SERVING THE UNDERSERVED

TOWARDS IMPROVING PALLIATIVE CARE FOR PERSONS EXPERIENCING HOMELESSNESS

HANNA KLOP

SERVING THE UNDERSERVED

Towards improving palliative care for persons experiencing homelessness

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COLOPHON

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Towards improving palliative care for persons experiencing homelessness

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CHAPTER 1

General introduction

INTRODUCTION

According to Statistics Netherlands (CBS), in 2021, about 32,000 people were found to experience literal homelessness.[1] This number of Dutch people experiencing homelessness has almost doubled compared to 2009, when CBS started registering homelessness.[2, 3] Although factors causing and complicating homelessness differ from one person to the next, homelessness is often accompanied by factors such as poverty, substance use, intellectual disabilities, a history of unstable housing, mental illnesses, severe and chronic somatic illnesses, lack of social support, and lack of health insurance.[4-10] Persons experiencing homelessness are often in poor health. At the same time, healthcare provision is often hampered by poor access to healthcare, unmet healthcare needs and underuse of care.[11-16] Hence, persons experiencing homelessness are often characterized by both complex comorbidities and a heavy symptom burden.[17-19] In line with this, morbidity rates among people experiencing homelessness are high, and people experiencing homelessness die approximately 10 to 30 years earlier compared to the general population.[4, 20-29] Consequently, palliative care provision is especially relevant and necessary for this population. Yet palliative care is often lacking or is only provided in a very late stage of serious illness.[30-32] Reaching the whole of this population has also proved to be difficult for healthcare professionals.[31, 33] Previous studies already showed a need for multidisciplinary collaboration between palliative care professionals and social service professionals in order to improve the access and quality of palliative care for this population.[34-37]

This thesis addresses the complexities and challenges surrounding provision of palliative care to persons experiencing homelessness from the perspective of healthcare professionals, social service professionals, and the persons experiencing homelessness themselves. Also, a context-sensitive and small-scale intervention that aims to equip professionals in delivering palliative care to people experiencing homelessness was set up and evaluated. To introduce these topics, this chapter starts with a definition of homelessness, numbers and trends over the past decades, and information about the Dutch social service system (*Wmo; the Social Support Act*). Next, a definition of palliative care and the context of the social service system for people experiencing homelessness are provided in this general introduction. This is followed by a discussion of the knowledge gaps in the field of palliative care for persons experiencing homelessness. Finally, the research methods and the structure of this thesis are presented.

DEFINITION OF HOMELESSNESS

Considerations for terms used

People experiencing homelessness are often referred as ‘homeless persons’. This term is used in some of this thesis’s chapters as well, namely Chapters 2, 3, 4 and 5; they were written earlier without the enhanced insight obtained by the time Chapters 1, 6, 7 and 8 were written. In this general introduction, however, the term 'persons experiencing homelessness' is used for homelessness. An underlying reason for choosing this term is the experienced stigma of homelessness, as described below. The studies gave a better understanding of this during the process of data collection and reporting. In short, 'homeless person' defines a person as a homeless person whose whole identity is affected by this and who is characterized by the same issues as all other people in this situation. The term 'person experiencing homeless' does not stigmatize the person as being totally homeless, and leaves space for individual personalities and differences. The same reasoning applies for the use of 'people with less access to care' instead of 'care avoidance'.

International and Dutch definition of homelessness

Different views exist on the definition of homelessness, which accordingly varies between countries and organizations. In European contexts and studies, the European Typology of Homelessness and Housing Exclusion (ETHOS) is regularly used. It was initiated by the European Federation of National Organizations Working with the Homeless (FEANTSA). This broad definition of homelessness provides a common language for defining homelessness. The definition distinguishes four living situations: i) rooflessness (without a shelter of any kind, sleeping rough); ii) houselessness (without a place to sleep except temporarily in shelter institutions); iii) living in insecure housing (severe threat of exclusion due to insecure tenancies, eviction or domestic violence); iv) living in inadequate housing (in caravans on illegal campsites, in unfit housing, or in extreme overcrowding).[38] In the Netherlands, amongst others by CBS, a more narrow definition of homelessness is frequently used. It is based solely on people who are literally homeless, defining individuals as homeless when they sleep in public areas such as stations, shopping centres or a car, or stay in emergency shelters or 24-hour shelters, or on a non-structural basis with friends, acquaintances or family.[2]

NUMBERS AND CHARACTERISTICS OF PERSONS EXPERIENCING HOMELESSNESS IN THE NETHERLANDS

Estimated numbers of people experiencing homelessness

Estimated numbers for homelessness in the Netherlands by CBS mainly rely on numbers for literal homelessness, as explained above. This is a narrower definition than the FEANTSA definition as it excludes people who live in insecure or inadequate housing, people who are undocumented, people who do not make use of the social service system and people older than 65. One source for numbers of houseless persons is the Personal Records Database (BRP, *Basisregistratie Personen*), in which data is registered of persons residing in emergency day and night shelters. Other sources are the Social Assistance Register (*Bijstandsregister,* as determined by the Work and Social Assistance Act) for persons without a fixed residence, and data on persons experiencing homelessness who are known to one of the three probation organizations in the Netherlands (3RO).[39] One of the limitations of the CBS registration method is that it distinguishes between 'literal homelessness' and 'residential homelessness', defining residential homelessness as residing in long-term stay facilities. Consequently, estimated numbers of the population include people who use emergency shelters, but exclude many persons who reside in a long-term facility while waiting for a permanent place to live.[40, 41] Also, certain conditions have been set for the use of emergency shelters, for example that a person is insufficiently self-reliant and cannot rely on their own network.[42, 43] Further, the capacity of emergency shelters in the Netherlands is often limited.[44, 45] In addition, there are approximately 500,000 people in the Netherlands who are not registered in the BRP; they may also include persons experiencing homelessness who are not covered by the official registration method. To date, it is not known how many people are not included in these estimated numbers of the size of the population due to long-term residence, self-reliance or limited shelter capacity. Thus, actual numbers of individuals experiencing homelessness are expected to exceed the official number of 32,000.[46, 47]

Characteristics of CBS-registered persons who experience homelessness in the Netherlands

CBS provides an estimate of the size of the homeless population and also provides insight in to the characteristics of the persons experiencing literal homelessness. CBS shows the following characteristics. 83% are male, 62% of this population are aged between 27 and 49 and 21% are aged between 50 and 65 years. In total, 62% of this population have a migration background, of whom 50% are from non-Western countries and thirteen percent from Western countries. Of the registered persons experiencing homelessness, 37% are located in the four biggest cities, which are Amsterdam, Rotterdam, The Hague and Utrecht.[1] A cohort study, in which over 500 persons experiencing homelessness in these four cities were followed during two and a half years, showed that more than 70% had a low or very low level of education. A high percentage (87%) of the people in this cohort suffered physical complaints and almost all participants scored high on psychological complaints. Cannabis use was relatively common among this cohort; 43% of the adults used cannabis in the month prior to the interview.[48]

DUTCH SOCIAL SERVICE SYSTEM

The Dutch social service system, which is regulated by the Social Support Act (*Wmo*), is responsible for providing emergency shelter to individuals experiencing homelessness. It aims to provide temporary accommodation and professional help to people without housing. Overall, the social service system aims to guide these individuals from short-term accommodation to long-term housing and supervision, and strives to let them lead an independent life as much as possible.[42] In general, the Dutch social service system offers various accessible emergency shelters that individuals experiencing homelessness can go to when in urgent need of shelter. These emergency shelters can provide a place to sleep (night shelters) or a place to spend the day (day shelters) or both (24-hour shelters). Within these social service facilities, medical services can be available such as outreach nurses or nursing wards. Social service professionals employed at these facilities include a wide variety of social service workers and street nurses. Municipalities are responsible for taking care of people without housing, which means that in practice facilities and capacity differ between municipalities.[49] Also, collaboration with medical services differs between municipalities and between social service facilities such as shelters. In general, an emergency shelter has a few beds for sick people, or consultation hours where residents can consult a street doctor or street nurse are facilitated within the shelter. In some municipalities, there is a nursing ward specifically for this population. In other municipalities, medical care relies mainly on external healthcare professionals, such as (outreach) general practitioners (GPs), outreach street nurses or district nurses.

