, the mean observed TDS in the intervention group was almost 7 points higher ( $31.03 \pm 17.21$ ) than that of the control group ( $24.33 \pm 14.54$ ). Over the study period, the control group showed a slight decline in the mean observed TDS. The intervention group also showed a decline in the mean observed TDS during the first 8 weeks of the study; however, in the last 4 weeks, the mean TDS increased almost 9 points to  $36.62 (\pm 20.14)$  at week 12, compared to  $22.38 (\pm 11.27)$  in the control group (*Table 2*). The adjusted TDS scores became significantly higher in the intervention group, indicating a growing symptom burden in this group over time compared to the control group (*Fig. 2*). When testing specific points in time, this difference reached significance at week 12 (adjusted difference at week 12: 6.90; 95% CI, 0.17 to 13.63;  $P = 0.04$ ; *Table 3*).

The mean observed HADS-anxiety scores in the control group declined somewhat during the first 4 weeks of the study (from  $6.22 \pm 3.91$  to  $5.23 \pm 3.41$ ) and thereafter remained rather stable. Within the intervention group, the mean observed anxiety scores were relatively stable during the first 8 weeks of the study, but increased between week 8 and week 12 from  $7.11 (\pm 3.39)$  to  $8.46 (\pm 4.25)$ . Within the intervention group, the mean observed HADS-depression scores remained stable during the study period. The mean observed depression scores declined in the control group during the first 8 weeks (from  $6.49 \pm 4.57$  to  $5.76 \pm 3.92$ );

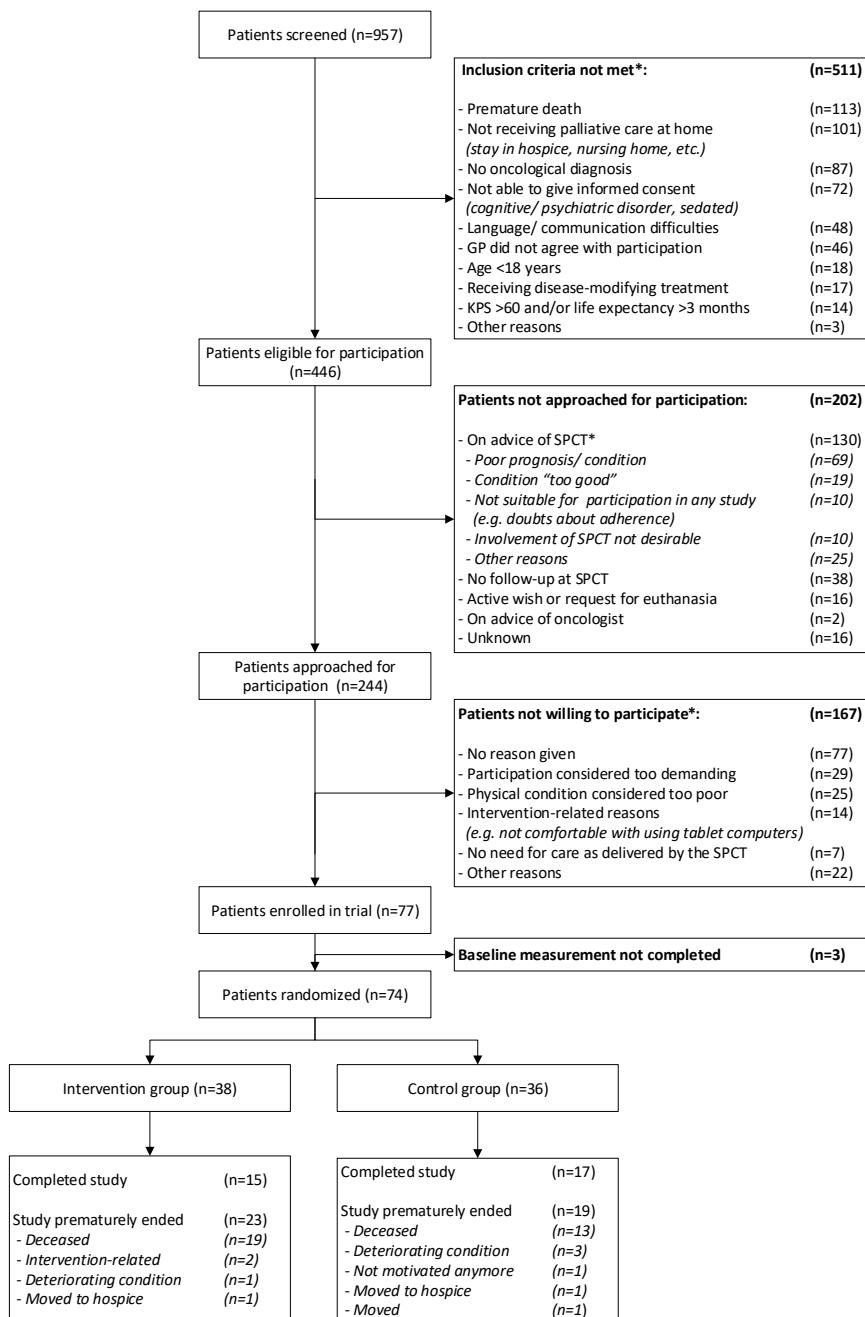


Figure 1. Screening and participants, \*More than one reason may apply

however, over the last 4 weeks, depression scores increased to 7.00 ( $\pm 4.95$ ) at week 12 (Table 2). The adjusted anxiety scores were significantly higher in the intervention group than in the control group (estimate effect: 1.40; 95% CI, 0.14 to 2.66;  $P = 0.03$ ). The depression scores did not differ between the two groups (estimate effect: 0.30; 95% CI,  $-1.39$  to 1.99;  $P = 0.73$ ; Table 3).

**Table 1.** Baseline Characteristics of the Participants (n= 74)

	Intervention group (n=38)		Control group (n=36)	
<b>Demographics</b>				
Age, mean (SD), years	62.3	(9.0)	61.9	(10.6)
Female, n (%)	11	(29)	14	(39)
Diagnosis, n (%)				
Urogenital cancer	13	(34)	15	(42)
Gastro-intestinal cancer	6	(16)	5	(14)
Hepatobiliary and pancreatic cancer	4	(11)	5	(14)
Lung cancer	6	(16)	2	(6)
Head and neck cancer	3	(8)	5	(14)
Breast cancer	3	(8)	0	(0)
Skin cancer	0	(0)	1	(3)
Other type of cancer	3	(8)	3	(8)
Marital status, n (%)				
Married/ permanent relationship	27	(71)	29	(81)
Divorced	5	(13)	1	(3)
Single	4	(11)	5	(14)
Widow(er)	2	(5)	1	(3)
Having one or more children, n (%)	32	(84)	30	(83)
Living situation, n (%)				
Together with partner and/or children	28	(74)	29	(81)
Alone	9	(24)	6	(17)
Other living situation	1	(3)	1	(3)
Household, mean number of persons (SD)	2.0	(0.9)	2.0	(0.6)
Highest educational level, n (%)				
No education/ primary school	1	(3)	3	(8)
Lower vocational education	10	(26)	7	(19)
Lower general secondary education	4	(11)	8	(22)
Intermediate vocational education	11	(29)	7	(19)
Higher general secondary education / pre-university education	3	(8)	2	(6)
Higher professional education/university	9	(24)	9	(25)

**SD** = Standard deviation.

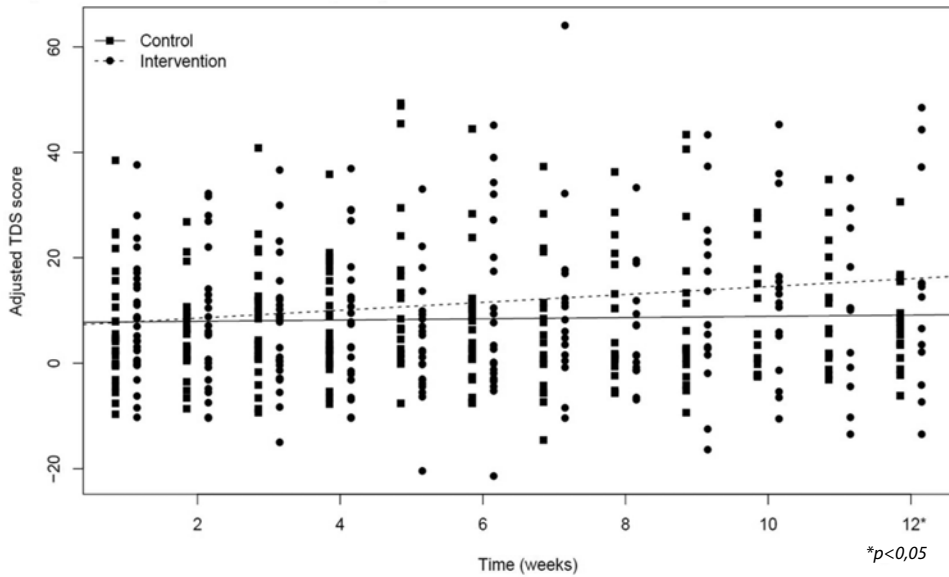
Percentages may not add to 100% due to rounding.



**Table 2.** Observed values at baseline and weeks 4, 8 and 12.

		Group	Baseline	Week 4	Week 8	Week 12
<b>ESAS</b>						
TDS, mean (SD)	(0-90)	Intervention	31.03 (17.21) n= 38	30.68 (19.58) n= 22	27.73 (15.87) n= 15	36.62 (20.14) n= 13
		Control	24.33 (14.54) n= 36	24.17 (13.79) n= 27	22.20 (10.89) n= 20	22.38 (11.27) n= 16
<b>HADS</b>						
Anxiety, mean (SD)	(0-21)	Intervention	7.24 (4.70) n= 38	7.48 (4.19) n= 23	7.11 (3.39) n= 16	8.46 (4.25) n=13
		Control	6.22 (3.91) n= 36	5.23 (3.41) n= 26	4.71 (3.08) n= 21	5.06 (3.21) n= 16
Depression, mean (SD)	(0-21)	Intervention	7.66 (3.87) n= 38	7.45 (4.82) n= 23	7.31 (4.45) n= 16	7.85 (5.10) n= 13
		Control	6.49 (4.57) n= 36	6.25 (4.16) n= 26	5.76 (3.92) n= 21	7.00 (4.95) n= 16
<b>PNPC-sv</b>						
Number of unmet needs, mean (SD)	(0-32)	Intervention	3.94 (5.68) n= 37	2.07 (3.82) n= 23	1.31 (3.48) n= 16	2.02 (3.88) n= 13
		Control	2.92 (4.36) n= 36	2.57 (3.75) n= 25	1.42 (2.60) n= 17	2.80 (5.21) n= 15
<b>NCQ</b>						
Personal continuity, mean (SD)	(6-30)	Intervention	24.33 (3.76) n= 36	24.52 (3.10) n= 23	24.73 (3.26) n= 15	24.38 (3.55) n= 13
		Control	22.81 (4.43) n= 33	23.00 (3.43) n= 25	23.28 (5.33) n= 18	21.92 (4.27) n= 13
Team continuity (within hospital), mean (SD)	(4-20)	Intervention	14.20 (3.26) n= 30	15.89 (2.27) n= 18	15.75 (2.01) n= 12	14.60 (3.24) n= 10
		Control	15.12 (3.15) n= 31	15.59 (2.92) n= 17	15.42 (2.61) n= 12	13.73 (2.45) n= 11
Cross-boundary continuity, mean (SD)	(4-20)	Intervention	15.83 (3.09) n= 24	16.56 (3.01) n= 18	14.20 (2.78) n= 15	16.59 (2.98) n= 13
		Control	15.16 (3.13) n= 25	15.35 (2.57) n= 18	14.10 (4.25) n= 13	14.33 (3.20) n= 9
<b>EDIZ</b>						
Total score, mean (SD)	(9-45)	Intervention	15.78 (5.87) n= 36	14.54 (7.09) n= 21	16.09 (8.39) n= 16	15.95 (8.25) n= 12
		Control	15.54 (6.46) n= 35	17.45 (8.39) n= 25	14.74 (5.88) n= 19	15.00 (7.10) n= 14

SD: standard deviation. **ESAS**: Edmonton Symptom Assessment System **TDS**: Total Distress Score **HADS**: Hospital Anxiety and Depression Scale **PNPC-sv**: Problems and Needs in Palliative Care-Short Version **NCQ**: Nijmegen Continuity Questionnaire **EDIZ**: self-perceived burden of informal care.



**Figure 2.** Adjusted Total Distress Score (TDS) during the study period

**Table 3.** Primary outcome measures – mixed models.

	B (SE)	95% CI		p-value
		Lower limit	Upper limit	
<b>ESAS - Total Distress Score (TDS)</b>				
Intercept	7.26 (3.17)			
Group <sup>a</sup>	-0.66 (3.26)	-6.99	5.66	0.84
TDS score at baseline	0.78 (0.11)	0.57	0.99	<0.001
Time <sup>b</sup>	0.12 (0.17)	-0.21	0.45	0.48
Group *time	0.63 (0.25)	0.14	1.11	0.01
<b>HADS-anxiety</b>				
Intercept	0.54 (0.76)			
Group <sup>a</sup>	1.40 (0.65)	0.14	2.66	0.03
HADS-A score at baseline	0.78 (0.09)	0.61	0.95	<0.001
Time <sup>b</sup>	0.12 (0.06)	0.01	0.23	0.04
<b>HADS-depression</b>				
Intercept	1.56 (1.03)			
Group <sup>a</sup>	0.30 (0.87)	-1.39	1.99	0.73
HADS-D score at baseline	0.70 (0.11)	0.49	0.91	<0.001
Time <sup>b</sup>	0.13 (0.08)	-0.03	0.29	0.12

B: estimate effect. SE: Standard Error. 95% CI: 95% Confidence Interval

ESAS: Edmonton Symptom Assessment System, TDS: Total Distress Score, HADS-A: Hospital Anxiety and Depression Scale – Anxiety, HADS-D: Hospital Anxiety and Depression Scale – Depression

<sup>a</sup>Group: intervention = 1; control = 0.

<sup>b</sup>Time: week number, baseline = week 0.

### Secondary and other study outcomes

The mean number of unmet needs did not differ between the intervention and control groups (estimate effect:  $-0.01$ ; 95% CI,  $-0.07$  to  $0.04$ ;  $P = 0.67$ ). Additionally, the number of participants having at least one unmet need did not differ between the groups (OR:  $0.79$ ; 95% CI,  $0.19$  to  $2.92$ ;  $P = 0.66$ ). On all three subscales of the NCQ for continuity of care, i.e., personal continuity (estimate effect:  $0.15$ ; 95% CI,  $-0.09$  to  $0.38$ ;  $P = 0.22$ ), team continuity (estimate effect:  $0.16$ ; 95% CI,  $-0.20$  to  $0.51$ ;  $P = 0.39$ ), and cross-boundary continuity (estimate effect:  $0.29$ ; 95% CI,  $-0.08$  to  $0.67$ ;  $P = 0.13$ ), there were no differences between groups. Finally, the mean number of hospital admissions during the study period did not differ between the intervention group ( $0.47$ ) and the control group ( $0.38$ ;  $P = 0.60$ ).

Study outcome measures regarding GP contacts and complex interventions did not statistically differ between both groups. The mean satisfaction scores after the first two teleconsultations were high for both the participants ( $90.4 \pm 8.2$  and  $89.4 \pm 9.7$ ) and the SPCT members ( $87.0 \pm 7.1$  and  $85.5 \pm 15.2$ ).

When comparing the number of informal caregivers with a high perceived burden (defined as the upper third of the group), there was a trend towards a lower proportion of informal caregivers with a high perceived burden in the intervention group (estimate effect:  $-2.24$ ; 95% CI,  $-5.24$  to  $0.02$ ;  $P = 0.05$ ).

## DISCUSSION

### Main results

We found a difference in reported symptom burden between home-dwelling patients with advanced cancer receiving palliative care “as usual” and patients who additionally had weekly teleconsultations with a hospital-based SPCT.

Therefore, we can reject our null hypothesis, which stated that there would be no difference in patient-experienced symptom burden between the intervention group and the control group. Contrary to our expectations, this additional intervention led to a higher reported symptom burden in the intervention group than in the control group. The number of unmet needs, experienced continuity of care, and reported hospital admissions did not differ between groups.

