END OF LIFE CARE AND DECISION MAKING

Opinions and experiences of the general public, bereaved relatives, and professionals

Natasja Johanna Helena Raijmakers

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COLOFON

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CHAPTER 1

General introduction

END-OF-LIFE CARE

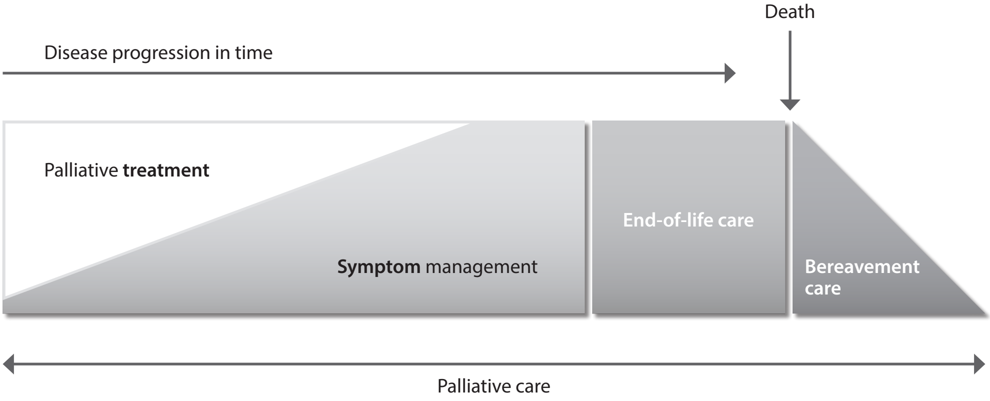
Death comes to us all. Nowadays, acute deaths due to infectious diseases have largely been replaced by non-sudden deaths, caused by e.g. cancer or cardiovascular diseases [1-2]. Advances in health care technologies have improved life expectancy and have also expanded the range of interventions which potentially prolong the life of severe ill patients. These changes involved more prolonged death trajectories, which are likely to involve some form of end-of-life care [2].

Palliative care has been defined by the World Health Organization (WHO) as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". Palliative care is promoted as the preferred approach to care for people with life-threatening illnesses, and has defined it as a major public health priority for all countries [3]. Palliative care has been divided into three stages [4]:

- advancing disease with the goals to decrease disease;
- increasing decline, with the goal to prevent and treat symptoms;
- end-of-life care, with the goal to have a dignified death.

End-of-life care is a special part of palliative care, which refers to the management of patients and relatives during the final stages of life (see figure 1). In the last decades, many advances have been made to alleviate patients' suffering at the end of life, such as better management of pain through thoughtful use of common analgesics, including opioids, and improved management of other symptoms than pain [5].

Figure 1. The scope of palliative care



END-OF-LIFE DECISIONS

End-of-life decision-making is a sensitive but important aspect of end-of-life care that can have a significant impact on the process of dying and dying patients' comfort in the last days of life. Moreover, death is often preceded by medical end-of-life decisions with a certain or potential life-shortening effect: the frequency of such decisions has been found to be 44% of all deaths in the Netherlands and to range from 23-51% of all deaths in Europe [6].

The Dutch tradition

The Netherlands have a long tradition, since 1990, in conducting research on end-of-life decisions [7-11]. Within this research tradition, medical end-of-life decisions are classified into five categories:

- Euthanasia; the administration of drugs with the explicit intention of hastening death at the patient's explicit request
- Physician-assisted suicide; the prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life
- Ending of life without an explicit patient request; the administration of drugs with the explicit intention of hastening death without an explicit patient request
- Alleviation of pain and symptoms; in dosages which are large enough to include the hastening of death as a likely or certain side-effect
- Withholding or withdrawing potentially life-prolonging treatment

Internationally, the practice of these five end-of-life decisions varies [6]. Furthermore, also which decisions are defined as being an end-of-life decision differs. Our international survey among palliative care experts that aimed at getting insight into important end-of-life decisions showed a broad scope of different end-of-life decisions, going beyond the five medical end-of-life decisions mentioned above. These international palliative care experts mentioned decision-making regarding withdrawing or withholding treatment, symptom management and place of dying often as important end-of-life decisions. Euthanasia was mentioned less often, although it was also mentioned also by some countries without legislation regarding assistance in dying [12].

Dutch legalization regarding end-of-life decisions

End-of-life decision-making is regulated by legislation, guidelines, and professional codes. Two important legislations in the Netherlands are the Dutch Euthanasia Act and the Dutch Act on Medical Treatment (in Dutch: WGBO).

Dutch Euthanasia Act

In the Netherlands, the discussion about euthanasia and physician-assisted suicide has started in the previous century, which has led to the Dutch Euthanasia Act (formally referred to as the Termination of

Life on Request and Assisted Suicide Act). Since 2002, this Act regulates the practice of euthanasia and physician-assisted suicide in the Netherlands and formulates criteria of due care. The physician has to perform euthanasia or physician-assisted suicide according to these criteria; otherwise his actions still will be punishable. The criteria of due care require the physician be convinced that:

- there is a voluntary and well-considered request from the patient;
- the patient is suffering unbearably without prospect of improvement;
- the patient is informed about his situation and prospects;
- there are no reasonable alternatives to relieve suffering;
- an independent physician must be consulted;
- euthanasia or physician-assisted suicide is performed with due medical care and attention.

Furthermore, physicians have to report euthanasia or physician-assisted suicide to one of the five regional multidisciplinary review committees. These review committees assess whether or not the physician has acted in accordance with the criteria of due care. The judgments of the review committees and case law, as being jurisprudence, provide a definite interpretation of the act.

Although the Dutch Euthanasia Act is for more than ten years in place, public and professional debates remain, especially about the boundaries and interpretation of the Dutch Euthanasia Act. Nowadays, the debate mainly focuses on euthanasia or physician assisted suicide in older people who are tired of living, without having a serious medical condition and in patients with late-stage dementia and the role of an advance directive. For the former, a citizens' initiative was launched in 2010, aiming to achieve legal assistance of dying in older people who are tired of living. The House of Representatives has rejected the proposal of this citizens' initiative, but the debate continues.

Dutch Act on Medical Treatment

In the Netherlands, the Dutch Act on Medical Treatment regulates the relation between the patient and healthcare professionals [13]. This act states that patients have to consent with a medical treatment and that the patient has the right to refuse medical treatment at any moment. Moreover, patients can also record their preferences for end-of-life care in an advance directive. A physician has to respect a negative advance directive, in which the patient refuses treatment, whereas a positive advance directive only guides a physician to better understand the patient's values and preferences. In the Netherlands, such a positive advance directive may also include a request for euthanasia. With such a request, patients ask their physician for assistance in dying in specific situations, which is a relatively common type of advance directive in the Netherlands [14]. As stated by the Dutch Royal Medical Association, such advance directives for euthanasia are mere supportive, and do not replace the need for personal communication.

NUTRITION AND HYDRATION AT THE END OF LIFE

End-of-life care often involves decisions about withholding or withdrawing potentially life-prolonging treatment, such as artificial nutrition and hydration. Decisions about artificial nutrition and hydration are important decisions at the end of life, as demonstrated by our international survey among palliative care experts [12]. Although most terminally ill patients have a decreased oral intake and loss of appetite at the end of life (39-82%) [15-17], providing artificial nutrition and hydration to all terminally ill patients at the end of life does not seem to be widely accepted among physicians in Europe. Moreover, decision-making regarding forgoing nutrition and hydration at the end of life occurs quite frequently, varying from 2.6% in Italy and 10.9% in the Netherlands [2].

Despite the fact that decision-making regarding artificial nutrition and hydration occurs frequently and is perceived to be important, little is known about the burden and benefits of the provision of artificial nutrition and hydration at the end of life. Currently, no consensus exists about the most appropriate management for terminally ill patients at the end of life with limited oral intake [18-19]. This lack of consensus is also reflected in the variety of provision of artificial nutrition and hydration in clinical practice within Europe [6]. Moreover, end-of-life decision-making regarding artificial nutrition and hydration might also be influence by social, cultural and religious factors [20-22].

PUBLIC OPINION ON END-OF-LIFE DECISIONS

Societal debate about end-of-life decisions might be strengthened by better understanding of the public opinion. Also for healthcare professionals it is important to be aware of the public opinion, expectations, and preferences regarding end-of-life care. Members of the general public are future patients or relatives who might be involved in end-of-life decision-making. Furthermore, from a democratic viewpoint the public opinion is also important; it informs the political agenda and give insight into the level of societal support for current legislation.

Several studies on the opinions on end-of-life care and decision-making of the general public have been performed, most often focusing on euthanasia or physician-assisted suicide. Several Dutch studies concerning the public opinion on euthanasia have been conducted. These studies showed that 83-88% of the general public supports euthanasia [23-24]. Internationally, opinions on euthanasia has been studied by the European Value Study that showed large cross-national differences in the acceptance rate of euthanasia in Europe, and it ranged from 2.2-6.7 on a 10-point scale [25]. Furthermore, the European Value Study showed an increasing support for legalization of euthanasia and physician-assisted suicide throughout Europe [26], although different trends in euthanasia acceptance across Europe were present [27]. Beyond Europe, in Canada 66-71% of the general public supports legalizing of euthanasia [28-29] and a US-study showed that one-third of the general public supports euthanasia, one-third supports assistance in dying in certain circumstances and one-third opposes euthanasia [30].

Public opinions on withholding or withdrawing treatment at the end of life have been studied less frequently. In Canada, 85% of the general public approved forgoing life-sustaining treatment in a competent patient who was unlikely to recover. A key factor influencing public opinion regarding forgoing life-sustaining treatment was the patient's prognosis [29]. A recent Korean survey showed that 89-89% of the general public approves the withdrawing or withholding of life-sustaining treatment at the end of life in terminally ill patients [31], and in Japan 57-69% would not want life-sustaining treatments at the end of life when having cancer or being frail [32]. In Sweden, 78% of the general public was willing to withdraw treatment in a terminally ill patient, while only 40% would withhold treatment [33].

Advance care planning

Nowadays, people in Europe are less familiar with death and dying than a century ago. They generally experience death and dying in their near surrounding later in life, because of the increased life expectancy. Death and dying is also increasingly a private occasion. That said, end-of-life care has become more complex and medicalized, and end-of-life decision-making often occurs. Therefore, the need for end-of-life communication is more acute. Advance care planning is a process of communication among patients, healthcare professionals, and relatives regarding end-of-life care. It aims to ensure that patients' values remain central in decision-making and that the care provided is consistent with patients' preferences [34], and is encouraged extensively [35].

To effectively promote communication about end-of-life care, insight into the values and perceptions of the target population is important. Members of the general public have already been identified as a potential target population [36-37]. Moreover, in the UK a national program called 'Dying Matters' has recently been launched to encourage people to talk about their wishes and preferences regarding the end of life and to raise public awareness. STEM [38] is the Dutch equivalent. Insight into opinions on advance care planning and end-of-life discussions of the general public is needed to inform such initiatives. A recent Japanese survey showed that the majority of the general public have an interest in advance directives [39], and almost half of the general public had discussed life-sustaining treatments with their relatives [32]. Important themes within the public opinions on advance directives are trust in the family and the medical system, need for control, and knowledge about the legal status of advance directives [40]. Little information about the Dutch public opinions on advance care planning is available.

THIS THESIS

In the Netherlands, the Euthanasia Act came into effect in 2002, and after eight years of legislation societal debate remains, especially regarding the boundaries and interpretation of the Euthanasia Act. Nowadays, one main topic for debate concerns euthanasia or physician-assisted suicide in older people who are tired of living and want to die. Better understanding of the current public opinions on euthanasia and its boundaries can strengthen the societal debate. Therefore, this thesis aims to study the public opinions on end-of-life decision-making in the Netherlands.

End-of-life decision-making encompasses more than euthanasia and physician-assisted suicide. Another internationally shared important end-of-life decision concerns withholding or withdrawing potentially life-prolonging treatment, in particular artificial nutrition and hydration at the end of life. To contribute to better end-of-life decision-making regarding nutrition and hydration at the end of life, this thesis further aims to study nutrition and hydration at the end of life.

To achieve these aims, the following research questions will be addressed:

Part 1: The public opinion on end-of-life decision-making

1. What is the opinion of the Dutch general public on the legal requirements of euthanasia and PAS? (chapter 2)
2. What is the opinion of the Dutch general public regarding euthanasia and PAS in older persons who have a wish to die, without the presence of a serious medical condition? (chapter 3).
3. To what extent is the Dutch general public currently involved or inclined to be engaged in advance care planning? (chapter 4)

Part 2: Nutrition and hydration at the end of life

4. What key issues do healthcare professionals encounter when making decisions regarding artificial nutrition and hydration at the end of life? (chapter 5)
5. What are the practices, effects of, and attitudes towards artificial nutrition and hydration at the end of life in terminally ill patients? (chapter 6 and 7)
6. How do relatives perceive nutrition and hydration at the end of life of the patient? (chapter 8)

METHODS

This thesis is based upon three studies:

KOPPEL study

The KOPPEL study is a national study to determine the Knowledge and Opinions of the general Public and Professionals regarding End-of-Life care and decisions, supported by a national grant of ZonMw. The KOPPEL consortium existed of the Erasmus MC Rotterdam, University Medical Center Utrecht (UMCU), University Medical Center Groningen (UMCG), University of Utrecht and University of Groningen. The KOPPEL study has used a mixed method approach and involved a national questionnaire survey among physicians, nurses and members of the general public, qualitative interviews, case studies, and a media analysis.

National survey among the general public

For the national survey among the general public, we have used the CentERpanel of the University of Tilburg, a representative sample of the general Dutch public. This panel comprised a random sample of postal codes in the Netherlands. Multiple measures are in place to avoid selection bias of this internet panel, such as guaranteeing accessibility for all selected households without Internet access at time of study recruitment. The panel is a dynamic panel, and during the survey period 2503 were active member of the panel and received the questionnaire. Items in the questionnaire referred to knowledge and opinions regarding end-of-life care and decision-making, using statements, closed questions, and vignettes. The questionnaire has been sent between December 2009 and February 2010. In total, 1960 completed the questionnaire (response rate: 78%).

OPCARE9 collaborative

OPCARE9 is a European collaborative project to optimize research for the care of cancer patients in the last day of life, supported by a 3 year EU FP7 Coordination & Support Action grant. In total, nine countries were involved: Argentina, Germany, Italy, Sweden, Switzerland, the Netherlands, New Zealand, and the UK. Through systematically investigating current end-of-life practices across a range of healthcare environments and diverse cultures, it shared the existing knowledge base and identified knowledge gaps to reach consensus positions on optimum care and develop innovative research protocols to address identified needs. Methods used within OPCARE9 were Delphi studies, expert meetings and systematic literature reviews.

Erasmus MC Rotterdam was the lead of work package 2: end-of-life decision-making. The first step for our work package on end-of-life decision-making was to establish a shared base by finding a common definition of what constitutes an end-of-life decision. End-of-life decision was defined as a decision involving a person who is in the last days of life that has (or may have) a significant impact on the quality, place and/or time of dying. An international inventory was conducted to get insight into which end-of-life decisions palliative care experts considered most important in care at the end of life. In total, 114 experts mentioned more than 800 end-of-life decisions. Regardless of country or profession, most frequently mentioned decisions involved withdrawing and/or withholding medical treatment and symptom management. Decisions about withdrawing and/or withholding of medical treatment frequently concerned artificial nutrition and hydration, or anti-cancer treatment. Decisions about symptom management often concerned the use of sedatives.

Systematic literature reviews

Based on the results of this international inventory, we conducted two systematic literature reviews regarding artificial nutrition and hydration at the end of life. The first review addressed the practice and effects of artificial nutrition and hydration in the last week of life of cancer patients, the second review focused on attitudes towards artificial hydration. We conducted an electronic search of several databases for papers that were published in English. In addition, we hand searched the most recent issues of relevant peer-reviewed journals.

Delphi study

We also conducted an international Delphi survey among 90 international palliative care experts. We aimed to include four physicians, three nurses, two other professional caregivers and one volunteer per country, resulting in 90 experts in total. These experts received two structured questionnaires, the first to identify important issues they encounter when making end-of-life decisions, by using open questions (round 1). The second round was informed by the results of round 1 and explored the extent to which experts thought that research on the important issues would be useful. The questionnaires were written in English and distributed electronically. The first questionnaires were sent between October 2009 and November 2009, and the second between May 2010 and June 2010. The response rate of the first round was 76% and of the second round 60%.

COMMEND study

The COMMEND study is a collaboration between the Arohanui Hospice, Palmerston North, New Zealand and Erasmus MC Rotterdam to improve insight into communication at the end of life regarding nutrition and hydration. This study was supported by the Dutch Cancer Society, Genesis Cancer Society NZ and the Erasmus Trust Fund. The COMMEND study involved qualitative interviews with bereaved relatives and healthcare professionals and participatory observations of patients who had been referred to the palliative care service in Palmerston North, New Zealand.

Interviews with bereaved relatives

We performed a qualitative interview study among bereaved relatives of patients who had been referred to a New Zealand palliative care service to study the bereaved relatives' experiences and perspectives on the patient's oral intake of nutrition and hydration at the end of life. We used a semi-structured questionnaire, addressing the following topics; experiences in last month of life, awareness of dying (patient and relative), satisfaction with care, experiences with food and fluids intake, perception of food and fluid intake, communication at the end of life. At the end of the interview, the respondents completed the Quality of Death and Dying Questionnaire (QODD) [41]. All respondents gave written consent prior to the interview; all interviews were audio-taped and transcribed verbatim by a confidential transcribing service. The interviews were held between January 2012 and March 2012. In total, 23 bereaved relatives participated in an interview.

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PART I

Public opinion on end-of-life decisions

CHAPTER 2

Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach

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ABSTRACT

Background

The practice of euthanasia and physician-assisted suicide (PAS) in the Netherlands has been regulated since 2002 by the Euthanasia Act. In the on-going debate about the interpretation of this Act, comparative information about the opinions of the different stakeholders is needed.

Aim

To evaluate the opinions of Dutch physicians, nurses and the general public on the legal requirements for euthanasia and PAS.

Design

A cross-sectional survey among Dutch physicians and nurses in primary and secondary care and members of the Dutch general public, followed by qualitative interviews among selected respondents. The participants were: 793 physicians, 1243 nurses and 1960 members of the general public who completed the questionnaire; 83 were interviewed.

Results

Most respondents agreed with the requirement of a patient request (64–88%) and the absence of a requirement concerning life expectancy (48–71%). PAS was thought acceptable by 24–39% of respondents for patients requesting it because of mental suffering due to loss of control, chronic depression or early dementia. In the case of severe dementia, one third of physicians, 58% of nurses and 77% of the general public agreed with performing euthanasia based on an advance directive. Interviewees illustrated these findings and supported the Act.

Conclusions

Health care professionals and the general public mostly support the legal requirements for euthanasia and PAS. The law permits euthanasia or PAS for mental suffering but this possibility is not widely endorsed. The general public is more liberal towards euthanasia for advanced dementia than health care professionals. We conclude that there is ample support for the law after eight years of legal euthanasia.

INTRODUCTION

Legalizing euthanasia and physician-assisted suicide (PAS) is an issue for debate in many countries. The practice of euthanasia and PAS in the Netherlands has been regulated since 2002 in the Dutch Euthanasia Act (Termination of Life on Request and Assisted Suicide Act). The Act formulates criteria of due care. Only if a physician performs euthanasia or PAS according to these criteria, will his actions not be punishable. The criteria of due care require that the physician be convinced that (1) there is a voluntary and well-considered request from the patient, (2) the patient is suffering unbearably without prospect of improvement, (3) the patient is informed about his situation and prospects, (4) there are no reasonable alternatives to relieve suffering, (5) an independent physician must be consulted and (6) euthanasia or PAS is performed with due medical care and attention. The act does not entail a legal right to euthanasia or PAS nor does it contain a limit on a patient's life expectancy. Physicians have to report euthanasia or PAS to one of five regional multidisciplinary review committees. These review committees assess whether or not the physician has acted in accordance with the criteria of due care. The judgments of the review committees and case law thus provide a definite fulfilment of these criteria. Dutch opinions have been studied before [1]. In previous research as well as in the on-going societal debate about the interpretation of this Act, growing divergence is claimed between the knowledge and opinions of health care professionals and the general public [2]. Comprehensive current comparative information about the opinions of the different stakeholders is lacking and is needed. The aim of this study was to evaluate opinions about the law among Dutch health care professionals and the general public after eight years of official euthanasia legislation. The following research question was addressed: What are the opinions of physicians, nurses and the general public in the Netherlands on legal requirements for euthanasia and PAS?

METHODS

Design and population

We conducted a cross-sectional survey among physicians, nurses and members of the Dutch general public, followed by a qualitative interview study among a selection of the respondents. Regarding ethical approval, according to Dutch law, this kind of observational study is exempt from ethical review.

Survey

A questionnaire was sent to a random sample of 1250 medical specialists of internal medicine, cardiology, pulmonology, neurology and surgery, 500 general practitioners and 250 elderly care physicians. Addresses were taken from the Royal Dutch Medical Association (KNMG), the Dutch Institute for Research of Health Care (NIVEL) and the Dutch Association of Elderly Care Physicians (Verenso), respectively. Respondents had to: (1) be working in the Netherlands, (2) have at least two years of experience in their current specialty, and (3) if retired, have been retired no longer than two years prior to participation or be under 67 years of age. The questionnaire could be completed by mail or electronically over a four-month period (January through May 2010). Two reminders were sent. During the same period, a similar questionnaire was offered to nurses by various professional nursing organizations in the Netherlands, through websites and journals. This questionnaire was freely accessible on the internet. To be eligible for the study, respondents had to: (1) be a registered nurse, (2) be working as such for at least two years, and (3) be working in the Netherlands. The questionnaire started with three selective questions. If respondents did not meet the criteria, they were automatically excluded from completing the questionnaire. A comparable online questionnaire was offered to an established panel of members of the Dutch general public (CentERdata, University of Tilburg, The Netherlands). This panel comprises a random sample of postal codes in the Netherlands. Multiple measures are in place to avoid selection bias of this panel, such as guaranteeing accessibility for all selected households by providing all selected members of the panel with a free tool that enables response by internet or television. During the survey period (December 2009–February 2010), 2503 persons were active members of the total panel. We only included respondents aged 18 or over.

Interview study

At the end of the questionnaire, we invited respondents to participate in an interview and if they consented, to provide us with their personal contact details. Anonymity was indicated to the respondents to be lost in this case. For all groups, based on their responses to the questionnaires, we selected candidates who were willing to participate in in-depth interviews. We used the method of purposive sampling [3] in order to guarantee a wide range of different opinions. We selected respondents with and without experience with euthanasia and with different attitudes towards euthanasia (liberal, conservative or neutral). Besides this, we strived for a balanced distribution of age, education and gender. We selected 25 respondents per subgroup, 125 respondents in total. We continued enrolling subjects for interviews in each group until we had achieved conceptual saturation for each group.

Data collection

The questionnaires involved questions on respondent characteristics as well as on experiences and opinions regarding euthanasia and PAS. Statements on euthanasia were rated using a five-point Likert scale, ranging from ‘totally agree’ to ‘totally disagree’. Respondents were also asked about their opinions regarding unbearable suffering as a reason for euthanasia and PAS, presented in different vignettes (Box 1).The questionnaire was pretested for length, comprehensibility and feasibility for online use among 10 physicians, 8 nurses and 14 members of the general public. These pilots resulted in small adjustments in the questionnaire. Interviews were conducted by five researchers (PK, NR, DvT, BvdV and HW) and two medical students. There was no relationship between the interviewees and the interviewers prior to the study and no personal characteristics of the interviewers were known to the interviewees. Most interviews with professionals were conducted at their working place and with the public in the privacy of their homes. Before the start of the interview, the voluntary character and confidentiality of participation were emphasized. The one-hour interviews were semi-structured with use of an interview guideline with open questions and topics. First, we asked about the respondents’ association with the term ‘euthanasia’. To explore opinions about euthanasia further, we asked what the participant would say to a foreign colleague (for professionals) or a foreign tourist (for members of the general public) about

Dutch euthanasia practice and how it is regulated. The interviewees were asked to reflect on some of the vignettes that were used in the questionnaires. Finally, personal experiences (if any) with (requests for) euthanasia were addressed. The interview guideline was tested for length and comprehensibility. This led to some minor adjustments. Because several researchers performed the interviews, the use of the interview guideline was discussed and practised in detail during training for all interviewers.

Box 1. Vignettes of patients requesting euthanasia or physician-assisted suicide: different ways of suffering*

1(a)	Mrs de Jong (60 years old) has breast cancer with metastases. Despite undergoing several treatments, her disease is no longer curable. She is in severe pain that cannot be sufficiently relieved. In addition, she dislikes the feeling of loss of control that she experiences. In her working days, she always felt in control. She indicates that she cannot take it anymore. She asks her general practitioner for physician-assisted suicide. The general practitioner decides to honour her request and performs physician-assisted suicide.
1(b)	Mrs de Jong (60 years old) has breast cancer with metastases. Despite undergoing several treatments, her disease is no longer curable. She has no physical symptoms at the moment. She dislikes the feeling of loss of control that she experiences. In her working days, she always felt in control. She indicates that she cannot take it anymore. She repeatedly asks her general practitioner for physician-assisted suicide. The general practitioner decides to honour her request and performs physician-assisted suicide.
1(c)	Mr de Bruyn is 86 years old. He used to be a professor at the university. He enjoyed his life at that time. He never married and has no children. Now he has grown old, many of his friends have died. He often feels lonely. He is in good physical and mental condition. Though Mr de Bruyn is aware that he could live for many years he fears this. He would rather be dead and has told his general practitioner this several times. Mr de Bruyn repeatedly asks his general practitioner for physician-assisted suicide. The general practitioner decides to honour his request and performs physician-assisted suicide.†
1(d)	Mrs Langezaal is middle-aged. She is physically well, but mentally ill. She has been suffering from severe depression for years and her psychiatrist's treatment has not worked. She regularly tells her physicians that she wants to die. She already has had one unsuccessful suicide attempt. Mrs Langezaal visits her psychiatrist and repeatedly asks for physician-assisted suicide. The psychiatrist decides to honour her request and performs physician-assisted suicide.
1(e)	Mrs de Koning is 65 years old. She suffers from early dementia and sometimes she is forgetful. She fears what is to come, the progressive loss of memory and the moment she will not recognise her surroundings anymore. Her own mother suffered from severe dementia and she absolutely doesn't want to experience this process herself. Mrs de Koning repeatedly asks her general practitioner for physician-assisted suicide. The general practitioner decides to honour her request and performs physician-assisted suicide.
1(f)	Mr Smit is 62 years old and suffering from dementia. He doesn't recognise his wife and children anymore, refuses to eat and withdraws into himself more and more. It is no longer possible to communicate with him about his treatment. Shortly before he became demented, he drafted an advance directive with a euthanasia request in case of dementia. His family agrees. The physician decides to honour his patient's advanced directive and performs euthanasia.

* For the general public, these vignettes were the same in contents, but slightly adapted in language in order to be understandable for this group of respondents

† 1(c): Not in accordance with the Dutch Euthanasia Act (2002)

Statistical analysis

The quantitative data were analysed with descriptive statistics using SPSS 17.0. Valid percentages are presented in the tables; missing values did not exceed 10%. Opinions on euthanasia and PAS were recoded and reported in three categories: 'agree', 'neutral' and 'not agree'. For each group of physicians a weight factor was calculated in order to make the results representative for all physicians in the Netherlands. All interviews have been transcribed verbatim and were analysed with content analysis using Atlas.ti version 6.1.1. Two researchers per group coded all interviews, using a uniform code tree that was developed and agreed on by all interviewers on the basis of the results. Transcripts were not returned to the interviewees.

RESULTS

Characteristics of respondents

The numbers of respondents were 793 for physicians (response rate 41%), 1243 for nurses and 1960 for the general public (response rate 78%). The mean age was 51 years for physicians, 53 years for the general public and 44 years for nurses. Two-thirds of the physicians, 10% of nurses and 54% of the general public were male; 81% of nurses and 39% of the general public respondents were highly educated. Most physicians and nurses had experience with a request for euthanasia or PAS in the last five years. Most respondents of the general public had no such experience (Table 2.1). In total 83 interviews were conducted until saturation was reached; 49 with physicians, 18 with nurses, and 16 with members of the general public.