PALLIATIVE CARE DEFINITION AND PROVISION

The World Health Organization (WHO) defines palliative care as person-centred care that improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. Palliative care aims to prevent and alleviate suffering, through early identification and careful assessment and treatment of pain and other problems of a physical, psychological, social and spiritual nature.[50] Palliative care can improve the quality of care and well-being at the end of life, and reduce fear and pain. Palliative care is pre-eminently holistic, multidisciplinary care involving various disciplines, and maintaining the quality of life as long as possible. According to the WHO, palliative care is explicitly recognized under the human right to health.[51]

Palliative care provision in the Netherlands

In the Netherlands, palliative care is in general provided in the primary care setting, where it mainly falls under the responsibility of GPs, in close collaboration with district nurses. These healthcare professionals are guided by the Dutch Quality Framework for Palliative Care (*Kwaliteitskader Palliatieve Zorg*). This framework provides healthcare professionals and care organizations with standards for good-quality palliative care that are based on the values, wishes and needs of patients and their loved ones.[52] Palliative care is often provided at home and is not a medical specialty in the Netherlands. However, elderly care physicians, GPs with additional training in palliative care (*Kaderarts Palliatieve Zorg*), and nurse specialists in palliative care have received thorough training in palliative care provision. Besides, healthcare providers can make use of palliative care consultation facilities where they receive advice about a patient from a palliative care consultant.[53, 54] We define these professionals and consultation facilities as 'palliative care professionals'. Also, PaTz groups (palliative homecare groups), are used to improve palliative care in the primary setting in the Netherlands. In these groups, GPs, (district) nurses and a palliative care consultant meet regularly and identify and discuss patients with a life-threatening illness.[55]

Palliative care provision for persons experiencing homelessness

Specific facilities offering palliative care for persons experiencing homelessness, such as specialized hospices or hospices that are willing to admit a person experiencing homelessness and/or using substances, are currently scarce in the Netherlands. Moreover, at the end of life, many persons experiencing homelessness reside in shelters run by the social service system. In addition, persons experiencing homelessness are sometimes not registered with a GP or fall under the responsibility of social services where medical care is provided on an ad hoc basis. In these facilities, medical care generally focuses on urgent somatic issues, which are usually presented late. From previous international and Dutch studies, it is already known that recognizing palliative care needs is hard for social service professionals, and the death of a resident is often unexpected and makes a deep impression on them.[11, 30, 56-59] In addition, palliative care facilities and the degree of collaboration between social services and healthcare services differ amongst municipalities. Several studies already endorsed the need for improving the quality and timing of palliative care for persons experiencing homelessness.[11, 56, 59] Some international studies have reported evidence on initiatives to enhance palliative care provision for persons experiencing homelessness and the quality thereof, such as the use of advance directives,[60-62] offering shelter-based palliative care,[34, 59] and harm-reduction services aimed at limiting health damage caused by substance use.[63] More recently, British studies presented an intervention in which hostel staff were trained and supported by palliative care specialists,[64, 65] resulting in partnerships between hostel staff and palliative care specialists and a more holistic perspective on persons experiencing homelessness who are at the end of life.

KNOWLEDGE GAPS

Little is known about palliative care provision and barriers and facilitators in palliative care for persons experiencing homelessness in the Netherlands. There is also little knowledge about using consultations, multidisciplinary meetings and training to better equip Dutch palliative care professionals and social service providers in providing palliative care. In addition, to date no interventions have been studied regarding the provision of interdisciplinary palliative care for persons experiencing homelessness, using the three combined activities of consultations, multidisciplinary meetings, and training, whether in the Netherlands or worldwide.

AIMS OF THIS THESIS

The first aim is:

1 *To provide insight into important aspects of palliative care for persons experiencing homelessness and important elements for reaching persons experiencing homelessness*.

Data was obtained through a systematic review (*Chapter 2)* and a qualitative semi-structured interview study into the phenomena of people with less access to care (*Chapter 3).*

Second, the thesis aims:

2 *To obtain insight into the current provision of palliative care for persons experiencing homelessness in the Netherlands, and to explore future needs for improving palliative care provision.*

To achieve this, a retrospective medical record study was conducted of deceased homeless persons in shelter-based nursing-care settings (*Chapter 4)*, as well as a focus group study of palliative care experiences in the Netherlands among professionals and persons experiencing homeless (*Chapter 5)*.

Third, the aim is:

3 *To provide insight into how a threefold intervention to improve palliative care for this population was evaluated regarding the added value and implementation process.*

Data was derived from a study of both the added value of the intervention (*Chapter 6*) and a process evaluation (*Chapter 7*) during its implementation in three Dutch regions.

OUTLINE OF THIS THESIS AND METHODS USED

This thesis is divided into three parts, which are outlined below.

Part 1 | Important aspects of palliative care and reaching persons experiencing homelessness

Chapter 2, entitled 'Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care', provides insight into:

i. what is known from previous research about the concerns, care needs and preferences people experiencing homelessness regarding palliative care
ii. what is known from previous research about what barriers are found in the delivery of palliative care for people experiencing homelessness
iii. what is known from previous research about recommendations for practice regarding palliative care for people experiencing homelessness.

Data from 27 included papers were derived using quantitative and qualitative methods. Most of the studies were American and Canadian.

Chapter 3, 'Care avoidance among homeless people and access to care: an interview study among spiritual caregivers, street pastors, outreach workers for persons experiencing homelessness, and persons who were formerly experiencing homelessness', provides insights into:

i. why do spiritual caregivers, street pastors, outreach workers and persons who formerly experienced homelessness think homeless people avoid social care or healthcare;
ii. suggestions provided by spiritual caregivers, street pastors, outreach workers and persons who formerly experienced homelessness regarding making care accessible for homeless people who have less access to care.

This qualitative study relied on data from 28 semi-structured topic-list guided individual interviews with street pastors, spiritual caregivers, outreach workers and persons who formerly experienced homelessness.

Part 2 | Current palliative care provision for persons experiencing homelessness and future improvements

Chapter 4, 'End-of-life care for homeless people in shelter-based nursing care settings: A retrospective record study':

i. describes the characteristics of persons experiencing homelessness who reside at the end of life in Dutch shelter-based nursing care settings;
ii. examines the end-of-life care provided to them as well as the documented difficulties in end-of-life care.

This study reports on retrospective data retrieved from 61 medical records of deceased homeless persons who had resided in two Dutch shelter-based nursing care settings. Both quantitative and quantitative analysis methods were used.

Chapter 5, 'The views of homeless people and healthcare professionals on palliative care and the desirability of setting up a consultation service: a focus group study', explores:

i. the experiences and perceptions of professionals and persons experiencing homelessness who are severely ill regarding care and support provided for this population, including barriers and facilitators within that care
ii. whether reciprocal consultations between professionals in social services and palliative care would be appropriate for improving palliative care for homeless people.

This study relied on data from six topic-list guided focus groups, four with professionals (n=19) and two with severely ill persons experiencing homelessness (n=15).

Part 3 | A threefold intervention: evaluation of added value and process

Chapter 6, 'Evaluating the use and added value of a threefold intervention to improve palliative care for persons experiencing homelessness: a mixed-method study', describes:

i. how a threefold consultation service was received by social service professionals and palliative care professionals, and which professionals and patients were reached by the intervention;
ii. the perceived added value of the threefold consultation service for collaboration between professionals, competences of professionals, and the timing and quality of palliative care for persons experiencing homelessness, according to the social service professionals and palliative care professionals involved.