### Comparison with the literature

To the best of our knowledge, this is the first RCT to show that, despite difficulties in recruitment, technical challenges, and relatively high drop-out rates, it is possible to perform an RCT on telemedicine, which can be considered a complex intervention, in palliative care.<sup>46</sup>

We found an observed mean TDS ranging from  $21.4$  to  $36.6$ . This is comparable to other studies reporting ESAS scores from patients with advanced cancer visiting outpatient clinics,<sup>47–49</sup> although higher scores have been reported.<sup>50</sup>

While the TDS in the control group remained relatively stable during the study period, the TDS of the intervention group increased. For both the observed and the adjusted TDS, this increase was of more than 4 points, indicating a clinically relevant deterioration according to Hui *et al.*<sup>49</sup> This deterioration seems to be in contrast with earlier research in which video technologies did not affect symptom burden or even led to a possible improvement in clinical outcomes.<sup>21, 25</sup> On the other hand, the adjusted difference between both groups at week 12 was less than 8 points, which is the minimum clinically important difference stated in the power calculation of our study protocol.<sup>15</sup> Therefore, and given the relatively wide confidence intervals of the adjusted difference in TDS, the clinical relevance of the difference in TDS should be interpreted with proper caution.

The higher reported symptom burden found in this study might be partially explained by the participant's perceptions of symptoms. Participants in the intervention group received weekly attention for their (potential) symptoms. This might have led to a higher awareness of symptoms among participants, leading to a worsening symptom experience. This phenomenon is referred to as the "nocebo effect".<sup>51</sup> In a review on this topic, Häuser *et al.*<sup>51</sup> state that patients are "*highly receptive to negative suggestion, particularly in situations perceived as existentially threatening*". This negative suggestion includes focusing one's attention towards the presence of particular symptoms. The "nocebo effect" may be avoided by adapting the frequency and timing of the teleconsultations to the actual needs of the individual patient.

Another explanation for our findings might be the differential recall bias among participants. For participants in the intervention group, the reported symptom burden was strongly related to the content of their weekly teleconsultations. As a result, their symptom burden may have been registered more precisely, possibly leading to higher symptom scores.

### **Strengths and limitations**

An important strength of this study is that we have systematically screened a large group of patients for participation in this trial. Despite considerable difficulties in recruitment, the intended sample size was nearly reached, although over a longer period of time and with adjusted inclusion criteria. Finally, this is the first completed RCT on telemedicine in palliative care with outcome measures that are clinically relevant and relate directly to patient care and experienced quality of life. This study also has some limitations. First, a considerable group of patients who were eligible for participation in this trial were not approached, mostly as a result of clinical considerations, which may have caused non-differential selection bias. Additionally, the relatively small number of patients who were eventually approached for participation might also reflect that offering teleconsultations in the context of a randomized study might not fit the needs of palliative care patients. Second, the attrition rate in this study was relatively high and attrition may depend on the clinical condition of participants. Although in our statistical models we have corrected for baseline measurements (i.e.,

the clinical condition of participants at the start of the study), study outcomes may have been influenced by participants' worsening clinical condition during the study. Third, the participants sometimes had difficulty adequately completing the questionnaires as a result of their varying clinical conditions. This might have led to information bias, although likely non-differential. Fourth, the outcome measure "place of death" was described in the study protocol, however, it was not included in the information request at the patient's GP; thus, this study outcome is missing. Fifth, two amendments had to be made to the study protocol to improve the recruitment rates. As a result of widening the inclusion criteria of this study, the study population may have become more heterogeneous, which may have led to a dilution of the effect of the intervention. Finally, the involvement of GPs in this study was less than expected; therefore, the participants were not recruited by their GP but were instead recruited at the outpatient clinic of the SPCT, probably leading to higher levels of specialist care in both groups, which may have positively affected symptom scores.

### **Clinical implications**

In this study, we introduced a model for teleconsultation in palliative care that was intended to be proactive and was mainly supply driven. Teleconsultations were scheduled on a weekly basis for a period of 3 months, irrespective of the actual needs of the patient regarding the timing and frequency of these teleconsultations. This model was shown to be ineffective in reducing experienced symptom burden, even though patients and caregivers showed a high degree of satisfaction. Therefore, we propose focusing on care models that are patient-tailored and demand-driven, i.e., patients themselves indicate when they are in need of palliative care (tele)consultations. This model could prevent a possible excess of medical care regarding palliative care, death, and dying. At the same time, to avoid a rather reactive palliative care approach, patients should be provided tools and support to guide them in proactively contacting their caregivers when problems arise.

## **CONCLUSIONS**

Telemedicine is emerging in all fields of medicine, including palliative care. Despite promising earlier research, the present study shows that telemedicine does not necessarily lead to a better quality of advanced cancer care. Indeed, the use of telemedicine might create a situation in which patients experience a higher symptom burden, despite high degrees of satisfaction. Future research and care models should therefore explore the beneficial as well as the potentially harmful aspects of teleconsultations within advanced cancer care, thereby focusing on (1) ways to optimize multidisciplinary care via teleconsultations, (2) the appropriate timing and frequency of palliative care teleconsultations for patients with advanced cancer and other groups of vulnerable patients, (3) possibilities for patient-tailored, demand-driven teleconsultations, and (4) the potential impact of technology as such on the patient's sense of wellbeing. These issues should be adequately addressed, both in future research and in implementation trajectories regarding the use of telemedicine in palliative home care.

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# 5

## USING TRIPARTITE TELECONSULTATIONS TO PROVIDE INTERDISCIPLINARY PALLIATIVE CARE TO ADOLESCENTS AND YOUNG ADULTS (AYAs) WITH ADVANCED CANCER – A QUALITATIVE MULTIPLE CASE STUDY

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## ABSTRACT

### Background

Palliative care for adolescents and young adults (AYAs) is complex due to a combination of AYA-related factors and healthcare system-related factors. Interdisciplinary collaboration between general practitioners (GPs) and medical oncologists (MOs) can optimize palliative care for home-dwelling AYAs with advanced cancer. Tripartite teleconsultations directly involving AYA patients may facilitate interdisciplinary care. The purpose of this study was to explore and describe the use of tripartite teleconsultations in the context of interdisciplinary care for AYAs with advanced cancer.

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### Methods

We performed a qualitative multiple case study with each case consisting of an AYA with advanced cancer, their GP, MO and other relevant hospital-based caregivers. AYAs were recruited from the Medical Oncology outpatient clinic of a tertiary university hospital. Per case, four interdisciplinary meetings were organized by means of tripartite teleconsultations. Serial, semi-structured interviews, using a “stimulated recall” video method, were used to gain insights into how participants used and experienced these teleconsultations. The interviews were analyzed using thematic analysis.

### Results

A total of 16 teleconsultations were organized for the 6 cases in this study, resulting in 29 interviews. From these interviews, six main themes were discerned. *Care for AYA patients with advanced cancer* describes the current, mainly hospital-based organisation of care for AYAs with advanced cancer. *Teleconsultations facilitate team care* describes and explains how tripartite teleconsultations facilitate interdisciplinary collaboration between GPs and hospital caregivers. The other four main themes, *Visual Reality: you gain some, you lose some*; *Front stage communication*; *Backstage communication* and *Organisation and Logistics* describe how tripartite teleconsultations change communication dynamics, how communication etiquettes are challenged, and how technical impairments and logistical issues seriously hamper the use of these teleconsultations in daily practice.

### Conclusions

Tripartite teleconsultations can contribute to interdisciplinary collaboration and a more integrated care approach for AYAs with advanced cancer. However, technical and logistical issues require rigorous refinements and improvements when considering the use of these teleconsultations in daily practice. Furthermore, tripartite teleconsultation introduces new dilemmas and challenges regarding communication dynamics and etiquettes that need to be carefully addressed, explored and evaluated prior to and during its use in daily practice.

## BACKGROUND

Adolescents and young adults (AYAs) can be considered a separate group within the field of oncology.<sup>1</sup> Although definitions of age limits differ internationally, AYA cancer patients in the Netherlands are commonly defined as those patients diagnosed with cancer when aged between 18 -35 years.<sup>2,3</sup> In line with international observations, a rise in cancer incidence in the AYA population has been seen in the past two decades in the Netherlands.<sup>2,4-6</sup> Globally, it is estimated that approximately one million patients aged between 15-39 years are diagnosed with cancer every year.<sup>2</sup> In the Netherlands, almost 2,500 AYAs were diagnosed with cancer in 2016.<sup>7</sup>

In general, 5-year survival rates among AYA cancer patients are slightly over 80%.<sup>4,5</sup> As a result, approximately one-fifth of these AYA patients die within 5 years after diagnosis and will most likely need some form of palliative care, somewhere in their illness trajectory. Palliative care focuses on quality of life for patients with life-threatening illnesses, including advanced cancer.<sup>8</sup> Palliative care for AYA patients with advanced cancer is considered more complex than that of other patients, as a result of both AYA-related factors and healthcare system-related factors.

### AYA-related factors

Ongoing physical, cognitive, psychological, social and spiritual development in AYAs may affect all domains of palliative care. For example, while AYA patients with cancer may suffer from a more intense symptom burden compared to other age groups,<sup>9</sup> there is a risk of suboptimal pain treatment due to the fear among healthcare providers about drug abuse or addiction.<sup>10</sup> Moreover, while young adulthood in general can already be considered a high-risk period for the onset of major mental conditions, being confronted with a life-threatening disease and the accompanying uncertainty, loss of independency and isolation from peers may further contribute to the development of mood and anxiety disorders. Furthermore, feelings of shame regarding these issues and AYA patients variably accepting help on this domain may further complicate these problems.<sup>9</sup> Finally, while imminent death is a complex subject in palliative care in general, in AYA cancer patients this may be even more complex due to the high number of lost (potential) years of life, issues regarding legacy formation and, for some patients, worries about their young children.<sup>9-11</sup>

### Healthcare system-related factors

In their review, Clark and Fasciano described the lack of specific AYA patient-focused palliative care as the healthcare system is generally divided into adult-oriented and child-oriented care.<sup>9</sup> Furthermore, healthcare professionals may feel uncomfortable providing palliative care to AYA patients with cancer due to feelings of unfairness or difficulties setting professional boundaries, and they are often insufficiently trained to provide age-appropriate care to young patients with a life-threatening condition.<sup>9,12,13</sup> Moreover, AYA patients with cancer relatively often receive intensive treatments during their last weeks of life, which may cause a barrier to discussing end-of-life care needs.<sup>14</sup>

Most AYA patients with cancer seem to have a preference to be cared for and eventually to die at home.<sup>15,16</sup> Therefore, a substantial part of palliative care takes place in the patient's home-environment. Within the context of the Dutch healthcare system, general practitioners (GPs) are the main and coordinating caregivers for patients at home. As a result, the GP plays a central role in palliative care for home-dwelling patients.<sup>17</sup> However, GPs generally have limited experience in delivering palliative care to young patients, and consider palliative care for AYA patients as "more difficult".<sup>18</sup> In some cases, GPs might even have little to no care history with an AYA patient with cancer, as oncology care largely takes place in hospitals.<sup>18</sup>

In order to overcome these barriers and to optimize palliative care for home-dwelling AYA patients with advanced cancer, we developed a teleconsultation model to provide home-based palliative care with an interdisciplinary character, combining both the skills and knowledge of generalist and specialist healthcare providers. Earlier research on the use of teleconsultations in home-based adult palliative care showed that the use of teleconsultations fitted the practice of palliative homecare,<sup>19</sup> although it did not quantitatively improve palliative care outcomes.<sup>20</sup> However, direct interdisciplinary GP involvement was scarce,<sup>21</sup> or GP involvement was considered suboptimal.<sup>20</sup> Therefore, in this study, we used advanced teleconsultation techniques to organize digital interdisciplinary meetings directly connecting hospital caregivers, GPs and patients using synchronous audio-visual communication.<sup>22</sup> We hypothesized that young patients are familiar with the use of teleconsultation techniques in daily life. Therefore, we assumed that these techniques would fit the practice of AYA cancer care and AYA palliative care.

To the best of our knowledge, little is known about the use of these techniques in complex care settings, such as AYA palliative care. Therefore, the aim of this study is to explore and describe the use of digital interdisciplinary team meetings in the context of palliative care for AYA patients with advanced cancer.

## METHODS

### Design

We performed a qualitative multiple case study that included semi-structured qualitative interviews with AYA patients with advanced cancer, GPs, medical oncologists (MOs) and, if relevant, other hospital caregivers concerned in AYA care.

This study design fitted both the intervention that was central to this study (i.e. interdisciplinary, tripartite teleconsultations) as well as the characteristics of the study population. First, the teleconsultation intervention central to this study should be considered as a complex intervention "*still under construction*", demanding a qualitative study design that offers room for exploration and unanticipated outcomes.<sup>23</sup> Second, the population of AYAs with advanced cancer receiving palliative care is both relatively small and heterogeneous when it comes to age- and developmental-related factors such as family situation, working situation, etc.<sup>7,9</sup> A multiple case study design, therefore, best accounts for these population characteristics.<sup>24</sup> In this study, a case consisted of one AYA cancer patient, their GP, their MO and other hospital caregivers, if relevant.

The Committee on Research Involving Human Subjects, Region Arnhem-Nijmegen reviewed the study protocol (reg.2014/027) and stated that no further ethical assessment was needed for this research. Oral informed consent was obtained from all participants. Data was collected during the period October 2014 – July 2015.

## Participants

### *Setting and location*

Participants were recruited from the outpatient clinic of the department of Medical Oncology of the Radboud university medical center (Radboudumc), Nijmegen, the Netherlands. The Radboudumc, as part of the Dutch National AYA 'Young and Cancer' Platform, is able to offer age-specific care for AYA cancer patients, delivered by a multidisciplinary team. Furthermore, in the Netherlands, the Radboudumc is an expert centre for the treatment of bone and soft tissue sarcomas; rare types of cancer that are relatively common among AYA patients.

### *Inclusion criteria*

As discussed, the population of AYA cancer patients receiving palliative care is relatively small and heterogeneous. Therefore, participants were recruited following a theoretical replication logic sampling procedure in order to obtain contrasting results, but for anticipated reasons.<sup>24</sup> We aimed to recruit a heterogeneous group of participants based on two main characteristics: gender and living situation (living with parents or living together with a partner and/or children).

One of the authors (PH or JvG) approached the MO and/or a clinical nurse specialist involved in AYA oncology care to identify potential participants. These participants had to be able to give informed consent and meet the following inclusion criteria: 1) aged between 18-35 at the time of cancer diagnosis, 2) diagnosed with cancer for which they no longer received treatment with curative intent, 3) speak Dutch to a sufficient degree to participate in this study. Furthermore, given the nature of the intervention, the participant's GP and medical oncologist also had to give oral consent for participation.

## Intervention

Per case, four interdisciplinary team meetings were organized by means of synchronous audiovisual teleconsultations over a time span of three to eight months. It was suggested that these teleconsultations take place on a monthly basis, but participants were free to plan these meetings within variable time intervals, depending on their possibilities and needs.

To participate in these teleconsultations, participants could use their own device (pc, laptop or tablet computer) or could use a tablet computer (*iPad; Apple Inc.; United States*) provided by the department of Medical Oncology of the Radboudumc. In order to participate, all participants had to install a video application (*VSee; VSee Lab, Inc.; United States*) on their device.

Participants received an e-mail invitation, containing a hyperlink with which they could enter the digital meeting room (*PatientHub, FocusCura Inc.; the Netherlands*). At the prescheduled time, and when all participants had entered the digital meeting room, a connection between the participants was established by one of the researchers (PH, JvG). From then on, the researchers did not actively participate in the teleconsultation. For study purposes, participants had given consent to the researchers to directly observe and audio-visually record the teleconsultation.

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### *Data collection*

We used serial, semi-structured qualitative interviews using a “stimulated recall” video method in order to gain insights in how participants experience and co-design these interdisciplinary palliative care teleconsultation practice over time.<sup>25,26</sup> This method uses video fragments to help participants remember the general content of the teleconsultation and to reflect on specific events that occurred during the teleconsultation. One of the researchers (PH) selected and used fragments from the video recordings and combined them with direct observations to specify and personalize the general interview guide. Per case, participants were interviewed four times during the study period, i.e. after every meeting by one or two of the researchers (PH and/or JvG). The participant’s MO, GP and other relevant hospital caregivers were interviewed once or twice during the study period. Interviews took place within a month of the digital interdisciplinary meetings and were audio-recorded.