Opinions on the Dutch Euthanasia Act

Broad support for the Dutch Euthanasia Act was displayed among interviewees, irrespective of their personal attitude. Interviewees based their approval mainly on two arguments. First, euthanasia can be morally right because it is the last resort to end unbearable suffering without prospect of improvement. Second, autonomy is highly valued (Box 2 (1a)). Even principal opponents among the interviewees often defended the Act against allegedly misinformed (foreign) critics (Box 2 (1b)). Also interviewees considered its function as a safeguard to both careful and transparent practice to be an important benefit of the Act (Box 2 (1c)). Furthermore, some physicians experienced the Act as a helping hand in making decisions that they experience as highly demanding. Some felt that it could be used as a shield against patients who claim euthanasia as their right (Box 2 (1d)).

Opinions of health care professionals on legal requirements

In our survey, almost two-thirds of physicians (56%) and more than one-third of nurses (36%) agreed with the current absence of a right to euthanasia and PAS (Table 2.2). A majority of physicians (71%) and nurses (64%) agreed that euthanasia and PAS should not be limited to patients who have a life expectancy of only several weeks. A vast majority of physicians (88%) and nurses (77%) agreed with the need for a patient request.

Reviewing a vignette of a cancer patient suffering from loss of control and severe pain, 77% of physicians and 49% of nurses personally agreed with the performance of PAS (Box 1, Table 2.3). If in the same vignette physical symptoms were absent, fewer professionals agreed (36–37%). A minority of professionals agreed with providing PAS in vignettes of a patient with chronic depression (35–36%) or early dementia (28–31%). One-third of physicians (33%) and almost two-thirds of nurses (58%) agreed with performing euthanasia

Table 2.1 Background characteristics of respondents

	Physicians* (n=793) %	Nurses (n=1243) %	General public (n=1960) %
Age			
Mean ± SD	51 ± 8	44 ± 11	53 ± 15
Gender			
Male	65	10	54
Female	35	90	46
Education†,‡			
Low	n.a.	n.a.	32
Middle	n.a.	19	29
High	100	81	39
Experience with euthanasia request§			
Yes	71	64	14
No	29	36	86
Care setting			
Hospital care	39	41	n.a.
Home care	51	23	n.a.
Nursing home care	10	28	n.a.
Years of working experience‖			
2-5 years	6	15	n.a.
5-10 years	16	13	n.a.
>10 years	78	72	n.a.
Attitude towards euthanasia and physician-assisted suicide			
Liberal	45	59	-
Reserved	48	27	-
Against	7	14	5

n.a.: not applicable; SE: standard deviation
* Weighted percentages
† Low = level 1-3 according to International Standard Classification of Education (ISCED) guidance (primary school, lower secondary general education, lower vocational education), middle= level 4 according to ISCED (intermediate vocational or higher secondary general education), high= level 5-7 according to ISCED (higher vocational education or university)
‡ Nurses: middle=assistant-nurse, high=registered nurse
§ Experience with a patient's (for physicians and nurses) or relative's (for the general public) actual request in the last five years
‖ Physicians: mean ± SD= 19 ± 9

Box 2. Example quotations of responses	
1a: **Arguments for the possibility of euthanasia: 'end suffering' and 'autonomy'**	'Anyhow, I think it is very good we have a euthanasia law in the Netherlands. Because I think every person that really suffers unbearably should have the right to end his life.' (member of the general public) 'I think we have a very correct legal system in the Netherlands, which clearly prescribes what is allowed and what is not. So we have said, we highly esteem the autonomy of the patient. If someone wishes to end his life, and there is unbearable suffering, there is careful deliberation and there is freedom, then I think that we, as doctors, can cooperate with that.' (physician with experience with euthanasia)
1b: **Defence against misinformed critics**	'People from outside the Netherlands seem to think that it is just a phone call to the doctor who prescribes a recipe for a lethal drug in order to put you out of this world. Well, that is not how it is. There are many conversations and checks before a wish is granted. So before something like that is done, there have been a lot of control moments, in order to make sure it is all done in a careful manner. So it is not easily done.' (member of the general public) 'I would say it happens in the most careful way, and always in a situation of endless suffering. But doctors are really not eager to perform euthanasia. It is not part of everyday practice, but it may be an ultimate act in a situation of necessity, which is never decided alone but always in consultation of another doctor. The Netherlands is not a country in which you can just say 'I don't want to go on anymore, and I step out'.' (nurse)
1c: **Euthanasia Act as a safeguard for careful and transparent practice**	'It is not as easy as one may think. There have to be very good reasons. There have to be two doctors. Only if they are both convinced that this euthanasia is really what the person wants and if they think the suffering becomes unbearable. Only then you can perform euthanasia.' (nurse) 'I have some difficulties with it (euthanasia). Yet it is good such a law exists and that one should follow strict criteria. But actually I would want that things like euthanasia and abortion did not happen.' (nurse) 'You still perform a criminal act and you can go to jail for it. I think there is a strong urge for doctors to act in a careful manner. There is a procedure that has to be followed. And it has to be reported. I think it is an honest procedure, I don't have problems with that.' (physician who refuses to perform euthanasia himself)
1d: **Legal rules as a 'helping hand' and as a 'shield'**	'I think the law is good. It is a helping hand, because listen, you do end some one's life. The law is not without a purpose, it was constructed very carefully. In such a way that you always have to act very carefully and I think that is good. It is a highly demanding process. For the patient, but also for the doctor.' (physician with experience with euthanasia) 'Sometimes you come in the ward and then, all of a sudden, you get a request to perform euthanasia. Then I say 'that is not how it works'. Unless it is a very exceptional situation. But then you may use that argument and tell the patient 'I have to protect myself as well. I have to fulfil the due care requirements, it is not so easily done'. So in that way I am happy with the rules. It may help to keep off patients who think too easy about it. Personally I may not have huge difficulties with it, but I do not think it should ever become a routine. I won't go that far. So I agree with those criteria of due care, they are very logical to me.' (physician with experience with euthanasia)

in a vignette of a patient with advanced dementia based on a written advance directive. Almost two-thirds of professionals disagreed (64–66%) with PAS in the case of being tired of living.

In reviewing some of the same vignettes during the interviews, professionals often considered physical symptoms without prospect of improvement as a necessary part of unbearable suffering. Some professionals felt it to be difficult to empathize with patients requesting euthanasia due to mental suffering. Also the absence of the terminal phase was sometimes seen as problematic.

Opinions of the general public on legal requirements

Almost a quarter of the general public (23%) agreed with the current absence of a right to euthanasia and PAS (Table 2.2). Two-thirds of the general public (64%) agreed with the need for a request of the patient. Almost half of respondents (48%) agreed with the absence of a limitation of euthanasia to patients who have a life expectancy of only several weeks. The majority of the general public (65%) personally agreed with PAS in the vignette of a cancer patient suffering from loss of control and severe pain (Box 1, Table 2.3). Seventy-seven percent did so in a patient with advanced dementia who had completed a written advance euthanasia directive. Reviewing other vignettes of mental suffering, a minority of the general public agreed with PAS. In the cases of mental suffering from loss of control due to cancer (without severe pain), chronic depression or early dementia, respectively 39%, 28% and 24% agreed with PAS. Furthermore,

Table 2.2 Opinions on euthanasia and physician-assisted suicide

	Physicians* (n=793) %	Nurses (n=1243) %	General public (n=1960) %
In my opinion everybody should have a right to get euthanasia or physician-assisted suicide when he or she wants			
(Totally) agree	28	45	57
(Totally) disagree†	56	36	23
Neutral	14	19	20
In my opinion a physician is only allowed to perform euthanasia or physician-assisted suicide in persons with a life expectancy of a few weeks			
(Totally) agree	16	18	27
(Totally) disagree†	71	64	48
Neutral	12	19	25
In my opinion euthanasia and physician-assisted suicide should only be allowed to be performed at explicit patient request			
(Totally) agree†	88	77	64
(Totally) disagree	7	14	16
Neutral	5	9	21

* Weighted percentages

† In accordance with the Dutch Euthanasia Act (2002)

a minority agreed in case of suffering due to being tired of living (26%). In the interviews respondents related unbearable suffering primarily to physical suffering. In case of mental suffering interviewees found it difficult to assess the request for PAS and would like to explore other solutions, such as counselling for the patient.

Table 2.3 Opinions on euthanasia and physician-assisted suicide: agreement with the physician's act in different cases of suffering. See box 1 for vignettes

	Yes (%)	No (%)	I don't know (%)
(a) Cancer with loss of control and severe pain			
Physicians* n=156	77	17	7
Nurses n=254	49	38	13
General public n=421	65	15	19
(b) Cancer with loss of control, without physical symptoms			
Physicians* n=161	37	45	19
Nurses n=245	36	48	15
General public n=393	39	44	17
(c) Old age and tired of living†			
Physicians* n=143	18	66	16
Nurses n=245	19	64	18
General public n=378	26	58	16
(d) Severe depression			
Physicians* n=173	35	39	26
Nurses n=253	36	46	19
General public n=380	28	52	20
(e) Early dementia			
Physicians* n=156	28	53	17
Nurses n=246	31	49	20
General public n=388	24	60	16
(f) Advanced dementia and written advance directive for euthanasia			
Physicians* n=197	33	56	11
Nurses n=316	58	29	13
General public n=472	77	14	9

* Weighted percentages

† Not in accordance with the Dutch Euthanasia Act (2002)

INTERPRETATION

Our study shows support for the Dutch Euthanasia Act both among health care professionals and in wider society. Major arguments for this support are the possibility of relief of unbearable suffering and respect for the patient's autonomy. Moreover, the Act safeguards careful and transparent practice. The majority of the general public is in favour of a (currently non-existing) right to euthanasia. However, most professionals and members of the general public seem to be more conservative regarding the boundaries for euthanasia or PAS than the Act. Both professionals and members of the general public tend to consider suffering as unbearable and qualifying for assistance in dying particularly in the presence of physical symptoms. They are more reticent about early dementia, depression and being tired of living. This is in line with previous studies in which more variation in the acceptance of euthanasia and PAS was found among health care professionals for non-physical as compared to physical suffering [4-5]. An exception is advanced dementia. In a case of a patient with advanced dementia who had a written advance request for euthanasia, a majority of the general public and nurses agreed with granting this request, but only a minority of physicians did. Another study among elderly care physicians and relatives of people with dementia who had an advance directive for euthanasia also found them to be reticent in adhering to advance directives for euthanasia [6]. Physicians have become more accepting over time [2], but variance in views on the admissibility of euthanasia in a case of advanced-stage dementia between physicians, nurses and the general public has been demonstrated elsewhere too [7-8]. Although all parties seem to be guided by the best interest of the patient, different responsibilities in end-of-life decision-making may play a role here. The fact that performing euthanasia is solely allowed for physicians and has a clear emotional impact on them [9] may explain their reticence. Euthanasia for a patient in an advanced stage of dementia may involve an even greater emotional burden due to the fact that the person receiving it is not capable of confirming his wish anymore.

The general support for the Dutch Euthanasia Act is in line with an international trend towards public acceptance of euthanasia [10-11]. Also, earlier studies have shown a small number of opponents among the Dutch general public [12]. However, international professional acceptance of euthanasia varies widely [13-20].

The strengths of our study include the large and high quality nationwide samples of physicians and the general public. Our mixed-methods approach gives more in-depth understanding of the underlying reasoning of our quantitative data and makes a more accurate interpretation of quantitative results possible. Moreover, the questionnaires were highly comparable between all groups of respondents and consisted of a combination of different types of questions and presentations including statements and vignettes. Vignettes are widely used in decision-making research [21] and have shown their value [22]. However, it should be taken into account that respondents could have based their judgments on different aspects of the vignettes. Our study has some other limitations as well. No random sample was available for nurses, due to the absence of a national registry for nurses in the Netherlands. Therefore we aimed at reaching as many nurses as possible by open invitation. For all groups, possible selection bias should be taken into account. For physicians, the response rate was rather low (41%). However, the results were made representative for all physicians from the studied groups by applying a weight factor. It is possible that especially physicians and nurses with experience and affinity with the discussion about euthanasia have participated in this study. This should be taken into account when interpreting the results, but is not likely to alter the direction of our findings. Since the interview study showed even physicians who have principled objections against euthanasia to be content with the Act, it can be concluded that there is ample support for the law in this group. Moreover, the number of opponents of euthanasia and physician-assisted suicide is comparable to earlier studies in the Netherlands. Therefore we think that bias is not very likely.

Additionally, despite a good response rate among the general public, respondents were not fully representative of the Dutch population; they were slightly older, more often male, higher educated and more often sharing a household. Also migrants were underrepresented. This latter issue is known to be the case in nationwide surveys on other topics too. To assess their opinions purposive sampling should be considered. Furthermore, the questionnaires were rather extensive, which resulted in a substantial number of missing answers at the end of the questionnaires.

In conclusion, health care professionals, as well as the general public, mostly support the legal requirements for euthanasia and PAS. The law permits euthanasia or PAS for mental suffering, but this principle is not widely endorsed. There is one exception. The majority of the general public and nurses agree with the possibility of euthanasia in advanced dementia. Physicians are more reticent. We conclude that the Dutch Euthanasia Act can count on ample support both among health care professionals and within general society.

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CHAPTER 3

Assistance in dying for older people without a serious medical condition who have a wish to die: a national cross sectional survey

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Submitted

ABSTRACT

Background

The Dutch Euthanasia Act regulates physicians' assistance in dying for patients who are suffering unbearably from a medical condition. We studied the attitudes of the Dutch population regarding assistance in dying for older persons who have a wish to die, without the presence of a serious medical condition.

Methods

A national cross-sectional survey was conducted among a representative sample of 1960 adults (response rate 78%), using an online questionnaire. Statements and vignettes regarding attitudes towards assistance in dying in older persons who are tired of living were used.

Results

A minority of 26% agreed with a vignette in which a physician warrants the request for physician-assisted suicide of an older person with a wish to die, who is tired of living without having a serious medical condition. Furthermore, 21% agreed with the statement "In my opinion euthanasia should be allowed for persons who are tired of living without having a serious disease". A majority of 65% agreed with a vignette of a physician providing assistance in suicide to a terminally ill cancer patient.

People supporting the possibility of assistance in dying for older persons who are tired of living, were more likely to be highly educated (OR 1.6; CI:1.1-2.3), to be non-religious (OR 1.7; CI:1.3-2.3), to have little trust in physicians to comply with their wishes (OR 1.6; CI: 1.2-2.2) and to consider it important to be able to make one's own health care decisions (OR 1.7; CI:1.3-2.3) than opponents. Age and health status were unrelated to people's attitudes.

Conclusions

A substantial minority of the Dutch population supports allowing assistance in dying for older people who are tired of living without having a serious medical condition. Those who support assistance in dying in such cases are more likely to be highly educated and to prefer a sense of control in medical decision making.

BACKGROUND

Populations around the world are ageing, and high quality medical care for older people has become more important than ever. However, excellent care cannot always prevent that for some older people aging coincides with such a declined sense of purpose in life that they develop a wish to die. Previous studies reported this to be the case in 5-25% of older persons [1-7]. Often, such wishes are associated with suffering from physical and mental health problems, such as progressive diseases and increasing disability. However, sometimes older persons have this wish without having serious health problems. In these cases, these wishes have been found to be associated with loneliness, a small social network, a perceived lack of control, visual/hearing impairment, speech impediment, involuntary urine loss and residential care [1, 3-4, 8-9]. Older persons without a serious medical condition who have a wish to die are often referred to as being "tired of living" [9].

Studies on people with death wishes have shown that having a wish to die does not necessarily mean they want to pursue this wish. A distinction has been made between passive and active ideators. Passive ideators report a wish to die but do not pursue their wish, while active ideators seriously consider taking their own life. The estimated prevalence of active ideators among older persons is 1-9% [3, 6-7]. Furthermore, it is known that suicide attempts at older age have a higher case fatality compared to attempts at a younger age [10].

In the Netherlands, since 2002, assistance in dying, both as euthanasia and as physician-assisted suicide, is legally regulated. Core conditions are an explicit request of the competent person and unbearable and hopeless suffering as a result of a medical condition. Assistance in dying for persons who are tired of living without having serious medical problems is not subject to this legislation and is therefore criminalised. Nevertheless, there is currently a sparking debate in the Dutch society about whether it could be justified to allow euthanasia and physician-assisted suicide for older persons who are tired of living, since a group of prominent older citizens is seeking societal, medical and legal support for the allowance of euthanasia and physician-assisted suicide in such instances. This claim echoes earlier debates, starting in the early nineties when professor Drion suggested that older persons should be allowed to use a suicide pill, when they are tired of living. In 2002, the Supreme Court stated that unbearable suffering, resulting in a request for physician-assisted suicide, should arise from a medical cause to be subject to the Dutch Act. The reasoning behind it was that in non-medical suffering physicians are not able to judge the extent of suffering and whether or not other treatment options are available. More recently, the Royal Dutch Medical Association followed this reasoning by stating that they consider the presence of a medical condition to be a strict prerequisite for euthanasia and physician-assisted suicide.

The level of public support for assistance in dying in older persons who are tired of living remains unclear, and more insight would enrich this often emotional debate with empirical evidence. Therefore the aim of this study is to gain insight into the attitudes of the Dutch general public regarding assistance in dying for older persons who have a wish to die, without the presence of a serious medical condition and to describe the characteristics of supporters and opponents.

METHODS

Study design and population

This cross sectional survey was conducted in the Netherlands. An online questionnaire was administered to a representative sample of the general Dutch population, using an established panel (CentERdata, University of Tilburg, the Netherlands). This panel comprised a random sample of postal codes in the Netherlands, and during the survey period 2503 persons were included in the panel. Multiple measures were in place to avoid selection bias of this digital panel, such as guaranteeing accessibility for all selected households by providing them with a free tool that enabled response by internet or television. If needed additional devices were provided.

Questionnaire

The structured questionnaire assessed attitudes towards euthanasia and physician assisted suicide for older persons without a serious medical condition. The questionnaire included statements, vignettes and closed questions. The respondents were asked to indicate to which extent they agreed with five statements regarding their attitude towards euthanasia, using a 5-point Likert scale. Further, respondents' attitudes towards the acceptability of physician assisted suicide were assessed using two vignettes (Box 1), i.e. hypothetical case descriptions, representing an older person being tired of living and asking for physician assisted suicide versus a reference case of a patient with incurable cancer who asks for physician assisted suicide. Respondents were asked whether they thought that the person described in the vignette suffered unbearably, whether they agreed with the physician's act, and whether they would request physician assisted suicide if they imagined themselves in this situation. Answer categories were: 'yes', 'no' and 'I don't know'. Additionally, respondents were asked whether they trusted physicians to comply with their wishes about medical care and treatments at the end of life. Preferences for end of life decision-making styles were measured by providing three options: 'physicians should make decisions, based on what is best for me', 'physicians and I should make decisions together' and 'I should make decisions, based on what is best

Box 1. Vignettes of persons requesting physician-assisted suicide

I Old age and tired of living *	Mr de Bruyn is 86 years old. He used to be a professor at the university. He enjoyed his life at that time. He never got married and has no children. Now he has grown old, many of his friends have died. He often feels lonely. He is in good physical and mental condition. Though Mr de Bruyn is aware that he could live for many years, he fears that. He would rather be dead and has told his family doctor this several times. Mr de Bruyn repeatedly asks his general practitioner for physician-assisted suicide. The general practitioner decides to honour his request and performs physician-assisted suicide.
II Cancer: loss of control and severe pain	Mrs de Jong (60 years old) has breast cancer with metastases. Despite undergoing several treatments, her disease is no longer curable. She is in severe pain that cannot be sufficiently relieved. In addition, she dislikes the feeling of loss of control that she experiences. In her working days, she always felt in control. She indicates that she cannot take it anymore. She asks her general practitioner for physician-assisted suicide. The general practitioner decides to honour her request and performs physician-assisted suicide.

* Not in accordance with the Dutch Euthanasia Act

for me'. All questions were based on previous research[11-12], literature and expert opinion.
A pilot study was conducted to examine the length, comprehensibility and feasibility for online use among 14 members of the Dutch general public. They varied in educational level, age and gender. This pilot resulted in small adjustments of the questionnaire. The digital questionnaire and two follow-up reminders were sent between December 2009 and February 2010.
Socio demographic data for the panel were obtained through CenERdata (age, gender, education level, composition of the household, religious beliefs, urbanization of living area and health status), based on self-reported data. For comparison, background characteristics of the whole Dutch population were obtained from Statistics Netherlands (CBS)[13].

Statistical analyses

Summary data are presented as frequencies and proportions for categorical variables. Univariate analyses, followed by logistic regression analyses were used to calculate odds ratios with 95% confidence intervals for the relationships between positive attitudes towards assistance in dying in case of being tired of living and personal characteristics. The personal characteristics education, religious belief, health status, trusting a physician to comply with wishes, and the importance to make one's own health decisions were dichotomized. Age was imputed as numeric into the model. All statistical analyses were carried out using SPSS for Windows software, version 17.0.

Ethical considerations

The Dutch Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO) does not apply to this study. Therefore, no ethical approval of the Medical Ethical Committee was needed.

RESULTS

Sample characteristics

In total, 2004 of 2503 questionnaires were returned, and 1960 were complete and eligible for analyses (response 78%). The reasons for exclusion of 44 questionnaires were incompleteness (n=17) and age of the respondent < 18 (n=27). The respondents were aged between 18 and 95 years. Compared to the Dutch general public, respondents in the sample were somewhat more often older, male, highly educated, living with a partner, and native Dutch (Table 3.1).

Attitudes towards assistance in dying

Of the respondents, 21% agreed with the statement "In my opinion euthanasia should be allowed for people who are tired of living without having a serious disease". Furthermore, 36% was in favour of enabling the oldest old to get medication to end their life if they would want so (suicide pill). Somewhat over half of the respondents thought that everybody should have the right to receive euthanasia when they want (57%) and was in favour of the right for everybody to determine their own life and death (53%) (Table 3.2). Table 3.3 shows the opinions of the respondents regarding the vignettes, describing physician-

Table 3.1 Background characteristics of the respondents of the online survey, as compared to the Dutch population

	Respondents 2010 (n=1960)	Dutch population *
Age (mean ± SD)	53.4 ± 15.1	48
	% (95% CI)	**% (95% CI)**
Gender		
Male	54 (52-56)	50
Female	46 (44-48)	50
Education †		
Low	32 (30-34)	32
Middle	29 (27-31)	40
High	39 (37-41)	29
Composition household		
Living with partner	76 (74 -78)	64
Living without partner	22 (20-24)	36
Religious beliefs		
Yes	58 (56-60)	59
No	42 (40-44)	41
Urbanisation living area		
Low/middle	61 (59-63)	57
High	39 (37-41)	43

* Data based on statistics from 2009 of Statistics Netherlands (CBS); http://statline.cbs.nl/statweb

† Low = level 1-3 according to ISCED guidance, (primary school, lower secondary general education, lower vocational education), middle = level 4 according to ISCED guidance (intermediate vocational or higher secondary general education), high = level 5-7 according to ISCED guidance (higher vocational education or university).

Table 3.2 Opinions of the respondents regarding assistance in dying

In my opinion	% agree	% neutral	% disagree
…euthanasia should be allowed for people who are tired of living, without having a serious disease.	21	27	52
…the oldest old should be able to get medications that enable them, if they want so, to end their life	36	30	35
…a physician is only allowed to perform euthanasia in persons with a life expectancy of a few weeks	27	25	48
… everybody should have a right to euthanasia	57	20	23
… every human being has the right to determine their own life and death	53	25	23

assisted suicide in two cases with different types of suffering (Box 1). Respondents less often judged the suffering of an old person who is tired of living as unbearable suffering (20%), compared to the suffering of a patient with terminal cancer (69%) (p<0.001). Respondents also less often agreed with the physician to perform physician-assisted suicide in case of a person being tired of living (26%) than in case of a patient with cancer (65%) (p<0.001). 19% would ask for euthanasia themselves if they would be in a situation as described in a vignette of an old person who was tired of living, versus 48% if they would have cancer as described in a vignette (p<0,001). Respondents who judged the suffering described in the vignettes as unbearable, more often than others agreed with the physician performing physician-assisted suicide (p<0,001) and more often would ask for euthanasia for themselves when being in a similar situation (p<0,001).

Table 3.3 Opinions on physician-assisted suicide in different cases of suffering

	Vignette I Old age and tired of living %	**Vignette II Cancer: loss of control with severe pain %**	***P*-value**
In your opinion, does this situation concern unbearable suffering?			
Yes	20	69	<0.001
No	65	13	
Don't know	15	18	
Do you personally agree with the physician's act?			
Yes	26	65	<0.001
No	58	15	
Don't know	16	19	
Imagine yourself as the person in this situation. Would you ask your physician for euthanasia?			
Yes	19	48	<0.001
No	53	16	
Don't know	28	36	

Characteristics of supporters and opponents

Euthanasia for a person who is tired of living without having a serious medical condition was significantly more likely to be accepted by people with a higher education (OR 1.6; CI: 1.1-2.3), having no religious belief (OR 1.7; CI: 1.3-2.3), having little trust in the physician to comply with their wishes (OR 1.6; CI: 1.2-2.2) and considering it important to be able to make one's own end-of-life decisions (OR 1.7; CI:1.3-2.3), than by others. The acceptance rate was not associated with respondents' age (OR 1.0; CI: 0.99-1.0) or by their health status (OR 1.2; CI: 0.8-1.7). Agreeing with the vignette describing physician-assisted suicide in case of a person who is tired of living was associated with the same personal characteristics, except for higher education (OR 0.9; CI 0.4-2.1).

Respondents who were in favour of enabling the oldest old to get medication to end their life if they want so were more likely to be higher educated (OR 1.5, CI:1.1-2.1) and not religious (OR 2.2 CI:1.7-2.8) than those who opposed that option. They also were more likely to have little trust in the physician to comply with their wishes (OR 2.4; CI: 1.8-3.2) and to consider it important to be able to make own end-of-life decisions (OR 1.8; CI: 1.4-2.3). Age and health status were not related to respondents' opinions.

DISCUSSION

Our study shows that a substantial minority of the Dutch general public supports euthanasia and physician assisted suicide for older people who have a wish to die because they are tired of living without having a serious medical condition, which is significantly less compared to the 65% acceptance of physician-assisted suicide for patients who are terminally ill. Furthermore, 36% supports the idea of enabling the oldest old to get medication to end their life if they would want so.

Recently, a trend analysis of Dutch older people's attitudes towards euthanasia showed that in 2008 one third agreed with making a suicide-pill available for older people who have a wish to die because they are tired of living, in the absence of a severe disease [14]. Little is known about the true prevalence of older people who have a wish to die because they are tired of living. Recently, it has been estimated that Dutch physicians annually receive 400 requests for assistance in dying from older people because they are tired of living [15]. Thus, the medical practice of euthanasia and physician-assisted suicide for older people who are tired of living appears to be relatively small, given our aging society with 2.5 million individuals aged 65 or older, and 19% of the general public indicating that they would ask for physician-assisted suicide in case they would be tired of living.

A second finding of our study is that age and health are not associated with acceptance of assistance in dying for older people who are tired of living. This might suggest that experiencing declining health as well as old age does not instigate favouring or opposing of assistance in dying for persons who are tired of living. Furthermore, those in favour of assistance in dying for older people were more likely to be higher educated, have less trust in their physician to comply with their wishes and more often prefer to make their own health decisions rather than physicians making these for them. The bottom line seems to be that those who accept assistance in dying for older people who are tired of living value control over their health care decisions. A feeling of loss of control is known to play a role in suicide among older people, especially in those who had been predominately 'action-oriented' persons all their lives [16-17]. In the Netherlands, the debate on assistance in dying for older persons who are tired of living is sparked with arguments related to the need to maintain control [18]. The fact that older people are often negatively portrayed in the media [19], such as being a burden on society and frail non-contributors as a result of declining health, might play a role in the shaping of these notions of control. Furthermore, a recent interview study aiming to understand why older people want to die also found that the need to control is an important issue. Traumatic events, early or late in life, a life of adversity and agony, poor quality of life or

a recurring depression, resulted in people experiencing a lack of control to change their life [15].
For this study, some methodological considerations should be taken into account. First, despite a good response rate, the respondents were not fully representative for the Dutch population; the respondents were slightly older, more often male, higher educated and more often sharing a household. Furthermore, migrants were underrepresented. This has possibly led to an overestimation of the support for assistance in dying for older people who are tired of living. Secondly, an internet panel for surveys may involve some degree of selection bias. To minimize such bias, the CentERpanel was used that consist of a randomised sample of people (not self-selected) and that enables all selected members to participate (no restriction to internet users only). Thirdly, another limitation to a quantitative survey is that statements and vignettes, in order to be standardized, are inevitably simplifying the complex reality, stripping it of its emotional and personal context. To ensure the veracity and quality of the vignettes, the vignette of tired of living has been based on a true court case. Our study shows less support for the statement regarding assistance in dying in case of being tired of living, compared to the vignette addressing the same topic. Whether these results reflect the use of different measures (vignette vs. statement) or the use of different ways of assistance in dying (euthanasia vs. physician assisted suicide) is unclear.