Chapter 7, entitled ‘Implementation of a threefold intervention to improve palliative care for persons experiencing homelessness: a mixed-method process evaluation using the RE-AIM framework’, describes:

i. the Reach, Adoption, Implementation and Maintenance of a threefold consultation service according to the social service and palliative care professionals involved in the threefold intervention;
ii. perceived barriers and facilitators during this implementation process.

Both chapters rely on the same mixed-method study conducted using structured questionnaires filled in by consultants (n=34), requesting consultants (n=14) and attendees of multidisciplinary meetings (n=22), diaries filled in by consultants (n=216) and an implementation diary by the researcher, semi-structured group interviews with attendees of multi-disciplinary meetings (n=10), training sessions (n=10) and semi-structured individual interviews with managers of the organizations involved (n=8) and the consultants involved (n=5). This study evaluated the added value and the implementation process of the threefold consultation intervention as perceived by social service and palliative care professionals. The dimensions Reach, Adoption, Implementation and Maintenance of the RE-AIM framework were used to structure the process evaluation.

General discussion

Chapter 8 provides a general discussion of the main findings in relation to the literature, methodological considerations, reflections on the findings and recommendations for practice, research, and policy.

PART 1

Important aspects of palliative care and reaching persons experiencing homelessness

Kan ik iets voor je zijn
Met een blik een gebaar
Met een arm om je heen
Of een hand uit je haar

De Dijk

CHAPTER 2

Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care

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ABSTRACT

Background. Homeless people often suffer from complex and chronic comorbidities, have high rates of morbidity and die at much younger ages than the general population. Due to a complex combination of physical, psychosocial and addiction problems at the end of life, they often have limited access to palliative care. Both the homeless and healthcare providers experience a lot of barriers. Therefore, providing palliative care that fits the needs and concerns of the homeless is a challenge to healthcare providers. This systematic review aims to summarize evidence about the concerns, palliative care needs and preferences of homeless people, as well as barriers and facilitators for delivering high quality palliative care.

Methods. PubMed, Embase, PsycINFO, CINAHL and Web of Science were searched up to 10 May 2016. Included were studies about homeless people with a short life expectancy, their palliative care needs and the palliative care provided, that were conducted in Western countries. Data were independently extracted by two researchers using a predefined extraction form. Quality was assessed using a Critical Appraisal instrument. The systematic literature review was based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.

Results. Twenty-seven publications from 23 different studies met the inclusion criteria; fifteen studies were qualitative and eight were quantitative. Concerns of the homeless often related to end-of-life care not being a priority, drug dependence hindering adequate care, limited insight into their condition and little support from family and relatives. Barriers and facilitators often concerned the attitude of healthcare professionals towards homeless people. A respectful approach and respect for dignity proved to be important in good quality palliative care.

Conclusions. A patient-centred, flexible and low-threshold approach embodying awareness of the concerns of homeless people is needed so that appropriate palliative care can be provided timely. Training, education and experience of professionals can help to accomplish this.

BACKGROUND

Homeless people are those without permanent housing, e.g. living in sheltered housing or on the streets.[66, 67] It is known that homeless people often have substance abuse problems, high rates of mental illness and serious physical illness, lack of social support, and lack of health insurance.[4, 68-72] Many of them suffer from complex and often chronic comorbidities, such as liver cirrhosis, cancer and human immunodeficiency virus (HIV).[8, 70, 73] In addition, they die at much younger ages than the general population.[23, 25, 71, 74, 75]

It is therefore evident that a large proportion of homeless people can benefit from palliative care. According to the widely accepted definition of the World Health Organization (WHO), "palliative care is an approach that improves the quality of life of patients and their families facing the problems 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".[50] The definition shows that palliative care covers a broad range of domains and can start in an early phase of a life-threatening illness. Given the multiple problems homeless people have, it is apparent that providing good and accessible palliative care to homeless people is a challenge.

Until now, research conducted on this topic has been addressed in three reviews.[31, 73, 76] First, Sumalinog et al. reviewed the effectiveness of three interventions during homeless people's final stage of life, including: an intervention encouraging the completion of advance directives (AD), a shelter-based palliative care programme, and an intervention aiming to improve cooperation between palliative care services and social services for the homeless. They tentatively conclude that there is some evidence that the interventions lead to the completion of more advance care directives and better access to palliative care.[73] In addition, a review by Hubbell also focused on the completion of advance care planning (ACP), concluding that clinician-guided interventions with homeless individuals were effective in getting advance directives completed and in obtaining surrogate decision-makers. Hubbell also found that homeless people had several concerns at the end of life, such as a fear of dying alone and concerns regarding burial and notification of family.[76] Furthermore, Hudson et al. summarized the findings in qualitative studies on palliative care among homeless people to get a better understanding of the challenges for palliative care access and delivery.[31] In the review by Hudson et al., three types of challenges were identified, which they described as challenges related to chaotic lifestyles, challenges concerning the delivery of end-of-life care in hostels, and the challenges of caring for homeless people in mainstream palliative care settings.

While the three reviews provide valuable information, they do not provide a complete overview of the existing literature on palliative care for homeless people. First of all, the reviews of Sumalinog et al. and Hubbell focus exclusively on the terminal phase of life, excluding earlier stages of the palliative care trajectory. Additionally, both reviews of Sumalinog et al. and

Hubbell are mainly concerned with structure (such as cooperation), ethical decisions (such as advance directives) and homeless people's attitudes towards dying. These two reviews do not look at the care needs of homeless people and how to meet these needs. Furthermore, Hudson's review limits itself to qualitative studies and only focuses on challenges concerning the access and delivery of palliative care, without looking at possibilities for improvements. Given the relatively narrow focus of each of the three previous reviews, we found the need for a more comprehensive review providing a broader overview of relevant literature on palliative care for homeless people. In this review we offer such a comprehensive overview by using the broad definition of palliative care as defined by the WHO, which emphasizes care in four domains - somatic, psychological, social and spiritual - and also recognizes that care can start before the terminal phase. Besides this, by looking at the possibilities available for providing good palliative care (barriers and facilitators), and by including both qualitative, quantitative and mixed-method studies, this review contributes to the existing literature.

In order to provide palliative care tailored to the needs of homeless people, the objective of this systematic review is to summarize what evidence already exists about concerns and healthcare needs, as well as the conditions for delivering good quality palliative care for the target group. The research questions are therefore:

i. What is known from previous research about the concerns, care needs and preferences of homeless people regarding palliative care?
ii. What is known from previous research about what barriers are found in the delivery of palliative care for homeless people?
iii. What is known from previous research about recommendations for practice regarding palliative care to homeless people.

METHODS

Design and eligibility criteria

A systematic review of the research literature was carried out to identify studies that examined the concerns and needs in palliative care for homeless people, and/or provided care to seriously ill homeless people. A review protocol was developed based on the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement.[77]

Studies eligible for inclusion had to meet the following criteria:

1. The study concerns homeless people who provided information about their views, wishes, and/or preferences towards the end of life, including homeless people having a life limiting condition.
2. The study includes data derived from homeless people themselves, from their healthcare professionals or data from registration, medical files or cohorts (either qualitative or quantitative).

3. The study concerns the palliative care provided (somatic, psychological, social and/or spiritual), factors influencing that care, palliative care needs and/or care interventions or innovations for palliative care.

Commentaries, editorials, abstracts, posters for conferences and non-empirical studies were excluded. In addition, studies conducted outside the Western World (outside Northern, Eastern, Southern and Western Europe or Anglo Saxon countries) were excluded. Since Western countries already differ in the way care for homeless people is organized within the health and welfare system, we did however want to ensure comparability in terms of living conditions and welfare levels. There were no restrictions on the setting, year of publication and language of the publication.