### *Data analysis*

Qualitative data from the interviews were analyzed using the 6 phases of thematic analysis.<sup>27</sup> First, interviews were transcribed verbatim by two research assistants. The researchers (PH and/or JvG) read the transcripts and randomly checked the transcripts for errors. PH and JvG independently read and analyzed the first four interviews from case 1 (i.e. two interviews with the AYA patient, one with the MO and one with the GP), using a process of open coding. After every one or two interviews, PH and JvG met to discuss and compare the emerging codes and to accompany these codes with explanatory memos. Based on this coding process, PH and JvG developed a preliminary code book consisting of main themes and sub-themes, using a process of axial coding. Subsequently, PH and JvG used this preliminary code book to independently code the other 4 interviews from the first case. After coding, PH and JvG discussed the coding process and subsequently adapted and refined the preliminary code book. This further refinement of the code book was the result of a process of constantly comparing emerging themes to already formulated themes (do these themes form a coherent pattern?) and to the original data (do themes reflect the content of the data set?).<sup>27</sup> For all themes and subthemes a more detailed explanation was included in the code book and relevant extracts (“quotes”) were selected and included in the code book. All cases were linked to a unique colour in the code book, enabling the researchers to distinguish the cases throughout the codebook and to identify whether codes were unique for one case

or applicable to more cases. Finally, the main themes and sub-themes were defined that formed the basis for the content of the result section.

### *Quality measurements*

The following measures were taken to increase the reliability and validity of this study. PH was trained and guided by an experienced qualitative researcher in the context of palliative care (JvG). Furthermore, the following aspects from the “checklist of criteria for good thematic analysis” developed by Braun *et al.*,<sup>27</sup> further contributed to the validity of this study:

- Data were transcribed verbatim and transcripts were randomly checked for accuracy. Unintelligible interview fragments were highlighted by the research assistants and specifically checked by one of the researchers (PH).
- The two researchers (PH and JvG) performed the process of open coding independently and differences in coding were discussed. These discussions led to further refinement and accentuation of emerging codes and themes. Furthermore, when developing a code book (phase 3-5), emerging themes were checked for validity in a process of constant comparison.
- As we used a system based on colours, individual cases were distinguishable during the complete process of coding and could be compared mutually, which can also be considered a process of constant comparison. Altogether, this contributed to the validity of the final main and subthemes.

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## RESULTS

This study consisted of 6 cases. Central to each case was the participating AYA cancer patient (table 1). The study protocol was completed in three cases. In the other three, the study protocol ended prematurely. Reasons for prematurely ending the study protocol were: 1) patients indicated that teleconsultations had no added value due to their deteriorating condition and/or due to technical complexities, or 2) the patient could not or did not want to (further) participate in interviews.

During the study, 16 teleconsultations were organized. Two teleconsultations were eventually replaced by telephone consultation due to technical problems (case 4 - teleconsultation 1 and case 6 - teleconsultation 1). In one of the other 14 teleconsultations (case 3 - teleconsultation 2) the GP joined the teleconsultation by phone due to technical problems. These 14 teleconsultations resulted in 29 interviews (table 1). The duration of the interviews ranged from: 16.37 – 71.10 minutes.

From the interviews six main themes and accompanying sub-themes were discerned (table 2) and are discussed in this paper. The first main theme describes the current organisation of care for AYA patients with advanced cancer. The other five themes describe and explain the use of tripartite teleconsultations in the care for AYA patients with advanced cancer within the triangle patient – GP – hospital caregivers.



**Table 1.** Patient characteristics and description of cases.

Case	Sex	Age (y)	AYA patient		Teleconsultations - participants	Interviews
			Living Situation	Diagnosis		
1	M	24	With parents	Urachal carcinoma	1: patient, GP, MO 2: patient, GP, MO 3: patient, GP, MO 4: patient, GP, MO	1: patient, GP 2: patient, MO 3: patient, GP 4: patient, MO
2	F	31	With children	Melanoma	1: patient, GP, CNS-MO 2: patient, GP, MO 3: patient, CNS-MO 4: patient, MO	1: patient, GP 2: patient, MO 3: patient, CNS-MO 4: patient, MO
3	F	37	With partner	Breast carcinoma	1: patient, GP, MO 2: patient, GP, MO 3: patient, GP, MO 4: patient, GP, MO	1: patient, GP 2: patient, MO 3: patient, GP 4: patient, MO
4	M	22	With parents	Osteo-sarcoma	1: patient, GP, MO, CNS-MO	1: no interviews
5	F	30	With partner	Osteo-sarcoma	1: patient, GP, MO	1: GP
6	M	22	With parents	Ewing sarcoma	1: patient, GP, MO, CNS-PC 2: patient and family, GP, MO, CNS-PC	1: no interviews 2: patient's mother, GP, MO, CNS-PC

GP: general practitioner; MO: medical oncologist; CNS-MO: clinical nurse specialist medical oncology; CNS-PC: clinical nurse specialist palliative care.

### Care for AYA patients with advanced cancer

AYA patients with advanced cancer considered the hospital as the place where specialist cancer care is provided. The hospital environment not only provides options for specialist diagnostic procedures (e.g. CT- or MRI-scan) and treatments (e.g. radiation- or chemotherapy), but also provides opportunities to use the expertise of other medical specialists for specific problems, such as pain. A downside to the presence of various subspecialists can be fragmented care:

*[With a loud voice]"How can it be that four doctors don't know from each other what [...] medication they prescribed me"? (AYA patient)*

For AYA patients with advanced cancer, the MO was regarded as the expert and the main responsible caregiver in the field of anti-cancer treatment. Although some patients discussed psychosocial issues with their MO, this was not regarded as the MO's main responsibility:

**Table 2.** Main themes and sub-themes

Main themes	Sub-themes
Care for AYA patients with advanced cancer	Hospitals provide specialist cancer care GPs provide generalist care with a particular responsibility towards the end of life. The patients allots roles and sets the agenda within a framework of relational autonomy
Teleconsultations facilitate team care	Teleconsultations facilitate direct shared policy and decision making Teleconsultations facilitate the transition towards end-of-life care The appropriate timing to initiate teleconsultations remains controversial
Visual reality: you gain some, you lose some	Gain of visual appearance in relation to telephone consultations Limitations of senses in relation to face-to-face contact Loss of attention
Front stage communication	Initial role distribution is determined by current status. Delicate communication due to the patient's presence
Backstage communication	Backstage communication smoothes front stage communication Backstage communication "follows" front stage communication
Organisation and logistics	Visual reality relies on adequate functioning of technique Synchronizing real life to visual reality

*"(Name MO) is more involved in the physical things [...], if he also discussed psychological issues with all patients, then he wouldn't have any time left"*  
(AYA patient)

As the MO was associated with anti-cancer treatment, for some patients the MO may also represent some form of hope regarding (future) treatment options.

Patients discussed psychosocial problems, including end-of-life issues, with the clinical nurse specialist involved in their cancer care. Although she was considered medically well-equipped, patients mainly valued her for her human-centred care. Some patients also regarded her as a mediator between the MO and the patient regarding (small) physical complaints and logistic issues:

*"With (name specialist nurse)(...) it is very focused on me (...), not necessarily on the disease, but much more like: how are **you**?"* (AYA patient)

The role of the patients' GP varied among the different cases, which is considered as being inherent to providing generalist care, and mainly depended on: 1) the position of the patient in the illness trajectory and 2) the history a patient already had with his/ her GP before cancer diagnosis. During anti-cancer therapy, some patients considered their GP as redundant, as the hospital took care of all their needs. In other cases, GPs were considered an integral part of the patient's medical/ oncology care or their care was considered complementary to the oncology care. In the latter cases, GPs were consulted for specific psychosocial support, discussions about end-of-life issues or about alternative therapies:

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*"She [the patient's GP] could, regarding the wish of [name of the patient] to get to know more about alternative therapies (...), she could, I think, sketch that in the right perspective... (MO)*

Respondents agreed that the role of the GP would become more pronounced as the patient's condition deteriorates, however, they differed in their opinion of what would be the appropriate moment to involve the patient's GP in the illness trajectory.

Finally, the role of the patient was to set the agenda by defining "quality of life" and subsequently determining goals for treatment and therapy. The patient also allotted roles to caregivers by dividing his/ her problems between different caregivers and by deciding who is involved in which problem and to what extent.

Some patients were quite docile regarding involvement in their care and decision-making on (future) treatments, while others took a more leading position:

*It's about me, but I am, I mean, I have a right of veto, no? It's my treatment, I have to do it, eventually. (AYA patient)*

Either way, respondents acknowledged that the patients' autonomy regarding their care and (future) treatment exists in a relational framework in which the opinions and views of healthcare professionals (HCPs) co-shaped patients' autonomy. Furthermore, patients' ability to play an active role in their care trajectory also depend on their clinical condition.

### **Teleconsultations facilitate team care**

During teleconsultations, HCPs were able to directly share information on the patient's past and current situation. In most cases this meant "updating" the GP by the MO and the AYA patient. This process created a situation of information equality and facilitated shared policy and decision making:

*"... until now, it [the teleconsultations] had added value, but it was more informative, you know, one to another. However, I notice that all these conversations before have led to... because now I thought: now it really has added value, I am in another village, ill in a bed, I need something, one knows what and the other knows how: exactly what I need!" (AYA patient)*

From the perspective of the patient, teleconsultations created room for patients to share personal considerations on (future) diagnostics and treatment directly to all HCPs involved. As a result, information equality was not only at the level of medical content, but also at the level of the patient's experience. Although most HCPs were positive on this aspect of direct communication, not all HCPs personally needed this:

*"I think that we could involve [the GP] more and that the care would be better, but this is not a necessary requirement for me" (MO)*

In addition to the content of a teleconsultation, creating information equality also depended on careful planning. By planning teleconsultations at a significant moment, relevant information could be exchanged between participants:

*"Well, we very consciously had timed it [the teleconsultation] two days after the patient's appointment at the outpatient clinic, knowing in advance that there would be [the result of] an important CT-scan to discuss. So that was a bit set up like that, yes". (MO)*

Further to information exchange, teleconsultations also provided an opportunity to directly outline and align policy for current health problems or regarding future treatments. However, not all participants agreed; some mentioned that teleconsultations were quite laborious for policy making regarding current health problems:

*"Yes, then I'd rather go to tea at [name of the patient], and then I'd have the idea that I get more down to the essentials than when we are talking around in a triangle for 19 minutes." (GP)*

Teleconsultations also have the ability to facilitate the transition towards end-of-life care by providing opportunities for a timely acquaintance between all involved in AYA care,

including AYA patients themselves. This “getting to know each other” could pave the road for contact in times of crises:

*“Mine [referring to her GP] already takes up **now**, well, since we started with this study. So, she already follows the whole process. [...]. But, for example, she also knows which medication I have used and that I get so ill from those morphines and, yes, she does not have to find out everything all over again if the end is there” (AYA patient)*

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Besides timely contact between participants, some participants suggested that teleconsultations may provide an opportunity for MOs to extend their involvement in the care for AYA cancer patients by following them during their end-of-life care trajectory, although the GP has formally taken over responsibility for care. Although the expertise of the MO might be helpful during end of life care, this extended involvement might introduce new issues for MOs concerning the appropriate time and way of bidding a patient farewell.

The appropriate timing to initiate teleconsultations remained controversial among participants. Some considered teleconsultations particularly useful at those times when many physical problems could be expected, e.g. during chemotherapy, when a teleconsultation even might replace some hospital visits:

*“And a teleconsultation would then actually be [...], more effective for someone who has a lot to discuss or who has many appointments or undergoes chemotherapy or something like that” (AYA patient)*

Others considered it particularly useful for when their condition would (further) deteriorate. However, some participants experienced having a teleconsultation in a period in which they felt very ill or even during the terminal phase of their disease, where it appeared that they were a heavy burden for the patient and that patients were unable to actively participate in the teleconsultation:

*“Well, to be honest, we found it of little added value.[...] So, eh, [name of the patient] is unconsciously worrying about it all day or working towards it [...] and then you actually think: yeah, you know, what news do you discuss that you do not discuss with your GP? Well, actually nothing. And this may not sound so nice towards you, but I think: we have turned a lot of things upside down, with little to no return on investment” (mother of an AYA patient)*

**Visual reality: you gain some, you lose some**

Teleconsultations add a visual dimension in relation to phone consultations, which enabled participants to “show” things, such as a skin lesion and to observe non-verbal clues from other participants. As a result, HCPs may receive more complete information about the patient compared to indirect communication or communication by phone:

*“In itself I think I can describe it well, but still: seeing, yeah, it nevertheless is different I think. That, yes, if you see someone, how he’s lying in his bed or how he’s moving or talking or...yes. So, in itself, I think I can describe it well, I think that it’s easier if someone – you just see it, if someone talks, if you know someone, then you know how fast they are declining or, yes, how it’s going. So, I think that images indeed then say more than a description, yes.” (GP)*

One GP stated that the patient concerned lived just around the corner. As a consequence, this visual dimension was considered superfluous: he could easily visit the patient and meet her face-to face, while at the same time being able to see the MO had little added value, given the complex organisation and logistics of a teleconsultation.

However, most participants indicated that they missed the physical presence of their conversation partners:

*“That piece of walking from the waiting room to the consultation room, then I already know whether I’m going to give someone a next [chemo]therapy or not.” (MO)*

Furthermore, several HCPs described how they missed their “sixth sense” during teleconsultations to adequately assess the situation and how meta-communication (for example: naming negative emotions) was hampered. As a result, respondents indicated that they had reservations about having deep or emotional discussions during teleconsultations:

*“And I think that via a computer you cannot really share these emotions with each other. [...]. Sometimes, then I fall silent and then you’re sitting there, watching me, while I’m sad, so to say, no, I don’t see that, no.” (AYA patient)*

*“..watching someone in the eyes, next to each other, being able to stand next to someone, that is...you get that, right?” (MO)*

However, during one teleconsultation, the MO informed the patient about the results of a recent CT-scan, which could be considered quite a heavy emotional topic to discuss during a teleconsultation. The MO explained that he would not regularly do it this way, but it was a result of the circumstances at that moment combined with his knowledge that the outcomes of the CT were quite good:

*“Because we-, because I know that she is very uncertain about it. And because I had already agreed with [name specialist nurse]: I am going to tell her it [the results]. [...] and because she knew I have the results. That is really awkward, that is very forced, if everyone knows I have the results and I say: ‘No, you’ll only get them on Friday.’ (MO)*

*“Now I found it not so hard to discuss the results with her, also because these were good.” (MO)*

Finally, due to the visual component, a phenomenon referred to as “magnification” appeared. Some respondents indicated that they were more aware of their own presence and appearance, which may result in less focus on their conversation partners:

*“You see at one time these eyes going to the left and then: then it strikes you. And then you think: yes, I’m doing that myself as well. Because, I too- you are watching your own image: does my hair still look good, or...?” (GP)*

### **Front stage communication**

Front stage communication takes place in the presence of all conversation partners, i.e. during the teleconsultations. The role distribution during front stage communication was largely determined by the participants’ current status in the patient’s illness trajectory. The MO usually had the function of “chairman”, as the MO was, in most cases, considered the main responsible caregiver, was most familiar to the patient, and was, by most participants, seen as the initiator of these teleconsultations. The GP mostly had a more passive role, characterized by listening and asking the MO or the patient specific questions.

In most cases, the patient set the agenda for the teleconsultations. This happened both implicitly (depending on the current symptoms or condition of the patient) or explicitly (the patient indicated which subject he/she would like to discuss, or initiated a discussion on a particular subject).

The presence of a patient forced HCPs to find a more delicate way of communication, both with regard to the content of a conversation and the language used, compared to mutual conversations between HCPs:

*"...but you watch your words carefully, you are going to be careful with what you are saying [...], be careful that you do not tell the sensitive matter [...], you have to be more tactical, you cannot tell everything. I cannot just honestly say: yes, in 2 weeks when the patient is dying..." (GP)*

At the same time, some HCPs avoided certain subjects (e.g. psychosocial issues), as they were not sure whether patients wanted to discuss them with other HCPs present.

Some patients also felt the need to adapt, for example by showing socially acceptable behaviour, such as remaining friendly, although they experienced that teleconsultation was a waste of time. For patients at the end of life, this might take up a great deal of their energy.

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### **Backstage communication**

In the context of this study, backstage communication can be defined as "off-screen" communication between participants. Backstage communication was used when participants prepared for a teleconsultation (i.e. a front stage performance) and, as a result, shaped the front stage communication. This occurred both on an inter-professional level as well as between an HCP and a patient:

*"...that GP texted me once with the request to stay positive, that was prior to the first or second video consultation[...] whether I could stay a bit positive during the video consultation." (MO)*

*"Ehm, I realized that I thought: it [the teleconsultation] should not be too long, because [name of the patient] didn't look well, wasn't particularly interested in a teleconsultation, and she mailed me in advance, 'I'm very tired' [...]" (MO)*

In addition, front stage communication also resulted in the use of backstage communication: as a result of teleconsultations, some HCPs indicated that they more easily contacted each other afterwards.