In conclusion, a substantial minority of the Dutch public considers euthanasia and physician-assisted suicide acceptable for older people who have a wish to die because they are tired of living, while a majority of the Dutch public considers assistance in dying acceptable for patients whose suffering is rooted in a serious medical condition. Those who support assistance in dying for older people who are tired of living are more likely to be higher educated and to prefer a sense of control than others.

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CHAPTER 4

Involvement of the Dutch general population in advance care planning: a cross sectional survey

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ABSTRACT

Background

Advance care planning (ACP) is a process of communication among patients, healthcare providers and relatives regarding end-of-life care and decision making, to ensure patients' preferences remain central in end-of-life care when the patient is no longer capable of decision-making. Health policies state that ACP promotes high quality end-of-life care and should, therefore, be promoted. However, little is known about the actual and preferred involvement of people in ACP as a process.

Objective

To describe the actual and preferred involvement in ACP of the Dutch general population.

Design

A national cross-sectional survey.

Setting/subjects

Random sample of Dutch adults (1,960 respondents: response rate 78%).

Measurements

Questionnaire on the actual and preferred involvement in ACP.

Results

Of all respondents, 70% had thought about ACP and 64% had discussed ACP with their relatives. Furthermore, 13% had actively discussed ACP with their physician and 7% had an advance directive. About 20% need more information about ACP. Factors positively associated with actual involvement in ACP were: age ≥ 55 years, having had an experience with a relative who requested euthanasia, acceptance of euthanasia, a preference for making one's own health decisions rather than physicians doing this, and having some knowledge about end-of-life issues.

Conclusions

The majority of the Dutch general public has thought about their ideas and preferences regarding end-of-life care and decision-making or has actively discussed these ideas with relatives, whereas a substantial subgroup indicated a need for more information about ACP. However, ACP is rarely discussed with physicians. In clinical practice, it is important to be aware of this potential interest among older people in ACP.

INTRODUCTION

Advance care planning (ACP) is a process of communication among patients, healthcare providers, and relatives regarding the end-of-life care. ACP aims to ensure that patients' values remain central in decision-making when patients can no longer make decisions and that this care remains consistent with patients' preferences [1]. ACP encompasses various components, including the consideration of treatment goals, and communication with relatives and physicians [2]. ACP may also involve the designation of a surrogate decision-maker, or an advance directive (AD) in which treatment preferences are recorded. ADs can contain a refusal of treatments (negative directive) or preferences for care and treatments to be applied (positive directive) under specified conditions.

In the Netherlands, the Dutch Medical Treatment Act states that patients have the right to refuse medical treatment and can do this in writing through an AD. In principle, a physician has to follow such a negative AD when it is clear and sufficiently detailed. In contrast, a positive AD only serves to support a physician in understanding the preferences of the patient [3-4]. In the Netherlands, a positive AD might include a specific request for euthanasia, which is a relatively common type of AD in the Netherlands [5].

Although ACP comprises more than drafting an AD, most research has focused on ADs that have been subject to increasing criticism [6]. Important limitations of ADs are related to its drafting (e.g. it is difficult to foresee future wishes, people may change their preferences) and its interpretation (e.g. it is difficult to interpret the content; ADs may involve incomplete or conflicting information). Furthermore, research on the impact of ADs has shown disappointing results. Over the last decades, the prevalence of having an AD ranged from 3-36% among the general public [5, 7-12] and from 5-19% among (deceased) patients [10, 13-14]. Various efforts to improve patients' completion rate of an AD have not been very successful [15, 16] and minimal effects of ADs on directing end-of-life care and its quality have been reported [13, 17-18].

Currently, the focus of research on ACP has shifted towards ACP as a *process* of communication, and aims to approach ACP as a concept that is wider than solely drafting an AD[19-20]. One study showed that ACP, as a process, improves end-of-life care for elderly patients, as well as patients' and families' satisfaction with care; also among surviving relatives, ACP leads to stress reduction, less anxiety and less depression [21]. Because of these potential benefits of ACP, it might be seen as a healthy and useful behavior to promote among the general public [22]. Although qualitative studies have assessed the patient's perspective on ACP [2, 19, 23-24] and the barriers they define for ACP [25-27], little information is available on the involvement of the general public in ACP. Therefore, the aim of the present study is to determine if people are currently involved or are inclined to be engaged in ACP, and to delineate the factors associated with greater engagement.

METHODS

Design and population

This cross-sectional survey was conducted in the Netherlands. An online questionnaire was completed by a representative sample of the Dutch general public, derived from an established internet panel (CentERdata, University of Tilburg, the Netherlands). This panel comprised a random sample of national postal codes. Multiple measures were in place to avoid selection bias of this internet panel, such as guaranteeing accessibility for all selected households without internet access at time of study recruitment by providing them with a free tool, the so-called Net.Box. This tool enabled those without internet access to respond via a telephone line and a television set. During the survey period 2,503 persons were active members of the total panel.

Questionnaire

The structured questionnaire addressed actual and preferred involvement in ACP, as well as factors associated with engagement. The questionnaire was developed by the KOPPEL research group, comprising physicians, ethicists, researchers and a methodologist. Questions were based on literature [28], previous research [29-30] and expert opinion. The questionnaire was pretested for length, comprehensibility and feasibility for online use by 14 members of the Dutch general public. The pretest population varied in educational level, age and gender. The questionnaire and two reminders were sent between December 2009 and February 2010.

Additional background characteristics were provided by CentERdata, based on self-reported data. For comparison purposes, background characteristics of the whole Dutch population were obtained from Statistics Netherlands (CBS) [31].

Statistical analyses

Descriptive statistics were computed on background characteristics, involvement in ACP, need for information, health, experiences, attitudes and knowledge. Univariate analyses, followed by multivariate logistic regression analyses, were used to calculate odds ratios with 95% confidence intervals for the relationships between involvement in ACP and demographic characteristics, health, experiences, attitudes and knowledge. Involvement in ACP was analyzed based on three items: 'having thought about end-of-life decisions', 'having discussed end-of-life decision-making with relatives or physicians' and 'having a written AD'. Having discussed end-of-life decision-making was scored on a 4-point Likert scale and dichotomized (seldom, sometimes and often were recoded to 'yes' and never as 'no'). The variables of trust, attitudes toward decision-making, knowledge of palliative care and need for more information were also dichotomized. Respondents were defined as having 'substantial knowledge of the Euthanasia Act' if they answered all of four related questions correctly.

Four indicators concerning attitude towards euthanasia were used to compose an index measuring acceptance of euthanasia of the respondent, based on the outcome of factor analysis (1 factor with eigenvalue > 1.0, 78% explained variance) and reliability analysis (Cronbach's alpha = 0.79). Using the median score of the sum scores, we distinguished respondents who generally accept or reject euthanasia.

Ethical considerations

The Dutch Medical Research Involving Human Subjects Act does not apply to this research proposal. Therefore, no ethical approval of the Medical Ethical Committee was needed.

RESULTS

Sample characteristics

Of the 2,503 questionnaires, 2,004 were returned, and 1,960 were complete and eligible for analyses (response 78%). The age of the respondents ranged from 18-95 years. Reasons for exclusion of 44 questionnaires were incompleteness (n=17) and age of the respondent <18 years (n=27). Compared to the Dutch general public, respondents in the sample were older, more often male, more highly educated, more often living with a partner, and more often native Dutch (Table 4.1). Furthermore, non-respondents were younger, more often female, more often living without a partner, and more often had a lower education level.

Table 4.1 Background characteristics of the respondents of the online survey compared with the Dutch general population

	Respondents (n=1.960)	**Dutch adults ***
Age (mean ± SD)	53.4 ± 15.1	48
	(%)	**(%)**
Gender		
Male	54	50
Education †		
Low	32	32
Middle	29	40
High	39	29
Composition of household		
Living with partner	76	64
Religious beliefs		
Yes	58	59
Urbanisation living area		
Low/middle	61	57
High	39	43
Nationality		
Native Dutch	96	80
Immigrants ‡	4	20

* Based on 2009 data of Statistics Netherlands (CBS); http://statline.cbs.nl/statweb

† Low=level 1-3 according to the ISCED guidance, (primary school, lower secondary general education, lower vocational education), middle=level 4 according to the ISCED guidance (intermediate vocational or higher secondary general education), high=level 5-7 according to the ISCED guidance (higher vocational education or university)

‡ Immigrants are defined as being born in a country other than the Netherlands, or having a mother or father who was born in a country other than the Netherlands.

Of the 1960 respondents, 85% reported good general health, and 11% reported to have (had) a life-threatening disease, 14% have had experience with a relative requesting euthanasia and 16% with a relative receiving palliative sedation (Table 4.2). In addition, 77% expressed trust that physicians would comply with their wishes about medical care/treatment in the last days of life. Most respondents favored shared decision-making (67%), 31% preferred making their own decisions and 2% preferred the physician to make the decisions. Respondents expressing little trust that physicians would comply with their wishes about medical care/treatment in the last days of life more often preferred to make their own decisions ($p<0.001$). Of all respondents, 18% believed that a physician's current judgment about a patient's situation/treatment is better than the patient's judgment in an earlier stage. Almost all respondents were aware of the existence of the Dutch Euthanasia Act (95%), 37% correctly answered all four questions regarding this Act and 53% were familiar with the term 'palliative care'.

Table 4.2 Other characteristics of the respondents of the online survey: experiences, attitudes and knowledge related to end of life issues

	Respondents (n=1.960) (%)
Good self-reported general health *	85
Having (had) a life-threatening disease	11
Experience with euthanasia request of a relative	14
Experience with palliative sedation for a relative	16
Trusting physicians to comply with patient's wishes at the end of life †	77
Believing that physician's current judgment is better than the patient's in an earlier stage ‡	18
Preference for end-of-life decision-making style:	
Physicians should make decisions, based on what is best for me	2
Physician and I should make decisions together	67
I should make decisions, based on what is best for me	31
Substantial knowledge of the Dutch Euthanasia Act §	37
Familiar with the term 'palliative care'	53

* Missing values on self-reported health were >10%. Valid percentage was based on 1403 respondents

† Trusting=a lot of trust and quite a lot of trust.

‡ Agree=agree; completely agree. Not agree= neither agree nor disagree; don't know, disagree; completely disagree

§ Substantial knowledge includes those who gave a correct answer to all four questions about the Act

Involvement and preferences to be involved in ACP

Of all 1,960 respondents, 70% indicated to have thought about issues related to medical decision-making at the end of their life (Table 4.3). Of all eligible respondents, 64% had discussed at least one of these issues with their relatives (6% often, 35% sometimes, and 24% seldom), and 13% had discussed these issues with a physician (0.3% often, 3% sometimes, and 9% seldom). In total, 33% had thought about end-of-life decision-making and had discussed it with their relatives, but had not discussed it with a physician and had not written an AD. Of all respondents, 7% had documented their wishes in a written AD. Of all respondents with an AD (n=139), 24% had discussed the AD with their physician, and 81% had discussed it with their relatives. Overall, 21% of the respondents wanted more information on end-of-life decision-making, e.g. medical care and treatments at the end of life, ADs or euthanasia. These respondents would look for information on the internet (54%) or ask their general practitioner (GP) (69%). Older persons, people who had thought about or discussed end-of-life issues with a relative or a physician, or who had an AD, more often wanted information than others.

Table 4.3 Involvement in advance care planning (ACP) among Dutch adults

	Respondents (n=1.960) (%)
Has thought about one of the following topics regarding end-of-life decision-making	**70**
Medical treatments that I would (not) want at the end of life	57
Whether and in which circumstances I would want resuscitation	48
Whether and in which circumstances I would want euthanasia	55
Who decides about medical treatments when I am no longer able to	53
Has discussed one of these topics with relatives *	**64**
Has discussed one of these topics with a physician *	**13**
Has a need for more information about these topics †	**21**
Possible sources for information on these topics:	
General practitioners	69
Internet	54
Relatives	44
Has a written advance directive, describing:	**7**
The circumstances in which I would not want certain medical treatments	4
The circumstances in which I would not want resuscitation	4
The circumstances in which I would want euthanasia	3
Who decides about my medical treatments when I am no longer able to	4
Other	1

* Responses measured on a 4-point Likert scale. 'Yes' includes seldom, sometimes, and often.

† Responses measured on a 4-point Likert scale. 'Yes' includes sometimes and often.

Factors associated with involvement in ACP

The probability of having thought about end-of-life decision-making was higher for persons aged ≥ 55 years, as well as for females, for persons without religious beliefs, persons with a poor health status, persons who had experienced a euthanasia request of a relative, persons who generally accept euthanasia, persons who expressed little trust that physicians would comply their wishes, persons not preferring physicians to make decisions for them, and persons who knew the term 'palliative care' and were familiar with the Dutch Euthanasia Act (Table 4.4). Similar patterns were found for discussing and having a written AD. Persons living with a partner less often had a written AD than persons living without a partner.

Table 4.4 Factors associated with involvement in advance care planning in the respondents of the online survey *

	Thought about end-of-life decision-making OR (95% CI)	Discussed preferences with relatives or physicians OR (95% CI)	Has a written advance directive OR (95% CI)
Demographic characteristics			
Age≥55 years	1.83 (1.37 – 2.45)	1.91 (1.45 – 2.51)	2.96 (1.76 – 5.00)
Male	0.59 (0.45 – 0.79)	0.60 (0.46 – 0.78)	1.37 (0.84 – 2.23)
High education	0.87 (0.65 – 1.17)	0.79 (0.59 – 1.04)	0.78 (0.47 – 1.27)
Living with partner	0.82 (0.58 – 1.16)	1.02 (0.74 – 1.41)	0.54 (0.33 – 0.90)
Having religious beliefs	0.64 (0.48 – 0.86)	0.71 (0.54 – 0.94)	0.98 (0.61 – 1.59)
Health			
Good health status	0.64 (0.42 – 0.98)	0.66 (0.45 – 0.98)	0.47 (0.28 – 0.80)
Having (had) a life-threatening disease	1.17 (0.72 – 1.90)	1.33 (0.84 – 2.10)	1.30 (0.71 – 2.35)
Experience with end-of-life decision-making			
Experience with euthanasia request of a relative	2.65 (1.50 – 4.70)	2.61 (1.55 – 4.38)	1.99 (1.08 – 3.67)
Experiences with palliative sedation for a relative	1.39 (0.88 – 2.20)	1.46 (0.95 – 2.25)	0.80 (0.42 – 1.53)
Attitudes			
Acceptance of euthanasia	1.58 (1.09 – 2.29)	1.67 (1.19 – 2.36)	2.71 (1.65 – 4.44)
Trusting physicians to comply with patient's wishes at the end of life	0.40 (0.28 – 0.59)	0.51 (0.37 – 0.72)	1.00 (0.59 – 1.70)
Preference for physician to make end-of-life decisions for me	0.19 (0.07 – 0.49)	0.24 (0.10 – 0.62)	-
Knowledge			
Familiar with the term 'palliative care'	2.76 (2.05 – 3.70)	2.35 (1.78 – 3.09)	0.98 (0.59 – 1.63)
Knowledge of the Dutch Euthanasia Act	2.06 (1.51 – 2.82)	2.13 (1.59 – 2.85)	1.63 (1.02 – 2.63)

* Adjusted odds ratios (ORs) were estimated with multivariate logistic regression analyses. These analyses included 1.231 respondents with complete information of all variables.

DISCUSSION

This study shows that the majority of the Dutch population has thought about end-of-life care and decision-making, and a substantial part of the population has actively discussed their preferences with relatives. Furthermore, it shows that one fifth of the general public indicated a need for information on end-of-life care, and would use the GP as the major source of information. However, discussions with physicians about end-of-life care are rare among the general public, even among people who have an AD.

Several findings deserve particular attention. First, although many people think about end-of-life care and decision-making, only 13% had discussed these issues with their physician. This is less compared to a recent study that found that Dutch and Belgian GPs had discussed medical treatment in the last phase of life in advance with 34% of their patients who had died non-suddenly [32]. The higher percentage in this study might be explained by differences in the population studied, i.e. the general population vs. deceased patients, and by the respondents' perspective, i.e. physicians' vs. patients' perspective.

Second, in the present study, 7% of the members of the general public reported to have an AD. This finding supports previous research on the prevalence of ADs in the general population with percentages ranging from 3-36% [5, 7, 9, 11, 33-34]. Compared to the United States where the estimated prevalence of ADs in the general population varies from 18-36% [7, 12, 34], the prevalence of ADs in the Netherlands seems lower. It has to be noted that the US Patient Self-Determination Act (PSDA), requiring healthcare institutions to provide information about ADs to adult patients upon their admission [35], came into effect earlier than the Dutch Medical Treatment Act. However, the SUPPORT study showed no effect of the PSDA on completion rates of ADs [36]. As said, the effects of ADs have been subject to major criticism, such as that they are not able to direct end-of-life care [13] and that they even involve a false promise, i.e. that the advance directive concept itself is fundamentally flawed [6]. The limited effects of ADs have been suggested to be partly due to little involvement of physicians in the completion of ADs, to physicians often being unaware of the availability of ADs, and to nonspecific wording of preferences in ADs [13, 18, 37]. Our study confirms that physicians are rarely involved in completing an AD as only 24% of all respondents with an AD had discussed it with their physician.

Third, most demographic factors associated with engagement in ACP are consistent with earlier studies on the drafting of ADs. Patients who have completed an AD were found to be older, more highly educated, more often female, and have increased dependency [5, 7, 11, 33, 38], and older age has also been reported to be positively associated with ACP as a process [25]. Furthermore, a predictor of being interested in AD is the wish of having control [39]. Our results support this idea of control. Those respondents in favor of physicians making decisions and expressing trust that physicians would comply with their wishes were significantly less inclined to be involved in ACP. Persons who accept euthanasia, also associated with wish for control [29], were also more inclined to be involved in ACP.

Besides individual factors, societal and legal factors can influence the level of involvement in ACP. In the Netherlands, an accessible health system is present with compulsory social health insurance and a special role for GPs as gatekeepers. Dutch people often have a long-lasting relationship with their GP, which might contribute to the high level of trust in physicians in the Netherlands. This trust might diminish the perceived need for ADs. Furthermore, the Dutch societal and public debate on euthanasia (which resulted in the Euthanasia Act in 2002) might influence the prevalence of ACP in the Netherlands and limit international comparability of the Netherlands. The Dutch general public is highly familiar with the advanced euthanasia directive [5], indicating the dominance of the issue of euthanasia in the Netherlands regarding end-of-life decision-making [8]. This context hampers the generalisability of our results to other settings. Also some other methodological considerations of the study need to be addressed. First, despite a good response rate, the respondents were not fully representative of the Dutch general population; the respondents were older, more often male, more highly educated and more often sharing a household. This may have led to an overestimation of the involvement in ACP of the Dutch general public. Moreover, non-native Dutch people were underrepresented and cultural factors are known to impact health care use [40] and health communication [41], thus influencing end-of-life care and decision-making [42]. In studies from the United States, ADs are more common among the white population [7, 11, 43]. Additionally, an internet panel used for surveys may involve selection bias. To minimize this bias, we made use of an existing panel consisting of a randomized sample of people (thus not self-selected) and this enabled all selected members to participate (no restriction to internet users only). Finally, because this study only examines the respondents' report of their involvement, without triangulation, the results may be subject to recall bias.

Although until now only one study has shown positive effects of ACP as a process [21] and more research is needed to confirm these results, ACP may be a potential contributor to better end-of-life care. Our study shows that most people are open to discussions about end-of-life care, that a need for more information is present. Since only a very small percentage of our study population has discussed end-of-life issues with their physician, our findings suggest that a more active role of physicians in initiating end-of-life discussions would be useful. In line, it has been suggested earlier, that physicians have a responsibility to start end-of-life discussions in a timely way [44-47], by informing and educating their patients. Therefore, to facilitate ACP, we suggest a dual approach to inform both the public and health care professionals. Firstly, to increase the awareness of the general public regarding the need to take the next step in ACP, i.e. to have timely discussions with physicians about their preferences at the end-of-life, such as the 'Dying Matters' initiative in UK [48]. This will contribute to overcome known barriers related to end-of-life discussions at the patient level, such as patients' ambivalent attitudes towards their prognosis, and a general reluctance to (spontaneously) talk about their problems and needs [46]. Secondly, physicians need to be educated and supported in how to initiate and have end-of-life discussions, because physicians are reluctant to discuss end-of-life issues and wait until the patient raises the topic [49]. This training and support should reach beyond technical aspects of communication and involve reflection of the physicians' own emotions and values [50].

In conclusion, the majority of the Dutch population has thought about their ideas and preferences regarding end-of-life decision-making or has actively discussed these ideas with relatives, and a need for information on end-of-life care is present. Despite the fact that the majority of Dutch population seems open to discussions about end-of-life care, our study reveals that discussions with physicians are exceedingly rare. To improve ACP as a joint process between patients, relatives and physicians, the general public's awareness of the importance of end-of-life discussions with their physicians needs to be increased and physicians need to play a more active role by initiating conversations and dialogue regarding end-of-life care.

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PART II

Nutrition and hydration at the end of life

CHAPTER 5

Issues and needs in end-of-life decision-making: an international modified Delphi study

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ABSTRACT

Background

End-of-life decision making is an important aspect of end-of-life care that can have a significant impact on the process of dying and patients' comfort in the last days of life.

Aim

The aim of our study was to identify issues and considerations in end-of-life decision making, and needs for more evidence among palliative care experts, across countries and professions.

Participants

90 palliative care experts from nine countries participated in a modified Delphi study. Participants were asked to identify important issues and considerations in end-of-life decision making and to rate the need for more evidence.

Results

Experts mentioned 219 issues in end-of-life decision making related to the medical domain, 122 issues related to the patient wishes and 92 related to relatives' wishes, regardless of profession or country ($p > 0.05$). In accordance, more than 90% of the experts rated the comfort and wishes of the patient and the potential futility of treatment as important considerations in end-of-life decision making, although some variation was present. When asked about issues that are in need of more evidence, 87% mentioned appropriate indications for using sedatives and effects of artificial hydration at the end of life. A total of 83% mentioned adequate communication approaches.

Conclusions

Palliative care experts from different professions in different countries encounter similar issues in end-of-life decision making. Adequate communication about these issues is universally experienced as a challenge, which might benefit from increased knowledge. This shared experience enables and emphasizes the need for more international research.

INTRODUCTION

End-of-life decision making is a sensitive but important aspect of end-of-life care that can have a significant impact on the process of dying and dying patients' comfort in the last days of life. Such decision making may involve withdrawing or withholding treatment, such as artificial nutrition (AN) and hydration (AH), or providing intensive treatment to alleviate suffering, for example by using opioids or sedatives. Some countries, such as the Netherlands and Belgium, allow the provision of life-ending drugs upon the explicit request of the patient.

To date evidence on the effects, either beneficial or harmful, of providing or not providing different types of treatment in the last days of life is limited [1-2]. Current research focuses mostly on practices and experiences or attitudes of physicians, nurses, patients, relatives or the general public and is often locally based. However, some international research has been conducted [3]. Hence, we know that the frequency of foregoing treatments, such as AH and AN [4], and the manner of alleviation of severe suffering at the end of life [5-6] vary between countries. Many factors can contribute to this variation, such as cultural, legal and practice differences, for example in the organization of health care. Research has shown that European intensive care unit (ICU) physicians' primary consideration in decision making on withdrawing or withholding life support or actively shortening the dying process was the patient's medical condition, while quality of life, patient age and patient or family request were less important [7]. In the Netherlands, important considerations in decision making about anti-cancer treatment for end-stage cancer patients were found to be the chance of improvement, patient wishes, the degree of suffering and the chance of therapy being successful [8].

Besides variation in end-of-life decision-making practices between countries, previous research has also shown differences between professions in attitudes regarding end-of-life decision making [9], which are probably related to different responsibilities, roles and levels of involvement.

More insight into the international and interdisciplinary variety in end-of-life decision-making practices can contribute to international understanding and debate and to the identification of international research themes [10]. The aim of this study was therefore to get more insight into the most important issues and considerations in end-of-life decision-making processes. We asked palliative care experts from different countries and professions to identify the key issues they encounter when making end-of-life decisions, their considerations when making end-of-life decisions, and the extent to which they feel that more evidence on these issues is needed.

METHODS

Design and population

A modified two-round digital Delphi survey was conducted. This study was framed within the European research collaborative OPCARE9, in which palliative care practitioners and researchers from nine countries are identifying areas for optimizing care for the dying. These countries are Argentina, Italy, Germany, the Netherlands, New Zealand, Slovenia, Sweden, Switzerland and the UK. Within OPCARE9, every country constructed a national reference group, a multidisciplinary group comprised of palliative care experts, known leaders in the field and volunteers. Convenience sampling was used to construct these reference groups. Using these national reference groups, a purposive strategy was applied to identify experts with an interest and involvement in end-of-life decision making. We aimed at including four physicians, three nurses, two other professional caregivers and one volunteer per country.

Data collection

Two structured questionnaires were developed. In these questionnaires, decisions on AH, AN, and the use of sedatives were used as examples of topics for end-of-life decision making. A pre-Delphi survey among 114 experts in nine countries showed that they considered these topics as very important at the end of life. In the first questionnaire, we asked the experts which important issues they encounter when making end-of-life decisions on AH, AN and using sedatives, by using open questions. We also presented them with 43 statements on eight considerations when making such decisions. The eight considerations assessed were comfort of patient, relative and professional caregiver, the wish of patient and relative, the effect on length of survival, futility of the treatment and ability to die at home. Participants were asked to rate the importance of these considerations on a seven-point Likert scale, ranging from unimportant (1) to highly important (7). The second questionnaire explored the extent to which experts thought that research on the issues that were frequently mentioned in round 1 would be useful. They were asked to which extent they agreed with statements that decision making would significantly improve if there would be more knowledge and/or evidence-based guidance on these issues. They rated their agreement on a five-point Likert scale, ranging from 1 'totally disagree' to 5 'totally agree'. The background characteristics of the experts (country, profession, work setting, age and experience) were asked in both questionnaires. The questionnaires were written in English and distributed electronically. The first questionnaire was sent between October 2009 and November 2009, and the second between May 2010 and June 2010. For both questionnaires reminders were sent in the case of non-response within three weeks.

Statistical analysis

All issues mentioned in response to the open question were labelled, categorized and counted. We used the analysis of variance (ANOVA) to compare the number of issues mentioned in different domains between countries and professions, for those domains which met the requirements. Likert scores on the importance of considerations were dichotomized (1–4 'not important' and 5–7 'important') and the percentage of scores in either consideration was calculated. Likert scores on the potential of research to contribute to the quality of end-of-life decision making were also dichotomized (1–3 'not important, 4–5 'important'). Differences between countries and professions in percentage of respondents who thought that specific considerations and research needs were important were tested using the non-parametric Fisher's Exact Test. For statistical analyses, we used SPSS software (SPSS PASW 17 17.0.2 ENG, WinWrap Basic, Polar Engineering and Consulting).

Ethical considerations

This study was evaluated by nine ethics committees in all beneficiary countries, as part of the whole project OPCARE9. No ethical objections were raised.

RESULTS

Response

In the first round the response rate was 76% (n = 68) and in the second round 60% (n = 54). The mean age of the experts was 45.8 years in the first round and 47.9 years in the second round. All professions were represented as planned (Table 5.1). All countries were represented and the distribution of professions per country did not differ in either round. Almost all experts were working in institutions and they had an average experience in palliative care of 12 years.