Searches

The following sources were searched from inception: Embase.com and Ebsco/PsycInfo (up to 1 April 2016), Ebsco/CINAHL (up to 5 April 2016), Thomson Reuters/Web of Science (up to 3 May 2016) and PubMed (up to 10 May 2016). To identify studies about homelessness and palliative care, we used a pre-defined search strategy. The string for PubMed is shown in Figure 1, detailed information for all search strings is shown in Appendix 1.

```
"Homeless Persons"[Mesh:NoExp] OR homeless*[tiab] OR street people*[tiab]

"Terminal Care"[Mesh] OR "Palliative Care"[Mesh] OR "Palliative Medicine"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Death"[Mesh:NoExp] OR "mortality"[Subheading] OR terminal*[tiab] OR end of life[tiab] OR life care end[tiab] OR hospice*[tiab] OR bereavement car*[tiab] OR palliati*[tiab] OR limited life*[tiab] OR death*[tiab] OR dying*[tiab] OR die[tiab] OR "Advance Care Planning"[Mesh] OR "Attitude to death"[Mesh] OR mortal*[tiab] OR advanced care*[tiab] OR advance care*[tiab]
```

Figure 1. Search string PubMed

References listed in review articles and references in papers which were excluded in the full text round were also checked. In order to find grey literature, relevant websites of organizations that are involved in palliative care for homeless people or research into it were consulted by searching for relevant keywords using Google (e.g. Simon Communities Ireland – Homeless Charity and St. Mungo Community Housing Association). Duplicate articles were excluded.

Study identification and data extraction

All the references obtained by searching databases as mentioned above were independently reviewed by two researchers, using Covidence online software (a primary screening and data extraction tool).[78] Firstly, titles and abstracts were screened in order to determine whether studies met the eligibility criteria. The exclusion criteria were:

1. Homeless people could not be distinguished as a separate subgroup;
2. Study was not about somatically ill homeless adults with a short-life expectancy;
3. Search outcomes included: comments, editorials, abstracts and posters;
4. Study was not conducted in N-E-W Europe or Anglo-Saxon countries; and
5. Study was not about palliative/end-of-life care.

Cohen's kappa for the first selection of titles and abstracts was 0.92 (unweighted), which is almost perfect according to Landis & Koch.[79] In the second round, the remaining full text papers were independently assessed by two reviewers against inclusion criteria. Cohen's kappa for the second round was 0.81 (unweighted), thus also reflecting almost perfect agreement according to Landis & Koch.[79] Disagreements about whether or not the criteria were met were solved by discussion and a third researcher was consulted in the event of disagreement. There was disagreement in eight of the 91 studies (8.8%).

For data extraction and analyses we followed the assumptions for an integrated design of a systematic review, which indicate that qualitative, quantitative and mixed-method studies can be jointly analysed and synthesized.[80] The extraction form was developed by two researchers, discussed by the research group and adjusted in response to comments. Extracted data included information about the country of the research, the research aims and questions, methods and data collection, characteristics of participants, setting, perspective of the publication (homeless people, healthcare providers, relatives/friends, open answer questionnaire), results, strengths and limitations of the study design and key conclusions. The results were extracted with a focus on the research questions; with regard to recommendations for practice we limited ourselves to recommendations given by the authors that were related to the results found in that study. For the first five publications, two researchers extracted the data independently, without any extraction software. When necessary, adjustments were made and conflicts were resolved. For the other papers, data was extracted by one reviewer and checked by a second.

Analysis

Because our aims were 'to summarize evidence about the concerns, palliative care needs and preferences of homeless people, as well as barriers and facilitators for delivering high quality palliative care', we used the findings from the selected studies mainly to describe common themes. Thus, data was analysed using the meta-summary method[80] to identify common themes. The extracted data was classified manually into categories by sorting according to common themes, carried out by one researcher until no new categories came up. These themes were then discussed with a second researcher before discussion in the project team. In the tables the common themes are shown, indicating in which studies they occurred.

Critical appraisal of the methodological quality

The methodological quality of the studies that met the inclusion criteria was assessed by the General Appraisal instrument of Hawker et al.[81] The instrument, which is applicable to quantitative as well as qualitative studies, consists of nine elements (abstract, background, methodology, sampling, data analysis, ethics, results, transferability and implications). Each element is scored on a four-point scale (ranging from very poor to good). Scores for the various are added to give a total score. Total scores range from 9 to 36; scores less than or equal to 18 are rated as 'poor methodological quality', scores from 19 to 27 as 'moderate' and above 27 as 'good quality'. All methodological assessments were done by two reviewers independently. If there was a mismatch of more than five points, disagreements were solved by discussion. The scores of assessment can be found in Table 1, more details of the assessments can be found in Appendix 2.

RESULTS

Review selection

The review process is shown in Figure 2. We identified 3245 records through database searches, seven additional records were found through websites of organizations. After removing 1656 duplicates, 1596 papers were screened on title and abstract. Of these, the full texts of 91 were checked, resulting in 27 papers meeting our inclusion criteria (Table 1). No additional papers were found by contacting project members.

General characteristics of studies

Table 1 shows the characteristics of all the studies included. A number of authors, namely Ko et al.,[82, 83] McNeil et al.,[63, 84, 85] and Song et al.[86, 87] discussed their own same study in several papers; each paper discussed various aspects of the study. The 27 papers that were included cover 23 different studies. All studies were published in the period 1986 – 2016 and published in English. Most studies were conducted in the USA (n=15) or Canada (n=7).

Fifteen studies had qualitative designs, generally using semi-structured individual interviews and focus groups. Eight studies had quantitative designs using a variety of methods, such as an e-mail survey and a review of medical records. Of these quantitative studies, five studies evaluated an intervention. The methodological quality was assessed as good for fifteen papers, moderate for nine and poor for three (Table 1).

Setting and participants

Of all 23 studies, twelve derived data from homeless participants, nine studies from healthcare professionals engaged in caring for homeless people (including review or analysis of medical records) and two studies from both homeless participants and healthcare professionals (Appendix 3). Of the twelve studies that derived their data from homeless people and the two studies with both homeless participants and healthcare professionals, the homeless people were terminally ill in three studies (Table 1).[57, 88, 89]

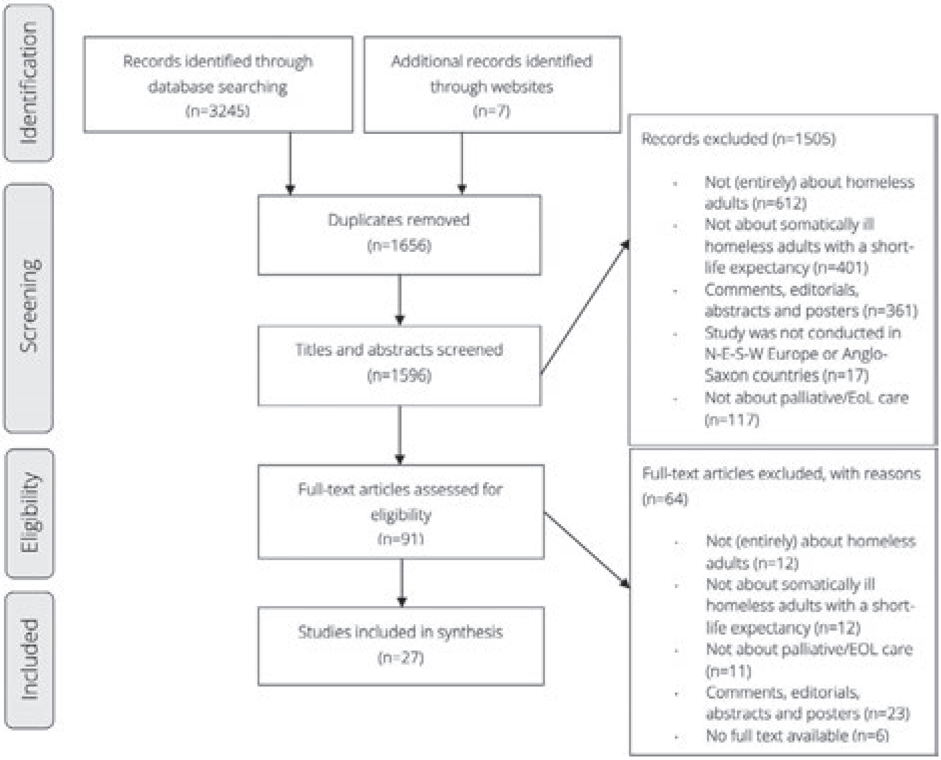

Figure 2. PRISMA flow diagram

Homeless people in the studies stayed or lived in a variety of settings. The most frequently mentioned were various types of shelters, e.g. drop-in shelters and homeless shelters. Other settings mentioned were support homes, housing facilities, hospitals and medical centres, healthcare programmes, palliative care services and hospices, hostels, social service agencies and sites or communities for homeless people (Table 1). Appendix 3 shows more information about the characteristics of the study populations. Most studies stated the age, sex and ethnicity of homeless participants. A large proportion of homeless participants were male, with percentages ranging between 60% and 100% of the study population. The average age of homeless participants varied between 43 and 65. In the studies that provided information about ethnicity, homeless people of several ethnic groups participated. The educational level of homeless participants, health status of homeless participants and characteristics of healthcare providers were reported less often.