### **Organisation and logistics**

With regard to technical preconditions, participants considered adequate functioning of the technique of great importance: when the technique failed, this directly influenced communication and the content of a conversation. Sensitive or emotional topics were avoided due to technical impairments or malfunction:

*"... I think: yes, pfff, oh dear, it [a teleconsultation] concerns precarious subjects, sometimes. And if the communication is not going well, yes, then you get*



*confusion of tongues or I have to switch between thoughts, or I have to ask again: 'what did you say?'. That's unpleasant." (AYA patient)*

Although most participants marked this as disturbing, some participants stated that technical impairments, e.g. sound and pictures being unsynchronized, also might have some advantages:

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*"So, actually you are going to, this way you have to listen to each other even better. So let someone really totally finish and only then the other participants join in again. So that's actually a kind of conversation hygiene that you get automatically."(GP)*

Participants indicated that they needed experience with the technique in order to gain confidence and better skills when using teleconsultations. This also implied synchronizing real-life practice to visual reality. First, planning and logistics of teleconsultations remained a challenge in the current HCPs' practice, particularly when technical impairments caused delay and, as a result, the teleconsultation overran its schedule. Second, the participant's social environment had to get used to teleconsultations as a means of consultation: as a teleconsultation did not have the status of a real consultation, participants did not always have an adequate room available. In some cases this led to disturbance during the consultations, directly interfering with the content of the teleconsultation and undermining the patient's privacy:

*"...you really have to do your best to keep your attention, because of the technical things, and then I find a roommate coming in, [...], yes, I find that disturbing, yes, yes. I'd rather not see these kind of things, I don't like them entering my consultation room just like that either, it actually distorts the intimacy a little, and it distracts." (MO)*

## DISCUSSION

In this multiple case study we organized and researched digital interdisciplinary teleconsultations in which AYA patients with advanced cancer, their relevant hospital caregivers, and their GPs were simultaneously involved. It was shown that tripartite, interdisciplinary teleconsultations have the potential to contribute to integrated care for AYAs with advanced cancer. At the same time, simultaneously involving both patient and relevant caregivers changed communication dynamics and made the organisation and logistics of teleconsultations complex and time-consuming.

Furthermore, teleconsultations may improve the quality of remote consultations by adding a visual dimension when compared to telephone consultations. However, in

comparison to face-to-face contact, participants experienced a lack of physical presence and proximity, hampering discussions on sensitive topics. Technical impairments were relatively common and compromised both the content as well as the logistics of the teleconsultations.

### Comparison with the literature

Palliative care for AYA patients with advanced cancer can be considered complex and relatively rare.<sup>4,5,7,9,10,12,13</sup> As a result, specialist care may be needed in addition to generalist palliative care.<sup>28</sup> Our data shows that AYA cancer care largely takes place in the hospital, while the perspective on the role of the GP during cancer care trajectories varied among AYA patients: some considered GP care redundant, while others had regular contacts with their GP for medical, psychosocial and/or supportive care. In general, respondents differed in their opinion on what the optimal moment for GP involvement would be. They agreed, however, that the role of the GP became (or was expected to become) clearer towards the end of life. This seems to be in line with earlier research on the involvement of GPs in adult cancer care.<sup>29</sup>

Nevertheless, based on literature and our findings from this study, we suggest that early GP involvement in (AYA) cancer care and thus a more integrated care approach can be beneficial for several reasons. First, Lang *et al.* found that, in general, patients prefer their GP to be involved during cancer therapy and early GP involvement may warrant timely integration of palliative care in cancer care.<sup>30</sup> Early integration of palliative care is increasingly supported by evidence and is currently widely advocated.<sup>31-34</sup> Furthermore, it is suggested that it improves end-of-life experiences for AYA cancer patients.<sup>35</sup> Moreover, it may possibly cause the transition to palliative care to be less emotionally charged. Second, in this study we found that GPs, compared to the MO, might have complementary skills and specific knowledge on individual AYA patients that can improve the overall quality of AYA cancer care. These complementary competences form an essential basis for interdisciplinary cooperation and teamwork.<sup>36,37</sup> Third, we hypothesize that if GPs get the opportunity “to get to know” a patient, they will be more able to adequately deliver end-of-life care when needed.

To our best knowledge, direct GP involvement by means of face-to-face meetings between GPs and MOs (or other hospital specialists) is logistically challenging and, therefore, scarce. Teleconsultation can be considered a potential solution for facilitating interdisciplinary meetings between GPs and hospital specialists.<sup>21</sup> Compared to telephone consultations, we found that teleconsultations enable participants to (partly) see a patient’s physical appearance, as well as each other’s non-verbal communication. This visual aspect may deepen and broaden conversations.<sup>19,38</sup> In addition, the use of teleconsultations also provides an opportunity for patients to actively participate in these meetings, which may contribute to a more patient-centred care approach. However, our study showed that patient participation may be limited during the last phase of the palliative care trajectory as patients lack the energy to participate once clinical deterioration increases.

In this study, we observed and experienced the integration of specialist and generalist care. During some teleconsultations, information on the patient’s past and current health

status was exchanged, which increased information equality among participants. This sharing of information is regarded an essential precondition for shared decision-making, and is therefore a vital aspect when aiming for integrated care.<sup>39</sup> Careful planning of teleconsultations at relevant moments (e.g. a few days after a patient received the results of a follow-up CT-scan) was suggested to contribute to the experienced relevance of a teleconsultation.

However, some respondents regarded teleconsultations as inefficient or even redundant. This may be partly related to the timing and planning of teleconsultations; teleconsultations planned in advance, irrespective of current problems and needs may result in “unnecessary teleconsultations” with no relevant topics to discuss (see also:<sup>20</sup>). Furthermore, some participants considered teleconsultations unnecessarily complex (both technically and logistically) and unsuitable for purposes of direct patient assessment and diagnostics of (physical) complaints. In these situations it was easier for a GP to visit the patient for direct, face-to-face assessment and physical examination. If physical examination is required, teleconsultations generally do not fit clinical practice.<sup>19, 40</sup>

As a result of the experienced lack of physical presence, participants, both patients and HCPs, tended to avoid sensitive or emotionally laden topics during teleconsultations. This is in line with earlier research on the use of teleconsultation in palliative care, although in these previous studies this topic was mainly touched upon by HCPs, while it was not generally acknowledged by participating patients.<sup>19,41</sup> However, these studies mainly involved one-on-one teleconsultations instead of tripartite teleconsultations. Mutual trust and getting engaged in a teleconsultation may be a greater challenge in a tripartite teleconsultation, as participants might experience a feeling of “being judged” by other participants or do not feel comfortable discussing sensitive topics while a third person is “watching”.<sup>21</sup> Furthermore, technical impairments were common during tripartite teleconsultations and increased the reluctance to share sensitive topics.

Finally, given the fact that GPs and hospital caregivers have different working practices, planning of teleconsultations was logistically challenging. The conflicting practices and working arrangements between GPs and hospital-based HCPs are considered important barriers for cooperation and integration of care.<sup>37,39</sup> Logistic challenges were complicated by technical impairments causing several teleconsultations to be delayed or not run as scheduled.

### **Strengths and limitations**

An important strength of this study is the research method used. The complexity and changeability of both palliative care for AYA patients with advanced cancer,<sup>9,10,12,13</sup> and the use of teleconsultations<sup>23</sup> required an innovative use of research methods. The case study approach in combination with serial interviewing<sup>25</sup> gave us the opportunity to closely follow patients over a set period of time. Furthermore, the “stimulated recall” video method<sup>26</sup> helped us to focus on all the meaningful, sometimes inconspicuous particularities of the teleconsultations. Altogether, the combination of these research methods enabled us

to observe, record and describe the complex reality of teleconsultations in the context of interdisciplinary AYA palliative care.

This study also has some limitations. First, we aimed to follow a theoretical replication sampling procedure, based on two characteristics: gender and living situation. However, due to recruitment difficulties, we chose to include all AYAs with advanced cancer who were willing to participate. Furthermore, although we used serial interviews, we did not structurally start to analyze the data after each interview in order to test and develop themes and concepts in further interviews (in contrast to<sup>25</sup>). As a result of these two aspects, relevant concepts may have been missed or only superficially developed.

Second, we used “stimulated recall” video methods<sup>26</sup> in order to reflect on specific events that occurred during the teleconsultations. However, due to technical impairments video registration could not always be performed. Furthermore, for reasons of time, video fragments used during the interviews were selected by one of the interviewers. As a result, important fragments may have been missed; interviews were mainly based on topics or events that were noticed and labelled as interesting by the interviewer. Third, we did not perform a “member check” in which we verified our findings and interpretations with the study participants. This may have affected the validity of our findings.

5

### **Practical implications and future research**

In this study, we introduced a model for tripartite teleconsultation in the care for AYA patients with advanced cancer. These teleconsultations enable participants to share (medical) information and align medical policy and, as a result, may facilitate early GP involvement, interdisciplinary cooperation and (partial) integration of care.

Whether a teleconsultation can be an appropriate means of consultation, depends on its timing and purpose. Careful planning of a teleconsultation at meaningful moments in a patient’s illness trajectory was suggested as an important precondition for a teleconsultation to be of added value. This requires exercise and experience in using interdisciplinary teleconsultations. Moreover, in order to plan teleconsultations at meaningful moments, we believe that any participant should be able to take the initiative for planning a next teleconsultation. Avoiding prescheduled teleconsultations at fixed moments may prevent teleconsultations from being inefficient or redundant. Furthermore, tripartite, interdisciplinary teleconsultations are considered inefficient or ineffective when physical examination is required or when non-complex (physical) complaints are discussed.

We propose that teleconsultations be initiated early in the course of AYA cancer care, as this enables participants to fully benefit from an integrated interdisciplinary care approach and it provides room for participants to get used to each other and the techniques. This habituation may increase the potential for interdisciplinary teleconsultation and may help to overcome some communicative, technical and logistic challenges. Future research should focus on the optimal timing, frequency and planning of these teleconsultations. Furthermore, research should evaluate whether and how these teleconsultations affect patient-related outcome measures and the quality of (palliative) care.

The use of tripartite teleconsultations requires new communication etiquettes, both regarding the ethical aspects (is it appropriate to inform a patient about the results of a CT-scan by means of teleconsultation?) as well as regarding the interaction between participants (whether and how should HCPs discuss a patient's prognosis in the presence of that patient?). Furthermore, the use of tripartite teleconsultations may "force" GPs and MOs to share thoughts front stage, i.e. in the presence of a patient, where they would have preferred to discuss these back stage with professionals only.<sup>42</sup> Tripartite teleconsultations not only concern exchanges of medical information, but they are also about jointly defining "good care", aligning medical policies accordingly, and building mutual trust, a process known as "normative integration". In addition to functional integration, this is considered an essential requirement when aiming for integrated care.<sup>39</sup> This "normative integration" is not likely to be achieved through front stage activities only, and usually requires backstage activities as well. For example, in one case we observed how a patient's GP and MO explicitly discussed the results a patient's blood tests and accordingly aligned medical policy by phone, just before the start of a tripartite teleconsultation. These communication-related dilemmas and issues should be carefully addressed and evaluated when using interdisciplinary teleconsultations in daily practice.

Technical and logistic challenges were common during tripartite teleconsultations. These can be considered as major limitations as it makes teleconsultations vulnerable to failure and inefficiency. Although the use of teleconsultations may always require some additional investment in terms of time, effort and experience from all participants, technical improvement and refinement is an absolute precondition when aiming for further use and implementation of tripartite, interdisciplinary teleconsultations in daily care.

In the context of the Dutch healthcare system, the GP is usually located geographically near the patient's home. A part of the technical and logistic challenges can be overcome if the GP visits the patient at home so that they can together participate in a teleconsultation with hospital-based caregivers, such as the MO. However, this might introduce new logistic challenges, particularly for the patient's GP who would then have to perform an additional home visit.

## CONCLUSIONS

Tripartite teleconsultations can contribute to interdisciplinary collaboration and to a more integrated care approach for AYAs with advanced cancer. These teleconsultations may provide a cautious start of a functional integration of hospital-based AYA cancer care and community-based generalist palliative care. Future research should evaluate the effect of these teleconsultations on patient-related palliative care outcomes in AYAs with advanced cancer.

Several logistic challenges and technical limitations need to be overcome, as these issues seriously hamper the use of teleconsultations in daily practice. Furthermore, the use of tripartite teleconsultations introduces new dilemmas regarding normative integration

of different healthcare practices and communication etiquettes. These issues should be carefully addressed, explored and evaluated when considering the use of teleconsultations, and during its actual use in daily practice.

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# 6

## GENERAL DISCUSSION AND CONCLUSIONS



## GENERAL DISCUSSION

In this thesis, we have described the practice of expert consultation within the field of home-based palliative care, focusing on telemedicine as an innovative approach to optimize the process and outcomes of these consultations. Central to this research is the NWO-project<sup>a</sup> 'Optimization of complex palliative care at home by means of teleconsultation' that was developed and initiated in Nijmegen in 2009, consisting of both an empirical-ethical analysis as well as an evaluation of the effectiveness of teleconsultations. In his thesis "*Teleconsultation: enhancing personalized palliative care at home. An empirical-ethical analysis*",<sup>1</sup> Van Gorp focused on the ethical and philosophical issues regarding the use of teleconsultation in palliative home care, using qualitative research methods.

In this thesis, we evaluate whether and how the use of teleconsultation affects the quality of palliative homecare, using both quantitative and qualitative research methods. In the following paragraphs, we will discuss the main findings of this thesis, thereby answering the following research questions:

1. What is the current practice regarding (expert) consultation in palliative care for home-dwelling patients with complex palliative care needs?
2. How do weekly teleconsultations between patients receiving palliative homecare and a hospital-based specialist palliative care consultation team affect the quality and outcome of palliative home care?
3. What is the potential of an innovative interdisciplinary care model using teleconsultation techniques to affect the quality and outcome of palliative home care for adolescents and young adults with advanced cancer?

### **Expert consultation practices among GPs mainly involve the use of informal consultation services, focus on physical aspects of palliative care, and primarily occur during a patient's last month of life. (research question 1)**

We found that GPs play a central role in the practice of palliative care consultations. Based on data of formal, national Palliative Care Consultation (PCC) teams, the majority of all registered palliative care consultations were requested by GPs (*Chapter 3*). Nonetheless, in a survey among GPs (*chapter 2*), these figures proved to be an underestimation of the actual number of consultation requests among GPs, as GPs reported that they preferred the use of "unofficial" or "informal" consultation sources, i.e. fellow GPs, when in need of additional knowledge or expertise on palliative care. Witnessing the high degree of satisfaction with these informal consultations, this practice seems to fit the needs of most GPs

Based on the national statistics of formal PCC teams as well as the results of our survey among individual GPs, consultations are mostly requested for patients with cancer, and these mainly concern the physical domain of palliative care, including physical symptoms,

<sup>a</sup> Netherlands Organisation for Scientific Research (NWO)

pharmacological problems and medical-technical procedures. Social and existential problems are hardly discussed during consultations. Finally, requests for palliative care consultations frequently occur relatively late during the illness trajectory: most requests concern patients in their last month of life.

The high level of cooperation, broadly defined as: “*working together with the specific care provider*”, between fellow GPs in the context of palliative home care has been described before.<sup>2</sup> However, the concept of cooperation differs from the concept of consultation, the latter implying a different level of expertise between the consultant and the requesting caregiver. In line with this, van Heest *et al.*, described promising results on the use of GPs with a special interest in palliative care to support fellow GPs in delivering palliative home care.<sup>3</sup> However, these GPs had all obtained a Degree in Palliative Medicine at Cardiff University and therefore could be regarded as experts in palliative care. As it was beyond the scope of our study to describe specific characteristics of different consultation sources, we were not able to obtain any additional information on these fellow GPs, such as their “level of expertise”. However, this level of expertise may influence the content and quality of advice given during consultations. Therefore, given that only a small minority of all Dutch GPs have formally received additional training in palliative care (<1% in 2013<sup>4</sup>), future research should evaluate the role of fellow GPs (“sparring partner” or expert in palliative care?) in palliative care consultations and focus on whether and how these consultation practices could be further optimized. This is of particular interest for consultations concerning complex palliative care issues, such as palliative sedation, which requires the expertise of adequately trained, skilled and experienced professionals. Regarding the content of consultations, our findings are in line with earlier research revealing that social and existential issues receive relatively little attention during palliative care consultations<sup>5,6</sup> and end-of-life communication between patients and their GPs in general,<sup>7,8</sup> although these issues are considered important for most patients at the end of their lives.<sup>9,10</sup> Schrijnemaekers *et al.* suggest that the method used for consultation may affect the subjects discussed during the consultation: more social and spiritual problems were identified during bedside consultations (i.e. when a consultant visits the patient) compared to telephone consultations.<sup>11</sup> Future research should focus on reasons why social and existential issues receive relatively little attention during consultation, and on how to prevent underexposure of these issues in the current organisation of palliative care consultations.