Table 5.1 Profile of respondents in the first and second round of the Delphi study

	Round 1	Round 2
Response rate % (n)	76% (n = 68)	60% (n = 54)
Age (mean, SD)	45.8 (8.5)	47.9 (7.9)
Profession		
Physician	46% (31)	52% (28)
Nurse	25% (17)	33% (18)
Other caregiver *	29% (19)	15% (8)
Setting		
Hospital	27% (18)	26% (14)
Hospice	31% (21)	32% (17)
PCU	34% (23)	33% (18)
Other	8% (5)	9% (5)
Country		
Argentina	16% (11)	18% (10)
Italy	15% (10)	9% (5)
Germany	12% (8)	6% (3)
New Zealand	12% (8)	13% (7)
Slovenia	3% (2)	4% (2)
Sweden	15% (10)	16% (9)
Switzerland	7% (5)	9% (5)
The Netherlands	9% (6)	15% (8)
United Kingdom	12% (8)	11% (6)
Expertise	Mean (SD)	Mean (SD)
Years working in palliative care	11.1 (7.1)	12.4 (6.8)
Attending deaths per year	159 (146)	120 (111)

* Other caregivers were social workers, psychologists, spiritual caregivers, occupational therapists, volunteers and a dietician.
PCU: palliative care unit

Issues in end-of-life decision making

The experts mentioned 552 issues that they encounter when making end-of-life decisions: 189 related to AN, 182 related to AH and 181 related to the use of sedatives at the end of life. The issues mentioned could be categorized into nine domains. Most issues were related to the medical domain, followed by issues related to addressing patients' wishes, addressing relatives' wishes and to multidisciplinary team decision making. Issues in the cultural and legal domains were least often mentioned. The number of issues mentioned per domain did not differ between professions or countries.

Considerations in end-of-life decision making

According to the experts, the most important consideration in end-of-life decision making is the comfort of the patient, for all three types of decisions, followed by the potential futility of treatment and the wishes of the patient (Table 5.2). The least important considerations were the comfort of professional caregivers and the (expected) effect of treatment on postponing death or foreshortening life. The importance of these considerations was rated similarly by all professions. There were significant differences between countries: futility of treatment was least often rated as an important consideration in the UK (overall $p<0.05$) and enabling people to die at home was most often rated as important in Argentina and least often in Sweden (overall $p<0.01$).

Need for more guidance in end-of-life decision making

Table 5.3 shows the percentage of experts who thought that end-of-life decision making could significantly improve if there were more evidence-based guidance. Of the experts, 87% (totally) agreed with the statement that more evidence-based guidance on 'optimal strategies for communication with the patient' could improve end-of-life decision making, and 83% agreed with a comparable statement on communication with relatives. Other important research themes were indications for using sedatives at the end of life (87% of the experts), the effects of (de)hydration at the end of life (83% of the experts) and the dosage of sedatives to use at the end of life (80% of the experts). No differences between countries were found in the rating of the importance of more evidence for the different themes. There were some differences between professions: the effect of dehydration on quality of life was more often considered important by physicians and nurses than by other caregivers (overall $p < 0.05$) and multidisciplinary team decision making was more often considered important by nurses (overall $p = 0.01$).

Table 5.2 Percentage of respondents rating considerations in end-of-life decision making as important

Considerations in end-of-life decision making	Physicians % important	Nurses % important	Other caregivers % important	Total % important	Difference professionals p-value	Difference countries p-value
Comfort of patient	100	100	100	100	n.a.	n.a.
Futility of treatment	90	81	100	90	0.30	<0.05
Wishes of patient	83	100	93	90	0.17	0.13
Enable patients to die at home	79	75	57	73	0.33	<0.01
Comfort of relatives	30	41	50	38	0.45	0.43
Wishes of relatives	28	32	36	31	0.93	0.21
Possible effect on length of survival	11	0	15	9	0.42	<0.05*
Comfort of professional caregivers	7	18	0	9	0.23	0.39

Dichotomized scores on a seven-point Likert scale (1–4 = not important, 5–7 = important).

* Little relevant differences between countries, although statistically significant, due to very low % of experts who rated this consideration as important.

Table 5.3 Percentage of respondents agreeing that more evidence on end-of-life decision making issues could improve end-of-life decision making

End-of-life decision making on AN/AH/sedatives could substantially improve if there would be more general knowledge and/or evidence-based guidance on…	Physicians % agree	Nurses % agree	Other caregivers % agree	Total % agree	Difference professionals p-value*	Difference countries p-value*
… optimal strategies for communication with patients	86	94	71	87	0.32	0.82
… for what indication to use sedatives	93	78	88	87	0.28	0.47
… optimal strategies for communication with relatives	85	89	63	83	0.32	0.67
… the effect on quality of life of dehydration †	89	89	50	83	<0.05	0.33
… what dose to use for sedation ‡	79	83	75	80	0.90	0.45
… diagnosing dying	82	67	88	78	0.44	0.93
… what medications to use for sedation‡	82	72	75	78	0.67	0.38
… the side effects	75	83	50	74	0.25	0.91
… the effects on quality of life	75	72	63	72	0.77	0.52
… how to improve multidisciplinary team decision making	56	94	63	70	0.01	0.59
… the impact of cultural perception	67	72	63	68	0.85	0.99
… relatives' perceptions	71	53	75	66	0.42	0.43
… ethical considerations; respecting autonomy of patients	54	72	83	64	0.33	0.27
… legal aspects of making decisions	56	67	75	62	0.59	0.91
… patients' wishes	61	56	63	59	0.93	0.55

Continued

Table 5.3 Percentage of respondents agreeing that more evidence on end-of-life decision making issues could improve end-of-life decision making

… ethical considerations; possible shortening life of patients	44	67	75	57	0.23	0.47
… reasoning behind patients' wishes	57	47	63	55	0.75	0.83
… the effects on patients' length of life	57	44	63	54	0.70	0.45
… relatives' wishes	29	38	50	35	0.52	0.95

Dichotomized scores on a five-point Likert scale (1–2 = agree, 3–5 = disagree). AN: artificial nutrition, AH: artificial hydration

* p-values are based on Fisher's Exact Test.

† statement only on use of artificial hydration at the end of life

‡ statement only on using sedatives at the end of life.

DISCUSSION

This study shows that palliative care experts from different professions in nine countries encounter similar issues in end-of-life decision making. Important issues were often related to the medical domain, such as uncertainty about the effects of (de)hydration and appropriate indications for the use of sedatives, and to communication, such as how to address patients' and relatives' wishes and how to inform those involved. The most important considerations for all professions, when making end-of-life decisions, were the comfort and the wishes of the patient and the potential futility of treatment. Improved knowledge regarding appropriate indications for using sedatives, the effects of AH at the end of life and adequate communication approaches was identified as contributing to better end-of-life decision making.

It is important to emphasize that the term 'end-of-life decision' is surrounded by some confusion. In the early 1990s this term was predominantly used for decisions in the patient domain, involving advance care planning and gaining insight into the values of the patient. A significant amount of research on medical end-of-life decision-making practices focused on decisions in which the physician aims at or takes into account a life-shortening effect [3, 11-16]. In this international collaborative, the term 'end-of-life decisions' was defined as a broad concept that included all decisions that may have a significant impact on how, where and when patients die. A preparatory survey, utilizing this definition over 100 experts in all participating countries, identified decisions on medical issues such as AH, AN and use of sedatives as the important end-of-life decisions.

Our study has both strengths and limitations. To assess issues, considerations and needs related to end-of-life decisions, a large international expert panel was used. The experts were selected within the nine beneficiary countries of the OPCARE9 consortium. It is not possible to determine if the panel is representative of the population of palliative experts. Nevertheless, the presence of different professions and the average length of palliative care experience (12 years) suggest that our panel represents a broad and experienced group. The response was satisfactory, namely 76% in the first Delphi round and 60% in the second. It is important to note that almost all experts worked in an institutional setting, which makes it difficult to generalize our results to home care settings. In addition, the participants were predominantly physicians and nurses, because they were more inclined to respond. This partly explains the emphasis on medical issues.

This study shows that palliative care experts from different countries share experiences regarding issues and considerations in end-of-life decision making. The fact that these shared opinions regarding the importance of patient comfort, futility of the treatment and patients' wishes in end-of-life decisions making do not seem to involve similar practices [3] may be related to the fact that evidence-based end-of-life care is still evolving. Therefore practices can only result from the limited objective data informed by experience and humanistic considerations.

We also identified some variation between countries and professionals. 'Enabling the patient to die at home' was least often rated as an important consideration in end-of-life decision making in Sweden. This finding coincides with a relatively low rate of about 21% home deaths (of all non-sudden deaths) in Sweden [17]. This consideration may also be of less importance in Sweden, due to the high availability of technical devices in palliative home care in Sweden. Hence, decision making about AH or AN is not a determinate of place of care and dying. In Argentina, where approximately 59% of all people die at home [18], it was most often mentioned as an important consideration.

This Delphi study also assessed the extent to which experts believed evidence-based guidance in end-of-life decision making would be helpful. This practice-based identification of research themes is not only useful and feasible, but it also may increase ownership of the future research results and the likelihood of these results influencing clinical practice[19]. Stakeholders in many fields are already involved in identification and prioritization of research themes, and increasingly so in palliative care [10, 20-22]. However, this mostly national involvement of stakeholders in end-of-life research is still insufficient. Recently an international study identified 'lack of culture for research in palliative care services' and the 'disconnection in understanding between clinician and researcher' as important barriers in end-of-life research [23]. Using an international, multidisciplinary expert panel, our study may contribute to improving involvement in end-of-life research. In addition, our findings regarding the need for evidence-based guidance in end-of-life decision making are in line with previous research: communication has been shown to be considered as an important theme for end-of-life research by patients and their relatives too[10].

In conclusion, we found a large degree of international and interdisciplinary consensus on important issues and considerations in end-of-life decision making. Communication with terminally ill patients and their relatives is a challenge that could benefit from more evidence, together with appropriate indications for and effects of end-of-life therapies. This international and interdisciplinary consensus underlines the possibility of and need for more international research.

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CHAPTER 6

Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects

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ABSTRACT

Background

The benefits and burdens of artificial nutrition (AN) and artificial hydration (AH) in end-of-life care are unclear. We carried out a literature review on the use of AN and AH in the last days of life of cancer patients.

Materials and methods

We systematically searched for papers in PubMed, CINAHL, PsycInfo and EMBASE. All English papers published between January 1998 and July 2009 that contained data on frequencies or effects of AN or AH in cancer patients in the last days of life were included.

Results

Reported percentages of patients receiving AN or AH in the last week of life varied from 3% to 53% and from 12% to 88%, respectively. Five studies reported on the effects of AH: two found positive effects (less chronic nausea, less physical dehydration signs), two found negative effects (more ascites, more intestinal drainage) and four found also no effects on terminal delirium, thirst, chronic nausea and fluid overload. No study reported on the sole effect of AN.

Conclusions

Providing AN or AH to cancer patients who are in the last week of life is a frequent practice. The effects on comfort, symptoms and length of survival seem limited. Further research will contribute to better understanding of this important topic in end-of-life care.

INTRODUCTION

Most terminally ill cancer patients have a reduced oral intake in the last days of life. This can be due to different causes, related to either cancer or its treatment, such as dysphagia [1], anorexia, nausea or vomiting [2-6], or mechanic problems, such as a physical obstruction in the digestive tract due to gastrointestinal or gynaecologic malignancies [7,8]. Reduced oral intake may be seen as part of the natural dying process, or it may result in clinically relevant dehydration or malnutrition. Terminal cancer patients [9,10] often have symptoms that compromise their quality of life, but an association with reduced oral intake has not been proven for the last days of life [9,11,12].

Patients in whom medical treatment for dehydration or malnutrition seems indicated can be treated with artificial nutrition (AN), artificial hydration (AH), or artificial nutrition and hydration (ANH). Different routes of administration are possible, such as enteral (tube into any part of the gastrointestinal system) or parenteral access (i.v. or s.c.). Such treatments are used in different settings for several populations of severely ill patients, such as patients with dementia, nursing home residents, pre-, peri- and postoperative patients and patients undergoing chemotherapy or other anticancer treatment [7,13-21].

Recently, two Cochrane reviews have been published on the effects of medically assisted hydration and nutrition in adult patients receiving palliative care, including the terminal and dying phase. These reviews only included level A evidence studies, i.e. randomised controlled trials and high-quality prospective controlled studies. It was concluded that the currently available evidence is insufficient to make any recommendations for practice with regard to the use of medically assisted nutrition and hydration in patients receiving palliative care [22,23].

Patients have different symptoms [24] and different needs [25] in different phases of their disease. When investigating practices and effects of ANH in advanced cancer patients, it is therefore important to distinguish different phases, such as the review dying phase where life expectancy is hours or a few days at most. Randomised controlled trials in the dying phase are complex and rare because of ethical and practical considerations related to randomisation, informed consent and follow-up. Observational studies can also provide useful information. The objective of this review was to give a comprehensive overview of currently available evidence on practices and effects concerning AN and AH in the last week of life of cancer patients.

METHODS

Research questions

We aimed at addressing the following research questions: (i) how and how often are AN and AH provided in the last week of life of cancer patients; (ii) what is the effect of AN and AH during the last week of life on symptoms, comfort and quality of life of cancer patients and (iii) does providing or not providing AN and AH hasten death or prolong life?

Literature search

We conducted an electronic search of the databases such as PubMed, CINAHL, PsychInfo and EMBASE for papers that were published in English between January 1998 and May 2009. We used MeSH headings (palliative care, terminally ill, terminal care, fatal outcome, nutrition support, feeding methods, fluid therapy) and a broad range of search keywords for end of life and AN and AH. The complete search strategy is presented in Table 6.1.

In addition, we hand searched the most recent issues (January 2008–February 2009) of 10 relevant peer-reviewed journals: Journal of Pain and Symptom Management, Journal of Palliative Care, Palliative Medicine, Journal of Clinical Oncology, New England Journal of Medicine, Lancet, British Medical Journal, JAMA, Annals of Internal Medicine and Archives of Internal Medicine.

Table 6.1 Electronic search strategies

Databases	Keywords	MESH headings
	End of Life	
Medline; PsychInfo; CINAHL; EMBASE	#1 "End of Life" in All Text	Terminally Ill [Mesh]; Terminal Care [Mesh]; Palliative Care [Mesh]
	#2 ("End" in All Text near/1 "Life" in All Text)	
	#3 "Ending life" in All Text	
	#4 "Terminally Ill" in All Text	
	#5 ("Terminal" in All Text near/1 "Care" in All Text)	
	#6 ("Terminal" in All Text near/1 "Ill" in All Text)	
	#7 "Palliat*" in All Text	
	#8 "Die" in All Text	
	#9 "Dying" in All Text	
	#10 "Dying process" in All Text	
	#11 "Approaching death" in All Text	
	#12 "Dying Phase" in All Text	
	#13 "Care for dying" in All Text	
	#14 "Final days of life" in All Text	
	#15 "Last days of life" in All Text	
	#16 "Last 24 hours" in All Text	
	#17 "Last 48 hours" in All Text	
	#18 "Last 72 hours" in All Text	
	#19 "Advanced Cancer" in All Text	
	#20 "Life-sustaining" in All Text	
	#21 "Life-shortening" in All Text	
	#22 "Hastened Death" in All Text	
	#23 "Delaying Death" in All Text OR "Delayed Death"	
	#24 "Proximity to Death" in All Text	
	#25 "imminently dying" in All Text	

Continued

Table 6.1 Electronic search strategies

	Artificial Nutrition and hydration	
Medline; PsychInfo; CINAHL; EMBASE	#1 “Nutrition” in All Text	Nutrition Support [Mesh]; Feeding methods[Mesh]; Fluid Therapy[Mesh]
	#2 “Hydration” in All Text	
	#3 “Fluid” in All Text	
	#4 “Food” in All Text	
	#5 “Artificial feeding” in All Text	
	#6 “Artificial nutrition” in All Text	
	#7 “Artificial hydration” in All Text	
	#8 “Artificial” in All Text near/3 ”Feeding”	
	#9 “Artificial” in All Text near/3 ”Nutrition”	
	#10 “Artificial” in All Text near/3 ”Hydration”	
	#11 “Tube feeding” in All Text	
	#12 “Infusion” in All Text	
	#13 “Parenteral fluid” in All Text	
	#14 “Parenteral hydration” in All Text	
	#15 “Parenteral nutrition” in All Text	
	#16 “Nasogastric tube” in All Text	
	#17 “Gastrotomy tube” in All Text	
	#18 NOT (“Cell Death” or “Apoptosis” or “Cell”)	

Study selection

Two reviewers (NR and AvdH) used a stepwise procedure to identify relevant studies. First, all papers’ titles were assessed as probably relevant, possibly relevant and not relevant. Not relevant titles were excluded. In the second step, abstracts of the remaining papers were screened on potential relevance. In step 3, abstracts of all potentially relevant papers were formally screened on the following inclusion criteria: studies had to (i) include cancer patients and (ii) describe original empirical research, thus excluding case reports, reviews, discussion papers and ethical papers. If the abstracts met these two inclusion criteria, papers were assessed full text.

Full text papers were assessed on the following criteria: (i) they had to include data on the last week of life, (ii) they had to describe frequencies of practices or effects of AN or AH and (iii) at least 25% of included patients had to be cancer patients.

Data extraction and synthesis

We collected information on general aspects of the studies and results related to our research questions. Extracted data included number of patients, study setting, study design (prospective or retrospective) and general patient characteristics. We also assessed frequencies, administration routes, measurement of effects and direction of effects. Data were extracted using a standardised data extraction form. Reviewers were not blinded for authors, institutions or journal of publication. We compared results across papers that addressed similar research questions. We used SPSS 15.0 for Windows (LEAD Technologies, USA) for data management and descriptive statistics.

RESULTS

Selection of papers

We identified 2198 articles from the different electronic databases, excluding 780 duplicates. In the first step, 1682 papers were excluded on assessment of relevance of title. In the second step, 134 papers were excluded because their abstracts proved their non-relevance. Reading abstracts of possibly relevant papers resulted in the exclusion of another 124 papers. This resulted in a total of 258 potentially relevant papers. Of these, 102 were excluded because the abstracts proved that they did not include cancer patients; 32 were excluded because they did not include original patient data. Finally, a total of 124 papers were assessed full text: this resulted in the exclusion of another 110 papers, 51 because they did not report about the last week of life but on earlier phases, 25 because they only described knowledge of and attitudes towards AN or AH instead of practices and effects, 7 because they did not include at least 25% cancer patients and 27 because they included no relevant data on AN or AH. After screening the references of the remaining 14 papers, 1 paper was added. So, finally 15 papers were included in this review (Figure 1).

Practices of ANH

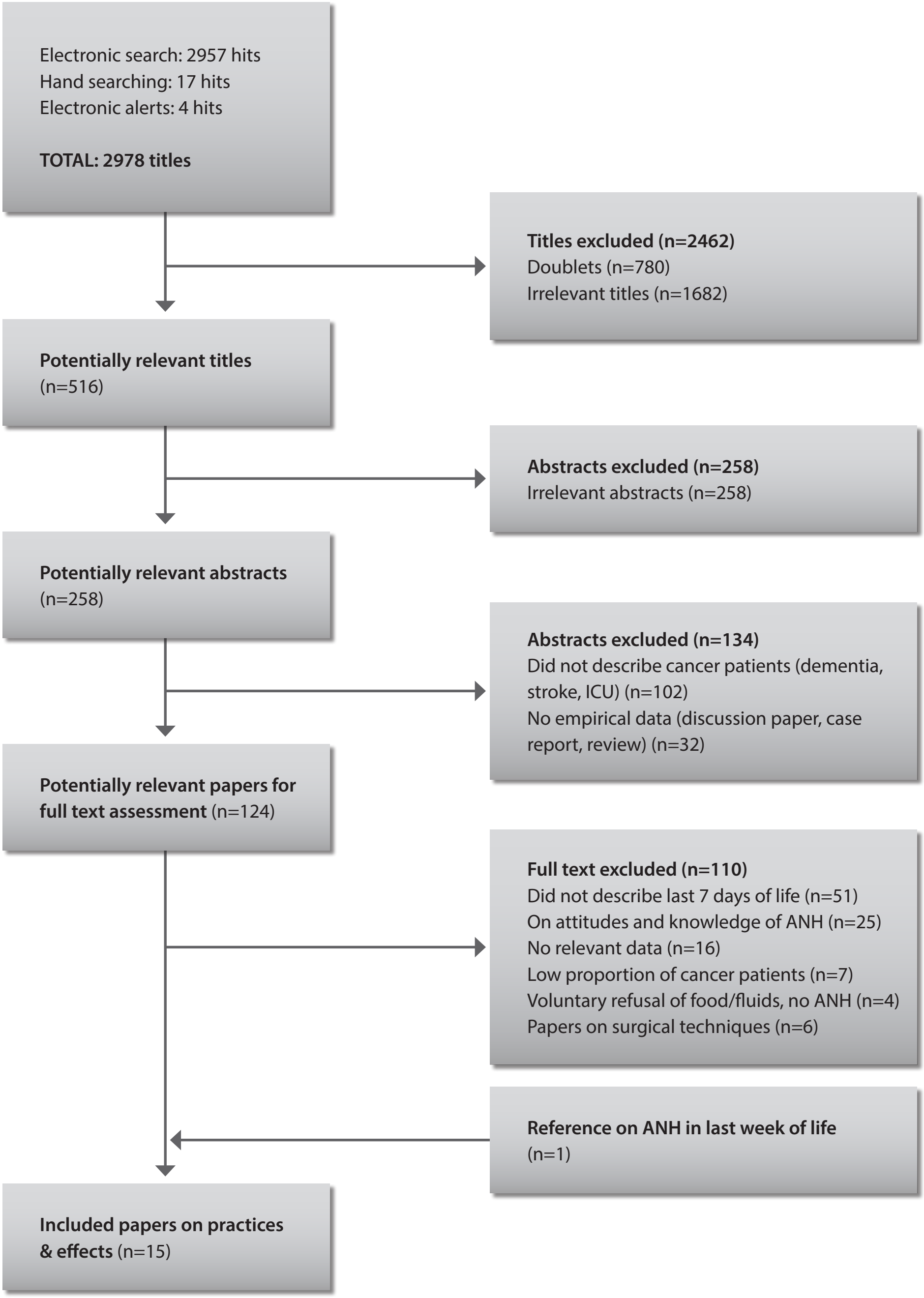
Frequencies of AN in the last week of life

Four papers reported on frequencies of AN during the last week of life: two involved retrospective [26,27] and two prospective studies [3,28]. All studies reported on hospital practices and described several ways of administering AN, such as tube feeding and total parenteral nutrition. Reported frequencies of providing AN varied from 3% to 50%. Overall, there was a higher frequency of AN in prospective studies (range 3%–50%) compared with retrospective studies (range 2%–15%) and on non-palliative hospital wards (range 8%–53%) compared with palliative wards (range 3%–10%). All studies were conducted in Asian countries (Table 6.2).

Frequencies of AH in the last week of life

Seven papers have reported on frequencies of AH during the last week of life: four retrospective [26-28,30] and three prospective [3,29,31] studies. Six studies reported on practices in hospital settings, including one that also studied patients in a palliative home care setting and one that was carried out in a hospice setting. The studies described several ways of administering AH, such as i.v. and s.c. administration. Reported frequencies of providing AH in the last week of life ranged from 10% to 88%. Overall, there was a tendency towards a higher frequency of AH in retrospective studies (range 10%–88%) compared with prospective studies (range 12%–43%). In hospital settings, the frequency of AH was higher (range 10%–88%) than in the hospice (range 33%–44%) (Table 6.2). The frequencies of AH on a palliative care unit (PCU) and an acute ward in the same hospital were similar, but these wards differed on the amount of AH given: patients in the acute ward received significantly larger volumes of AH, with or without palliative care consultation, compared with patients in the PCU [30].

Figure 1. Flowchart inclusion and selection papers



Withholding and withdrawing of ANH in the last week of life

Four papers reported on frequencies of withholding and withdrawing of ANH while taking into account or intending hastening of death as a possible result; AN and AH were not separated. In a nationwide study in the Netherlands, ANH was found to be withheld or withdrawn in 8% of all deaths [33]. A subsequent international study found nationwide percentages in several European countries of withholding and withdrawing ANH ranging from 2.6% to 10.9% of all deaths [16,34]. A retrospective medical chart study in a large urban teaching hospital in the United States found a comparable frequency of withdrawing ANH, namely in 5.5% of all deceased patients in a large urban teaching hospital. When only looking at deceased patients who were actually receiving AN or AH before death, such treatment was withdrawn in 19% [35].

Effects of ANH

Effect of AN in the last week of life on quality of life

No studies of the effect of AN in the last week of life on quality of life were found. However, a prospective observational study reported the combined effect of ANH. In this study, medical staff assessed the comfort level of 196 terminal cancer patients who received ANH. Two days before death, 145 patients still received ANH: 75% of them did not perceive any changes in comfort compared with an earlier assessment, 6% perceived more discomfort and 18% perceived more comfort [3].

Effect of AH in the last week of life on quality of life

None of the studies used quality-of-life assessments to measure effects of AH compared with no AH. Five papers reported on the effects of AH on symptoms during the last week of life. Details of these studies are described in Table 6.3. The number of patients included in these studies ranged from 78 to 284 patients. Four studies had a prospective design, one of which used randomisation for the allocation of AH; one study had a retrospective design. All studies included cancer patients who were admitted to a hospital ward; one study also included cancer patients who were participating in home-based palliative care programme.

The prospective randomised trial found no significant effects in controlling several symptoms, except for chronic nausea that had improved significantly more after 48 h in the AH group [37]. When comparing patients receiving or not receiving AH, two prospective studies found respectively significantly more ascites [38] and more intestinal drainage in the AH group [29]. The latter study found no differences in ascites and pleural drainage. It is not clear was the authors meant by intestinal drainage. Secondary analyses of data from a large, prospective observational study revealed a significant association between AH 24 h before death and the absence of physical signs of dehydration (dry mouth, axillary moisture and sunkenness of eyes) [38]. Another prospective study only reported the feasibility and side-effects of rectal AH [36] and a retrospective study compared two different protocols for preventing delirium by opioids and AH; no difference in delirium was found [32].

Table 6.2 Studies on frequencies of receiving artificial nutrition and hydration in last week of life in cancer patients

Author, country	Setting		Patient characteristics		Design	Sample size	Date collection methods	Time	Artificial nutrition			Artificial hydration		
			Diagnosis	Age*					Tube (%)	TPN (%)	Total (%)	IV (%)	SC (%)	Total (%)
Oh et al.[27], South Korea	Hospital		Cancer patients[†]	65	Retrospective	165	Medical records review	Last 48h of life	8	15	-	83	-	83
Masuda, et al. [28], Japan	Hospital	Hospice	All inpatients older >65[‡]	76	Prospective	191	By professionals	Last 48h of life	3	7	10	-	-	-
		Geriatric		80					18	32	50	-	-	-
Sato et al. [26] Japan	Hospital	PCU	Cancer patients	71	Retrospective	305	Medical records review	Last 48h of life	2	2	3	-	-	10
		General		68					2	10	12	-	-	67
Morita et al [29], Japan	Hospitals & home palliative care		Lung or abdominal cancer patients[§]	67	Prospective	125	By professionals	Last 7 days of life	-	-	-	35	-	35
Lanuke et al. [30], Canada	Hospital	PCU	Cancer patients	71	Retrospective	100	Medical records review	Last 7 days of life	-	-	-	-	-	84-87
		Acute care		70					-	-	-	-	-	80-88
Goncalves et al. [31], Portugal	Hospital		Cancer patients[†]	61	Prospective	300	By professionals	Last 48h of life	-	-	-	5	8	12
Morita, et al. [32] Japan	Hospice	1996-97	Cancer patients	64	Retrospective	284	Medical records review	Last 7 days of life	-	-	-	-	-	33
		2000-01		63					-	-	-	-	-	44
Chiu et al. [3], Taiwan	Hospital		Cancer patients	62	Prospective	344	By professionals	Last 48h of life	13	18	53[‖]	43	-	53[e]

* Mean age in years

† Cancer patient who were receiving no active cancer direct treatments.

‡ Ninety-nine percent of all hospice patients had cancer and 42% of the patients admitted to the geriatric hospital had cancer.

§ Secondary analyses of data of patients who received laboratory examinations during the last week.

‖ AN and AH has been studied as one (artificial nutrition and hydration).