Table 1. Characteristics of the papers included

Ref	Aim	Country	Setting	Method	Participants	n	Information on 1,2, 3**	Critical appraisal score***
89	To know more about the content of advance directives completed by homeless people who participated in a guided intervention arm	USA	Homeless drop-in shelter	Qualitative analysis of participants' responses to individual items in an advance directive*	Homeless people with a terminal illness	Homeless people (n=17)	1, 2, 3	24/20 Moderate
57	To identify the observed changes in general condition or behaviour of homeless people with advanced liver disease who may be in deteriorating health and approaching the end of life in order to better recognize an increased likelihood of death and to explore staff's experiences of death of residents	UK	Homeless shelter	Case note review, focus groups (qualitative)	Case notes about homeless people with advanced liver disease, staff members of a supporting home for homeless people	Case notes (n=27), staff members (n=13)	1, 2, 3	22/21 Moderate
59	To explore the staff members' experiences of and reasoning about the palliative care they provided	Sweden	Support home for homeless	Paired and individual conversations (qualitative)	Staff members of a support and housing home for homeless	Staff members (n=12)	1, 2, 3	34/31 Good
36	To describe challenges of caring for homeless veterans at end of life as perceived by Veterans Affairs Medical Centre (VAMC) homeless and EOL care staff	USA	Veterans Affairs Medical Centres (VAMC) with programmes for homeless veterans with a short life expectancy	E-mail survey (quantitative)	Care staff of homeless and EOL programmes	50 VAMCs	2	28/23 Moderate

Table 1. Continued.

Ref	Aim	Country	Setting	Method	Participants	n	Information on 1,2, 3**	Critical appraisal score***
11	To assess the extent to which homeless persons may underuse healthcare services even when they are at a high risk of death and to examine potential opportunities for intervention in this population	USA	Boston Health Care for the Homeless Program	Review of medical records (quantitative)	Deceased homeless adults	Medical records (n=558)	2, 3	27/25 Moderate
82	To explore the views, concerns, and needs regarding advance care planning among older homeless adults	USA	Transitional housing facility	Semi-structured face-to-face interviews (qualitative)	Homeless adults aged 60 and older	Homeless (n=21)	1, 2, 3	30/29 Good
83	To explore older homeless adults' perspectives toward good and bad deaths and their concerns regarding their EOL care needs	USA	Transitional housing facility	Semi-structured face-to-face interviews (qualitative)	Homeless adults aged 60 and older	Homeless (n=21)	1, 2, 3	30/33 Good
35	To explore how access to Toronto's palliative services can be improved to better serve the city's homeless	Canada	Providers of care for the homeless	Semi-structured interviews (qualitative)	Homeless care providers with extensive experience and experience dealing with death and dying	Registered nurses (n=3), outreach workers (n=4)	1, 2, 3	19/18 Poor
62	To determine the rate of advance directive completion using a one-on-one counsellor-guided intervention	Canada	Shelter for homeless men	Counsellor-guided intervention (quantitative)*	Chronically homeless individuals in a managed alcohol harm reduction program*	Shelter residents (n=205)	1, 2	31/33 Good

Table 1. Continued.

Ref	Aim	Country	Setting	Method	Participants	n	Information on 1,2, 3**	Critical appraisal score***
90	To identify best practice for managing the palliative care needs of clients experiencing homelessness in a community setting and to guide the development of policies for a community-based palliative care service working with these clients	Australia	Community-based palliative care service	Semi-structured individual interviews (qualitative)	Workers from hospital and community organizations	Staff members (n=6)	2, 3	27/24 Moderate
88	To explore and describe aspects of social networks that have a potential for caregiving during the terminal phase of a disease	USA	Patients of two medical centres, living in single room buildings	Semi-structured individual interviews (qualitative)	Homeless who had been diagnosed with unresectable lung cancer	Homeless (n=8)	2	21/19 Moderate
84	To identify challenges health and social service providers face in facilitating and delivering end-of-life care services to homeless illicit drug users	Canada	Health and social care services	Semi-structured individual interviews (qualitative)	Health and social services professionals involved in end-of-life care services delivery to homeless persons	Healthcare professionals and managers (n=50)	2, 3	29/31 Good
85	To identify barriers to the end-of-life care system for homeless populations and generate recommendations to improve their access to end-of-life care	Canada	Health and social services	Semi-structured individual interviews (qualitative)	Health and social services professionals involved in end-of-life care services delivery to homeless persons	Healthcare professionals and managers (n=54)	2, 3	32/35 Good

Table 1. Continued.

Ref	Aim	Country	Setting	Method	Participants	n	Information on 1,2, 3**	Critical appraisal score***
63	To explore the role of harm reduction services in end-of-life care services delivery to homeless and marginally housed persons with problematic use of alcohol and/or illicit drugs	Canada	Health and social services	Semi-structured individual interviews (qualitative)	Health and social services professionals involved in end-of-life care services delivery to homeless persons	Healthcare professionals and managers (n=54)	2, 3	32/33 Good
91	To determine the benefits and barriers of in-shelter palliative care and possible enablers to future implementation in Toronto	Canada	Three shelters	Semi-structured individual interviews (qualitative)	Shelter-based social service providers	Case workers, social support workers, shelter managers (n=5)	2, 3	23/19 Moderate
92	To examine the treatment preferences of homeless (in comparison with preferences of physicians likely to be providing care for homeless persons and patients with oxygen-dependent COPD)	USA	Homeless shelters, hospitals	Cross-sectional survey (quantitative)	Visitors of homeless shelters, physicians providing care to homeless persons, patients with COPD	Homeless (n=229), physicians (n=236), COPD-patients (n=111)	1, 3	31/32 Good
93	To improve the understanding of elderly homeless persons and to describe the living circumstances of the group, especially housing	USA	Multidisciplinary Street Team of Boston	Analysis of an intervention* (quantitative)	Elderly homeless individuals (>50)	Homeless (n=30)	2, 3	15/13 Poor
34	To explore if effective shelter-based palliative care could be provided to terminally ill homeless individuals at substantial cost savings	Canada	Shelter-based palliative care hospice	Analysis of records of a cohort and a five-member panel (quantitative)	Terminally ill homeless	Records of homeless (n=28)	2, 3	32/30 Good

Table 1. Continued.