Regarding the methods used for consultation, as bedside consultations are considered time-consuming and expensive,<sup>11</sup> the use of teleconsultations might be an appropriate alternative. Teleconsultations add a visual dimension to remote consultations compared to phone consultations and they fit the practice of home-based palliative care.<sup>12</sup> The use of teleconsultations enables consultants to directly co-assess a patient from a distance, without the logistic challenges (e.g. travel time) inherent in bedside consultations. Furthermore, it provides an opportunity for interdisciplinary consultation between specialist and generalist palliative care providers. These interdisciplinary consultations have the potential to improve palliative care outcomes<sup>13</sup> and provide opportunities for generalist caregivers to train “on

the job” and build experience in palliative care. Experience from patient care was found to be an important learning strategy among GPs.<sup>14</sup>

**We were able to perform an RCT on the use of weekly teleconsultations in the context of palliative home care. These teleconsultations do not result in less patient-experienced symptom burden. (research question 2)**

We found that, although it is complex and time-consuming, it is possible to perform a randomized controlled trial (RCT) in the context of complex transmural palliative care (*chapter 4*). Although we experienced difficulties in recruitment, technical challenges and relatively high attrition rates, we were able to complete this RCT on telemedicine, which can be considered a highly complex intervention.

It can be debated whether an RCT-design “fits” the evaluation of a complex intervention such as telemedicine, as RCTs usually involve fixed outcome measures that cannot be adapted to unanticipated situations or findings during the study period.<sup>15,16</sup> However, literature identified a lack of robust research designs and highlighted the need for randomized controlled trials to formally evaluate the effectiveness of telemedicine in the context of palliative care.<sup>17</sup> Given this need for robust research designs, we decided that performing an RCT would significantly contribute to the evidence on the use of telemedicine in palliative care. Advantages and disadvantages of this study design are discussed in the “Methodological Evaluation” section.

Considering the outcomes, we found that weekly teleconsultations between home-dwelling patients and a hospital-based specialist palliative care consultation team (SPCT) had no added value above “care as usual”, despite high satisfaction scores among its users. Moreover, participants from the intervention group reported a higher symptom burden (both on physical symptoms as on anxiety) compared to the control group. With regards to the physical symptoms, the difference in total distress score (TDS) reached its maximum in week 12 of the study period. At this point, participants from the intervention group had a significantly higher mean TDS compared to the control group (adjusted difference 6.90; 95% CI: 0.17 – 13.63). Although some authors consider this difference clinically relevant,<sup>18</sup> higher clinically important differences were stated in the power calculation of our study protocol.<sup>19</sup> Furthermore, these adjusted differences in TDS should be interpreted with due care given the wide confidence interval.

Other, secondary, outcome measures on patient-experienced problems and needs, continuity of care and perceived burden from informal care, as well as indicators for GP contacts and hospital admissions showed no statically significant differences between groups.

We concluded that teleconsultation in its current form did not improve patient-reported outcomes in palliative home care. However, several other factors in addition to the teleconsultation intervention may have contributed to these negative findings.

First, weekly teleconsultations resulted in weekly evaluations of a participant’s wellbeing and the presence and/or absence of certain symptoms. Although we had not foreseen this,



a weekly focus on the presence of (expected) symptoms may lead to additional distress in patients,<sup>20</sup> a phenomenon also referred to as a “nocebo-effect”,<sup>21</sup> and may therefore have negatively influenced the experienced symptom burden. Future research should therefore evaluate optimal timing, frequency as well as content of teleconsultations. Adapting timing and frequency of teleconsultations to the participant’s wishes and needs may seem an obvious solution to this “nocebo-effect”, however if patients are in need of more frequent teleconsultations (several times a week or more), it may not fit the everyday practice of healthcare professionals. Moreover, if a patient’s situation is considered stable, less frequent teleconsultations may be preferred by both patients and healthcare professionals.<sup>1</sup> However, this approach may interfere with the intended goal of providing pro-active palliative care by means of teleconsultations, rather than providing reactive palliative care. Making use of a monitoring system, using input data concerning both the patient’s needs and the patient’s current health status (e.g.<sup>22</sup>) may also help in adapting teleconsultation services to better meet patients’ needs, while at the same time preventing a reactive palliative care approach.

Second, for the primary outcome, we were fully dependent on participant’s self-reported outcome measures. Although these outcome measures were considered relevant, valid and (relatively) easy to obtain (Edmonton Symptom Assessment System, ESAS<sup>23,24</sup> or were widely used in this setting (Hospital Anxiety and Depression Scale, HADS<sup>25</sup>), differential recall bias may have influenced patient-reported symptom burden. We hypothesize that patients who received weekly teleconsultations may have been more aware of their symptom burden and, as a result, reported symptom scores more precisely. This differential recall bias may have enhanced existing differences in experienced symptom burden between the intervention and the control group.

Third, we consider the intervention in this study to be a complex intervention, not only concerning the use of teleconsultations as such, but also implying the use of a new care model. Factors related to this care model may have contributed to the outcomes. For example, in our study, teleconsultations were planned on fixed, prescheduled moments, regardless of participant’s current need for teleconsultations in order to provide proactive palliative care. However, this may have led to redundant teleconsultations or may even have enhanced the “nocebo-effect” by confronting participants with their disease and (potential) symptoms during (relatively) calm and stable periods of their illness trajectory. Moreover, the initial goal of this project was to develop a model that would optimize (multidisciplinary or interdisciplinary) collaboration between palliative care specialists and GPs in the care of home-dwelling patients by using teleconsultation techniques. However, involvement of GPs and collaboration with GPs were suboptimal in the process of patient recruitment (GPs forgot about the study or did not want to participate) and during this study, due to logistic challenges (e.g. teleconsultations were planned during GP consultation hours); the frequency of teleconsultations (weekly); suboptimal backstage communication between the SPCT and GPs;<sup>13, 26</sup> and the need for (current) specialist support by a hospital-based consultation team that was not always acknowledged by participating GPs. As a result, patient recruitment by GPs was suboptimal and all patients were recruited via the hospital-based SPCT (instead of

via their GPs<sup>19</sup>), which may have influenced GP involvement during the study. Furthermore, as a result of suboptimal GP involvement, the interdisciplinary/ multidisciplinary character of these teleconsultations was compromised.

Future research should explore how transmural collaboration for patients receiving palliative home care could be further optimized, in order to fully profit from the potential of teleconsultation techniques for home-dwelling patients. In the next section, in which we describe and discuss the findings of a study among AYA cancer patients, we provide suggestions for optimizing transmural interdisciplinary collaboration using tripartite teleconsultations.

**Tripartite teleconsultations between adolescents and young adults (AYAs) with advanced cancer, their hospital caregivers and their GPs may optimize interdisciplinary collaboration and may contribute to an integrated care approach. (research question 3)**

Teleconsultations simultaneously involving AYA patients with advanced cancer, their GPs and relevant hospital-based caregivers may support transmural interdisciplinary palliative care and an integrated care approach. However, we found that the use of these tripartite teleconsultations in daily practice was seriously hampered by several technical impairments and logistical barriers. Furthermore, using tripartite teleconsultations introduced issues regarding communication dynamics and communication etiquettes that require further attention and evaluation.

In contrast to the teleconsultation model described in chapter 4, this tripartite teleconsultation model provided opportunities for interdisciplinary team care involving healthcare professionals with complementary backgrounds and skills (see also:<sup>27</sup>). The added value of specialist consultation by GPs is generally acknowledged in order to provide adequate palliative(home)care.<sup>28</sup> Although less commonly acknowledged in this context, GPs can have specific skills and knowledge regarding patients and their families that offer a relevant contribution to specialist (palliative) care (e.g.<sup>29</sup>).

An interdisciplinary care approach can be considered a key element in providing good (palliative) care.<sup>26,30-32</sup> We found that in some cases these tripartite teleconsultations enabled participants to directly share (clinical) information, thereby increasing information equality among all participants. In line with the framework provided by Valentijn et al.,<sup>33</sup> this sharing of information facilitates the process of shared decision-making and, as a result, may be a cautious first step in the functional integration of hospital-based oncology care and generalist palliative care for AYA patients with advanced cancer.

In general, this integration of care may occur on 2 “levels” in the context of palliative home care.

First, in chapter 5, we focused on the integration of hospital-based oncology care and generalist palliative care. GP involvement in hospital-based cancer care may warrant early integration of (generalist) palliative care for patients diagnosed with cancer.<sup>34</sup> Early integration of palliative care is widely advocated and may improve (palliative) care outcomes.<sup>35-37</sup>

Second, in Chapter 4 we focused on the integration of specialist palliative care (provided by the hospital-based SPCT) and generalist palliative care (provided by the GP) for home-dwelling patients. This integration was considered suboptimal due to limited GP involvement. Based on our findings (chapter 5), we hypothesize that an interdisciplinary care model might also contribute to the integration between specialist palliative care and generalist palliative care. Using tripartite (or quadripartite) teleconsultations may support integration of both cancer care and palliative care, as well as specialist and generalist palliative care. Moreover, the presence of patients themselves during these teleconsultations may further optimize a person-focused care approach.<sup>33</sup>

Although the use of tripartite interdisciplinary teleconsultations showed promising results in the context of AYA cancer care, these findings can not be generalized to palliative home care. We assumed that teleconsultation techniques would “fit” the context of AYA care, as young patients are generally familiar with the use of teleconsultation techniques in daily life. The “fit” of teleconsultation techniques may considerably differ in an elderly population.

Although this interdisciplinary teleconsultation model has the potential to contribute to an integrated palliative care approach, our study revealed several challenges and barriers that hamper the use and (further) implementation of these teleconsultations in daily practice.

One of the main challenges concerns the optimal use of a tripartite teleconsultation regarding its content, timing and frequency to prevent it from becoming ineffective or inefficient. Based on our findings, we hypothesize that these interdisciplinary teleconsultations may be an appropriate means for directly exchanging (medical) information, outlining and aligning (medical) policy (e.g. regarding future treatment options), shared decision-making and integration of care. The timing and frequency of these teleconsultations should be tailored to the wishes and needs of participants and requires careful planning.

Second, some main barriers concerning the use of tripartite, interdisciplinary teleconsultations in daily care were technical impairments and logistical challenges. As a result, teleconsultations were considered demanding, time-consuming and, in some cases, inefficient. This emphasizes the need for further technical refinement or for alternative teleconsultation models in which the GP visits the patient at home and together they have a teleconsultation with one or more hospital-based caregivers. Although this might help overcome technical impairments and contribute to an interdisciplinary care approach,<sup>13</sup> it might introduce additional logistical challenges for the GP, who has to perform additional home visits.

Third, the use of tripartite interdisciplinary teleconsultations changes communication dynamics. Several communication-related issues may arise and need to be carefully addressed and evaluated when using these teleconsultations in daily practice. For example, some participants experienced feelings of “being judged” or “being watched” by a third person, which may hamper discussions about sensitive or emotional topics. Also, etiquettes regarding “medical communication” may need to be redefined, both regarding the technique used (“Can any topic be discussed during a teleconsultation?”) as well as regarding

the composition of participants (“Whether and how should healthcare professionals discuss sensitive topics, such as prognosis, in the presence of a patient?”).

In line with these dilemmas, the use of tripartite teleconsultations may “force” GPs and MOs to have some of their inter-professional communication front stage, i.e. in the presence of a patient. This inter-professional communication not only concerns the exchange of medical information, it may also be about “getting to know each other”, defining “good care” and aligning medical policies accordingly, and building mutual trust. This process is known as “normative integration” and is, in addition to functional integration, an essential requirement when aiming for integrated care.<sup>38</sup> Some aspects of “normative integration” may require (regular) backstage communication between HCPs, particularly when they have different opinions regarding “good care” and medical policy.

In conclusion, tripartite interdisciplinary teleconsultations may contribute to an integrated care model for patients with cancer. However, several logistic and technical issues hamper its use in daily practice and need to be overcome. Dilemmas regarding changed communication dynamics and the appropriate communication etiquettes in tripartite teleconsultations should be carefully addressed and evaluated. Furthermore, future research should focus on whether and how such teleconsultations improve patient-related palliative care outcomes.

## METHODOLOGICAL EVALUATION

This thesis has some important strengths and limitations considering the methodologies used. In chapter 2 and 3 we provided insights in current consultation practices in the field of palliative care. An important strength of these chapters is that we not only evaluated consultation practices based on the registration of formal consultation services, but we also specifically focused on the viewpoint of general practitioners (GPs) who play a key role in palliative home care and who are the most frequent “users” of palliative care consultation services. For this purpose we used a digital survey.

Another important strength of this thesis is that we were able to conduct and complete a randomized clinical trial in the field of complex transmural palliative home care. On the one hand, this is quite unique in the field of palliative care, as challenges concerning recruitment of participants and high levels of attrition can hamper a successful completion of this type of study. (e.g.<sup>39</sup>). On the other hand, randomized clinical trials are considered to provide high levels of evidence needed for solid evaluation and building evidence regarding the effectiveness of (complex) interventions in palliative care.<sup>17, 40</sup>

Finally, an important strength of this thesis is the combination of quantitative and qualitative research methods used; both within this thesis (e.g. chapter 4 and 5) as well as that this thesis forms part of a larger research project in which both quantitative and qualitative methods have been used to evaluate the use of teleconsultations in the field of palliative home care. (See also *“The telemedicine research project: lessons derived from the qualitative evaluation”*)

There are also a number of methodological limitations. First, although there was a need for a quantitative analysis of teleconsultations in palliative care, the use of fixed, quantitative outcome measurements to evaluate complex interventions, such as teleconsultations, is not unquestioned. Pols stated that RCTs are “*not particularly fit to study innovative practices*”, such as teleconsultations, as RCTs usually have rigid outcome measures and therefore are not able to adapt to unanticipated outcomes. Therefore, open, exploratory, qualitative study designs may better fit such interventions,<sup>15</sup> although the generated evidence may be valued differently. In order to overcome such rigidities, more innovative RCT designs, such as mixed methods or pragmatic RCTs, can be appropriate alternatives for the evaluation of the effectiveness of telemedicine interventions in daily practice. Mixed methods might help researchers in defining relevant outcome measures and interpreting quantitative study results,<sup>41</sup> while the use of pragmatic RCTs may be helpful in developing a study design that “fits” daily practice.<sup>42</sup> These research designs might provide an opportunity for participants to “use” the intervention according to their needs and experiences (e.g. lower the frequency of teleconsultations during stable phases in their illness trajectory) and allows room for implementing newly gained insights during the study period. Furthermore, quantitative findings, such as patient-reported symptom scores, can be interpreted by using qualitative research methods to gain more insights in the cause and meaning of these outcomes (e.g. deteriorating condition; “nocebo-effect”, differential “recall-bias”, unmet needs, etc.).

Second, in chapter 5 we used a more open, exploratory study design that better “fits” the innovative practice of digital interdisciplinary meetings, directly involving the patient. However, once developed as a pilot project, the methodology used was innovative (serial interviewing using “stimulated recall” video methods<sup>43,44</sup>) combined with an intervention that was both innovative and technically challenging. As a result of this complex study design, this study had some important limitations: 1) researchers were frequently involved in technical support, which may have influenced their observations; 2) due to technical issues, video registration could not always be obtained, hampering the use of “stimulated recall” during the interviews, and 3) data was not analyzed between two interviews, thereby reducing the potential of the use of “serial interviewing”.<sup>43</sup>

## THE TELEMEDICINE RESEARCH PROJECT: LESSONS LEARNED FROM THE EMPIRICAL-ETHICAL ANALYSIS

In this section, we discuss some of the main findings from the qualitative evaluation performed by Van Gorp in his thesis: “*Teleconsultation: enhancing personalized palliative care at home. An empirical-ethical analysis*”<sup>1</sup> in relation to the outcomes described in this thesis. In retrospect, although we used both qualitative and quantitative methods to evaluate the telemedicine project as a whole, due to the initial planning of this project (i.e. both the quantitative and qualitative evaluation started approximately at the same time), we were unable to fully benefit from each other’s findings and to utilize the full potential of a mixed-method design.

With regard to the main outcomes of our RCT, we defined patient-experienced physical and psychological symptom burden as primary outcome measures. Although considered relevant, these outcome measures solely cover the physical and psychological domain of palliative care. However, at the same time, Van Gorp found that teleconsultations enabled patients and SPCT-members to build empathic, intimate relationships, providing patients with personal attention and feelings of safety and relief.<sup>12</sup> These outcomes are more related to the social and existential domain of palliative care. These domains were relatively neglected in the quantitative evaluation of the telemedicine project and, as a result, relevant primary outcome measures may have been missed.