IV, intravenous; PCU, palliative care unit; SC, subcutaneous; TPN, total parenteral nutrition

Table 6.3 Studies on effects of artificial hydration (AH) in last week of life on quality of life in cancer patients

Author, country	Setting	Patient characteristics		Design	Sample size	Date collection methods	Intervention	Outcomes	Effects on quality of life		
		Diagnosis	Age[*]						+	+/-	-
Bruera et al.[36], USA	Hospital	Cancer patients	56	Prospective	78	By professionals	Rectal hydration	VAS[§] of overall discomfort			Little discomfort after infusion
Cerchietti et al.[37], Argentina	Hospital	Cancer patients	54	Prospective, randomised	42	By professionals	1L/day AH	Thirst Chronic nausea Delirium Mental status	Better control of chronic nausea after 48h in AH group (p<0.05)	No differences in thirst and delirium	
Morita et al.[38], Japan	Hospitals and home palliative care	Abdominal cancer patients	68	Prospective	226	By professionals	>1L /day AH	Clinical signs of dehydration	Less dehydration in AH group (p<0.005)	No difference in other clinical signs of dehydration[†]	More ascites in AH group (p<0.05)
Morita et al.[29], Japan	Hospitals and home palliative care	Lung or abdominal cancer patients[‡]	67	Prospective	125	By professionals	>1L /day AH	Clinical signs of dehydration Fluid retention		No differences in ascites and pleural drainage	More intestinal drainage (p<0.05)
Morita, et al.[32], Japan	Hospital	Cancer patients	64	Retrospective	284	Medical records review	>0,5L/day AH	Delirium severity: MDAS, ADS and CCS[‖]	-	No differences in delirium and agitation	

[*] Mean age in years.

[†] Other clinical signs of dehydration are dry mouth, axillary moisture and sunkenness of eyes.

[‡] Secondary analyses of data of patients who received laboratory examinations during the last week.

[§] VAS, visual analogue scale. *

[‖] MDAS, memorial delirium assessment scale; ADS, agitation distress scale; CCS, communication capacity scale.

Effect of ANH on survival

Only one study reported on the effect of ANH in the last week of life on survival of terminal cancer patients admitted to the hospice or PCU of the university hospital in Taiwan (Table 6.4). The study did not distinguish AN and AH. Providing ANH in advanced cancer patients at either the time of admission or 2 days before death was found not to be a significant determinant of survival [3].

Table 6.4 Studies on effects artificial nutrition and hydration (ANH) in last week of life on length of life in cancer patients

Author, country	Setting	Patient characteristics		Design	Sample size	Date collection methods	Inter-vention	Outcome	Effects
		Diagnosis	Age*						
Chiu et al. [3], Taiwan	Hospital	Cancer patients	62	Prospective	344	By professionals	ANH	Survival	Using ANH 48h before death did not influence survival significant; hazard ratio 1.03 (95% confidence interval 0.76-1.38)

DISCUSSION

Although research with patients who are in the last week of life is challenging, we could include 15 papers in our review. AN and AH appear to be a substantial part of medical care in the last week of life of cancer patients, especially in hospital, with frequencies up to 50% and 88%. Explicit withholding or withdrawing AN or AH was rarely studied. Several studies reported on the benefits and burdens of AN or AH. No studies that assessed the effect of AN on symptoms and quality of life during last week of life were found, except one that studied the combined effect of ANH and found no change in comfort, as perceived by the patients. AH was found to have a limited impact on patients' symptoms: one study found less chronic nausea after receiving AH and another study found some association between AH and signs of dehydration. No significant relationships between AH and general comfort or quality-of-life measures were found. One study assessed the effect of ANH on survival and found no association.

The frequent practice of providing AN or AH during the last days of life is thus not based on evidence of its effectiveness. However, dying cannot be predicted in all cases. The studies that are included in our review probably often involve the provision of AN or AH to patients who were not expected to die within a few days. This hypothesis is supported by our finding that the frequencies were generally lower in specialized palliative or hospice care settings. Dying was probably less often diagnosed in general hospital settings. In specialised palliative or hospice care settings, diagnosing dying is an integral aspect of care. Several care pathways for the dying have been developed, such as the Liverpool Care Pathway for the dying [39,40] and the Gold Standard Framework in Care Homes [41]. These instruments contribute to the care for the dying patient, as shown in recent studies [42,43], although more research is needed [44].

Professional caregivers working in palliative care have been shown to be more reserved about the benefits of AN and AH than other professionals: most of them do not believe that they contribute to the alleviation of symptoms and many are concerned about the burdens of ANH in the last week of life [28,45,46].

On the other hand, terminal patients and relatives often have a positive attitude towards hydration in the last week of life and often perceive AH and AN as clinically useful standard care at the end of life [47-50]. Whereas shared decision making is considered standard practice in modern end-of-life care, such positive attitudes of patients and relatives most likely influence the practice of providing AN or AH, despite limited evidence of their effectiveness. Professionals therefore should communicate clearly with patients and relatives about the limited evidence of beneficial effects of AN and AH. Evidently, this communication involves ethical challenges. These ethical issues in decision making on AN and AH at the end of life have been widely debated in the last decades [51,52].

The overrepresentation of Asian studies in our review was notable: 75% of studies on frequencies were Asian studies and all data on AN in the last week of life originated from Asia. Cultural differences in end-of-life decision making [53-57] and legal issues may have influenced both the number of studies on these topics and the frequencies of using AN or AH. For example, Taiwan was the first Asian country to pass the Natural Death Act in 2000. This act gives dying patients and their families the right to refuse unnecessary medical management that only prolongs a state of agony [58]. Such legal developments and public debate may have given rise to an interest in and relatively large number of Asian studies on medical treatment at the end of life.

The studies in our review mainly had narrowly defined patient populations, which obviously limits the generalizability of the results too. Almost all studies only included patients who were admitted to a hospital; only one study also included patients receiving home palliative care. In this review, we focused on the last week of life of cancer patients because their needs concerning AN or AH may be different from those of cancer patients with a longer prognosis. However, our findings were in line with studies on medically assisted hydration and nutrition in palliative care in general [22,23]. Two systematic reviews found insufficient studies on the effects of AN and AH to draw firm conclusions. They describe two studies that found less sedation, myoclonus and dehydration after AH, but AH also led to fluid retention symptoms, such as pleural effusion, peripheral oedema and ascites. Other studies in these reviews did not show significant effects of AH. One of the studies involved a randomised trial on AH in dehydrated advanced cancer patients with no further treatment planned. It found improvement of myoclonus, sedation and an overall benefit of AH as assessed by the physician. It found no significant differences in the perceived benefit by patients and in symptoms such as fatigue and hallucinations [59]. None of the studies in our review used quality of life as an outcome measure for comparing AH with no AH; all assessed only physical signs and symptoms. The association of these physical findings with quality of life is unknown. Several quality-of-life instruments [60-63] have already been used in palliative care research, although, according to a recent review on the feasibility and clinimetric quality of these instruments, more work has to be done [64].

Overall, current literature suggests that the benefits of providing AH are limited and do not clearly outweigh the burdens for cancer patients. But, as known, cancer patients in the last days of life can be heterogeneous in (de)hydration, (mal)nutrition and related symptoms. Patients receiving AH already have been shown to differ from not receiving patients, on diagnoses, average days of admission and mode of death [65]. This heterogeneity of background, onset and process of dehydration needs more attention in future research to identify patients who can profit of AH or AN, as suggested earlier [66]. The need for more research on the benefits and burdens of AN and AH in the last days of life is clear. Research in the dying phase is a challenge, ethically and methodologically. Researchers have to be creative and innovative in developing new research methods, e.g. by obtaining the advance consent of patients [67]. The need to develop alternative methods is not solely a challenge in palliative care but also in other fields of medicine such as critical care [68,69], paediatrics [70] and surgery [71]. Much can be learned from initiatives in these fields, such as obtaining consent from a substitute decision maker (proxy consent) and clinical equipoise (a state in which clinicians are uncertain about the outcome of different treatments, no treatment prevails) as an inclusion criterion for yielding two comparable groups.

CONCLUSION

When a patient is recognised as having entered the dying phase, medical treatment should primarily contribute to the patient’s comfort. Issues concerning nutrition and hydration are an important and significant aspect of cancer patient care in the last days of life. Current literature suggests that the benefits of providing AH are limited and do not clearly outweigh the burdens, although some effects on specific symptoms may be present in some patients. Evidence concerning the effects of continuing or withdrawing AN in the last days of life is lacking and little is known concerning the life-shortening or prolonging effect of either AN or AH. Innovative and creative methodologies for research are needed to further improve the evidence base for care for the dying.

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CHAPTER 7

Variation in attitudes towards artificial hydration at the end of life: a systematic literature review

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ABSTRACT

Purpose of review

Artificial hydration in end-of-life care is an important and emotive topic that frequently raises concerns from patients, relatives and healthcare professionals (HCPs). The aim of this review was to give an overview of currently available evidence around opinions and attitudes towards artificial hydration at the end of life.

Recent finding

In total 11 studies reported on opinions towards providing artificial hydration, nine studies reported on attitudes towards the effect of artificial hydration on quality-of-life and four studies towards its effect on survival. Reported percentages of respondents in favour of providing artificial hydration at the end of life varied from 22 to 100% and for nonprovision from 0 to 75%. One-third of the general public has been found to think that artificial hydration improves comfort, while among patients a majority feels it can have a physical or psychological benefit. HCPs were found to be less optimistic: 1–43% thought patients benefit from artificial hydration at the end of life. HCPs mostly agree artificial hydration does not prolong survival, although up to 89% of patients expect it does.

Summary

Opinions and attitudes towards the use of artificial hydration at the end of life vary. Communication of this imperative topic in end-of-life care is important for better care and should be research-based.

INTRODUCTION

Most terminally ill cancer patients have a reduced oral intake in the last phase of life. This can be due to different causes, such as dysphagia [1], anorexia, nausea or vomiting [2-6] or mechanical problems [7,8]. Reduced oral intake may be seen as part of the natural dying process, or it may result in clinically relevant dehydration or malnutrition. Currently no consensus exists about what is the most appropriate management for terminally ill patients with limited oral intake [9,10], although artificial hydration seems a frequent practice [10].

Due to this lack of consensus, it is likely that not only the physical needs of the patient, but also social, cultural and religious factors influence physicians', patients' and relatives' views upon artificial hydration at the end of life. These factors have been discussed previously [11] highlighting the symbolic nature of fluids in the Jewish Culture, and discussing the social and cultural aspects of fluids [12]. There may also be variation in views among healthcare professionals (HCPs) depending on their speciality and clinical experience.

Understanding more about current opinions on artificial hydration at the end of life could help to highlight misconceptions surrounding the practice, to illuminate differences of opinions between different groups, and to inform clinical practice. The aim of this review was to give an overview of currently available evidence around opinions on the use of artificial hydration at the end of life. The following research questions were addressed: What are the opinions towards providing and not providing artificial hydration at the end of life? What are the expected effects of artificial hydration at the end of life on its quality? What are the expected effects of artificial hydration at the end of life on survival?

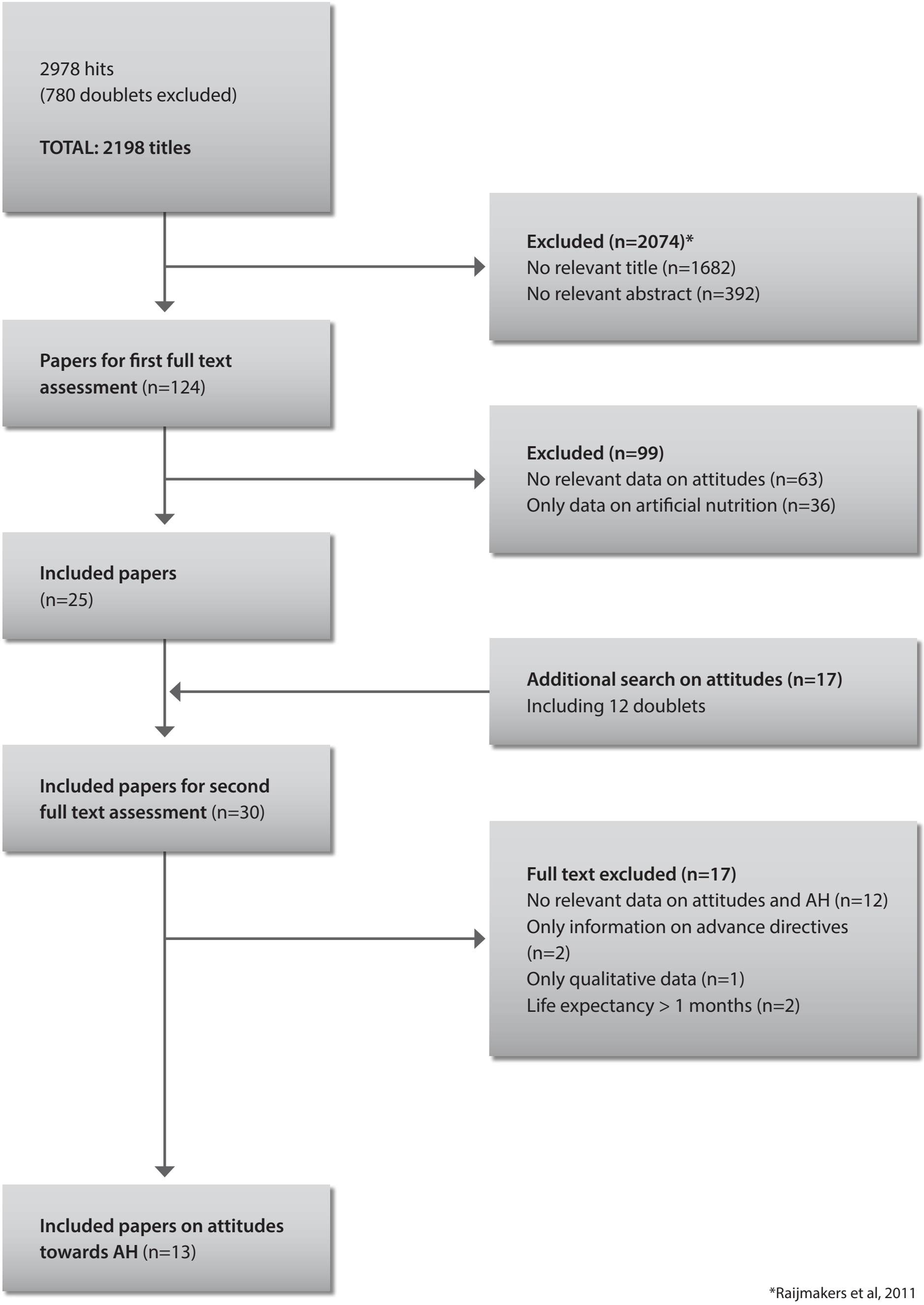
METHODS

We performed two extensive searches for studies that were published in English between January 1998 and December 2010 in different electronic databases. Search 1 was aimed at studies on artificial nutrition and hydration (ANH) at the end of life, using Medical Subject Headings (Mesh) and a broad range of keywords. In a stepwise procedure two reviewers (NR and AvdH) selected 124 studies for full text assessment [10]. For the current review, only those studies reporting on attitudes towards artificial hydration were included (n=25). An additional search (search 2) was performed focusing primarily on attitudes towards artificial hydration, which resulted in 17 studies. Both searches were merged and doublets (n=12) were excluded. This total resulted in 30 studies which were assessed full text by two reviewers (NR and SF). The selected studies had to include quantitative data about opinions regarding usage of artificial hydration or opinions about the effects of artificial hydration in the last month of life. These criteria resulted in the inclusion of 13 studies (Figure 1).

Data extraction

We collected information on general aspects of the studies and results related to our research questions. Extracted data included number of respondents, study setting, study design, response rate, selection bias and validation of the questionnaire used. Data were extracted using a standardized data extraction form.

Figure 1. Flowchart showing results search strategies and selection process



*Raijmakers et al, 2011

RESULTS

Providing or not providing AH at the end of life

Twelve studies reported on opinions of different populations towards artificial hydration at the end of life (Table 7.1).

General public

Two studies, both from Japan, reported on the opinions of the general public towards providing or not providing artificial hydration at the end of life. The first study used a random sample of the general public in four different areas in Japan (n=2548). Additionally they included a purposive sample of bereaved families from patients who had passed away in palliative care units (PCUs) in these areas (n=513). Thirty-eight percent of the general public without bereavement experience believed 'artificial nutrition and hydration should be continued as the minimum standard until death' compared with 43% of those who had experienced a recent bereavement [13]. The second study reported on a voluntary 1 h educational lecture on end-of-life care for cancer patients, open for the community. In total 595 respondents were included and 52–62% of the participants wanted to receive 'artificial hydration as life-prolonging treatment'[14].

Patients and relatives

Two studies have looked at the opinions of patients and their relatives regarding receiving artificial hydration at the end of life. The percentage that preferred receiving artificial hydration varied from 48 to 86% and 14 to 29% preferred not to receive artificial hydration. An Italian study included admitted patients to a PCU with an expected survival of more than 2 weeks. These patients required hydration, indicated by signs of dehydration, nausea/vomiting, opioid toxicity and diarrhoea. Seventy-one percent of these patients and 86% of their relatives stated they would want to continue hydration for a prolonged period of time [15]. In a Taiwanese study of 197 admitted patients with terminal cancer 48% of patients wished to use artificial hydration at the end of life and 24% did not wish to do so [16].

Healthcare professionals

Seven studies reported on the opinions of HCPs. Almost all HCPs were recruited via institutional care facilities, mostly hospitals; one study included nurses attending a nurse leaders' seminar. Overall, 22–100% of HCPs preferred providing artificial hydration at the end of life, whereas 1–75% preferred not providing artificial hydration.

In a nationwide Japanese survey among physicians (n=584) working in hospitals or PCUs, 74% recommended artificial hydration (1–2L/d) in a vignette of a gastric cancer patient, who was terminally ill and almost incapable of oral intake. Sixty-six percent recommended artificial hydration in a similar patient with terminal lung cancer; 15% and 26% recommended no artificial hydration, respectively, and the rest were undecided. Those specialized in palliative medicine had a less positive attitude towards providing artificial hydration [17]. This previous nationwide study was expanded with nurses (n=3328) also working in hospitals or PCUs. Forty percent of the physicians and 22% of the nurses believed artificial hydration to be a component of 'minimum standard of care' for terminally ill cancer patients [18]. Another study including 160 Japanese nurses attending a nurse leaders' conference showed that 75% of nurses thought it was ethical to withdraw ANH from a dying patient, if requested by the patient. Nurses thought withdrawing ANH was also ethical when it is causing pain (70%), when the patient is very near death (42%), when it would shorten the patient's life (41%), when the patient is unconscious (40%), when the patient is very old (39%), when ordered by the physician (28%) and when requested by the family (25%) [19]. A Taiwanese study [20] showed that 98% of 197 nurses, working in a Taiwanese hospital, were likely to provide artificial hydration in a terminal stomach cancer patient who cannot be fed orally because of intestinal obstruction. Thirty percent of these nurses agreed that it is ethically acceptable to withhold ANH in terminal cancer patients with multiple-organ failure and an expected survival of less than one month, 23% disagreed and 47% were undecided on this dilemma. A second Taiwanese study [21] included nurses as part of an educational intervention. It showed that 98–100% of 88 nurses were likely (59%) or very likely (41%) to give artificial hydration to terminal cancer patients. Another hospital-based survey among 36 nurse key workers and 77 clinicians (consultants and specialist registrars), both with a special interest in palliative care, was conducted in the UK. It showed that 61% of consultants agreed with the statement 'hydration by the parenteral route should be continued' applying to the clinical scenario of a patient in the last days of life; 21% disagreed and 18% was undecided. The nurses' responses were reversed: 25% agreed with the statement, 42% disagreed and 33% was undecided [22]. In a prospective study of 145 admitted inpatients of a Taiwanese hospice and PCU using ANH, 85% of the medical staff thought it was appropriate to use ANH 2 days before death in these patients, compared with 1% who thought it was inappropriate [23].

Effect of artificial hydration on quality of life at the end of life

Nine studies reported on attitudes or opinions regarding the effect on quality of life of artificial hydration at the end of life (Table 7.2).

General public

Two Japanese studies have looked at the general publics' opinions. In a population-based survey [13], 29% of the general public without bereavement experience and 15–31% of those with bereavement experience felt ANH relieves patients' symptoms. In a study [14] looking at knowledge on end-of-life care of people attending a voluntary 1 h educational lecture on end-of-life care for cancer patients, 24–35% of the respondents believed ANH relieves symptoms (n=595).

Patients and relatives

Three studies reported on patients' and relatives' opinions. These opinions were collected via a questionnaire in all studies [15,16,23]. In one study from Taiwan [23] on 145 admitted inpatients with terminal cancer using ANH, 19% perceived more comfort and 6% perceived discomfort. In 197 admitted inpatients with terminal cancer, 70% felt ANH increased physical strength and 61% felt it symbolised care of families [16]. An Italian study [15] asked 54 admitted inpatients and relatives about their knowledge and views

Table 7.1 Studies on opinions supporting providing or not providing artificial hydration at the end of life

Author, country	Setting	Population	Sample size	Date collection methods	Life expectancy	Artificial hydration	
						Providing	Not providing
Morita et al. [13], Japan	Nationwide	General public	2548	Questionnaire	Until death	38%	-
	Hospital, PCU	Bereaved relatives	513			43%	-
Miyashiata et al. [14], Japan	Community	General public	595	Questionnaire	End of life	52-62%	-
Mercadante et al. [15], Italy	Hospital and PCU	Patients Relatives	54 -	Questionnaire	>2 weeks	71% 86%	29% 14%
Chiu et al. [16], Taiwan	Hospital and PCU	Patients	197	Interview	Terminal	48%	24%
Morita et al. [17], Japan	Nationwide hospitals	Physicians	584	Questionnaire	1 month	66-74%	15-26%
Miyashiata et al. [18], Japan	Nationwide hospitals, PCU and oncology	Physicians Nurses	584 3328	Questionnaire	Terminal	40% 22%	- -
Ke et al. [21], Taiwan	Hospital; general wards	Nurses	88	Questionnaire	Terminal	100%	0%
Ke et al. [21], Taiwan	Hospital; general wards	Nurses	197	Questionnaire	1 month	98%	2%
Konishi et al. [19], Japan	Nationwide	Nurses	160	Questionnaire	Dying	-	20-75%
Chiu et al. [23], Taiwan	Hospital, PCU and hospice	Medical staff	344 (145 using ANH)	Assessment during team meeting	48 h	85%	1%
Pugh et al. [22], UK	Hospital, acute and adult care	Palliative consultants Nurses	77 36	Questionnaire	Dying	61% 25%	21% 42%

ANH, artificial nutrition and hydration; PCU, palliative care unit.

Table 7.2 Studies on attitudes towards effects of artificial hydration on quality of life at the end of life

Author, country	Setting	Population	Sample size	Data collection methods	Life expectancy	Attitudes towards effect of artificial hydration on quality of life	
						Positive	Negative
Morita et al. [13], Japan	Nationwide	General public	949	Questionnaire	Until death	29% believed ANH relieves patient's symptoms	-
		Bereaved relatives	2096			15-31% believed ANH relieves patient's symptoms	-
Miyashita et al. [14], Tokyo	Community	General public	595	Questionnaire	End of life	24-35% believed ANH relieves symptoms	-
Chiu et al. [23], Taiwan	PCU	Admitted patients	344 (145 using ANH)	Data collection tool	48 h	19% perceived more comfort	75% perceived no change in comfort 6% perceived discomfort
Chiu et al. [16], Taiwan	PCU	Patients	197	Questionnaire	Terminal	60% thought ANH is helpful to all patients 70% thought ANH increases physical strength 61% felt ANH symbolised care of families	-
Mercadante et al. [15], Italy	Acute pain relief and PCU	Inpatients	54	Questionnaire and interview	> 2 weeks	90% considered AH useful 93% thought AH would improve their clinical condition 93% felt AH is useful psychologically 92% felt it was an acceptable burden for their activity	-
		Relatives				96% considered AH useful 94% thought AH would improve the clinical condition 91% felt AH is useful psychologically 91% felt it was an acceptable burden for their activity	

Continued

Table 7.2 Studies on attitudes towards effects of artificial hydration on quality of life at the end of life

Author, country	Setting	Population	Sample size	Data collection methods	Life expectancy	Attitudes towards effect of artificial hydration on quality of life: Positive	Attitudes towards effect of artificial hydration on quality of life: Negative
Miyashita et al.[18], Tokyo	Nationwide hospitals, hospice and PCU	Physicians	584	Questionnaire	Terminal	43% felt AH alleviates thirst 34% felt AH alleviates fatigue 20% felt AH alleviates delirium	65% felt maintaining a venous route was a burden
		Nurses	3328			20% felt AH alleviates thirst 19% felt AH alleviates fatigue 11% felt AH alleviates delirium	71% felt maintaining a venous route was a burden
Morita T et al.[17], Japan	Nationwide	Physicians	584	Questionnaire	1 month	77% believed symptom alleviation was an important factor in indicating IV hydration	65% agreed that maintaining a venous route is a burden on the patient
Morita T et al.[24], Japan	Nationwide: hospitals, hospice and PCU	Physicians	3829	Questionnaire	Terminal	16-24% felt AH can improve thirst sensation 4-9% felt AH can improve consciousness 13-19% felt AH could improve malaise	9-65% felt AH could worsen pleural effusions 13-82% reported AH could worsen oedema 8-68% felt AH could worsen ascites
		Nurses				3-4% felt AH can improve thirst sensation 2-4% felt AH can improve consciousness 1-6% felt AH could improve malaise	27-65% felt AH could worsen pleural effusions 37-71% reported AH could worsen oedema 20-50% felt AH could worsen ascites
Yamagishi et al.[25], Japan	Nationwide	Nurses	76	Questionnaire	Several days	5-45% believed AH palliates the sensation of thirst	71-86% agreed that AH may worsen ascites 64-88% agreed AH would not improve general wellbeing

ANH, artificial nutrition and hydration; IV, intravenous; PCU, palliative care unit regarding intravenous and subcutaneous hydration. Ninety percent of patients and 96% of relatives considered artificial hydration useful while 93% of patients and 94% of relatives felt it would improve the patient's clinical condition. Ninety-three percent of patients and 91% of relatives also felt it was useful psychologically.

Healthcare professionals

Four Japanese studies [17,18,24,25] have looked at HCPs opinions. In a nationwide survey among physicians performed in 2007 [18], 43, 34 and 20% of physicians felt artificial hydration alleviates thirst, fatigue or delirium, respectively, compared with 20, 19 and 11% of nurses. Sixty-five percent of the physicians and 71% of the nurses agreed that maintaining a venous route is a burden for the patient, which is similar to findings in another survey of physicians [17] where 65% agreed that maintaining a venous route was a burden. However, 77% of physicians in this survey believed symptom alleviation is an important factor in indicating intravenous hydration.

In another nationwide survey of physicians and nurses [24] from different settings (palliative care, oncology, general hospital), less than 25% of all respondents felt artificial hydration could improve thirst, consciousness or malaise. Less than 7% of the palliative care nurses felt artificial hydration improves any of the above symptoms. Up to 82% of respondents felt artificial hydration could worsen fluid retention symptoms such as oedema (82%), ascites (68%) and pleural effusions (65%) with palliative care physicians and nurses reporting harmful effects more often than oncologists. This result is in agreement with findings of another study [25] conducted among nurses attending a voluntary workshop on the Japanese clinical guideline for artificial hydration for terminally ill cancer patients. Seventy-one to eighty-six percent of the nurses agreed that artificial hydration may worsen ascites or pleural effusion; 64–88% of participants agreed that artificial hydration does not improve general wellbeing.

Effect of artificial hydration on survival

Four studies, all from Asia, reported on attitudes or opinions regarding the effect of artificial hydration on survival (Table 7.3).

Patients and relatives

A Taiwanese study of 197 admitted patients with terminal cancer showed that 66% of the patients thought ANH would prolong life and 89% thought it could prevent starving to death [16].