Ref	Aim	Country	Setting	Method	Participants	n	Information on 1,2, 3**	Critical appraisal score***
94	To explore the importance of end-of-life care for homeless people and the type of concerns	USA	Sites for homeless in Minnesota	Focus groups (qualitative)	Homeless individuals	Homeless (n=57)	1, 2, 3	18 Poor
56	To understand the viewpoints of people who are homeless regarding end-of-life issues, to elucidate the barriers to good end-of-life care, and to offer insight into the most basic needs and wishes.	USA	Homeless shelter, two service organizations for homeless	Focus groups (qualitative)	Homeless individuals and social workers	Homeless (n=11), service providers (n=9)	1, 2, 3	23/24 Moderate
87	To explore the experiences and attitudes toward death and dying among homeless persons.	USA	Social service agencies which serve homeless	Focus groups (qualitative)	Homeless individuals	Homeless (n=53)	1, 2, 3	30/35 Good
86	To examine how homelessness influences concerns and desires about care at the time of death.	USA	Social service agencies which serve homeless people	Focus groups (qualitative)	Homeless individuals	Homeless (n=53)	1, 2, 3	29/32 Good
60	To improve the EOL decision-making process for homeless persons by facilitating ACP	USA	Drop-in centre	RCT comparing two types of interventions* (quantitative)	Homeless individuals	Homeless (n=59)	2, 3	32/35 Good
61	To determine whether homeless persons will complete a counselling session on advance care planning and fill out a legal advance directive designed to assess care preferences and preserve the dignity of marginalized persons	USA	Sites serving homeless persons	RCT comparing two type of interventions* (quantitative)	Homeless individuals	Homeless (n=262)	1, 2, 3	31/35 Good

Table 1. Continued.

Ref	Aim	Country	Setting	Method	Participants	n	Information on 1,2, 3**	Critical appraisal score***
95	To increase healthcare providers' understanding and insight into how to better provide EOL care for homeless people.	USA	Free urban healthcare clinic for homeless individuals	Focus groups (qualitative)	Homeless individuals	Homeless (n=20)	1, 2, 3	31/28 Good
96	To identify and examine the needs of older people who are homeless or who have previously experienced homelessness as they age and are faced with the issues of serious ill health, dying and death.	Ireland	Community where care, accommodation and support are being provided for people experiencing homelessness and those at risk	Interviews (qualitative)	Homeless individuals	Homeless (n=16)	1, 2, 3	22 Moderate
58	To explore the views of hostel staff regarding palliative and end-of-life care for the homeless population	UK	Intermediate or long stay hostels	Semi-structured individual interviews (qualitative)	Hostel workers	Hostel workers (n=7)	1, 2, 3	28/33 Good

* Method includes an intervention

** 1 = Concerns, care needs and future preferences for care and treatment of seriously ill homeless people needs; 2 = the care provided: barriers and facilitators; 3 = recommendations for practice

***Score 1 = HTK, score 2 = AJEV

Concerns, care needs and future preferences for care and treatment of seriously ill homeless people

Table 2 shows the main results we extracted from the publications regarding concerns, care needs and future preferences of seriously ill homeless people about the end of life. The 'concerns' considered problems that homeless people had or issues they worried about. Concerns in the physical domain often were about serious illnesses and physical distress.[87-89] Psychological concerns were mostly related to fear of death and dying.[56-58, 83, 86, 87, 96] Social concerns were mostly about being a burden to others.[58, 83, 86, 89] Spiritual concerns were hardly mentioned and were regularly described as consisting of fear of the unknown.[56, 89] Frequently mentioned concerns about care included homeless people expecting end-of-life care to be poor.[35, 59, 82, 87]

Care needs concerned topics about the care (including palliative care) that homeless people preferred or expected. Attitudes and behaviour of healthcare professionals was a theme that was often mentioned, in which treatment with respect and dignity was stated most often.[86, 89, 94] Needs concerning involvement of the family appeared to be somewhat variable. Some of the homeless want family nearby, others do not want to burden their families[86, 94] and some request some type of social contact with family and friends before dying even if they are estranged.[57, 83] Needs for treatment and care appeared to be an important theme; the most frequently mentioned were spirituality and religion.[56, 82, 83, 96] Although few spiritual concerns were mentioned in included studies, spirituality and religion appear to be important encouraging factors for homeless people when it comes needs for treatment and care. In addition, most mentioned was the possibility of expressing various concerns, such as anonymity, estrangement and maintaining control: advance care planning or documentation can help express these concerns.[56, 86, 87, 95] Only one study looked at the domain 'after death', showing an explicit and detailed desire that homeless people's bodies be laid to rest in a personally and culturally acceptable manner.[86] 'Preferences for future care and treatment'; was where we grouped the preferences homeless people had in advance for the end of life; we grouped them into three domains, namely treatment preferences, the dying process and surrogate-decision making. Regarding the first domain 'treatment preferences', a lot of studies mentioned resuscitation and life-sustaining treatments, preferences were found to vary among subgroups of homeless people.[61, 62, 89, 92] In terms of the wishes for the dying process, a natural death was mentioned most often,[56, 83, 94] e.g. no prolonged life support without hope of functional recovery. Lastly, surrogate decision-making appeared to be an important theme for homeless people at the end of life, in particular the naming of proxy to make decisions.[61, 62, 86]

Table 2. Concerns, care needs and future preferences for care and treatment among seriously ill homeless people

Concerns	Care needs	Preferences for future care and treatment
Physical domain • Concerns about serious illnesses and physical distress related to specific illnesses, e.g. heart disease, open heart surgery, multiple broken bones[87-89] • Fear of inappropriate and/or prolonged medical care and heroic treatments[56,86] • Concerns about losing control over basic physical functions[83] • Concerns about being off medication[89] Psychological domain • Fear of death and dying, partly due to bad and lonely deaths of other homeless people[56-58,83,86,87,96] • Concerns about psychiatric disorders, in particular schizophrenia, mental illness, depression, affective disorder, anxiety, hearing voices, PTSD, bipolarity, uncontrolled anger[83,89] • Fear of experiencing death by accident or violence[56,83] Social domain • Concerns about being a burden on others[58,83,86,89] • Fear of losing independence[56,83,89] • Concerns about dying alone[56,83,89] • Worries about relationships with friends and family, e.g. family not being notified, leaving a wife and children behind, lack of resources to cover burial costs, being alone, family may not show up[56,89] • Fear of dying anonymously and no-one will be there to view their body[56,86] • Fear that family may not know wishes, peers might help to a certain extent, but no assumptions of this help[56] • Concerns about being homeless[89]	Attitudes/behaviour of healthcare professionals • Homeless patients want to be treated with respect and dignity, e.g. treat patients like others, no judging/labelling, accept patients for who they are[86,89,94] • Physicians are preferred as decision-makers regarding end-of-life care treatment[82,92] • Wish for companionship at the end of life, seeking relationship-centred, compassionate care[86,95] • Acknowledging emotions; many homeless people have experienced tremendous losses in life. Intensifying of emotions could interfere with participants' future decision-making process[95] • Providers who tell the truth[89] • Providers who respect privacy[89] • Providers should recognize cultural differences, this will serve as the basis for increasing sensitivity and trust[82] • Death and dying are perceived to be temporary matters, and many thought dwelling on the end of life situation was undesirable[82] • Patients prefer to use a GP who specializes in the care of the homeless[57] Involvement of family • Some of the homeless persons want family nearby, others (often a majority) do not want to burden their families[86,94] • Requests for some form of social contact with family and friends and resolving remaining issues and disagreements before dying even if they were estranged[57,83] • Participants who are not in contact with their family desire to be placed in a familiar environment where they could be surrounded by a social support network[83]	Treatment preferences • *Resuscitation:* - Almost all homeless persons expressed a preferences to receive cardiopulmonary resuscitation (CPR) in the event of cardiorespiratory arrest if there was a chance of returning to their current state of health***[62] - Homeless people want resuscitation more than physicians and patients with COPD[92] - Homeless men are more likely to want resuscitation than homeless women[92] - Non-white homeless people are more likely to want resuscitation or life-sustaining treatment than white homeless people[61,92] • *Life sustaining treatment:* - Nearly half of the homeless participants (8/17) indicated that they would want all measures taken, a smaller proportion (7/8) would prefer limited treatment[89] - Between 20% and 37% want life-sustaining treatment depending on condition (lowest in case of dependence, highest for unconsciousness[61] - 31% desired no life-sustaining treatment if dying[61] - In the scenario of a permanent coma or severe dementia, homeless people are more likely to want CPR or mechanical ventilation than physicians [92]

Table 2. Continued.