Another important outcome based on Van Gorp,<sup>13</sup> is the potential of teleconsultations to (re)connect hospital-based and primary care for patients with life threatening conditions, such as advanced cancer. Furthermore, he distinguished a multidisciplinary care model and an interdisciplinary care model.<sup>13</sup> As part of the RCT, we evaluated the continuity of care as experienced by the patient using a multidisciplinary care model, however we found no differences between the intervention group and the control group. In our study among AYA patients with advanced cancer, we describe the potential of an interdisciplinary care model in facilitating and improving transmural care. We have not yet quantitatively evaluated whether and how interdisciplinary teleconsultations improve palliative care outcomes.

Furthermore, van Gorp performed exploratory studies that were flexible to change and unanticipated situations, resulting in important findings concerning the practical use of teleconsultations within daily practice. Some of these findings could be implemented during the study period of the RCT, e.g. the PAL-4 system was replaced by more practical and convenient tablet computers. At the same time, other relevant findings could not be implemented in the protocol of an ongoing RCT. For example, Van Gorp concluded that backstage communication between GPs and SPCT-members was key to a successful multidisciplinary model using teleconsultations. In our study protocol we mainly focused on the organisation of teleconsultations as such and (too) little on the process of backstage communication afterwards, both concerning the training for SPCT-members as well as concerning the practical execution. As a consequence, multidisciplinary care might have been suboptimal. Moreover, in our study protocol we stated that teleconsultations should be scheduled and performed on a weekly basis. Based on the findings by Van Gorp, most patients preferred teleconsultations to be scheduled less frequently, based on their current needs.

## **RECOMMENDATIONS** (*see also table 1*)

### **Recommendations for clinical practice**

This thesis has important implications for clinical practice. It appears that social and existential issues are still hardly discussed and/or documented during palliative care consultations, although these are considered vital parts of palliative care.<sup>32</sup> Healthcare professionals providing palliative care consultations should be aware of this and explicitly

ask questions on these topics, particularly in high-complex cases in relation to palliative sedation, given the controversial character of social and existential issues as an indication to start palliative sedation.<sup>45</sup>

In this thesis, we have focused on the use of teleconsultation to optimize palliative care for home-dwelling patients. We found that teleconsultations may have added value in the context of palliative care, given the following considerations:

1. Teleconsultations may support interdisciplinary collaborations and an integrated care approach. Therefore we recommend considering the use of teleconsultations for exchange of (medical) information, policy making and the alignment of care for patients with advanced cancer. Using tripartite teleconsultations enables hospital-based caregivers, GPs and patients to be actively involved and, as a result, has the potential to support interdisciplinary team work.

Based on our findings and the literature, teleconsultations may not fit clinical practice when physical examination is required or when it is used for purposes of direct patient assessment regarding non complex (physical) problems.

2. Planning teleconsultations on fixed, pre-scheduled moments, irrespective of the current wishes and needs of patient may cause teleconsultations to be inefficient, ineffective or superfluous. Therefore, we recommend flexible, patient-tailored, careful planning of teleconsultations, based on a patient's current (or future) wishes and needs.
3. Technical impairments and logistic challenges were common during tripartite teleconsultations and may hamper the efficiency and effectiveness of teleconsultations. Therefore, we recommend to consider the use of (tripartite) teleconsultations if participants a) are familiar with teleconsultation techniques and/or software, b) have adequate internet access and c) are willing to invest extra time and effort to gain further experience in the use of tripartite teleconsultations.
4. The use of tripartite teleconsultations introduces challenges regarding communication dynamics and etiquettes. These need to be acknowledged and carefully addressed and evaluated. This requires experience in using teleconsultations by all participants, particularly the HCPs involved, and fine-tuning of teleconsultation practices "along the way".

### **Recommendations for future research**

This thesis has added important insights on current consultation practices, both from the perspective of formal palliative care consultation services as from the perspective of GPs. It is of vital importance to include the viewpoint of GPs in future research on the use of teleconsultations and on palliative care consultation in general, as they are the largest group of consult-requesting caregivers in the context of palliative care and they fulfil a key role concerning the provision and coordination of home-based palliative care. Moreover, GP involvement is vital when aiming to develop a successful interdisciplinary care model in palliative care.

Although we described characteristics of consultation practices in the field of palliative care, the underlying reasons and considerations shaping these practices (e.g. why do GPs prefer to consult fellow-GPs instead of formal consultation teams?) need further study. Revealing these reasons might help further optimizing palliative care consultation services.

Furthermore, whether and how current consultation practices affect the quality of palliative care remains largely unknown. Although we were one of the first to evaluate the effect of weekly teleconsultations on the quality of palliative care as experienced by patients and informal caregivers, the vast majority of palliative care consultations still occur by phone. Therefore, future research should evaluate “regular” palliative care consultation practices: 1) to what extent is advice provided by consultants adopted in clinical care, and 2) whether and how does this affect clinically relevant outcome measurements such as patient-experienced symptom burden on all four domains of palliative care, the number of patients dying in their preferred location of death, and burden experienced by informal caregivers. This research should include the impact of consultation characteristics (such as source and time of consultation) on quality of care.

The use of teleconsultation may facilitate interdisciplinary collaboration and an integrated care approach for patients with advanced cancer. We have only started to explore the potential of (tripartite) teleconsultations to optimize the quality of palliative homecare. Therefore, future research should focus on the following aspects:

1. The effect of (tripartite) interdisciplinary teleconsultations on clinically relevant patient-related palliative care outcomes, such as quality of life, continuity of care, and experienced burden among informal caregivers.
2. The appropriate use of these teleconsultations in daily practice regarding timing, frequency and planning. This research should explicitly take into account how planning of teleconsultation could be patient-tailored and demand-driven, while preventing a reactive palliative care approach.
3. We observed the potential and “fit” of tripartite interdisciplinary teleconsultations, as well as several barriers and challenges in a population of adolescents and young adults with advanced cancer. Future research should reveal whether this potential and “fit” as well as the barriers and challenges regarding tripartite teleconsultations differ in other populations, for example in an elderly population or among patients diagnosed with other life-threatening conditions.
4. Although quantitative research does not always “fit” complex interventions such as the use of teleconsultations, future research should evaluate the effect of teleconsultations on patient relevant outcome measures in order to prevent proliferations of non-effective telehealth-interventions and to support evidence for effective interventions. This includes both outcome measures on the physical and psychological domain, as well as outcome measures on the social and existential domain of palliative care. RCTs are considered a robust research design, however they generally require extensive screening for participants and fixed methods. Therefore, researchers may use innovative research methods that, although methodologically



less robust, better “fit” the use of teleconsultations in the context of palliative care, such as “mixed methods” or pragmatic trials.

### Recommendations for education

First, given the increasing number of fragile elderly and patient suffering from chronic conditions, the need for palliative care will increase in coming decades. Therefore palliative care should receive adequate attention in medicine, nursing and other healthcare-related studies. The focus of healthcare is often on active treatment with a curative or life-prolonging intent. Talking about quality of life, end-of-life preferences and/or abandoning treatment(s) is not common practice and requires a holistic care approach.<sup>46</sup> Students should be aware that, in addition to the physical and psychosocial domain, the social and existential domains are integral parts of a patient’s life and, therefore of palliative care, and that these domains should be adequately assessed in all patients in need for palliative care. Furthermore, in line with the definition of palliative care as stated in the national framework for palliative care (Kwaliteitskader Palliatieve Zorg), patient autonomy and shared decision-making are considered essential aspects in palliative care.<sup>30</sup> This requires adequate knowledge, (communication) skills, and an open attitude in the communication with patients receiving palliative care.

Second, interdisciplinary collaboration is of vital importance for providing timely, multidimensional integrated palliative care. Face-to-face interdisciplinary meetings are logistically challenging and, therefore, scarce. Teleconsultations may be a “second-best” means for interdisciplinary collaboration and an integrated care approach. Furthermore, the (increased) use of teleconsultation techniques seem to be inevitable in current and future healthcare practice. Therefore, we believe that all healthcare-related studies, including the education and training of medical specialists, should educate and train students in both providing interdisciplinary care as well as in the appropriate use of teleconsultation techniques.

Furthermore, the use of teleconsultation techniques introduces new ethical and legal challenges and dilemmas regarding privacy, (digital) identity and safety of patient-related data. (Future) healthcare professionals should receive adequate and ongoing training on these (dynamic) issues (see also:<sup>47,48</sup>)

### Recommendations for policy makers

Technical innovations are rapidly developing and increasingly used in daily life. At the same time, safe and effective use of these innovations in healthcare practice requires solid evaluation and well-considered implementation strategies. As a result, despite the lack of robust evidence in palliative care, the use of teleconsultations and other digital techniques seems inevitable in (future) daily practice. We recommend timely and regular evaluation of the effectiveness and (unforeseen) side-effects of technical innovations in order to prevent potentially harmful interventions to be implemented in daily practice, while at the same time, to warranting implementation and further development of effective interventions.

Furthermore, the use and implementation of technical innovations in daily practice not only requires evaluation of their effectiveness. This thesis is part of an NWO-project that was embedded in the “Responsible Innovation” programme.<sup>49</sup> In line with this, we found that technological innovations involve several ethical and societal aspects, regarding privacy, the “fit” of technology in different fields of care, and appropriate communication. These issues require explicit and careful evaluation when developing, testing, and implementing technical innovations, such as teleconsultations, in medical practice.

**Table 1.** Recommendations.

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**Recommendations for clinical practice**

1. Although considered vital aspects of palliative care, social and existential issues are hardly discussed during palliative care consultations. Therefore we recommend that social and existential issues should be more adequately and explicitly addressed and explored by consultants during palliative care consultations, particularly in high-complex cases. (*Chapters 2 and 3*)
2. Tripartite teleconsultations between hospital caregivers, GPs and patients with advanced cancer may facilitate interdisciplinary collaboration and/or an integrated care approach. We recommend considering the use of these teleconsultations for direct exchange of information, policy making, and alignment of care. Teleconsultations may not fit clinical practice if used for direct patient assessment regarding non-complex (physical) problems or when physical examination is required. (*Chapters 4 and 5*).
3. The use of teleconsultations may be ineffective, inefficient or superfluous when planned at prescheduled, fixed moments, irrespective of patient’s wishes and needs. Therefore we recommend flexible, patient-tailored, careful planning of teleconsultations, based on participants’ current (or future) wishes and needs. (*Chapters 4 and 5*)
4. Technical impairments and logistical issues were common during tripartite teleconsultations. Therefore, we recommend considering the use of these teleconsultations if all participants a) are familiar with teleconsultation techniques/software, b) have adequate Internet-access and c) are willing to invest extra time and effort to gain (further) experience in the use of tripartite teleconsultations. (*Chapter 5*)
5. The use of tripartite teleconsultations will introduce communication-related dilemmas and challenges. To overcome these challenges, we recommend that participants gain experience in teleconsultations and carefully address and evaluate these issues “along the way”. (*Chapter 5*)

**Recommendation for future research**

1. All research regarding palliative care consultations in general or regarding the use of teleconsultations in palliative care should actively involve GPs, as they fulfil an essential role in palliative home care. (*Chapters 2-5*)
  2. We have gained insights in palliative care consultation practices and preferences among GPs. Underlying reasons for these practices and preference remain largely unknown and should be further explored in future research. (*Chapters 2 and 3*)
  3. It remains largely unknown whether and how these palliative care consultation practices (in general) affect the quality of care. Therefore, the impact of palliative care consultation practices on patient-related palliative care outcomes should be evaluated. (*Chapters 2 and 3*)
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**Table 1.** (continued)

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4. Teleconsultations have the potential to facilitate an interdisciplinary, integrated palliative care approach. Future research should focus on:
    - a. whether and how these (tripartite) teleconsultations influence patient-related palliative care outcomes;
    - b. the optimal timing, frequency and planning of teleconsultations in daily practice, considering the patient's wishes and needs, while preventing a reactive palliative care approach;
    - c. the potential, challenges and barriers of (interdisciplinary) teleconsultations in different populations, such as elderly patients or patients diagnosed with other life-threatening conditions;
    - d. what would be an appropriate research-design for evaluating the effect of teleconsultations in daily practice. This design should fit both the practice of palliative care as well as the innovative use of teleconsultation techniques. (*Chapters 4 and 5*)

**Recommendations for education**

1. In the coming decades, the need for palliative care will increase. Therefore, the main principles of palliative care should be incorporated in the curriculum of all healthcare-related studies. This should explicitly include the social and existential domains of palliative care. (*Chapters 2 and 3*)
2. Teleconsultation techniques are used and will be (increasingly) used in healthcare practice. We believe that they have the potential to facilitate interdisciplinary care and an integrated care approach. Therefore (future) healthcare professionals should be adequately trained in both providing interdisciplinary care as well as the appropriate use of teleconsultations in daily care. Ethical and legal issues on the use of teleconsultation should be explicitly addressed. (*Chapters 4 and 5*)

**Recommendations for policy makers**

1. Technical innovations (such as teleconsultations) should be timely and regularly evaluated in order to:
    - a. prevent the implementation of harmful or ineffective innovations,
    - b. promote implementation and further development of promising or successful innovations in daily care. (*Chapters 4 and 5*).
  2. When developing, testing and implementing technical innovations, such as teleconsultations, in medical practice, societal and ethical aspects require explicit and careful evaluation. (*Chapter 5*)
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## FINAL CONCLUSIONS

Palliative care consultations play an important role in the provision of palliative care to home-dwelling patients by GPs. Although GPs are largely satisfied regarding current consultation practices, some vital aspects of palliative care, i.e. the social and existential domains, threaten to remain neglected during consultations. Furthermore, fellow GPs appear to play a major role in the current practice of palliative care consultations. However, it remains unclear to what extent these consulted fellow GPs are considered "sparring partners" with general skills and knowledge in palliative care or as experts in palliative care. Future research should focus on the role and position of fellow GPs in palliative care consultations and whether and how the use of palliative care consultations affects the quality of palliative (home) care.

Evidence from this thesis regarding the effectiveness of teleconsultations in palliative care, involved one-on-one consultations in the context of a supply-driven care model and suboptimal GP involvement. This evidence does not support widespread use of such teleconsultations in palliative home care. However, we discovered that, if carefully planned, the use of tripartite teleconsultations between hospital-based specialists, GPs and AYA patients with advanced cancer, may improve interdisciplinary collaboration and contribute to an integrated care approach by providing opportunities for information exchange, policy making and alignment of care. Although promising, several technical barriers and logistical issues hamper the use of tripartite teleconsultations in daily practice, and several communication-related challenges and dilemmas need further exploration.

We were unable to evaluate whether and how these tripartite interdisciplinary teleconsultations actually improve patient-related palliative care outcomes. This requires further research in both adolescents and young adults with cancer as well as among other populations.

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SUMMARY

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## SUMMARY

The majority of patients with advanced cancer, as well as with other chronic, life-threatening conditions, wish to spend the last phase of their lives at home. For these patients, adequate home-based palliative care is required, aiming for the best possible quality of life, as well as the best possible quality of dying and death.

Palliative home care can be divided in *general* palliative home care and *specialist* palliative home care. In the Netherlands, general palliative home care is delivered and coordinated by the patient's general practitioner (GP), mostly in cooperation with home care nurses. However, some patients have or develop complex palliative care needs that require the input of a specialist palliative care team. Currently, consultation and collaboration between generalist and specialist palliative care providers largely depends on (single) phone contacts and, therefore, may have some important limitations. The use of teleconsultations, enabling participants to interact by means of synchronous, audio-visual communication, may lead to more sustainable and effective collaboration and consultation practices. This thesis focuses on whether and how the use of teleconsultations could improve the quality of palliative care for home-dwelling patients with advanced cancer.

The first aim of this thesis was to gain insight in current palliative care consultation practices. Therefore in **chapter 2** we used a cross-sectional web-based survey among all GPs in the region of Nijmegen to gain insight in current palliative care consultation practices from the GP's perspective. This survey contained questions about the delivery of palliative care by GPs, their consultation practices and satisfaction with current services. The results from this survey showed that GPs most often consulted informal caregivers or fellow GPs when in need for additional or expert palliative care advice. During consultations, physical problems were discussed most often, while social and existential issues were hardly covered. In their choice of a particular consultation service, GPs considered the quality of the provided advice to be the most important factor. GPs were satisfied with current consultation services, with fellow GPs receiving the highest satisfaction scores. Finally, when recalling their last palliative patient, most GPs started requesting consultation during this patient's last month of life. From this study, we concluded that, next to informal caregivers, GPs preferably seek advice from fellow GPs. Physical issues receive much attention during consultations; however, other vital aspects of palliative care seem to remain relatively neglected, such as social and existential issues and a proactive care approach.