Healthcare professionals

HCPs' opinions were assessed in a study among Japanese nurses attending a voluntary workshop on palliative care. The majority agreed that no improvement of survival can be obtained by fluid infusion in patients expected to die within several days (64–88%) [25]. Another Japanese study included both physicians and nurses working at cancer centres, general hospitals and PCUs. This study showed that 29% of the physicians and 23% of the nurses thought withholding artificial hydration would shorten

Table 7.3 Studies on attitudes towards effects on survival of providing or withdrawing artificial hydration at the end of life

Author, country	Setting	Population	Sample size	Data collection methods	Life expectancy	Effects of artificial hydration on survival	
						Providing artificial hydration	Withdrawing artificial hydration
Chiu et al. [16], Taiwan	Hospital, PCU	Patients	197	Interview	Terminal	66% thinks ANH prolongs life 89% thinks ANH can prevent starving to death	-
Yamagishi et al. [25], Japan	Hospital, acute care and PCU	Nurses	119	Questionnaire	Several days	64-88% thinks no improvement can be obtained	-
Miyashiata et al. [18], Japan	Nationwide hospitals, PCU and oncology	Physicians	584	Questionnaire	Terminal	-	29% thinks it will shorten life
		Nurses	3328			-	23% thinks it will shorten life
Morita et al. [17], Japan	Nationwide	Physicians	584	Questionnaire	1 month	-	15% thinks it is indistinguishable of death 29% thinks it shortens patient's survival

ANH, artificial nutrition and hydration; PCU, palliative care unit.

the patient's survival [17,18]. Fifteen percent of the physicians thought withdrawing artificial hydration is indistinguishable from an act of intentional acceleration of death [17].

Quality assessment of studies

All studies used self-developed questionnaires, which were not shown in the published studies. One study on the attitudes of non-HCPs reported the response rate of the study (range 54–75%) and four of the studies including HCPs did (range 53–83%). Four studies including HCPs and one study with non-HCPs reported on the validation of the questionnaires used.

DISCUSSION

Opinions on providing and not providing artificial hydration at the end of life vary: 38–62% of the general public have been found to be in favour of providing artificial hydration, compared with 48–86% of patients and relatives, and 22–100% of HCPs. Attitudes towards the effects of artificial hydration on quality of life and survival also differ. Overall the majority of professionals feel that artificial hydration at the end of life can have significant negative effects mainly related to fluid retention. The majority of patients and relatives and one third of the general public believe artificial hydration to have a positive effect on quality of life, including improvement in symptoms and overall clinical condition. Professionals appear to vary in their opinions regarding positive effects of artificial hydration: those with specialisation in palliative medicine seem less optimistic regarding positive effects of artificial hydration on quality of life and more wary of the burdens. Regarding the effect of artificial hydration on survival patients and their relatives often believe artificial hydration to prolong life, while only the minority of professionals believe so. Differences between professionals may be due to different levels of experience in caring for people with reduced oral intake at the end of life. Palliative medicine professionals are likely to have more experience than general physicians and oncologists. The amount of education and training received by HCPs regarding end-of-life care may also impact on attitudes that have been highlighted in the intervention study in this review [25]. A previous study has suggested that palliative medicine specialists are more reluctant to start artificial hydration in patients at the end of life and highlighted the possible implications of this for the relatives and also ethically and legally [26]. The over-representation of Asian studies in our review was notable: 80% of studies on attitudes were Asian studies. Cultural differences in end-of-life decision making [27-31] and legal issues may have influenced both the number of studies on this topic and the attitude towards artificial hydration. For example, Taiwan was the first Asian country to pass the Natural Death Act in 2002. This act gives dying patients and relatives the right to refuse unnecessary medical management that only prolongs a state of agony [32]. Such legal developments and public debate may have given rise to an interest in medical treatments at the end of life. Subsequently, the quality of the studies available for review was difficult to assess, due to limited information. All authors used self-developed questionnaires which were not shown in the studies. Hence, the results were difficult to compare. Additionally, the definition of artificial hydration was unclear in many studies and may therefore be interpreted differently, regarding administration route or dose. It is known that the practice of artificial hydration at the end of life varies and currently no clear consensus is present about the most appropriate management for terminally ill patients with limited oral intake [9,10]. This lack of consensus means that end-of-life decision making on this topic is influenced by personal opinions rather than objective and rational considerations. Obviously, cultural and social values should be taken into account in each individual case. However, there is a definite need for more validated research into the effects of artificial hydration on patients at the end of life, including effects on symptoms, quality-of-life, psychological aspects and survival.

CONCLUSION

Opinions on providing and not providing artificial hydration at the end of life vary, as well as attitudes towards its effects on quality of life and survival. The discrepancy in attitudes of physicians and patients underlines the importance of adequate communication on artificial hydration at the end of life. The more reluctant attitude of specialists in palliative medicine suggests that education for HCPs on this important topic in end-of-life care could be useful. For effective communication and education on artificial hydration at the end of life, more evidence of its effects is needed.

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CHAPTER 8

Bereaved relatives' perspectives of the patient's oral intake towards the end of life: a qualitative study

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ABSTRACT

Background

Patients approaching death often have a decreasing oral intake, which can be distressing for relatives. Little is known about the relatives' experiences with and perceptions of oral intake at the end of life.

Aim

This study aims to contribute to a more thorough understanding of relatives' concerns regarding decreased oral intake of the patient at the end of life.

Design

Qualitative interview study: semi-structured interviews were transcribed verbatim and analysed using qualitative content analysis.

Setting/participants

Twenty-three bereaved relatives of patients who had been referred to a New Zealand palliative care service were interviewed.

Results

All relatives experienced significant changes in patients' oral intake at the end of life. Oral intake towards the end of life was considered important and is perceived as meaningful by relatives in different ways, such as nutritional value, enjoyment, social time, daily routine and a way of caring. Relatives responded differently to decreasing oral intake; some accepted it as inherent to the dying process, others continued efforts to support the patient's oral intake. Some relatives perceived decreasing oral intake as the patient's choice, and some viewed maintaining oral intake as part of the battle against the disease. Relatives recalled limited communication with health-care professionals concerning oral intake at the end of life.

Conclusions

This study revealed the complexity of meaning relatives' experiences with dying patients' decreasing oral intake. Their perceptions and concerns were related to their awareness of the imminent death. These findings can guide staff involved in care delivery to better support relatives.

INTRODUCTION

Patients receiving palliative care often have a decreased oral intake of food and fluids and anorexia is a frequent problem at the end of life, occurring in 39-82% of patients receiving palliative care [1-3]. Furthermore, loss of appetite is one of the most common symptoms in patients when referred to palliative care [2]. It is known that decreased oral intake of the patient at the end of life causes considerable emotional distress for relatives [3-4]. Most scientific literature on oral intake at the end of life has focused on artificial (medically assisted) nutrition and hydration (ANH), including descriptions of practices [5-6], clinical effects [5, 7-8], ethical aspects [9], and attitudes of patients, relatives, or healthcare professionals [10-12]. The impact of decreasing oral intake at the end of life on patients and relatives has been scarcely researched, and there is little insight into underlying mechanisms of related distress. One study on the impact of decreasing oral intake among bereaved relatives has recommended that care aimed at reducing relatives' emotional distress related to a patient's inability to take nourishment orally, should include "relieving the relatives' sense of helplessness and guilt", "providing up-to-date information about hydration and nutrition at the end of life" and "understanding relatives' concerns and providing emotional support" [3]. Additionally, a qualitative study among relatives has demonstrated that 'doing what's best' is an overarching theme in beliefs and behaviour related to nutritional care for terminally ill patients [13].

Due to limited in-depth knowledge of the underlying mechanisms of relatives' distress related to the patient's decreased oral intake, there are few clues for health care providers to support relatives when caring for a terminally ill patient. The main purpose of this study is to contribute to a more thorough understanding of relatives' concerns regarding decreased oral intake of the patient at the end of life.

METHODS

Study design and setting

This qualitative study was conducted in a specialist palliative care service in New Zealand. The service included an in-patient unit, with a 10-bed capacity, a 24/7 community service and a consultation team in the allied hospital. We performed semi-structured interviews with bereaved relatives of patients who died under the care of this specialist palliative care service. Semi structured interviews as a method of data collection was appropriate to meet the study objectives.

Recruitment of respondents

Forty-five bereaved relatives of patients who died in November-December 2011 under the service received an information letter about the study. The bereaved relatives, as registered in the patient files as first contact person, were approached after consultation with the social worker from the service regarding the appropriateness to contact this relative. All bereaved relatives living within a circle of 100 kilometres of the hospice received the information letter about the study. After a week they were contacted by phone by a researcher (NR) to further inform them and enquire about their willingness to participate. In total, 23 bereaved relatives participated in an interview. Ten relatives refused to participate, due to emotional concerns (n=6), lack of time (n=3), unknown reasons (n=1), and eleven relatives were not reached. The interviews took place in February and March 2012.

Questionnaire

A semi-structured questionnaire, developed in collaboration with health care professionals (oncologists, palliative care physicians and nurses) was used for the interviews, to ensure consistency of topics addressed in all interviews. The questionnaire started with an open question 'Can you tell me about the last month of life of your loved one?', to encourage respondents to tell their story and experiences. Subsequently, different topics were addressed to investigate their experiences and perceptions of these topics (Box 1).

Box 1. Topics of questionnaire
Experiences in the last month of life
Awareness of dying (patient and relative)
Satisfaction with care
Experiences with food and fluids intake
Perception of food and fluid intake
Communication at the end of life
QODD (Quality of Death and Dying Questionnaire) [14]

Process

All interviews were conducted at the location of the participants' choice, i.e. respondents' homes (n=20) or the hospice (n=3). All respondents gave written consent prior to the interview, and in the introduction it was made clear to all respondents that they could stop the interview at any time. During the interview, only the respondent and the researcher were present for all but four interviews where the respondent had invited a support person. All respondents consented to the interview being audio-taped. The interviews were transcribed verbatim by a confidential transcribing service, and all transcripts were checked by the interviewer (NR).

Ethical approval

The Central Regional Ethics Committee, Ministry of Health, Wellington, New Zealand approved the study protocol (CEN/11/EXP/076).

Analysis

Data analysis was informed by qualitative methodology [15]. The focus of analyses was the words, meanings and phrases used by interviewees [16]. Each interview was considered in relation to its predecessors. During data collection general themes arising from the interviews were discussed (NR, JC). After completing all interviews, all transcripts were re-read and annotated for initial coding, using the general themes of the questionnaire (NR). A set of transcripts was independently read and analysed to identify specific categories within the general themes (NR, JC). The themes and categories were discussed until consensus was reached. Subsequently, the remaining interviews were coded (NR). The findings were later discussed with other members of the project group (AvdH, LZ), to support consistency and rigor in the data analysis [15]. Data were coded using ATLAS.ti (version 6.1.1, ATLAS.ti GmbH, Berlin). Verbatim data is included in the research findings to ensure transparency, to make the data explicitly available and understandable to the reader [15].

RESULTS

Characteristics of respondents

The characteristics of bereaved relatives and deceased patients are presented in Table 8.1 and 8.2.

Table 8.1 Characteristics of deceased patients

	Deceased patients n=23 **% (n)**
Age	
Mean ± SD	76±12
Gender	
Male	57 (13)
Female	43 (10)
Ethnicity	
NZ European/Pakeha	96 (22)
Maori	4 (1)
Primary diagnosis	
Cancer	74 (17)
End Stage Heart Failure	13 (3)
End Stage Renal Failure	9 (2)
End Stage Respiratory Disease	4 (1)
Place of death	
Home	13 (3)
Hospital	9 (2)
Hospice	44 (10)
Residential care facility	34 (8)
Months in specialist palliative care	
Mean ± SD	2 ± 2

SD: standard deviation

Table 8.2 Characteristics of bereaved relatives

	Relatives n=23 **% (n)**
Age	
Mean ± SD	65 ± 13
Gender	
Male	22 (5)
Female	78 (18)
Education*	
Low	78 (18)
High	22 (5)
Ethnicity	
European/Pakeha	91 (21)
Maori	9 (2)
Relationship to deceased patient	
Partner	65 (15)
Son/daughter	35 (8)

* Low = level 1-4 according to ISCED guidance (primary school, lower secondary general education, lower vocational education, intermediate vocational or higher secondary general education), high= level 5-7 according to ISCED guidance (higher vocational education or university)
SD: standard deviation; ISCED: International Classification of Education

Meaning of oral intake at the end of life for relatives

Almost all bereaved relatives recognized decreased oral intake at the end of life as an important issue. When a patient was still able to eat and drink at the end of life, this was perceived as meaningful by relatives in different ways. One important aspect was the nutritional value of food and fluids. Relatives perceived oral intake at the end of life as being beneficial for the body, e.g. as giving physical strength, energy, and as contributing to the preservation of life. As long as the patients could just eat something, even just a spoonful, relatives interpreted this as the body and therefore the person still going on, which appeased them.

> *I think if she didn't eat she wouldn't have been… she wouldn't have talked to us the way she did. Talking was a little bit hard but she always managed to keep herself going and I'm sure the food helped in that area.* [F, daughter, rest home]

> *While she was doing that [eating and drinking] I gathered she might keep some strength. I don't know, I mean, it's just. It was important for me.* [F, daughter, hospice]

The meaning of oral intake at the end of life appeared to hold more importance to relatives than the nutritional value of food. The patient's enjoyment of eating, drinking, or tasting meant a great deal to relatives, especially at the end of life where many enjoyments of life have disappeared. Happy memories of special occasions or when special food had been shared were recalled.

> *She seemed to enjoy the ice cream and a bit of jelly; I mean, as I say I took her whitebait fritters one night and she did have a smile on her face. She had those so it was good. So she did still appreciate food.* [F, daughter, rest home]

> *My most precious memory is probably the whitebait fritter, yeah that would have been the happiest I've ever seen him, having that whitebait fritter.* [F, daughter, rest home]

Partaking of food and drinks was often done together, creating a social activity that legitimized spending time together. Having a meal or having a cup of coffee was perceived as a social event, which facilitated conversations. Moments of eating or drinking together were often deeply appreciated by relatives. They made many efforts to create such moments, e.g. relatives had their meal on a tray, sitting next to the bed of the patient, and dressing the patient for the family Christmas dinner.

> *I spent a lot of time with her and we did a lot of talking, especially at that half past six morning cup of coffee. Normally I'd sort of get up, shower, gobble down our breakfast. I'd never have coffee; I'd go straight to work. So it made me sort of sit down and actually take time with people, actually having the coffee with her and I think probably that was probably the best you know, was just that little time and there was nobody calling in and just the two of us.* [F, daughter, hospice]

At the end of life, mealtimes also gave rhythm to the days and could serve as a reason for the patient to get dressed, which was appreciated by the family. Several rituals involving eating and drinking were described, such as having a whiskey every night together. These daily routines and habits were important for relatives, also as an attempt to hold on to normal life.

> *I spent as much time as I could with her. I'd go up and have my lunchtime with her. I'd come home, my son was at home at that point so I'd feed him, get him sorted even though he was 20 odd. And then I'd go up to the hospital or hospice for the evening.* [M, partner, hospice]

Finally, accommodating patients' wishes, regarding food, was also experienced as a way of caring and expressing love. Being able to do something, such as providing special food meant a great deal too relatives and made them feel less helpless. Relatives described many different ways they tried to accommodate patients' choices and desires, conveying the significance of oral intake at the end of life for relatives.

> *I'd always ring the night before and talk to her and ask her what she wanted brought over. The first thing was a coffee and the second thing was I think... but you know she just basically wanted to pick at things.* [M, son, rest home]

> *I'd go up at 8 o'clock in the morning, up at the hospice she like poached egg and toast, but yeah here [at the rest home] it was just cereals and I said, 'Right.'. So 8 o'clock in the morning I'd make her poached egg and take it to the rest home.* [M, partner, rest home]

> *Well I used to cook for him, and I'd go out and get whatever. You know he might say, "I'd like some mushrooms tonight." So I'd go and specially get mushrooms for him and cook them up and so forth.*
> [F, partner, home]

It was not easy to accommodate the patients' wishes. Relatives described occasions in which the patient requested something special, such as whitebait fritters or Indian curry, and the moment relatives offered this, the patient was not able to eat it. This was distressing for relatives, making them feel helpless and thwarted in caring for their loved-one. Consequentially they worked to understand what was happening and to find ways to console themselves.

> *I couldn't say to him, "Do you want to die?" […] I just said to him at that time and I could have bitten my tongue after but I said, "I don't know what you want to eat." I said, "I've tried everything, I've moulied," I said, "That was a roast meal and I've moulied the meat and the vegetables altogether for you." I said, "A little baby can eat that." "I don't want it." I said, "Well, I don't know what the hell you're going to live on." That was about the only time I sort of said anything to him about things then.*
> [F, partner, hospice]

> *I had all these things lined up, and my husband went out one night and mum said she wanted a curry and my darling husband went out and brought her curry from one of these places in town, it was really cold, wintery, yuk night and he went out and brought her a curry, and she said, "Oh you have it boy, I'm not hungry. […] But that's what she did, all the time. Just really finicky about stuff and you just couldn't do anything.* [F, daughter, rest home]

Responding to decreasing oral intake

It was difficult for relatives to witness the decrease in oral intake. In addition to their efforts to accommodate the patient's wishes, they also worked to understand what was happening and to find ways to console themselves.

Part of the process

Some relatives interpreted decreasing oral intake as being part of the normal (dying) process and saw it as a sign of approaching death. They phrased it as "beyond coping with oral intake". For them, this was directly linked to the stage of illness and to changing bodily needs, and they were aware that the end of life was near.

> *By that stage she didn't really want it anyway and I think people were throwing food at her and she really didn't want it anyway. By that stage I thought we were just forcing her to do something that… I guess in the last week for me, it was just let's just let this be, let it be.* [F, daughter, rest home]

> *Yeah, because even though I don't have a lot to do with dying people, I actually notice when they start to want to go because their eating gets less and less and less […] Yeah, so I sort of knew the telltale signs.* [F, partner, hospital]

Relatives may also realize that eating and drinking became a struggle for the patient, instead of something beneficial and enjoyable. Physical problems, such as lack of appetite, having no energy to eat, having no or an unpleasant taste, having trouble swallowing, or nausea and vomiting impaired their oral intake at the end of life.

> *He had no... well he didn't have an appetite because he couldn't... he said he couldn't taste food, the food was horrible and he refused to eat it, and he is a person who loved his food, I mean he loved food. And he just had no appetite, no taste in his mouth, no nothing and he had thrush.* [F, daughter, rest home]

> *He was eating less and less, but he did always try and eat a little bit each time. But you can imagine when you eat and then bring it back you get to the stage you don't want to eat because you don't want to be sick.* [F, partner, hospice]

Changes in oral intake were often referenced against the person's earlier preferences and appetite, when he or she was still healthy. What patients used to eat or drink or enjoyed were described as an intrinsic part of the patient's identity. Decreasing oral intake therefore also symbolized losing the patient.

> *I bought little ice blocks, so that she could suck on, just on that. But she didn't even want to do that, so, which was really quite unusual. For somebody who always loved her food. Such a difference, it was a big difference, yeah, getting used to it, the fact that she didn't have an appetite at all.* [F, daughter, hospice]

> *It was really difficult for her, so she… anyway I digress. But I'd go into the home and stuff and she just wasn't wanting to go out; she didn't feel like coffee, and her taste buds changed. She couldn't drink her coffee; her coffee was her thing you know… I used to buy a coffee for her on the way into the home and yeah, she just didn't want it, it tasted awful to her.* [F, daughter, rest home]

Patient's choice

Some relatives thought that a decreased oral intake was the patient's choice. They perceived it as giving up by the patient. The patient had decided that it was enough and therefore deliberately stopped eating and drinking. This could be upsetting for relatives who may feel helpless, because they couldn't do anything anymore for their loved one.

> *I had the feeling that he's starved himself in the end because he didn't like illness; he couldn't cope with illness and yeah [crying] […] Nothing we could do to make him eat because, as I said, I kept saying to him, "I'll go and get you something nice or some fish and chips or Chinese takeaway." "No, no, don't bother." He'd given up.* [F, daughter, rest home]

Perceiving decreased oral intake as the person's own choice, could allow some relatives to stop trying to persuade the patient to eat something. Efforts by relatives to make the patient eat could upset the patient, who knew best what was happening, what he or she needed, and what he or she wanted or not wanted. Perceiving eating and drinking as the patient's own responsibility relieved relatives' distress.

> *I came to the conclusion that it didn't matter how I fretted, all I was doing was making him upset and me getting more stressed. I was as stressed as I could be. So I just decided, I'll give him an offer of such and such, and let him choose and then I'll make it for him and see what happens. […] and then I almost sort of gave up and thought well, he knows whether he's hungry or not. He knows the repercussions; he knows what's happening in the end; this is his choice of how he wants it; at this stage in his life, let it be.* [F, partner, rest home]

However, other relatives perceived maintaining oral intake as part of the battle against the disease and therefore against dying. Central to this perception were efforts to tempt the person with special foods and supplements. Giving up eating was not an option for these relatives.

> *I spent a fortune on special little things […] One day he said, "Does [the Oncologist] know you're doing this?" I said, "I don't give a bugger what he thinks," I said, "I'm trying to get you some good blimmin` bacteria inside you again." I said, "We've gotta fight this damn thing," you know, so he'd do anything to please me.* [F, partner, hospice]

The vicious circle

Some relatives realized, in hindsight, that the patient was trying really hard to eat something because of them. They were caught in a vicious circle, in which the patient and the family didn't want each other to worry and both tried hard to maintain the oral intake and avoid talking about its decrease.

> *I think she thought it [eating and drinking] was important for me. I think she wanted me to have this false hope that she would get better just to help me cope I think, at the time. And it went pretty well cause she was you know; I tried to be strong for her and she tried to be strong for me [crying].*
> [F, daughter, hospice]

> *It [trying to make him eat and drink] upset me, but I was only trying to do it for his good. And then he would feel bad, because he didn't want to upset me. It was a vicious circle. He never complained, he was amazing, he just accepted that it was his lot, and took it all in his stride.* [F, partner, hospice]

Communication and information: talking about it

Relatives recalled few in depth discussions about decreased oral intake with both health professionals and patients. Conversations with the patient predominantly concerned if and what the patient preferred to eat or drink. Some relatives avoided talking about the decreasing oral intake, because they didn't want to upset the patient or considered talking about eating and drinking as futile. Furthermore, some relatives recalled having arguments with the patient when trying to persuade him or her to eat something. These arguments were perceived as upsetting and a struggle by the relatives, and remained vividly in their memory.

> *Not into any depth because he just… like he was a very placid man and you could never argue with him. […] Over this and the food, he did actually get a bit stroppy and he'd just say, "Oh leave me alone for goodness sake I can't eat, I can't eat." And then that would upset me because he'd been cross with me and he was never cross with me, so I thought, no, this is a fruitless exercise too, so I'm not even going to talk to you about it, if that's the way you're going to talk back to me. No, we didn't do it in depth because he got too… I think he knew that he should have been; or couldn't be bothered; or didn't have the heart to; or didn't want to; or whatever.* [F, partner, rest home]

> *I was always pumping drinks into him. I used to sit on the bed with a straw in his mouth and say "Suck!" He would say I was a bossy woman. It was a struggle.* [F, partner, hospice]

Conversations with healthcare professionals predominantly concerned information for the relatives about oral intake at the end of life and what to expect.

> *"Just let him eat whatever he wants", and they [nurses] weren't too worried about it. They said "Just get whatever you can and when you can into him."* [F, partner, home]

Relatives were sometimes given a written pamphlet on food and fluids at the end of life. This information was often perceived as reassuring by the relatives, because it lifted some of the weight of responsibility off their shoulders.

DISCUSSION

Decreasing oral intake in patients at the end of life is a meaningful change for relatives. When oral intake was still present at the end of life, relatives attributed multiple positive meanings to it, including nutritional, psychological and social meaning. Furthermore, it gave routine and structure to their daily life in a time of disorder. Relatives responded differently to a decreasing oral intake and also perceived different reasons for this decrease. Some viewed the decrease in oral intake as part of the dying process, related to the stage of illness, lack of appetite and physical inabilities. Others perceived decreasing oral intake as the patient's choice. Some relatives were able to accept the decrease in oral intake, while others viewed maintaining oral intake as an important part of the battle against the disease and for life. Other relatives realized that the patient and they were keeping each other in the dark through their mutual efforts to maintain oral intake. Relatives recalled limited communication with health care professionals concerning oral intake at the end of life.

Several findings deserve particular attention. First, the broader meaning of eating is significant and important at the end of life. Some data on the meaning of food in other patient populations resonate with our results, although most did not address the relatives' perspective. For head and neck cancer patients, physical, social and emotional losses related to eating problems have been described [17]. Also in cachexic cardiac patients the broader meaning of food has been identified. These patients described a feeling of deprivation due to fatigue and lack of appetite, because of missing both eating and the related social environment. This could even lead to a loss of personal identity [18]. These studies illustrate the broader social and relational meaning of eating and drinking, which our study shows also to be present for relatives of patients who are at the end of life. When addressing the issue of oral intake with patients and relatives, health care professionals should not only emphasize the nutritional element, but also be aware of these other elements.

Second, awareness of dying and relatives' perceptions of decreased oral intake at the end of life seems to be related. McClement et al [13] have identified fighting back versus letting nature take its course as two opposite positions, between which relatives may also vacillate. Those fighting back believed that the decreased intake was largely responsible for the patient's declining status instead of disease progression, while those who were letting nature take its course believed that the decreased intake was an expected occurrence as death became imminent. Our results showed similar patterns, and these ways of responding by relatives were not static or exclusive.

Third, our study showed that, despite the significance of decreasing oral intake for relatives, only a few relatives recalled conversations with health care professionals about what to expect regarding oral intake at the end of life. This lack of attention regarding oral intake at the end of life has been noted before. It has been shown that family call the out-of-hours general practitioner practice often because of problems related to oral intake such as vomiting and dehydration, which resulted in potentially preventable hospital admissions at the end of life [19]. Early communication regarding these problems may contribute to more efficient healthcare usage.

Since the primary goal of palliative care is not only to improve the quality of life of patients when facing the problems associated with a life-threatening illness, but also of their relatives [20], health care professionals should adequately address issues regarding patients decreasing oral intake, with family. Overall, more attention for issues regarding oral intake and related problems at the end of life may improve the quality of life of relatives and contribute to better healthcare usage.

There is a body of literature describing ANH at the end of life, discussing whether it is appropriate or not to administer ANH during the last weeks of life. To date, this controversy remains, although the positive effects seem limited [5,7-8]. It has therefore been suggested to make decisions on ANH preference-based [21]. When doing so, healthcare professionals should keep in mind that by administering artificial hydration probably not all issues relating to eating and drinking will be addressed. Health professionals should recognize the need for multiple conversations over the illness trajectory regarding declining oral intake and the broader meaning of eating and drinking at the end of life.

Strengths and limitations

One strength of this study is that perceptions regarding oral intake at the end of life in terminal illness were derived from bereaved relatives of patients dying in different settings. Some caution must be exercised when using our findings in practice, because all patients were under the care of one single palliative care service, which might hamper the generalizability of the findings to other bereaved relatives. Furthermore, this study included relatives who had different relationships with the deceased patient, and the patients' diagnoses were not restricted to cancer. Finally, the willingness of the bereaved relatives to participate in this research was noteworthy. Limitations include the following. First, the data collected for the study were generated from families receiving specialist palliative care. This might have led to a selection bias, which restricts the generalization of the results to other care settings. Second, ethnic minorities are underrepresented in this study, relatives were mainly of European descent, while in the New Zealand Maori constitute 17% of the population. The meaning of oral intake at the end of life for Maori and other ethnic groups should be further investigated, as it is known that cultural differences exist [22].

CONCLUSION

Oral intake at the end of life has multiple meanings, going beyond the nutritional value of food and fluids. Psychological and social aspects of oral intake at the end of life also are significant for relatives and should be addressed when supporting relatives who are caring for a terminally ill patient. Views on decreasing oral intake are interconnected with awareness of dying. Communication with health care professionals concerning oral intake at the end of life seems limited.

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CHAPTER 9

General discussion

The studies described in this thesis concern public opinions regarding end-of-life care and end-of-life decision making and (artificial) nutrition and hydration at the end of life. First, this chapter will address the research questions, as presented in the introduction chapter. This is followed by methodological considerations, a general discussion focusing on two important issues in these studies, i.e. management of suffering at the end of life and communication, and recommendations for policy, practice and future research.