Concerns	Care needs	Preferences for future care and treatment
Spiritual domain • Fear of the unknown[89] • Fear that the death rituals for their culture may not take place[56]	Treatment/care options • Spirituality and religion are important components in defining life and death[56, 82, 83, 96] • Desire for advance care planning/documentation; this relates to several concerns (anonymity, estrangement, maintaining control, discussion with significant others), with trust as an important condition[56, 86, 87, 95] • Requests for detoxification[57] • Patients predominantly interact with GPS for prescriptions[57] • End-of-life care focus on pain control[56] • Asking how they would like to be remembered, including post-death wishes[89]	Wishes for the dying process • A natural death (dying in sleep, no artificial medical interventions to prolong life, avoiding heroic measures such as prolonged life support without hope of functional recovery)[56, 83, 94] • Homeless people want to have their wishes represented when they become incompetent and/or dying[82, 95] • Dying peacefully, taking care of inner conflicts, being able to express love, apologizing to family and others[83] • Death without suffering[83]
Care domain • Many patients had bad experiences from previous healthcare and social service encounters, homeless persons believe that care will be poor at the end of life[35, 59, 82, 87] • Concerns about lack of insurance and receiving sub-optimal treatment due to discrimination by HCP's/insurance companies[89, 95] • Concerns about what will happen to the body after death, fear that their body will not be respected or taken care of[56, 86] • Homeless people who completed an advance direction worry more about the care they would receive if seriously ill or dying[35] • Fear of what will happen if no-one can speak for them[56] • Fear of being transferred to a nursing home[96]	After death • Explicit and detailed desires that homeless people's bodies be laid to rest in a personally and culturally acceptable manner (due to the misconceptions and fears about body disposal)[86]	Proxy decision-makers • A significant proportion of homeless people named a proxy decision-maker***[62] • Nearly all chosen surrogate decision-makers were not related; most often they were service providers, friends or (occasionally) romantic partners[86] • 29% to 34% of homeless participants showed a (written) preference for surrogate decision-making[61] • 87% of homeless participants named a family member as a surrogate decision-maker in their completed advance directives[61]

*These are specific symptoms and concerns of homeless people with advanced liver disease

** 8 patients with lung cancer

*** When completing an advance directive

The care provided: barriers and facilitators

Table 3 and Table 4 show the results in terms of the barriers and facilitators for providing care to seriously ill homeless people. To give an overview of those barriers and facilitators, we identified and described three perspectives. The perspective called 'barriers and facilitators relating to the homeless person' revealed a lot of barriers and some facilitators. The most commonly mentioned barriers were themes related to receiving healthcare, such as end-of-life care not being a priority and living on a day-to-day basis,[11, 82, 84, 94, 96] themes regarding social relationships such as the absence of support from family members and only having small networks,[56, 59, 88] and themes about health-related and other behaviour, such as the limited insights homeless people have into their own health.[57, 93] Although studies reported more barriers than facilitators within this theme, a widely mentioned facilitator for homeless people was the importance of religious beliefs and spiritual experience.[83, 86, 95]

Contrasting with the previous theme, a lot of studies in the theme 'relating to the interaction between homeless people and healthcare professionals' described facilitators and substantially fewer studies described barriers between homeless people and professionals. The attitudes of healthcare providers towards homeless persons proved to be a major theme, e.g. building and establishing relationships of trust.[57-59, 63] The treatment of homeless people was also reported to be an important theme as facilitator, e.g. a pragmatic and flexible approach from staff.[59, 63, 91] Furthermore, providing activities and therapies was also often mentioned as facilitator for the interaction between homeless people and healthcare professionals, e.g. counsellor-guided advance directive completion.[60-62] Feelings of being ignored, discriminated against and disrespected by healthcare providers and a lack of trust were often mentioned as barriers.[35, 56, 58, 59, 84, 91, 94] For barriers and facilitators in the third theme, 'relating to healthcare professionals', substantially more barriers than facilitators were mentioned. The most frequently mentioned barriers were lack of knowledge and skills of professionals, e.g. the difficulty for staff in determining when a patient is nearing the dying phase and meeting the palliative care needs.[11, 56-59] Another barrier mentioned relating to healthcare professionals was the organization of care, e.g. minimal access to palliative care.[35, 57, 84-86, 90, 94] On the other hand, facilitators relating to the knowledge and skills of professionals such as optimizing management of pain, symptoms and functional decline were often mentioned.[34, 36] Facilitators regarding the overall organization of palliative care for homeless people were not found in many papers; one facilitator mentioned in a Canadian study by Podymow et al. was in-shelter hospice care, which also substantially lowers the costs.[34]

Table 3. The care provided care: barriers relating to homeless people, interaction between homeless people and healthcare professionals, and healthcare professionals

Relating to the homeless people	Relating to the interaction between homeless people and healthcare professionals	Relating to the healthcare professionals
In relation to receiving healthcare • End-of-life care is not a priority; to obtain the basic necessities of survival and living on a day-to-day basis takes precedence over efforts to obtain health and/or end-of-life care[11, 82, 84, 94, 96] • Drug and/or alcohol dependence and non-disclosure of illicit drug use may lead to decreased opportunities for persons to remain in their usual abode or to receive and/or adhere to treatment at traditional end-of-life services due to anti-drug policies[59, 84, 85, 96] • Planning care activities and attending for hospital appointments is often difficult: patients frequently do not adhere to expected routines, arrangements for health service activities, GP and hospital appointments and often have to be reminded about their condition, homeless people are reluctant due to a long waiting time and/or they self-discharge[57, 59, 96] • Very late stage of seeking help and thus medical problems that are difficult to handle and multiple admissions before death[11, 59, 90] • A lot of homeless people are unwilling to accept the recommended treatment[90, 93] • Pain and symptom management of homeless persons who use illicit drugs (high levels of opioid tolerance) and specialists who are unable or unwilling due to fears that they would be liable for adverse reactions[84] • Lack of health insurance[11]	• Feelings of being ignored, discriminated and disrespected by healthcare providers and a lack of trust and suspicion (e.g. shown disrespect, withholding of pain medication, inappropriately short hospital stays, not respecting wishes) that initially has to be overcome before any treatment could be started[35, 56, 58, 59, 84, 91, 94] • End of life is an uncomfortable topic; some homeless persons do not want to know about their own diagnoses, do not want to talk about their health concerns or are incapable of talking comfortably about death and dying[35, 58, 82] • Barriers to achieving the level of communication and connections homeless people desired, e.g. too little time to chat with staff and volunteers because they were busy[35, 96] • Patients engage with internal services such as key and substance misuse workers but rarely with mental health or social workers[57]	Knowledge and skills • It is difficult for staff to determine when a patient is nearing the dying phase and to establish palliative care needs; staff members' notions of palliative care vary and opportunities to prevent deaths are being missed[11, 56-59] • Deaths of homeless patients are often sudden, staff were often upset[56, 57] • Hostel staff are often not able to plan for end-of-life care with patients[57] • Medical intake personnel (in hospital) do not know how to deal with a homeless person[90] • Little opportunity for funding or training shelter staff in palliative care[91] • Working with limited medical information[58] • Staff of healthcare services not being knowledgeable about the unique issues facing the homeless[35] • Often difficult to interpret reaction of patients suffering from mental illness and/or illicit drug use[59] • Trying to solve all of a patient's problems at once is seldom successful[59]

Table 3. Continued.