In **chapter 3** we performed a retrospective analysis of a longitudinal database containing all patient-related consultations by formal Dutch Palliative Care Consultation (PCC) teams, that were requested between 2004 and 2011. In this study we described the frequency and characteristics of these consultations, thereby focusing on consultations in which palliative sedation was addressed. Palliative sedation can be considered a complex intervention in palliative care. This study showed that the majority of consultations was requested by GPs and concerned patients with cancer. Palliative sedation was relatively more often discussed in consultations concerning patients with neurologic diseases or COPD compared



to consultations concerning patients with cancer. Furthermore, palliative sedation was also relatively more often discussed in consultations concerning patients suffering from dyspnea, agitation/ delirium or exhaustion and in consultations in which euthanasia-related questions or existential issues were addressed. Consultations in which palliative sedation was discussed may be exemplary of more complex cases. Therefore, the above mentioned case-related characteristics may help clinicians in timely identifying patients at risk for a more complex disease trajectory at the end of life and, as a result, can be helpful in estimating the need for specialist palliative care input.

The second aim of this thesis focused on the use of teleconsultations in the context of palliative home care. Although from the literature teleconsultation seemed to be a promising intervention for providing palliative care to home-dwelling patients, its effect on clinically relevant outcome measures remained largely unexplored. Therefore, in **Chapter 4** we reported on a randomized clinical trial (RCT) in which we determined whether weekly teleconsultations from a hospital-based specialist palliative care consultation team (SPCT) improved patient-experienced symptom burden compared to “care as usual” in home-dwelling patients with advanced cancer. Furthermore, we evaluated whether the use of such teleconsultations improved other patient- and caregiver-related palliative care outcomes regarding unmet palliative care needs, continuity of care, hospital admissions, satisfaction with teleconsultations, and the burden experienced by informal caregivers.

Seventy-four home-dwelling patients diagnosed with advanced cancer were recruited from outpatient clinics of a tertiary university hospital and from a regional home care organization. These participants were randomized to receive weekly, prescheduled teleconsultations with an SPCT-member (intervention group), or to receive “care as usual” (control group), for a period of 12 weeks. The Total Distress Score (defined as the sum of all nine subscales of the Edmonton Symptom Assessment System) became significantly higher in the intervention group than in the control group, reaching statistical significance at week 12 (adjusted difference at week 12: 6.90 points, 95% CI, 0.17 to 13.63;  $P = 0.04$ ). Also, the adjusted anxiety scores were higher in the intervention group than in the control group (estimate effect: 1.40; 95% CI, 0.14 to 2.66;  $P = 0.03$ ). We found no differences between the two groups with regard to the other outcome measures.

We concluded that adding weekly teleconsultations to usual palliative care leads to higher reported symptom scores among home-dwelling patients with advanced cancer. These findings may (partly) be explained by factors other than the teleconsultations as such: an excess of attention on symptoms and (potential) suffering (a so-called “nocebo-effect”), the supply-driven care model for teleconsultations used in this trial, suboptimal GP involvement, and the already high level of specialist palliative care provided to the control group in this study.

In **Chapter 5** we explored and described the use of teleconsultations in an interdisciplinary care model, in which we explicitly involved hospital-based caregivers, GPs and patients. This study was performed in the context of palliative care for adolescents and

young adults (AYAs) with advanced cancer. Palliative care for AYAs is considered complex due to several AYA-related factors (e.g. young age and ongoing physical and psychosocial development) and healthcare system-related factors (e.g. healthcare systems are usually strictly divided into adult-oriented and child-oriented care, leaving a “gap” for AYA-specific palliative care). Interdisciplinary collaboration between GPs and medical oncologists (MOs) can optimize palliative care for home-dwelling AYAs with advanced cancer. Using tripartite teleconsultations provided opportunities for interdisciplinary meetings between MOs and GPs thereby directly involving AYA patients.

We performed a qualitative multiple case study with each case consisting of an AYA with advanced cancer and their healthcare professionals (i.e. their GP, MO and other relevant hospital-based caregivers). AYAs were recruited from the Medical Oncology outpatient clinic of a tertiary university hospital. Per case, four interdisciplinary meetings were organized by means of tripartite teleconsultations. Afterwards, participants were interviewed using serial, semi-structured interviews and a “stimulated recall” video method. These interviews focused on how participants had used and experienced these teleconsultations.

A total of 6 patients and their healthcare professionals participated in this study. This resulted in 16 teleconsultations and 29 interviews. From these interviews, six main themes were discerned that: 1) described the current, mainly hospital-based organisation of care for AYAs with advanced cancer; 2) explained how tripartite teleconsultations facilitate interdisciplinary collaboration between GPs and hospital caregivers; and 3) described how tripartite teleconsultations change communication dynamics, how communication etiquettes are challenged, and how technical impairments and logistical issues seriously hampered the use of these teleconsultations in daily practice.

From this multiple case study we concluded that tripartite teleconsultations can contribute to interdisciplinary collaboration and a more integrated care approach for AYAs with advanced cancer. However, technical and logistical issues require rigorous refinements and improvements when considering the use of these teleconsultations in daily practice. Furthermore, tripartite teleconsultation introduces new dilemmas and challenges regarding communication dynamics and etiquettes that need to be carefully addressed, explored and evaluated prior to and during its use in daily practice.

In **Chapter 6** we discussed the main findings of this thesis. Furthermore, we critically evaluated some important strengths and limitations regarding the methodologies used for this thesis, mainly focusing on whether and how these methodologies “fit” the practice of teleconsultations in the context of palliative home care.

Since this thesis is part of a larger NWO-research project on the use of telemedicine in palliative care (*“Optimization of complex palliative care at home by means of teleconsultation”*), we also discussed some of the main findings from this thesis in relation to the previously published qualitative evaluation on this topic (described by Van Gorp (2016), in his thesis *“Teleconsultation: enhancing personalized palliative care at home. An empirical-ethical analysis”*).



In this chapter, we also provided recommendations regarding consultation in general and the use of teleconsultation in the context of palliative care. This concerned recommendations for clinical practice as well as recommendations for further research, education and policy.

We concluded that palliative care consultations in general play an important role in the provision of palliative care to home-dwelling patients by GPs. We have gained important knowledge and insights regarding the current practice of palliative care consultations.

With regard to the effectiveness of teleconsultations in palliative care, we found that the use of teleconsultations in one-on-one consultations, in the context of a supply-driven care model and suboptimal GP involvement does not improve patient-related palliative care outcomes.

However, the use of tripartite teleconsultations between hospital-based specialists, GPs and AYA patients with advanced cancer, may improve interdisciplinary collaboration and contribute to an integrated care approach by providing opportunities for information exchange, policy making and alignment of care. Although promising, several technical barriers and logistical issues hamper the use of tripartite teleconsultations in daily practice, and several communication-related challenges and dilemmas need further exploration.

Given the exploratory design of this study, we were unable to evaluate whether and how these tripartite interdisciplinary teleconsultations actually improved patient-related palliative care outcomes. This requires further research in both adolescents and young adults with cancer as well as among other populations.

In conclusion, the results from our RCT do not support a standardized implementation of teleconsultations in the practice of palliative home care. However, in a smaller multiple case study involving AYA patients with advanced cancer, we found that the use of (tripartite) teleconsultations may facilitate an integrated palliative home care approach, if carefully tailored to a patient's wishes and needs, the (local) care setting and associated healthcare providers, and technical and logistical possibilities. Therefore, further research is needed.









## NEDERLANDSE SAMENVATTING

De meeste patiënten met vergevorderde kanker of een andere chronische, levensbedreigende aandoening willen graag de laatste fase van hun leven thuis doorbrengen. Om een zo goed mogelijke kwaliteit van leven (en van sterven) na te streven voor deze patiënten is het van groot belang dat zij toegang hebben tot adequate palliatieve zorg in de thuissituatie.

Deze palliatieve zorg kan worden onderverdeeld in generalistische en specialistische palliatieve zorg. In Nederland is de huisarts verantwoordelijk voor het coördineren en het verlenen van generalistische palliatieve zorg voor patiënten in de thuissituatie. Meestal gebeurt dit in samenwerking met thuiszorgverpleegkundigen. In sommige gevallen krijgen patiënten binnen een palliatief zorgtraject te maken met complexe problematiek, waardoor overleg of samenwerking met een specialistisch palliatief team nodig is.

De samenwerking tussen de huisarts en een specialistisch team verloopt momenteel vaak via (één of enkele) telefonische contacten en kent daardoor de nodige beperkingen. Door gebruik te maken van teleconsultatie, krijgen deelnemers de mogelijkheid tot onderlinge synchrone, audiovisuele communicatie. Deze vorm van communicatie leidt mogelijk tot meer duurzame en effectieve samenwerking en consultatie. Dit proefschrift richt zich daarom op de vraag of en op welke manier het gebruik van dergelijke teleconsultaties de kwaliteit van palliatieve zorg voor patiënten met vergevorderde kanker in de thuissituatie verbetert.

De eerste doelstelling van dit proefschrift was om inzicht te krijgen in de huidige consultatiegewoonten binnen de context van palliatieve zorg voor patiënten in de thuissituatie. Daarom hebben we in **hoofdstuk 2** een digitale vragenlijst verspreid onder alle huisartsen in de regio Nijmegen om inzicht te krijgen in de huidige consultatiegewoonten vanuit het perspectief van de huisarts. Deze vragenlijst bevatte vragen over palliatieve zorgverlening door huisartsen, hun consultatiegewoonten en de tevredenheid van huisartsen ten aanzien van de huidige consultatiemogelijkheden. Uit de uitkomsten van deze vragenlijst bleek dat wanneer huisartsen behoefte hadden aan aanvullend advies of aanvullende expertise, zij zich het meest frequent wendden tot mantelzorgers of collega-huisartsen. Tijdens consultaties komen fysieke problemen het meest frequent aan de orde, terwijl sociale en existentiële problematiek nauwelijks ter sprake komt. In hun keuze voor één van de beschikbare consultatiemogelijkheden, is de kwaliteit van het gegeven advies de belangrijkste overweging. Huisartsen waren tevreden met de huidige consultatiemogelijkheden, waarbij collega-huisartsen de hoogste tevredenheidsscores ontvingen. Tot slot werd huisartsen gevraagd om een aantal vragen te beantwoorden met betrekking tot de laatste palliatieve patiënt aan wie zij zorg verleend hadden. De meeste huisartsen gaven daarbij aan dat zij voor het eerst een andere hulpverlener of instantie hadden geconsulteerd tijdens de laatste maand voor het overlijden van deze patiënt.

Uit deze studie concludeerden we dat huisartsen, naast mantelzorgers, bij voorkeur hun collega-huisartsen consulteren. Tijdens consultaties is er veel aandacht voor fysieke



problematiek, maar andere belangrijke aspecten van palliatieve zorg, zoals sociale en existentiële problematiek en een proactieve zorgbenadering lijken onderbelicht te blijven.

In **hoofdstuk 3** hebben we een retrospectieve analyse uitgevoerd op een meerjarige database van het IKNL (Integraal Kankercentrum Nederland). Deze database bevatte de karakteristieken van alle patiënt-gerelateerde consultaties die tussen 2004 en 2011 waren aangevraagd bij één van de consultatieteams van het IKNL. In dit onderzoek hebben we de aantallen en de karakteristieken van deze consultaties beschreven, waarbij we ons vooral gericht hebben op consultaties waarin het onderwerp palliatieve sedatie aan de orde is geweest. Palliatieve sedatie kan worden beschouwd als een complexe interventie binnen de context van palliatieve zorg.

Uit dit onderzoek kwam naar voren dat de meerderheid van alle consultaties bij het consultatieteam van het IKNL was aangevraagd door huisartsen en dat het patiënten betrof die gediagnosticeerd waren met kanker. Palliatieve sedatie kwam relatief vaker aan de orde in consultaties voor patiënten met neurologische aandoeningen of COPD vergeleken met consultaties voor patiënten met kanker. Daarnaast kwam palliatieve sedatie relatief vaker aan de orde in consultaties voor patiënten bij wie er sprake was van dyspnoe, agitatie/delir, vermoeidheid, euthanasie-gerelateerde vragen of existentiële problematiek.

Consultaties waarin het onderwerp palliatieve sedatie aan de orde komt, hebben mogelijk betrekking op meer complexe casuïstiek. De beschreven karakteristieken van deze consultaties kunnen daarom behulpzaam zijn voor hulpverleners bij het tijdig herkennen van patiënten met een verhoogd risico op complexe palliatieve zorgproblematiek en het inschatten van de behoefte aan specialistische ondersteuning hierbij.

De tweede doelstelling van dit proefschrift richtte zich op het gebruik van teleconsultaties bij het verlenen van palliatieve zorg aan patiënten in de thuissituatie. Hoewel uit de literatuur bleek dat teleconsultatie een veelbelovende interventie lijkt binnen deze context, waren de effecten ervan op klinisch-relevante uitkomstmaten nog nauwelijks onderzocht. Daarom beschreven we in **hoofdstuk 4** een gerandomiseerde klinische trial onder een groep thuisverblijvende patiënten met vergevorderde kanker. Binnen deze groep onderzochten we of wekelijkse teleconsultaties door een specialistisch palliatief consultatieteam (SPCT) uit het ziekenhuis leidden tot een verbetering van de ervaren symptoomlast in vergelijking met "standaard zorg". Daarnaast onderzochten we of het gebruik van deze teleconsultaties leidde tot een verbetering van andere relevante patiënt- en zorgverlener-gerelateerde uitkomstmaten. Deze uitkomstmaten hadden betrekking op onvervulde palliatieve zorgbehoeften, continuïteit van zorg, het aantal ziekenhuisopnames, de mate van tevredenheid ten aanzien van de teleconsultaties en de ervaren druk door mantelzorgers.

Vierenzeventig thuisverblijvende patiënten met vergevorderde kanker namen deel aan dit onderzoek. Zij werden geworven via een aantal poliklinieken van een universitair ziekenhuis en via een regionale thuiszorgorganisatie. Deze deelnemende patiënten werden door middel van randomisatie verdeeld over 2 groepen. Een groep had wekelijks

een, vooraf ingeplande, teleconsultatie met één van de zorgverleners van het SPCT (de interventiegroep). De andere groep ontving “standaard zorg” (de controlegroep). De duur van de studie was 12 weken.

De ervaren symptoomlast werd uitgedrukt in de zogenaamde “Total Distress Score” (dit is de som van de 9 items waaruit de ESAS (Edmonton Symptom Assessment System)-vragenlijst bestaat). Deze ervaren symptoomlast werd significant hoger in de interventiegroep in vergelijking met de controlegroep, waarbij het verschil in week 12 statistisch significant werd (gecorrigeerd verschil in week 12: 6,90 punten, 95% CI, 0.17 – 13.63,  $p=0.04$ ). Ook de gecorrigeerde angstscores waren hoger in de interventiegroep vergeleken met de controlegroep (geschat effect: 1.40; 95% CI, 0.14 – 2.66,  $p=0.03$ ). Ten aanzien van de andere uitkomstmaten vonden we geen verschillen tussen beide groepen.

We concludeerden dat het toevoegen van wekelijkse teleconsultaties aan de gebruikelijke palliatieve zorg leidt tot een hogere gerapporteerde symptoomlast bij thuisverblijvende patiënten met vergevorderde kanker. Deze bevindingen kunnen mogelijk (deels) worden verklaard door andere factoren dan de teleconsultaties op zich, namelijk: een overmaat aan aandacht voor symptomen en (toekomstig) lijden (een zgn. “nocebo-effect”), het aanbod-gestuurde zorgmodel waarin de teleconsultaties binnen dit onderzoek werden aangeboden, de suboptimale betrokkenheid van huisartsen binnen dit onderzoek en een hoge mate van specialistische palliatieve zorg die reeds aanwezig was in de controlegroep.

In **hoofdstuk 5** exploreerden en beschreven we het gebruik van teleconsultaties binnen een interdisciplinair zorgmodel, waarin zowel zorgverleners uit het ziekenhuis, huisartsen als patiënten actief werden betrokken. Dit onderzoek werd uitgevoerd binnen de context van palliatieve zorg voor adolescenten en jongvolwassenen (AYA's) met vergevorderde kanker. Palliatieve zorg voor AYA's wordt als complex beschouwd vanwege patiënt-gerelateerde factoren (bv. de jonge leeftijd van AYA's en de leeftijd-gerelateerde fysieke en psychosociale ontwikkelingen die zij doormaken) en gezondheidszorg-gerelateerde factoren (bv. het zorgsysteem dat meestal strikt onderverdeeld is in volwassenzorg en pediatrie, waardoor AYA's in een “gat” dreigen te vallen). Door interdisciplinaire samenwerking tussen huisartsen en medisch oncologen kan palliatieve zorg voor thuisverblijvende AYA's met vergevorderde kanker worden geoptimaliseerd. Deze interdisciplinaire samenwerking kan mogelijk worden ondersteund door gebruik te maken van drieweg teleconsultaties (dat wil zeggen: teleconsultaties waaraan 3 deelnemers tegelijkertijd deelnemen). Hierdoor konden niet alleen interdisciplinaire overleggen tussen medisch oncologen en huisartsen worden gefaciliteerd, maar konden ook de AYA-patiënten zelf direct betrokken worden bij deze overleggen.