MAIN FINDINGS

Public opinion of end-of-life decisions

After eight years of legislation of euthanasia and physician assisted suicide in the Netherlands, it is important to know to which extent the Dutch Euthanasia Act receives societal support. We examined the opinions of the general public and healthcare professionals on the legal requirements for euthanasia and physician-assisted suicide in written surveys (chapter 2). These surveys showed that the Dutch Euthanasia Act and its legal requirements are widely supported, both by the Dutch general public and by healthcare professionals. Major arguments for this support are the possibility of relief of unbearable suffering at the end of life and respect for the patient's autonomy. Overall, both members of the general public and healthcare professionals seem to interpret the boundaries for euthanasia or physician-assisted suicide in a rather restrictive way. Both groups tend to support assistance in dying particularly in the presence of physical symptoms, such as pain, whereas they are more reticent about euthanasia or physician-assisted suicide in case of psychological or existential suffering, and in patients with early dementia. The Dutch Euthanasia Act does not state the presence of physical symptoms to be mandatory and also allows euthanasia or physician-assisted suicide in the latter cases, provided that all criteria of due care are fulfilled.

One of the current topics of sparking debate in the Netherlands is euthanasia or physician-assisted suicide in older people who have a wish to die due to being tired of living. In our study, being tired of living was defined as the wish to die of older persons who do not have a serious medical condition. In such cases, euthanasia and physician-assisted suicide are not allowed in the Netherlands, because unbearable suffering needs to have a medical ground, as stated by the Supreme Court, the Royal Dutch Medical Association and the regional review committees. Our study (chapter 3) showed that a minority of the Dutch general public supports assistance in dying for older persons who are tired of living. This level of support is significantly less compared to the support for assistance in dying for patients who are terminally ill. In our study age and health of the respondents were not associated with acceptance of assistance in dying for older people who are tired of living. Our study further showed that those who support assistance in dying for older people who are tired of living were more likely to be highly educated, to be non-religious, to value control over their health decisions, and to have little trust in physicians to comply with their care wishes. A shared principle among these supporters seems to be respect for autonomy, which is one of the pillars of the Dutch Euthanasia Act.

A way to safeguard respect for patient's autonomy is advance care planning. Advance care planning is a process of communication among patients, healthcare professionals, and relatives regarding end-of-life care. It aims to ensure that patients' values remain central in decision-making and that the care provided is consistent with patients' preferences [1]. Because of the potential benefits, it has been suggested to promote advance care planning, not only among patients but also among the general public [2]. We investigated to what extent the Dutch general public is currently involved or inclined to be involved in advance care planning (chapter 4). Overall, the majority of the Dutch general public has thought about end-of-life care and decision-making, and a substantial part of the Dutch general public has actively discussed their preferences at least once with a relative. However, discussions with the physicians and written advance directives are rare among the Dutch general public. Older people and people having a poor health are more often (inclined to be) involved in advance care planning. Involvement in advance care planning is also associated with a preference to be involved in medical decision making and having little trust that physicians will comply with one's preferences.

Role of (artificial) nutrition and hydration in end-of-life care

End-of-life care often involves decisions about withholding or withdrawing potentially life-prolonging treatment. An international survey among palliative care experts that aimed at getting insight into issues that may complicate end-of-life decision-making showed that they often encounter issues that are complex in end-of-life decision-making about (artificial) nutrition and hydration [3]. We conducted a Delphi study to explore the type of difficulties. This study (chapter 5) showed that important issues were the lack of knowledge about the effects of artificial nutrition and hydration and about how to communicate about it, both with the patient and the relatives. The palliative care professionals reported that decision-making about artificial nutrition and hydration at the end of life could substantially improve if there would be more general knowledge and evidence-based guidance about the effects of providing or withholding artificial nutrition and hydration on quality of life and on optimal strategies for communication with patient and relatives.

To assess what knowledge about the effects of artificial nutrition and hydration on quality of life is currently available, we conducted a systematic literature review (chapter 6). This systematic literature review showed that providing artificial nutrition and hydration is a substantial practice in the last week of life of cancer patients, especially in hospitals, with frequencies up to 50-88%. However, the effects on patients' comfort, symptoms and length of life seem limited. We conducted a second systematic literature review on opinions on the use of artificial hydration at the end of life. This study showed a large variation in the opinions of physicians, nurses, patients, family members and the general public (chapter 7). The majority of patients and relatives and one-third of the general public believe that artificial hydration has a positive effect on terminally ill patients' quality of life, symptoms and overall clinical condition, while many healthcare professionals feel that artificial hydration at the end of life might have significant negative effects for the patient, such as worsening fluid retention symptoms (e.g. oedema, ascites, pleural effusions) and maintaining a venous route that is burdensome for the patient. These different expectations of (the benefits and burden of) artificial hydration at the end of life potentially complicates end-of-life care, communication and decision-making.

We finally studied how bereaved relatives perceive nutrition and hydration at the end of life of the patient (chapter 8). This qualitative interview study showed that relatives assign significant meaning to oral intake, in relation to its nutritional value, its psychological and social impact, and the fact that it gives routine and structure to daily life. Therefore, decreasing oral intake of the patient at the end of life is a meaningful change for relatives, who may respond differently. Some relatives accept the decrease in oral intake, others view maintaining oral intake as an important part of the battle against the disease and for life. Relatives may realize that the patient and themselves are 'keeping each other in the dark' through their mutual efforts to maintain oral intake until the end of life.

METHODOLOGICAL CONSIDERATIONS

This thesis is based on three studies, namely the KOPPEL study, the OPCARE9 collaboration and the COMMEND study, that all used different methods; a survey among the Dutch general public, an international Delphi study among palliative care professionals, two systematic literature reviews and a qualitative interview-study of bereaved relatives in New Zealand.

Public survey

In general, the aim of public surveys is to collect timely evidence on public opinions, attitudes and values. Surveys provide descriptive information at one specific point in time, as being a snapshot. Our survey among the Dutch general public aimed to evaluate opinions of Dutch general public regarding end-of-life decision-making. To enable more in-depth understanding of the quantitative results of the survey, we also conducted 16 qualitative interviews with selected respondents, using purposive sampling. In general, there are two major criticisms about internet panels; 1) internet panels are often self-selected, and 2) internet panels exclude people who do not have access to the internet or a computer. To address these criticisms, we have used the CentERpanel of the University Tilburg. This internet panel consists of a random sample of people based on postal codes (thus, it is not self-selected) and CentERdata enables all selected members to participate in the panel by providing them additional tools, such as a NexBox, television or internet connection (thus, no restriction to internet users only).

Despite a good response rate, the respondents were not fully representative of the Dutch population: the respondents were slightly older, more often male, more often highly educated and more often sharing a household. The overrepresentation of highly educated people has possibly led to an overestimation of the support for assistance in dying for older people who are tired of living and the overrepresentation of older people has possibly led to an overestimation of the actual involvement in advance care planning of the Dutch general public. Further, migrants were underrepresented. As known, cultural factors influence healthcare use [4], health communication [5], end-of-life care and decision-making [6], and they may influence opinions on these issues.

Delphi study

The Delphi technique is in essence a series of sequential questionnaires, or rounds, interspersed by controlled feedback, that seek to gain the most reliable consensus of opinion of a group of experts [7]. Within healthcare research, the Delphi technique has been used for several goals, such as identifying key issues, emerging trends, future developments, and research priorities. Our two-round Delphi study aimed at identifying the most important issues and considerations in end-of-life decision-making as experienced by palliative care experts. Some limitations should be taken into account when interpreting the results. The quality of the results of a Delphi study depends on two major aspects, the quality of the expert panel and the quality of the questionnaires. We used a large international panel consisting of palliative care experts (physicians, nurses, and other healthcare professionals). These palliative care experts were selected by members of the OPCARE9 consortium. In this consortium, every country (n=9) had a national reference group, consisting of palliative care experts. The contact person of each country selected ten experts for the Delphi study using this reference group. It is not possible to determine to which extent the expert panel was representative of the population of palliative care experts in these nine countries. Nevertheless, the presence of different professions as planned and the average palliative care experience of twelve years suggest that the expert panel represents a broad and experienced group of palliative care experts. One limitation is that all experts worked in an institutional setting, and the results can thus not be generalized to home care settings. In addition, the experts were predominantly physicians and nurses, because they were more inclined to respond. This might have led to an emphasis on medical issues. The response among experts who were asked to participate in the Delphi study was satisfactory, namely 76% in the first round and 60% in the second.

Systematic literature reviews

The process of systematic literature reviews consists of locating, appraising and synthesizing the evidence available from previous studies relevant to the research question. We have conducted two systematic literature reviews; the first aimed to get insight into the practices and effects of artificial nutrition and hydration at the end of life and the second aimed to get insight into the opinions on artificial hydration at the end of life. One of the methodological considerations of our systematic literature reviews is that we did not conduct a Cochrane review or meta-analysis, the golden standard among systematic literature review protocols. Because we only could include one randomized controlled trial, we decided to also include papers on studies involving other levels of evidence, such as observational studies. This limits the quality of the data found in the systematic literature review. Furthermore, we were not able to assess the quality of the papers systematically, because many papers did not give detailed information about the methods used. We aimed to have an overview of the current state of knowledge and therefore limited our search to papers that were published between 1998 and 2009. A consequence might be that not all studies on the practices and effects of artificial nutrition and hydration were included.

To improve the comprehensiveness of the search strategy, a hand search of ten high-impact medical journals publishing about palliative care was conducted. Further, all references of the included papers were checked. The latter resulted in one additional study. In the second review we combined the search strategy of the first systematic literature review with a newly developed search strategy focused primarily on opinions on the provision of artificial hydration at the end of life. This additional search resulted in five additional papers.

Qualitative interviews

Qualitative interviews are most useful when aiming for an in-depth insight into a topic which is little researched. A qualitative interview seeks to cover both a factual and a meaning level, with an emphasis on the latter. Our interview study among bereaved relatives aimed at contributing to a more thorough understanding of relatives' concerns regarding a decreased oral intake of the patient at the end of life.

To ensure the rigor of this study, all interviews with the bereaved relatives were audio-taped and transcribed by a professional transcribing service. Furthermore, all transcripts of the interviews were reviewed and two researchers independently developed a code tree, which was subsequently discussed. A set of transcripts was independently read to further identify specific codes within the general themes until saturation was reached. The final code tree was discussed until consensus was reached.

One methodological limitation of this study is the fact that all patients were under the care of one single palliative care service in New Zealand, which might hamper the generalizability of the findings to other bereaved relatives. Furthermore, we have only included bereaved relatives of European and Maori descent. The meaning of oral intake is culturally sensitive, so might be different for e.g. Asian people.

We contacted the bereaved relatives at least two months post bereavement and the interviews were planned at least three months post bereavement. This relatively short period was chosen because of earlier positive experiences with similar time periods, which suggested that at this point in time there might be an acceptable balance between the burden of an (early) interview or questionnaire and recall bias [8-9]. Furthermore, all deaths were more or less expected since all patients were under the care of a specialist palliative care service and expectedness of the death is known to be associated with a less severe bereavement reaction six weeks post bereavement [10].

INTERPRETATION OF FINDINGS

Suffering at the end of life

One of the due care criteria of the Dutch Euthanasia Act is that the physician has to be convinced that the patient's suffering is unbearable without prospect of improvement. Alleviating suffering at the end of life is a widely used argument in the debate on euthanasia. This thesis shows that the Dutch general public, nurses and physicians are inclined to accept euthanasia in case of unbearable physical suffering. If a patient's suffering is exclusively rooted in psychosocial problems or spiritual issues, there is substantially less support for granting a euthanasia request [11]. Moreover, euthanasia in case of suffering due to being tired of living (non-physical suffering) is clearly less supported in Dutch society: 25% of the general public and 18-19% of the healthcare professionals would accept euthanasia in such cases. These opinions are reflected in current euthanasia practices in the Netherlands: euthanasia and physician-assisted suicide mainly concern cancer patients [12]. Previous research concerning opinions of the Dutch general public and physicians showed similar findings, namely that the Dutch general public is somewhat more permissible towards euthanasia in case of physical suffering compared to non-physical suffering and compared to physicians [13]. Moreover, physicians are more inclined to grant a euthanasia request that is based on suffering due to physical symptoms [14-15].

End-of-life care is aimed at addressing all dimensions of suffering at the end of life, because suffering obviously entails more than physical symptoms. Suffering is a complex concept and has physical, psychological, social and spiritual components. Cassel defined suffering as "the distress brought about by an actual or perceived impending threat to the integrity or continued existence of the whole person, and it requires a sense of the future and of the past" [16]. Kahn defines suffering as "an individual's experience of threat to self and a meaning given to events such as pain or loss" [17]. Dame Cicely Saunders has introduced the concept of total pain, which includes physical symptoms, mental distress, social problems and emotional problems [18], inspired by a patient who said about her pain "All of me is wrong". For many, Cicely Saunders is the founder of the international hospice movement that has spearheaded new approaches to the care of dying people and their relatives. Moreover, her concept of total pain has inspired the WHO definition of palliative care that includes suffering due to "pain and other problems, physical, psychosocial and spiritual" [19].

A study among terminally ill cancer patients showed that one in every four cancer patients suffered unbearably at the end of life, and that half of the unbearable aspects occurred in the psychological, social and spiritual domain [20]. Our New Zealand study among bereaved relatives illustrates the social component of suffering: the relatives' experiences showed that the loss of the ability to eat of the patient was experienced as a social issue that affected the quality of life of both relatives and the patient. In addition, relatives and patients may mutually reinforce their distress concerning nutrition and hydration at the end of life [21]. The burden for relatives of being involved in the dying trajectory of a loved one at the social level is substantial, and this burden increases when the patient's functional status declines [22], and affects the patients as well [23].

Despite empirical and theoretical evidence of the multidimensionality of pain and suffering, palliative care practice and research largely focus on the physical dimension of suffering and quality of life. A recent systematic literature review showed that only seven of the 29 instruments to assess quality of life of terminally ill patients have incorporated a social dimension [24]. Obviously, this focus on the physical dimension of suffering does not reflect the complex burden of patients and their relatives when death approaches. To adequately address suffering and provide optimal end-of-life care, adequate assessment of the needs of the patients and relatives in all relevant dimensions is of utmost importance. High-quality communication between patients, relatives and healthcare professionals is of essence to achieve that goal.

Communication in end-of-life care

Open discussions of end-of-life contribute to a better quality of care [25]. Communication is one of the key elements of quality of end-of-life care for seriously ill patient and their family members [26], and it has been identified as the most important factor to explain variance in relatives' satisfaction with end-of-life care [27]. However, we demonstrated that international palliative care professionals perceive communication with both the patient and the relatives about end-of-life care and decisions on interventions such as artificial nutrition and hydration as difficult [28]. Furthermore, concrete end-of-life discussions between healthcare professionals and patients or their relatives seem to be rare. Our study among bereaved relatives suggests that there are limited in depth discussions between healthcare professionals and relatives about significant issues such as nutrition at the end of life [21]. People also tend not actively engage in end-of-life discussions with their physician, despite the fact that the majority of the Dutch general public has thought about end-of-life care and decision-making. Moreover, only 24% of the people who have drafted an advance directive have discussed it with their physician [29].

Shared decision-making is often seen as the ideal. Shared decision-making is an interactive, collaborative, and on-going process in which healthcare professionals and patients mutually engage by sharing information, wishes and decisions [30-32]. In our survey, two thirds of the general public reported to support shared decision-making at the end of life [29], which is in line with the findings of a systematic literature review showing that the majority of patients receiving palliative care want to be involved in decision-making [33].

Reality does not always correspond with the ideal of shared decision-making. A recent systematic literature review showed that although the majority of patients want to participate in treatment decisions to some extent, most do not achieve their preferred level of involvement because decisions are delayed and alternative treatment options are seldom discussed [33]. Known barriers for end-of-life discussions are physicians' and patients' ambivalent attitudes towards bad prognosis [34]. The initiation of end-of-life discussions seems to be the major bottle neck [29, 34-35]. It has been suggested that physicians are reluctant to discuss end-of-life issues and tend to wait until the patient raises the topic [36]. However, there is also a general reluctance among patients to (spontaneously) talk about their problems and needs. The use of difficult medical terms might also hamper effective communication [34]. An additional barrier for end-of-life communication is the fact that active participation in end-of-life discussions might be impossible for terminally ill patients because of their impaired capacity due to either the underlying illness or drug administration such as sedatives. It is therefore important to anticipate various scenarios, to timely communicate, and to think ahead.

To support both patient and the physician in initiating end-of-life discussions and achieve the preferred level of involvement in end-of-life decision-making, advance care planning has been widely promoted [37-38]. Advance care planning includes communication to clarify a patient's understanding of their illness and treatment options; to understand their values, beliefs, and goals of care; and to identify their wishes for end-of-life care. Advance care planning not only safeguards that patients' values remain central in end-of-life decision-making; it also prepares patients and their relatives for complex end-of-life decisions.

In the nineties of the previous century, research on advance care planning predominantly was focused on the use of advance directives, rather than on advance care planning as a communication process. Important limitations of advance directives have been identified; no positive effects of advance directives on the quality of care, quality of life, and satisfaction of patients and relatives [39-41]; and limited use of advance directives [42-46], despite many efforts to promote it [45, 47-49]. This incapacity of advance directives to affect future care has been described as the false promise of advance directives [50]. But when advance care planning is approached as a continuous process of communication that aims at understanding the patient's values and at preparing the patient and their relatives for complex end-of-life decisions it does improve end-of-life care. A recent randomized controlled trial showed that advance care planning improves end-of-life care and patient and family satisfaction and that it improves the quality of life of bereaved relatives (less stress, anxiety, and depression post bereavement) [51]. To effectively promote advance care planning, a dual approach is needed: both physicians and patients need to be indicated about how to initiate end-of-life discussions [36].

Communication at the end of life not only entails process-related aspects, it needs content as well. The currently limited evidence-base for end-of-life care might hamper communication at the end of life. Nutrition and hydration at the end of life is a clear example. As indicated by palliative care experts, end-of-life decision making regarding artificial nutrition and hydration would substantially improve if there would be more knowledge on the effects [28]. This lack of evidence regarding artificial nutrition and hydration is confirmed by our systematic literature review. Providing artificial nutrition and hydration seems to have limited effects on comfort, symptoms and length of survival, but we could only include one randomized controlled trial [52]. Further research is needed, as earlier suggested by two recent Cochrane reviews that also found too few studies to draw firm conclusions on the effect of artificial nutrition and hydration at the end of life [53-54].

The lack of evidence is also illustrated by the wide variety of opinions on the use of artificial nutrition and hydration [11,55], which underlines the importance of end-of-life communication about expectations and preferences. First, an important goal of end-of-life care is to honour patients' preferences based on their concept of a good death. Continuous communication is necessary to get insight into the patients' values, beliefs, and preferences for goals of care. Secondly, variety in opinions potentially hampers end-of-life communication, because patients and professionals approach end-of-life discussions with different expectations and preferences [56].

IMPLICATIONS FOR POLICY, PRACTICE AND FUTURE RESEARCH

Policy and practice implications

This thesis shows that there is ample societal support for the Dutch Euthanasia Act, both among the general public and healthcare professionals, especially in the presence of physical symptoms. Both the general public and professionals consider euthanasia more problematic if a patient's unbearable suffering is rooted in psychosocial or spiritual issues. Moreover, most professionals and members of the general public seem to interpret the boundaries of euthanasia or physician-assisted suicide in a rather restrictive way, and either expanding or limiting the scope of the Act does not seem to be indicated based on public opinions.

Although euthanasia seems not to be considered to be an appropriate way to alleviate all types of suffering at the end of life, obviously, suffering is not restricted to physical symptoms. Suffering is a complex, holistic concept and more attention for this multidimensional approach of suffering at the end of life is needed. Moreover, the importance of social suffering should be recognized. Outcome measures to assess quality of life should also incorporate the social dimension of quality of life of the patient. Further, addressing relatives' distress not only improves the quality of life of the relatives also contributes to the well-being of the terminally ill patient. Some validated tools to assess (and address) the distress and needs of relatives, e.g. FAMCARE [57-58], are available for clinical practice.

In order to provide high-quality end-of-life care, it is important to communicate adequately. Therefore, effective strategies to support (the initiation of) end-of-life discussions by patients and healthcare professionals are needed. Important societal initiatives, such as Dying Matters (UK) [59] and STEM [60] (the Netherlands), have been launched. These initiatives aim at further increasing people's consciousness of human mortality, and at stimulating people to consider their preferences for and attitudes towards end-of-life care and to discuss these with relatives and healthcare professionals. Furthermore, the Royal Dutch Medical Association has recently published a pamphlet "Timely end-of-life discussions with your physician", both for physicians and patients, to support communication at the end of life [61]. Moreover, clear evidence about the effects of end-of-life interventions might also contribute to adequate communication and decision-making.

Recommendations for future research

The findings reported in this thesis evoke several new questions. First of all, although this thesis shows that the Euthanasia Act has ample societal support, continued monitoring of euthanasia practices and opinions on euthanasia is valuable. At this moment, little is known about the true prevalence of older people who have a wish to die because they suffer of being tired of living [62]. How practices in this area develop in our aging society has to be awaited.

Secondly, the complex nature of suffering and in particular the importance of the social dimension of suffering needs more attention. We have studied social suffering from the relatives' perspective, within a specialist palliative care setting in New Zealand, but it is also important to further investigate the impact of social suffering on patients. Further research is also needed to verify our findings in other (cultural) settings.

Thirdly, end-of-life communication and decision-making should be fostered with evidence of effective strategies. Many initiatives and interventions to promote end-of-life discussions are present, which should be underpinned with research on their effectiveness. Advance care planning is such an intervention, but the effects of advance care planning on the quality of life and quality of care are not indisputable. More research on the effect of advance care planning and how to improve it is needed.

Lastly, in general, more evidence based end-of-life care is needed. To ensure high-quality end-of-life care, more insight is needed in the effects of (withholding or withdrawing) potentially life-prolonging treatments, such as artificial nutrition and hydration. Large international comparative studies are of the essence in this field.

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SUMMARY / SAMENVATTING

SUMMARY

In the introduction **(chapter 1)**, the background and aim of this thesis are described. End-of-life care aims to improve quality of life of patients and their relatives facing problems associated with life-threatening illness in the last days of life. End-of-life decision-making is an important aspect of end-of-life care that can have a significant impact on the process of dying and dying patients' comfort in the last days of life. Moreover, end-of-life decisions are known to occur in 23-51% of all deaths in Europe.

End-of-life decisions are subject to societal debate. Better understanding of current public opinion on end-of-life decisions can strengthen the societal debate in the Netherlands. End-of-life decision-making regarding artificial nutrition and hydration at the end of life is internationally shared to be important and better understanding can contribute to better end-of-life care.

The aim of this thesis was to contribute to better understanding of end-of-life decision-making practices. Two topics were addressed:

- public opinion on end-of-life decision-making in the Netherlands, and
- (artificial) nutrition and hydration at the end of life.

In **Part 1**, public opinion in the Netherlands on euthanasia, physician-assisted suicide and advance care planning is described. In the Netherlands, euthanasia has been debated extensively, which has led to the Euthanasia Act in 2002. After a decade, public debate remains vivid, especially regarding the boundaries and interpretation of the Euthanasia Act. Nowadays, one of the subjects of much debate concerns euthanasia or physician-assisted suicide in older people who are suffering due to being tired of living. Better understanding of current public opinions regarding the Act might strengthen the societal debate. The chapters in part 1 are based on the results of the KOPPEL study. This study involved a mixed-method design: in the cross-sectional survey among the general public, 1960 respondents completed a questionnaire (response rate 78%); 16 of those were personally interviewed.

Chapter 2 reports on the results of surveys among the general public and healthcare professionals which examined their opinions on the legal requirements for euthanasia and physician-assisted suicide. These surveys demonstrated that the Dutch Euthanasia Act and its legal requirements are widely supported, both by the Dutch general public and by healthcare professionals. Major arguments for this support are the possibility of relief of unbearable suffering at the end of life and respect for patient's autonomy. Overall, both members of the general public and healthcare professionals seem to interpret the boundaries for euthanasia or physician-assisted suicide in a rather restrictive way. Both groups tend to support assistance in dying particularly in the presence of *physical* symptoms, such as pain, whereas they are more reticent about euthanasia or physician assisted suicide in case of psychological or existential suffering, and in patients with early dementia. The Dutch Euthanasia Act does not state the presence of *physical* symptoms to be mandatory and also allows euthanasia or physician assisted suicide in the latter cases, provided that all criteria of due care are fulfilled.

Chapter 3 describes the results of the cross-sectional survey among members of the Dutch general public related to the opinions of the general public on assistance in dying in older people who are tired of living. Being tired of living was defined as the wish to die of older persons who do not have a serious medical condition. This is one of the current topics of sparking debate in the Netherlands. To date, euthanasia and physician-assisted suicide for older people who are tired of living is not allowed in the Netherlands, because unbearable suffering needs to have a medical ground, as stated by the Supreme Court, the Royal Dutch Medical Association and the regional review committees. Our study showed that a minority of the Dutch general public supports assistance in dying for older people who are tired of living. This level of support is significantly less compared to the support for assistance in dying for patients who are terminally ill. To better understand which subgroup supports assistance in dying for older people, we have analysed the characteristics of the supporters. In our study age and health of the respondents were not associated with acceptance of assistance in dying for older people who are tired of living. Our study further showed that those who support assistance in dying for older people who are tired of living were more likely to be highly educated, to be non-religious, to value control over their health decisions, and to have little trust in physicians to comply with their care wishes. A shared principle among these supporters seems to be respect for autonomy, which is one of the pillars of the Dutch Euthanasia Act.

Chapter 4 describes to what extent the Dutch general public is currently involved or inclined to be involved in advance care planning. Advance care planning is a process of communication among patients, healthcare professionals, and relatives regarding end-of-life care. It aims to ensure that patients' values remain central in decision-making and that the care provided is consistent with patients' preferences. Our study showed that the majority of the Dutch general public (70%) has thought about end-of-life care and decision-making, and a substantial part of the Dutch general public has actively discussed their preferences at least once with a relative (64%). However, discussions with the physicians (13%) and written advance directives (7%) are rare among the Dutch general public. Older people and people having a poor health more often (incline to) engage in advance care planning. Involvement in advance care planning is also associated with a preference to be involved in medical decision-making and having little trust that physicians will comply with one's preferences.

End-of-life decision-making encompasses more than euthanasia and physician-assisted suicide. An internationally shared important end-of-life decision concerns withholding or withdrawing potentially life-prolonging treatment, in particular artificial nutrition and hydration at the end of life. **Part 2** of this thesis concerns several studies about nutrition and hydration at the end of life; a Delphi study among 90 international palliative care experts (response rate 60-76%), two systematic literature reviews, and a qualitative interview study among 23 bereaved relatives in New Zealand. These studies derive from

OPCARE9, a European collaborative project to optimize research for the care of cancer patients in the last days of life.

Chapter 5 describes the results of a two-round Delphi study that aimed to investigate which key issues healthcare professionals encounter when making decisions about artificial nutrition and hydration at the end of life. This study among international palliative care experts showed that important issues were the lack of knowledge about the effects of artificial nutrition and hydration and about how to communicate about it, both with patients and relatives. The palliative care experts reported that decision-making about artificial nutrition and hydration at the end of life could substantially improve if there would be more general knowledge and evidence-based guidance about the effects of providing or withholding artificial nutrition and hydration on quality of life and on optimal strategies for communication with patient and relatives.

In **Chapter 6**, a systematic literature review about the effects of artificial nutrition and hydration is described. This systematic literature review aimed at synthesizing current knowledge of the effects of artificial nutrition and hydration in the last week of life on the quality of life and length of life of advanced cancer patients. The review included 15 papers, including one randomized controlled trial. It showed that providing artificial nutrition and hydration is a substantial practice in the last week of life of cancer patients, especially in hospital, with frequencies up to 50-88%. Several studies reported on the benefits and burdens of artificial hydration, but no studies that assessed the effect of artificial nutrition were found. Artificial hydration was found to have limited impact on patients' symptoms: one study found less chronic nausea after receiving hydration and another study found some association between hydration and signs of dehydration. No significant relationships between hydration and general comfort or quality of life measures were found. One study assessed the effect of artificial nutrition and hydration on survival and found no association.

Chapter 7 reports on a second systematic literature review, on opinions on the use of artificial hydration at the end of life. This review included 11 papers. It showed a large variation in the opinions of physicians, nurses, patients, family members and the general public. The majority of patients and relatives and one-third of the general public believe that artificial hydration has a positive effect on quality of life, symptoms and overall clinical condition, while many healthcare professionals feel that artificial hydration at the end of life might have significant negative effects for the patient, such as worsening fluid retention symptoms (e.g. oedema, ascites, pleural effusions) and maintaining a venous route that is burdensome for the patient. These different expectations of (the benefits and burden of) artificial hydration at the end of life potentially complicates end-of-life care, communication and decision-making.