We hebben voor dit kwalitatief onderzoek gebruikt gemaakt van een “multiple casestudy”-design. Elke casus bestond uit een AYA met vergevorderde kanker en de betrokken zorgverleners (dat wil zeggen: hun huisarts, hun medisch oncoloog en eventuele andere betrokken zorgverleners vanuit het ziekenhuis). Deelnemende AYA's werden geworven via de polikliniek Medische Oncologie van een universitair ziekenhuis.

Binnen iedere casus werden vier interdisciplinaire overleggen georganiseerd met behulp van drieweg teleconsultaties. Nadien werden de deelnemers geïnterviewd, met behulp van seriële, semigestructureerde interviews waarbij gebruikt werd gemaakt van videobeelden om terug te blikken op de teleconsultatie (de zogenaamde “stimulated recall video method”). Deze interviews richtten zich vooral op de manier waarop deelnemers gebruik hadden gemaakt van de teleconsultaties en hoe zij deze beleefd hadden.

In totaal namen 6 patiënten en hun zorgverleners deel aan deze studie. Dit resulteerde in 16 teleconsultaties en 29 interviews. Op basis van deze interviews konden 6 hoofdthema's worden onderscheiden, waarin de volgende onderwerpen centraal stonden: 1) de huidige zorg voor AYA's met vergevorderde kanker, die vooral plaatsvindt binnen het ziekenhuis; 2) de manier waarop de drieweg teleconsultaties de interdisciplinaire samenwerking tussen huisartsen en zorgverleners uit het ziekenhuis faciliteerde; en 3) de invloed van de teleconsultaties op communicatie en omgangsvormen en hoe technische en logistieke problemen het dagelijks gebruik van dit soort teleconsultaties in de weg konden staan.

Op basis van dit onderzoek concludeerden we dat drieweg teleconsultaties kunnen bijdragen aan interdisciplinaire samenwerking en meer geïntegreerde (palliatieve) zorg voor AYA's met vergevorderde kanker.

Echter, voordat het gebruik dit soort teleconsultaties in de dagelijkse praktijk kan worden overwogen, zijn nog wel aanzienlijke aanpassingen en verbeteringen nodig op technisch en logistiek gebied. Daarnaast leidt het gebruik van drieweg teleconsultaties tot nieuwe dilemma's en uitdagingen op het gebied van communicatie en onderlinge omgangsvormen. Dit vraagt om voortdurende en zorgvuldige reflectie en evaluatie voorafgaand aan en tijdens het gebruik van (drieweg) teleconsultaties in de praktijk van alledag.

In **hoofdstuk 6** werden de belangrijkste bevindingen uit dit proefschrift bediscussieerd. Daarnaast werden de gebruikte methodes in dit proefschrift kritisch geëvalueerd, waarbij we ons met name richtten op de vraag in hoeverre de gebruikte methodes passend waren voor onderzoek naar teleconsultatie binnen de context van palliatieve zorg in de thuissituatie.

Omdat dit proefschrift onderdeel is van een overkoepelend NWO-project naar het gebruik van telemedicine binnen de palliatieve zorg (*“Optimization of complex palliative care at home by means of teleconsultation”*) vergeleken we in dit hoofdstuk ook onze belangrijkste bevindingen met de bevindingen uit een eerder proefschrift rond dit thema, waarin met name de kwalitatieve evaluatie van de teleconsultaties centraal stond (zie hiervoor het proefschrift van Van Gorp (2016), getiteld: *“Teleconsultation: enhancing personalized palliative care at home. An empirical-ethical analysis”*).

In dit hoofdstuk formuleerden we ook aanbevelingen t.a.v. consultatie en het gebruik van teleconsultaties binnen de palliatieve zorg. Deze aanbevelingen richtten zich zowel op de klinische praktijk, als op verder onderzoek, onderwijs en beleid.

We concludeerden dat consultaties in het algemeen een belangrijke functie hebben binnen de palliatieve zorgverlening door huisartsen. De resultaten uit dit proefschrift

hebben geleid tot meer inzicht in de huidige manier van consulteren binnen de context van palliatieve zorg in de thuissituatie.

Het gebruik van teleconsultaties in een één-op-één setting, ingebed in een aanbodgericht zorgmodel met beperkte betrokkenheid van de huisarts leidt niet tot betere patiënt-gerelateerde palliatieve zorguitkomsten. Echter, de inzet van drieweg teleconsultaties tussen ziekenhuisspecialisten, huisartsen en AYA's met vergevorderde kanker, creëert nieuwe mogelijkheden voor het uitwisselen van informatie, het gezamenlijk opstellen van beleid en onderlinge afstemming. Mogelijkerwijs leidt dit tot betere interdisciplinaire samenwerking en meer geïntegreerde zorgverlening. Hoewel dit veelbelovend lijkt, zijn er nog verschillende technische en logistieke barrières die het dagelijks gebruik van drieweg teleconsultaties in belangrijke mate in de weg staan. Daarnaast zijn er nog verschillende uitdagingen en dilemma's op het gebied van communicatie en onderlinge omgangsvormen die nadere exploratie behoeven.

Vanwege het exploratieve design van dit onderzoek, hebben we niet kunnen nagaan of en hoe deze drieweg teleconsultaties ook daadwerkelijk leidden tot betere patiënt-gerelateerde uitkomsten op het gebied van palliatieve zorg. Hiervoor is verder onderzoek nodig, zowel binnen de AYA-populatie als ook binnen andere doelgroepen.

Concluderend, de resultaten uit onze gerandomiseerde klinische trial laten zien dat een gestandaardiseerde inzet van teleconsultaties binnen de palliatieve zorg voor thuisverblijvende patiënten niet leidt tot betere zorguitkomsten. Echter, uit ons kwalitatief onderzoek onder AYA- patiënten met vergevorderde kanker blijkt dat het gebruik van (drieweg) teleconsultaties mogelijk wel kan bijdragen aan meer geïntegreerde palliatieve zorg voor patiënten in de thuissituatie, mits zorgvuldig aangepast aan de wensen en behoeften van de patiënt, de (lokale) zorgsetting en de technische en logistieke mogelijkheden. Verder onderzoek is daarom noodzakelijk.





## DANKWOORD

Er zijn een groot aantal mensen die de afgelopen jaren een klein of groot deel van hun tijd en energie in dit proefschrift hebben gestoken. Deze mensen wil ik graag bedanken voor hun wetenschappelijke, inhoudelijke, persoonlijke en/of sociale bijdrage.

Allereerst mijn promotor, Kris Vissers. Ik heb veel van je geleerd. Jij had steeds het “grote plaatje” voor ogen en had duidelijk een visie op dit project en ten aanzien van palliatieve zorg in het algemeen op nationaal en internationaal niveau. Door onze promotie-overleggen werd dit “grotere plaatje” me steeds meer duidelijk, zowel inhoudelijk als op een meer politiek niveau. Tijdens deze overleggen maakte je vaak tekeningen en schema’s om je verhaal te ondersteunen. Het doorgronden van deze schema’s kostte me soms de nodige hoofdbreken en, ik zal eerlijk zijn, sommige heb ik nooit helemaal kunnen doorgronden.

Mijn copromotoren, Jeroen Hasselaar en Henk Schers.

Jeroen, vanaf het begin van het project was jij zo’n beetje mijn dagelijkse begeleider. Je hebt menig documentje, opzette of aanzette voor een artikel of hoofdstuk voorbij zien komen en was altijd bereid om mee te denken en, wanneer nodig, me wat moed in te praten. Je deur stond (vrijwel letterlijk) altijd open. Naast de wetenschap had je ook altijd oog voor de persoonlijke context: attent, sociaal en ook betrokken op zaken buiten het werk. Dank daarvoor!

Henk, goed om een huisarts in ons midden te hebben; een onmisbaar perspectief in de context van palliatieve zorg! Jij was steeds in staat om het onderzoek en mijn wetenschappelijke (en soms wat wollige) volzinnen naast de praktijk van alledag te zetten. Af en toe schreef je als commentaar in de zijlijn: “en dus...?”; een subtiele manier om mijn schrijven wat meer actief, direct en concreet te maken. Dank daarvoor!

Dit project speelde zich voor het grootste deel af binnen de PiPa-onderzoeksafdeling. Ik ging hier in 2012 aan de slag en moest toen nog helemaal ingewijd worden in de wonderde wereld van de wetenschap.

Jelle, op een of andere manier werd jij als mijn eerste kamergenoot ook een soort van mentor. Een taak die je met verve op je genomen en volbracht hebt. Dankzij jou maakte ik kennis met “kwalitatief onderzoek” en vroeg ik me verwonderd af: “Hoe kun je nu onderzoek doen, laat staan promoveren, zonder statistiek?” en “Is dat dan wel echte wetenschap?”. Eerlijk is eerlijk: er is een wereld voor me open gegaan. Je enthousiasme, impulsiviteit (met soms projecten die een “tikkeltje megalomaan” zijn als gevolg) en je oprechte interesse in mensen waardeerde en waardeer ik enorm.





Diana, gewaardeerde Mexicaanse collega. De uitwisseling van “onze” Nederlandse en “jouw” Mexicaanse gewoonten was een wederzijdse verrijking op meerdere gebieden: je hebt Jelle en mij tortilla’s leren maken en moest vaak lachen om onze typisch(e) Nederlandse gewoontes (zoals: een halfuur te vroeg op een afspraak zijn en afspraken met vrienden of familie inplannen in een agenda). Maar je vertelde dat je inmiddels vaak “on-Mexicaans” c.q. “Nederlands” stipt op je afspraken bent en je bent een liefhebber geworden van één van onze culturele hoogstandjes: de pannenkoekenhuizen. Dank voor de mooie tijd!

Na de verhuizing van onze afdeling, veranderde de tweepersoonskamer van Jelle en mij in een vierpersoonskamer. Marlieke en Ria, we zaten allemaal een beetje in hetzelfde schuitje. Dat maakte onze kamer de ideale plek om zo nu en dan eens even ons hart te luchten en onze frustraties te uiten. Dat was soms nodig en vaak goed: we zijn nu allemaal klaar met ons onderzoeksproject. Onze vierpersoonskamer voelde echt als een thuisbasis op de afdeling, inclusief bijbehorende huiskamersfeer. Ik zal het missen!



De dynamiek van de “andere kamers” maakte onze afdeling tot een levendig geheel; een open-deuren beleid, een centraal koffieautomaat en een aangenaam sociaal-wetenschappelijk klimaat, maakte onze afdeling, ondanks de technische en bouwkundige mankementen, tot een plaats waar het goed toeven was. Bedankt collega’s van het eerste uur en de nieuwe(re) collega’s: Marieke G., Hans, Yvonne E., Anne E., Tijn, Nienke, Marianne, Rianne, Yvonne B., Monique, Jackie, Bregje, Jeroen F., Herma, Loes, Agnes, Anne W., Nicole en Daisy.

Dit onderzoeksproject zou nooit tot een goed einde zijn gekomen zonder de lange adem van het palliatief consultteam. Het onderzoek werd een aantal keer verlengd en ik heb jullie heel wat keren lastiggevallen voor overleg over patiënten die deel konden nemen aan onze studie. Daarnaast namen jullie ook nog eens de uitvoer van de teleconsultaties voor jullie rekening. Jullie waren geduldig, behulpzaam en opbouwend kritisch en dat heeft echt geholpen, zowel voor mijn moraal als voor de concrete uitvoer van het telemedicine-project! Dankjewel José, Stans, Marieke v/d B., Wilma, Kees, Carel, Henny, Floor, Heinrich en Christel.

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Nadat mijn verschillende contracten waren afgelopen, mocht ik eind 2015 als docent aan de slag op de HAN. Collega's van IVS, dank voor jullie interesse en meelevende afgelopen jaren. Al sinds ik op de HAN aan de slag ging, zei ik dat mijn proefschrift "bijna", "in grote lijnen" of "in concept" af was. Gelukkig heb ik mijn geloofwaardigheid hierdoor niet verloren of jullie hebben dit goed verborgen weten te houden. Ondanks de fysieke krapte op sommige werkdagen, ben ik blij met de fijne werkomgeving op de Kapittelweg en de dagelijkse dynamiek, samenwerking en humor in team 4!

Dit proefschrift kon alleen tot stand komen door de bijdrage van patiënten, mantelzorgers, huisartsen, specialisten en verpleegkundigen. Ik wil jullie allemaal enorm bedanken voor jullie deelname aan de verschillende onderzoeksprojecten. In het bijzonder wil ik de patiënten en hun mantelzorgers bedanken die met onze onderzoeken hebben meegedaan. Jullie hebben belangeloos een deel van jullie kostbare tijd willen investeren in dit onderzoek. Ik ben getroffen door jullie openhartige verhalen. Buiten dat jullie bijdrage belangrijk is geweest voor het onderzoek, heb ik veel geleerd over wat het betekent om ernstig ziek te zijn en wat de term "kwaliteit van leven" concreet betekent in de praktijk van alledag. Belangrijke levenslessen die ik meeneem in mijn verdere loopbaan en mijn eigen leven.

Een van deze levenslessen luidt: "er is meer dan werk". Daarom mijn speciale dank voor al die personen die belangrijk voor me zijn, los van werk of onderzoeksprojecten. Natuurlijk, ook jullie waren en zijn oprecht geïnteresseerd in wat ik doe en waar ik mee bezig ben. Maar, het mooiste is: het maakt het voor jullie tegelijkertijd ook eigenlijk niets uit waar ik mee bezig ben.

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Tot slot, de drie meest dierbare mensen in mijn leven:

Elise, soms voel ik me schuldig dat ik de afgelopen jaren niet genoeg heb laten blijken hoe blij ik met je ben. Daarom nu "zwart op wit": je bent geweldig!



Ik ben blij dat je zo goed kunt relativeren, van aanpakken weet, flexibel bent, prettig pragmatisch kan zijn en knopen durft door te hakken. Dat kwam tijdens het schrijven van dit proefschrift soms goed van pas: als ik zei "ik stop ermee, het lukt toch nooit", maakte jij even een planning (met activiteiten per week) om het tegendeel te bewijzen. Dankjewel voor dit en veel meer!

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## CURRICULUM VITAE

Patrick D. Hoek was born on March 16, 1986 in Sliedrecht, the Netherlands. In 2004 he completed pre-university education (VWO) at “De Lage Waard” in Papendrecht and started studying Medicine at Utrecht University. During his last year in medical school, he conducted two clinical internships in Pediatrics (Gelre Ziekenhuizen, Apeldoorn) and Internal Medicine (Ziekenhuis Gelderse Vallei, Ede). Furthermore, he conducted a scientific internship at Internal Medicine (Ziekenhuis Gelderse Vallei, Ede). Under supervision of professor Witteman, he investigated the relation between Crohn’s disease and Restless Legs Syndrome (RLS), which resulted in a scientific publication.

After his graduation in 2010, he started working as a medical doctor in different care settings. First, at the department of Internal Medicine (Ziekenhuis Gelderse Vallei, Ede) and later at the department of Elderly Psychiatry (GGNet, Doetinchem). In 2012 he started working as a PhD-student on a research project on the use of telemedicine in palliative home care at the department of Anesthesiology, Pain and Palliative Medicine (Radboudumc, Nijmegen). In 2015, next to his research activities, he worked as a medical doctor in Elderly Care (De Waalboog, Nijmegen). Since December, 2015, while he continued working on his thesis, Patrick started working as a teacher at the HAN University of Applied Sciences at the institute of Nursing, particularly teaching medical subjects.





## PUBLICATIONS

### Original articles (peer reviewed)

**Hoek P**, Van Gorp J, Vissers K, Schers H, Jansen R, Van der Graaf W, Hasselaar J, Kaal S. Using tripartite teleconsultations to provide interdisciplinary palliative care to Adolescents and Young Adults (AYAs) with advanced cancer – a qualitative multiple case study. *Submitted*

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**Poster presentations**

- 2015 Palliative Care Consultation Practices of Dutch General Practitioners. 14th World Congress of the European Association for Palliative Care. Copenhagen, Denmark.
  
- 2014 Discussing palliative sedation during expert consultation-a descriptive analysis of a Dutch longitudinal database. 8th World Research Congress of the European Association for Palliative Care. Lleida, Spain.