Chapter 8 describes a qualitative interview study on bereaved relatives' perceptions of nutrition and hydration at the end of life of the patient. This study was performed in New Zealand. In total, 23 bereaved relatives were interviewed. It showed that relatives assign significant meaning to oral intake, in relation to its nutritional value, its psychological and social meaning, and the fact that it gives routine and structure to daily life. Therefore, decreasing oral intake of the patient at the end of life is a meaningful change for relatives, who may respond differently. Some relatives accept the decrease in oral intake, while others view maintaining oral intake as an important part of the battle against the disease and for life. Relatives may realize that the patient and themselves are 'keeping each other in the dark' through their mutual efforts to maintain oral intake until the end of life.

In the final chapter **(Chapter 9)**, the main findings are integrated and recommendations for policy, practice and future research are given. It is concluded that there is ample support for the Dutch Euthanasia Act, both among the general public and healthcare professionals, especially in the presence of physical symptoms. Both the general public and professionals consider euthanasia more problematic if a patient's unbearable suffering is rooted in psychosocial problems or spiritual issues.

End-of-life decision-making regarding nutrition and hydration can substantially improve by more evidence-based guidance and international palliative care professionals perceive communication with both the patient and the relatives about it as difficult. More attention is needed for the significance of (artificial) nutrition and hydration at the end of life and for communication about it.

SAMENVATTING

In **hoofdstuk 1** worden de achtergronden en de doelstelling van dit proefschrift beschreven. Zorg in de laatste levensfase heeft als doel het verbeteren van de kwaliteit van leven van patiënten met een levensbedreigende ziekte en hun naasten.
Medische beslissingen rond het levenseinde zijn een belangrijk onderdeel van zorg in de laatste levensfase en kunnen een belangrijke invloed hebben op het proces van overlijden en het comfort van patiënten in de laatste levensfase. In Europa wordt 23-51% van alle sterfgevallen voorafgegaan door medische beslissingen met een mogelijk levensbekortend effect.
Besluitvorming rond het levenseinde is regelmatig onderwerp van maatschappelijke debat. Kennis van publieke opinie op dit terrein kan dit debat informeren en verbeteren. Het al dan niet kunstmatig toedienen van vocht en voeding in de laatste levensfase wordt internationaal gezien als een belangrijk en complex onderwerp waarover beslissingen genomen moeten worden. Meer inzicht in de voors en tegens ervan zal bijdragen aan betere zorg in de laatste levensfase.

Het doel van dit proefschrift is om het inzicht in de opvattingen over en praktijk van zorg en besluitvorming rond het levenseinde te vergroten. Twee onderwerpen zijn uitgelicht:

- publieke opinie over besluitvorming rond het levenseinde in Nederland, en
- (kunstmatige toediening van) vocht en voeding in de laatste levensfase.

Deel 1 van dit proefschrift beschrijft de publieke opinie over euthanasie, hulp bij zelfdoding en proactieve zorgplanning in Nederland. In Nederland zijn de voorwaarden waaronder euthanasie toelaatbaar is gedurende de laatste vier decennia uitgebreid bediscussieerd, hetgeen in 2002 heeft geresulteerd in de inwerkingtreding van de Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (euthanasiewet). Daarna is het maatschappelijke debat steeds levendig geweest, vooral betreffende de reikwijdte van de euthanasiewet. Een van de veelvuldig bediscussieerde onderwerpen is euthanasie of hulp bij zelfdoding voor ouderen die ´klaar met leven´ zijn. Wij deden onderzoek naar de publieke opinie over dit onderwerp in de KOPPEL studie. Deze studie omvat zowel kwantitatief als kwalitatief onderzoek: wij voerden een vragenlijststudie uit onder het Nederlandse publiek, waarbij 1960 respondenten een vragenlijst hebben ingevuld (respons percentage 78%), en hielden persoonlijke interviews met 16 van deze respondenten. Het vragenlijstonderzoek werd ook onder zorgprofessionals uitgevoerd, zowel onder artsen (respons percentage 41%, n=793) als verpleegkundigen (n=1243).

Hoofdstuk 2 beschrijft de resultaten van de vragenlijststudies naar de opvattingen van het Nederlandse publiek en zorgprofessionals over de wettelijke voorwaarden voor euthanasie en hulp bij zelfdoding. Deze vragenlijststudies laten zien dat de euthanasiewet breed wordt gedragen, zowel door het Nederlandse publiek als door zorgprofessionals. Belangrijke argumenten voor de steun voor de euthanasiewet zijn de mogelijkheid om ondraaglijk lijden in de laatste levensfase te kunnen verlichten en het belang van respect voor de autonomie van de patiënt. Zowel het Nederlandse publiek als zorgprofessionals lijken de grenzen aan euthanasie en hulp bij zelfdoding vrij restrictief te interpreteren. Beide groepen vinden euthanasie en hulp bij zelfdoding vooral acceptabel in het geval van *lichamelijke* symptomen, zoals pijn, terwijl ze in het geval van psychisch of existentieel lijden terughoudender zijn. De euthanasiewet schrijft niet voor dat er sprake moet zijn van *lichamelijke* symptomen en geeft ruimte voor euthanasie en hulp bij zelfdoding in het geval van psychisch of existentieel lijden, mits aan alle zorgvuldigheidscriteria is voldaan.

Hoofdstuk 3 beschrijft de resultaten van de vragenlijststudie naar de opvattingen van het Nederlandse publiek over euthanasie en hulp bij zelfdoding voor ouderen die 'klaar met leven' zijn. 'Klaar met leven' is hier gedefinieerd als het hebben van een stervenswens zonder dat er sprake is van een ernstige medisch classificeerbare ziekte. Euthanasie of hulp bij zelfdoding bij ouderen die 'klaar met leven' zijn is niet toegestaan in Nederland. Ondraaglijk lijden moet volgens de Hoge Raad, de regionale toetsingscommissies en de Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (KNMG) voortkomen uit een medisch classificeerbare aandoening. Deze studie laat zien dat een minderheid van het Nederlandse publiek euthanasie en hulp bij zelfdoding bij ouderen die 'klaar met leven' zijn ondersteunt. Dit is duidelijk minder dan de steun voor euthanasie en hulp bij zelfdoding bij ongeneeslijk zieke patiënten. Er werd geen verband tussen de leeftijd en gezondheid van de respondenten en hun opvattingen over euthanasie en hulp bij zelfdoding voor ouderen die 'klaar met leven' zijn gevonden. Voorstanders hiervoor lijken meer waarde te hechten aan de autonomie van de patiënt bij verzoeken om euthanasie of hulp bij zelfdoding.

In **hoofdstuk 4** wordt beschreven in welke mate het Nederlandse publiek betrokken is, of betrokken zou willen zijn, bij proactieve zorgplanning (advance care planning). Proactieve zorgplanning is een proces van communicatie tussen patiënt, naasten, en zorgprofessionals over zorg rond het levenseinde. Proactieve zorgplanning heeft als doel te waarborgen dat de waarden van de patiënt centraal staan in beslissingen rond het levenseinde en dat zorg rond het levenseinde conform de wensen en voorkeuren van de patiënt is. De vragenlijststudie liet zien dat de meerderheid van het Nederlandse publiek (70%) wel eens heeft nagedacht over zorg rond het levenseinde en dat een substantieel deel van het Nederlandse publiek dit ook wel eens heeft besproken met naasten (64%). Een minderheid heeft de eigen wensen wel eens met een arts besproken (13%) of deze vastgelegd in een schriftelijke wilsverklaring (7%). Ouderen en mensen met een slechte gezondheid zijn relatief vaker betrokken bij een vorm van proactieve zorgplanning dan jongeren en gezonde mensen. Betrokkenheid bij proactieve zorgplanning hangt daarnaast ook samen met een algemene voorkeur voor betrokkenheid bij medische beslissingen en met minder vertrouwen hebben in het feit dat artsen de wensen over zorg en beslissingen rond het levenseinde zullen respecteren.

Besluitvorming rond het levenseinde omvat meer dan alleen beslissingen over euthanasie en hulp bij zelfdoding. Besluitvorming over het staken of onthouden van potentieel levensverlengende behandelingen in de laatste levensfase wordt internationaal als een belangrijke beslissing gezien, in het bijzonder besluitvorming over kunstmatige toediening van vocht en voeding. **Deel 2** van dit proefschrift bevat meerdere studies over vocht en voeding in de laatste levensfase, namelijk een Delphi studie onder 90 internationale palliatieve zorgprofessionals (response percentage 60-76%), twee systematische literatuurstudies en een interviewstudie met nabestaanden in Nieuw Zeeland. Deze studies komen voort uit OPCARE9, een Europees project waarin professionals uit negen landen met elkaar hebben samengewerkt om onderzoek naar de zorg voor kankerpatiënten in de laatste levensfase en voor hun naasten te optimaliseren.

Hoofdstuk 5 beschrijft de resultaten van de Delphi studie die als doel had om na te gaan welke belangrijke problemen palliatieve zorgprofessionals ervaren tijdens besluitvorming over kunstmatige toediening van vocht en voeding in de laatste levensfase. Deze studie liet zien dat gebrek aan kennis over de effecten van (het nalaten van) kunstmatige toediening van vocht en voeding en over adequate manieren van communicatie met zowel patiënt als naasten als belangrijke problemen werden ervaren. Daarnaast gaven de experts aan dat besluitvorming over kunstmatige toediening van vocht en voeding in de laatste levensfase verbeterd zou kunnen worden als over deze onderwerpen meer kennis en meer op wetenschappelijk onderzoek gestoelde richtlijnen zouden bestaan.

In **hoofdstuk 6** worden de resultaten van een systematische literatuurstudie naar de praktijk en de effecten van kunstmatige toediening van vocht en voeding in de laatste levensdagen van kankerpatiënten beschreven. In totaal zijn 15 artikelen geïncludeerd. Het toedienen van vocht en voeding in de laatste levensdagen bleek in veel landen veelvuldig plaats te vinden, vooral in het ziekenhuis. De effecten van kunstmatige toediening van vocht in de laatste levensdagen op het comfort van de patiënt lijken beperkt. Eén studie rapporteerde minder misselijkheid bij toediening van vocht en een andere studie vond een associatie tussen het toedienen van vocht en minder fysieke tekenen van dehydratie (droge mond en oksels en diepliggende ogen). Daarnaast beschreven twee studies negatieve effecten van kunstmatige toediening van vocht, namelijk meer ascites en meer drainage. Er waren geen studies die de effecten van kunstmatige toediening van voeding separaat bestudeerden. In één studie werd gekeken naar de effecten van kunstmatige toediening van vocht en voeding in de laatste levensdagen op overleving, maar er werd geen relatie gevonden.

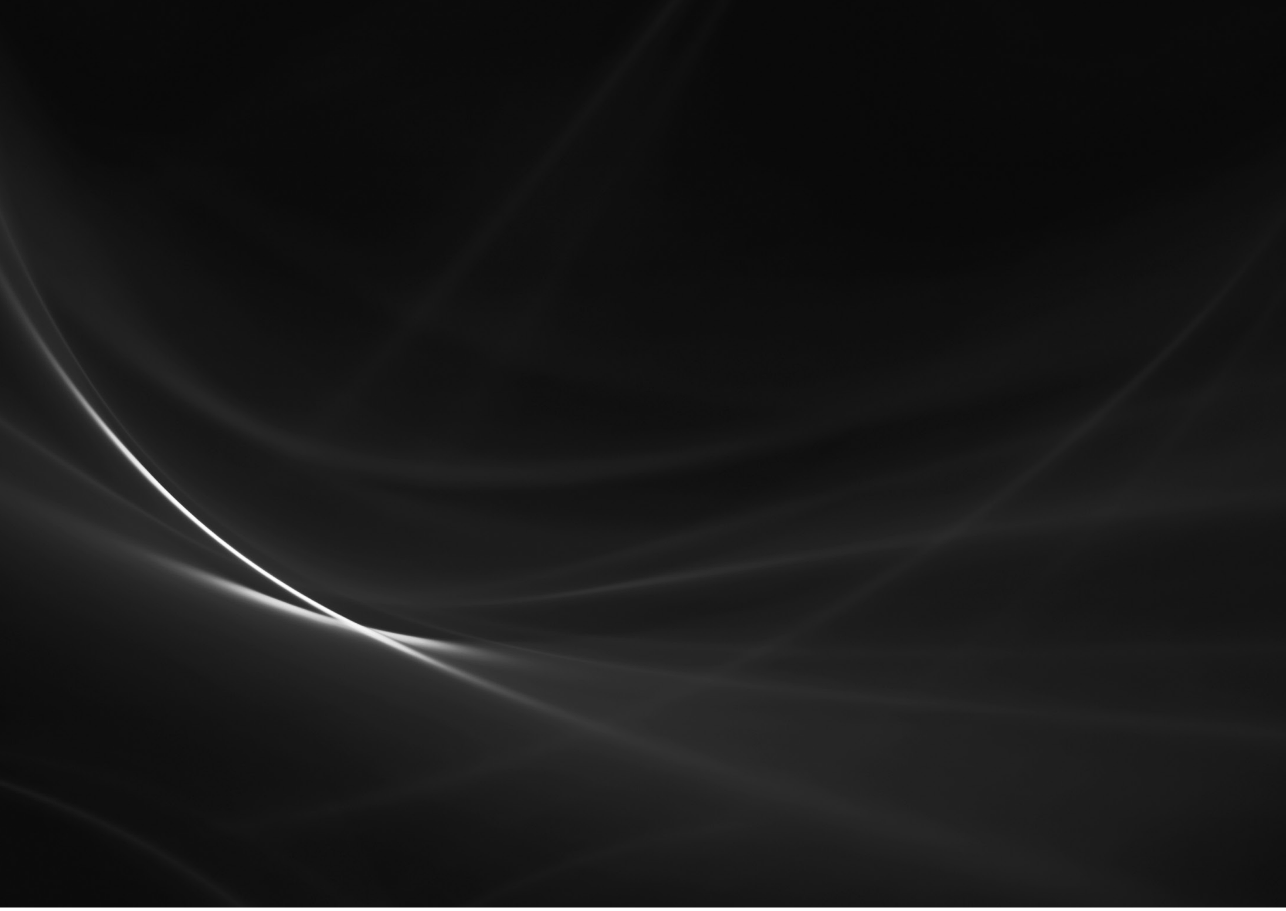
Hoofdstuk 7 beschrijft een tweede systematische literatuurstudie naar de opvattingen over kunstmatige toediening van vocht in de laatste levensdagen van kankerpatiënten. In deze literatuurstudie konden 11 artikelen worden geïncludeerd die een grote variatie aan opvattingen van artsen, verpleegkundigen, patiënten, naasten en het algemene publiek lieten zien. De meerderheid van patiënten en naasten en een derde van het algemene publiek meenden dat kunstmatige toediening van vocht in de laatste levensdagen een positief effect heeft op kwaliteit van leven, symptomen en de algehele conditie van de patiënt. De meeste zorgprofessionals echter dachten dat toediening van vocht juist negatieve effecten voor de patiënt heeft, zoals het verergeren van symptomen van vochtretentie en de noodzaak van het handhaven van een voor de patiënt belastend infuus. Deze verschillende opvattingen over (de effecten van) kunstmatige toediening van vocht in de laatste levensdagen kunnen adequate zorg, communicatie en besluitvorming in de laatste levensdagen in de weg staan.

Hoofdstuk 8 beschrijft een kwalitatieve interviewstudie over de opvattingen van nabestaanden over eten en drinken in de laatste levensfase van de patiënt. Deze studie is in Nieuw Zeeland uitgevoerd en in totaal zijn er 23 nabestaanden geïnterviewd. Deze studie liet zien dat nabestaanden veel betekenis toekennen aan voeding in de laatste levensfase, zowel in relatie tot de voedingswaarde zelf als aan psychologische en sociale aspecten en het feit dat voeding routine en structuur aan het dagelijkse leven geeft. Verminderde orale inname van voeding door de patiënt in de laatste levensfase is dan ook een belangrijke verandering voor naasten, die hierop verschillend kunnen reageren. Sommige naasten accepteren de verminderde orale inname als onderdeel van het stervensproces, terwijl anderen het handhaven ervan als een belangrijk onderdeel zien van het gevecht tegen de ziekte. Naasten gaven soms aan dat zij en de patiënt elkaar in het ongewisse hadden gelaten over het naderende afscheid door hun inspanningen om te blijven eten en drinken tot het einde van het leven.

Tenslotte wordt in **hoofdstuk 9** een samenvatting gegeven van de gevonden resultaten en worden deze resultaten beschouwd in relatie tot eerder onderzoek en methodologische overwegingen. Ook worden implicaties voor onderzoek, beleid en praktijk besproken.

Een van de belangrijkste conclusies van dit proefschrift is dat er ruime steun is voor de Nederlandse euthanasiewet, zowel onder het Nederlandse publiek als onder zorgprofessionals, voornamelijk als patiënten lijden aan fysieke symptomen. Zowel het Nederlandse publiek als zorgprofessionals vinden euthanasie meer problematisch voor patiënten bij wie het lijden voortkomt uit psychosociale of existentiële problematiek.

Daarnaast komt duidelijk naar voren dat experts verwachten dat besluitvorming in de laatste levensfase over (kunstmatige toediening van) vocht en voeding verbeterd kan worden door evidence-based richtlijnen. Daarin is ook aandacht nodig voor communicatie met patiënt en naasten over vocht en voeding in de laatste levensfase.



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Mijn allerliefste Joost, you make my world go round. Ik hou van je.

ABOUT THE AUTHOR

Natasja Johanna Helena Raijmakers was born in Odiliapeel on the 20th of January 1979. After graduating from secondary school at the Comenius College in Uden, she started studying General Social Sciences, specialisation Culture and Health at the University of Utrecht, the Netherlands. In 2002 she obtained her Master of Science degree by writing a thesis about the effects of a psychosocial group-therapy for cancer patients on quality of life. After her study she started working at the University Medical Center Utrecht, first as clinical research manager and later as research staff member. In February 2009 she started working as a junior researcher at the department of Public Health and the department of Medical Oncology of the Erasmus MC in Rotterdam. Here she was involved in the European OPCARE9 collaborative and the KOPPEL study and carried out the research presented in this thesis on end-of-life care and decision-making. In 2011 she worked one month as a visiting researcher at the Regional Palliative Care Network, San Martino-IST in Genoa, Italy, in 2012 she worked three months as a visiting researcher at the Arohanui Hospice in Palmerston North, New Zealand and in 2013 she visited the Brocher Foundation in Geneva, Switzerland, as a researcher for one month. Furthermore, she was involved in the evaluation of the implementation of the Zorgpad Stervensfase, in collaboration with the Comprehensive Cancer Center in Rotterdam and she obtained her Master of Science in Health Sciences, specialisation Epidemiology, at the Erasmus University Rotterdam. Since March 2013 she works at the Netherlands institute for health services research (NIVEL) in Utrecht.

Natasja Johanna Helena Raijmakers is geboren in Odiliapeel op 20 januari 1979. In 1997 behaalde zij haar VWO diploma aan het Comenius College in Uden waarna ze Algemene Sociale Wetenschappen ging studeren aan de Universiteit van Utrecht. In 2002 behaalde ze haar diploma voor de master Social Sciences met een afstudeeronderzoek naar de effecten van een psychosociale groepstherapie voor kankerpatienten op de kwaliteit van leven. Na haar studie startte haar loopbaan bij het UMC Utrecht, eerst als coördinator van klinisch onderzoek bij de afdeling Orthopaedie, later als stafmedewerker onderzoek bij de divisie Heelkundige Specialismen. In februari 2009 startte zij als promovendus bij de afdeling Maatschappelijke Gezondheidszorg en afdeling Interne Oncologie van het Erasmus MC. Hier was zij betrokken bij het Europese project OPCARE9, de KOPPEL studie en voerde zij het onderzoek uit dat is beschreven is dit proefschrift over zorg en besluitvorming rond het levenseinde. In 2011 werkte zij een maand als onderzoeker bij het Regional Palliative Care Network, San Martino-IST in Genua, Italië, in 2012 werkte zij drie maanden als onderzoeker bij het Arohanui Hospice in Palmerston North, Nieuw Zeeland en in 2013 heeft ze een maand als onderzoeker bij de Brocher Foundation in Genève, Zwitserland gewerkt. Daarnaast was zij betrokken bij de evaluatie van de implementatie van het Zorgpad Stervensfase, in samenwerking met het Integraal Kankercentrum Nederland, locatie Rotterdam en heeft ze de master in Health Sciences, specialisatie Epidemiologie voltooid aan de Erasmus Universiteit Rotterdam. Sinds maart 2013 is zij werkzaam als onderzoeker bij het NIVEL in Utrecht.

LIST OF PUBLICATIONS

In this thesis

Raijmakers NJH, Kouwenhoven PSC, van Delden JJM, Rietjens JAC, Schermer M, van Thiel GJMW, Trappenburg M, van de Vathorst S, van der Vegt B, Vezzoni C, Weyers H, van Tol D, van der Heide A. Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: a mixed method approach. Palliative Medicine 2013 Mar: 27(3): 273-80

Raijmakers NJH, van der Heide A, Kouwenhoven PSC, van Thiel G, van Delden JJM, Rietjens JAC. Assistance in dying for Older People without a Serious Medical Condition who have a Wish to Die: a National Cross-sectional Survey. (submitted)

Raijmakers NJH, Rietjens JAC, Kouwenhoven PSC, Vezzoni C, van Thiel GJMW, van Delden JJM, van der Heide A. Involvement of the Dutch general population in advance care planning: a cross sectional survey. Journal of Palliative Medicine 2013 (accepted)

Raijmakers NJH, van Zuylen C, Costantini M, Caraceni A, Clark J, De Simone G, Lundquist G, Voltz R, Ellershaw JE, van der Heide A. Issues and needs in end-of-life decision making: an international modified Delphi Study. Palliative Medicine 2012, Oct; 26(7): 947-53

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Raijmakers NJH, Fradsham S, van Zuylen C, Mayland C, Ellershaw JE, van der Heide A. Variation in attitudes towards artificial hydration at the end of life: a systematic literature review. Current Opinion in Supportive & Palliative Care 2011, Sep; 5(3): 265-72

Raijmakers NJH, Clark J, van Zuylen C, Allan S, van der Heide A. Bereaved relatives' perspectives of the patient's oral intake towards the end of life: a qualitative study. Palliative Medicine 2013, Feb 26

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Raijmakers NJH, van Zuylen L, Furst CJ, Beccaro M, Maiorana L, Pilastri P, Rossi C, Flego G, van der Heide A. Variation in medication use in cancer patients at the end of life: a cross-sectional analysis. Supportive Care in Cancer 2013 Apr; 21(4):1003-11

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Raijmakers NJH, van Zuylen L, van der Heide A. OPCARE9 work package 2- End-of-life decisions in Europe: shared experience. European Journal of Palliative Care 2012; 19(1)

Rietjens JAC, **Raijmakers NJH**, Kouwenhoven PSC, Seale C, van Thiel GJMW, Trappenburg M, van Delden JJM, van der Heide A. News media coverage of euthanasia: a content analysis of Dutch national newspapers. BMC Medical Ethics 2013 Mar 6; 14:11

Domeisen Benedetti F, **Raijmakers NJH**, Bragg C, Galshko M, Jorge M, Lundh Hagelin C, Popa Velea O, Romotzky V, Schuler S, Mason S, Lindqvist O. How to develop junior researchers in palliative care projects. European Journal of Palliative Care 2012;19(3); 127-30

Raijmakers N, van der Heide A, Rietjens J, Swart S, van Zuylen L. OPCARE9: European Collaboration to optimize the care for the dying. [OPCARE9: Samenwerken in Europa aan betere zorg in de stervensfase] Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg 2011; vol 1

Raijmakers N, van der Heide A, Rietjens J, Swart S, van Zuylen, L. The results of OPCARE9: towards better guidance for research and care at the end of life. [De resultaten van OPCARE9. Richtinggevend voor onderzoek en zorg in de laatste levensfase] Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg 2012; volume 3/4

Submitted

Kouwenhoven PSC, van Thiel GJMW, **Raijmakers NJH**, Rietjens JAC, van der Heide A, van Delden JJM. The choice between euthanasia and physician-assisted suicide is a physician's one. Physician-assisted suicide is preferred in cases of psychosocial suffering

Van der Kallen H, **Raijmakers NJH**, Rietjens JAC, van der Male A, Bueving H, van Delden JJM, van der Heide A. Opinions of the Dutch general public on palliative sedation: a mixed method approach

Kouwenhoven PSC, **Raijmakers NJH**, van Delden JJM, Rietjens JAC, van Tol DG, van de Vathorst S, de Graeff N, Weyers HAM, van der Heide A, van Thiel GJMW. Opinions of professionals and the public about euthanasia and late stage dementia: a mixed method approach

Geijtenman ECT, **Raijmakers NJH**, Lokker ME, Dekkers AGWM, van der Heide A, van Zuylen L. Ten years Zorgpad Stervensfase: a clear improvement for care at the end of life. [Tien jaar Zorgpad Stervensfsae: een belangrijke verbeterslag voor zorg in de laatste levensfase]

PhD PORTFOLIO

Name:	Natasja Johanna Helena Raijmakers
PhD period:	2009-2013
Erasmus MC Department:	Public Health
Promotor:	Prof. Dr. A.van der Heide & Prof. Dr. J.J.M. van Delden
Supervisors:	Dr. L. van Zuylen & Dr. J.A.C. Rietjens

1. PHD TRAINING

	Year	Workload (Hours/ECTS)
General academic skills		
Scientific writing course MGZ – Dr. Frank van Lenthe	2010	12 hours
Writing in English for Scientific Publication – James Boswell Institute, University of Utrecht	2012	30 hours
Research skills		
Master Epidemiology, NIHES	2009-2012	70 ECTS
In-depth courses		
Suffering, Death & Palliative Care, Nijmegen, the Netherlands	2010	1.1 ECTS
Oral presentations		
V&VN Oncology, Utrecht, The Netherlands	2009	1 ECTS
European Oncology Nursing Society, The Hague, The Netherlands	2010	1 ECTS
Flamish-Dutch research forum Palliative Care, Antwerp, Belgium	2010	1 ECTS
Hospice New Zealand Conference, Wellington, New Zealand	2010	1 ECTS
OPCARE9 conference, Liverpool, UK	2010	1 ECTS
Post EAPC, de Bilt, the Netherlands	2011	1 ECTS
Death, Dying and Disposal Conference, Nijmegen, the Netherlands	2011	1 ECTS
European Association of Palliative Care Conference, Trondheim, Norway	2012	1 ECTS
World Congress of Bioethics, Rotterdam, the Netherlands	2012	1 ECTS
International Collaborative for End-of-Life Care Research	2011-2012	2 ECTS
Presentations at Erasmus MC	2009-2012	3 ECTS
Presentations at Arohanui Hospice, New Zealand	2010-2012	2 ECTS
National conference on palliative care, the Netherlands	2012	1 ECTS
International conferences		
European Association of Palliative Care conference	2010-2012	3
European Oncology Nursing Society conference	2010	1

Continued

	Year	Workload (Hours/ECTS)
Hospice New Zealand Conference	2010	1
European Multidisciplinary Cancer Congress (ESMO/ECCO)	2011	1
World Congress of Bioethics	2012	1
Seminars and workshops		
Seminars department of Public Health, Erasmus MC	2009-2012	3
Flamish-Dutch research forum Palliative Care	2009-2012	3
KNMG Medical treatment at the end of life	2012	4 hours
KNMG Euthanasia and its boundaries	2012	4 hours
Scientific meeting Medical Oncology	2012	4 hours

2. TEACHING ACTIVITIES

Lecturing		
Zorgpad Stervensfase (Comprehensive Cancer Center)	2011	4 hours
Qualitative Research (Zorgacademie Erasmus MC)	2011	8 hours
Community projects for medical students (Erasmus MC)	2012	2 hours
How to make a good poster presentation? (ICER, Amsterdam)	2012	4 hours
Nutrition at the end of life (Erasmus MC)	2012	8 hours
Supervising practicals and excursions		
Supervisor medical students theme 3.C.4 (community projects)	2012	16 hours
Supervising Master's theses		
Hilde van Hallen, MD		40 hours