Relating to the homeless people	Relating to the interaction between homeless people and healthcare professionals	Relating to the healthcare professionals
In relation to social relationship • No support from family members or relatives and small networks and many without trusted peers[56, 59, 88] • A lot of homeless people who have psychiatric illness and are paranoia, refuse multiple offers of housing[93] • Travel and access to transport when living in a rural area[96] • Relationships between healthier and sicker patients are complex and sometimes manipulative to gain access to further alcohol[57] • Death and dying does affect other homeless patients[57] In relation to (health) behaviour • Limited insight into their condition or unable to acknowledge illnesses[57, 93] • Problems relating to alcohol and/or drug addiction, such as denial of addiction, bingeing, ignoring of risks of overdose[57] • Aggressive or changing behavior[57] • Unwillingness to pay attention to their personal hygiene[57]	• Homeless people express many misperceptions and uncertainties about surrogate decision-making[86] • Homeless persons often describe their problems in a jumbled manner, understanding the most prioritized needs is thus not always easy[59]	Organization • Access to palliative care, primary care and/or preventive services is minimal (due to competing priorities, attitude of healthcare professionals, anti-drug policies, not conforming to procedures, healthcare system's nonadherence to harm reduction strategies, a lack of caregiver support and/or financial resources) and a significant proportion of homeless persons may be underusing healthcare[35, 57, 84-86, 90, 94] • Lack of appropriate housing, beds, respite or hospice facilities and programmes and care sites for homeless people at the end of life and limited resources for providing end-of-life care[36, 63, 86, 91, 93] • Poor coordination and/or communication between secondary care and hostel staff or homeless programmes and end-of-life programmes[36, 57, 58] • Setting treatment goals according to routine guidelines were often regarded as unrealistic in this context[59] • In-shelter palliative care means more work for staff and a greater burden for a workforce already thinly stretched[91] • Cost of medications that was not covered by the benefits and had to be paid for in cash[88]

GP = General Practitioner

Table 4. The care provided: facilitators relating to homeless people, interaction between homeless people and healthcare professionals, and healthcare professionals

Relating to the homeless people	Relating to the interaction between homeless people and healthcare professionals	Relating to the healthcare professionals
• Primacy of religious beliefs and spiritual experience or connection; religious beliefs are a core component of homeless people's end-of-life beliefs and experiences; it provides comfort and solace through spirituality/religion[83, 86, 95] • Allow for patients to have "unscheduled" space to share their life stories and to acknowledge those stories[59] • Freedom is essential to homeless people[56] • Other homeless patients could become involved in the care of fellow residents who are unwilling to work with services[57] • Among homeless people who filled out an AD, there were increasing in plans to write down end-of-life wishes, plans to talk about these wishes with someone and less worrying about death[60]	Attitude towards homeless people • Building and establishing trusting and/or family-like relationships and contact by interacting with patients in everyday situations and staff taking a supportive and/or advocating role in encounters with other health providers[57-59, 63] • Upholding homeless residents' dignity and maintaining pride by showing human kindness, respect, love, comfort and to name accomplishments and elements of character[58, 59, 87, 89] • Staff must never judge a homeless person as impossible, or in terms of failure, and always patiently give them a new chance[59] • Persistence to engage the patient and to keep them engaged, with a constant effort required for effective follow-up[90] Treatment of homeless people • A pragmatic approach by staff, facilitating flexible care solutions, such as the choice where to die and accepting that planned activities may not happen or need to be cancelled[59, 63, 91] • Compassionate healthcare providers who are present (e.g. not leaving the individual alone during or after death[59, 63, 86] • Staff can respect individual's habits and needs (also if rather unconventional, friends and preferred surroundings (e.g. stay in the hostel) when they are at the end of life[35, 57] • Staff only contacting family members at the end of life if the patients so request[59] • Formulating simple messages towards patients about death and dying[59] Activities / therapies • Advance directive completion rate is higher when counsellor guided that compared to no counsellor guidance[60-62] • Low-threshold strategies have an increased capacity to deliver end–of-life care services[84, 85] • Harm reduction services (e.g. clean needle exchange, medically prescribed alcohol) are a critical point of entry to and source of end-of-life care and support for homeless people who use alcohol and/or illicit drugs and are unable to access services[34, 63] • Physical contact can enable feelings of safety and appreciation in patients (not all patients)[59] • Memorial services held by staff to give staff members and other patients or visitors a moment to remember and say farewell[59]	Knowledge and skills • Optimizing management of pain, symptoms and functional decline, e.g. by palliative care consultations[34, 36] • End–of-life care and addiction training[84] • To preserve integrity in being close to patients[59] • Treatment for symptoms and distress is often provided simultaneously with the use of illicit drugs and/or alcohol, this necessitates special skills for identification of signs and symptoms and treatment regimens[59] Organization In-shelter hospice care; without it, a large part of homeless patients might not have sought care or received services and died homeless with no pain and symptom management[34] • Costs of in-shelter hospice care are substantially less than the estimated costs of traditional care for the same patients[34]

AD = Advance directive

Recommendations for practice

A significant number of studies made evidence-based recommendations for practice regarding (palliative) care for seriously ill homeless people, themes are shown in Table 5 and more detailed information on the themes is shown in Appendix 4. Training, education and knowledge; delivering care, and overall organization appeared to be the comprehensive themes. A very often mentioned recommendation relating to training, education and knowledge was training for staff working with homeless people to provide palliative care as health deteriorates and death approaches.[35, 84, 85, 91, 96] Related to recommendations on delivering care, addressing themes related to a patient-centered approach concerning dignity and asking questions about death and dying in advance directive formats were most often mentioned.[35, 58-61, 83, 89] Trustful and respectful relationships were also mentioned as a recommendation for delivering care; as well as attention for different domain of concerns of homeless people compared to healthcare providers, flexible programs and availability and support after death. Recommendations concerning overall organization of palliative care to homeless people concerned mostly the availability of accommodation, involved persons and coordination, policies and guidelines and partnering and exchange of knowledge between organizations. This included partnering social communities with the end-of-life care system, such as accessibility and availability of palliative care beds.[91, 96]

Table 5. Themes regarding recommendations for practice

Training, education and knowledge	Delivering care	Overall organization
• Training regarding providing palliative care for (older) homeless people and their specific needs • Education about addressing preferences, advance directives, after death wishes and surrogate decision-makers	• Patient-centred approach • Trustful and respectful relationships •Reliability, experience, sensitivity and commitment of healthcare professionals • Attention to various areas of concern of homeless people • Flexible programmes and availability • Support after death	• Availability of accommodation • People involved and coordination • Hospital discharge policies • Policies and guidelines • Partnering and exchange of knowledge between organizations

DISCUSSION

This systematic review summarizes 23 relevant studies: fifteen qualitative and eight quantitative studies. The concerns, needs, preferences and the barriers and facilitators described in these studies often concern the attitudes and behaviour of healthcare professionals. In particular, a respectful approach and respect for dignity proved to be important to homeless people for good quality palliative care. In addition, the limited knowledge and skills of professionals turned out to be important barriers in palliative care for homeless people.

Related to that, recommendations in the studies included often concern a need for training, education and broadening of knowledge. This emphasis on change of attitudes and behaviour of healthcare professionals so that the needs of homeless people can be met was less apparent in the three other reviews that also concerned palliative care for homeless people.[31, 73, 76]

Furthermore, many of the barriers we found in the studies proved to be related to the homeless people themselves. End-of-life care is often not a priority for them. Besides this, homeless people are often dependent on drugs, have limited insight into their condition and little support from family and relatives, which all make good palliative care extra challenging. Moreover, the views of homeless people about what is needed for good palliative care might differ from the views of healthcare providers. Hence, palliative care for homeless people needs a tailored approach and dialogue between healthcare providers and homeless people, as recently mentioned by Tobey et al.[71] These outcomes are in line with the findings of the three other reviews. [31, 73, 76]

As this review included relatively many studies and the methodological quality of the majority of studies was rated as good, it provides good insights into what is presently known with regard to palliative care for homeless people. At the same time, the review also sheds light on gaps in that knowledge. A large majority of the studies were conducted in the USA and Canada. More studies from other countries are needed as it is very well possible that differences in culture, the organization of homeless care and the organization of healthcare could lead to different results for different countries. It remains for instance to be seen whether spirituality and religion – which proved very important to homeless people in this study – will be as important in more secular countries such as the Netherlands.

Furthermore, the studies that had qualitative designs often provide important insights into the experiences and ideas of homeless people and their care providers that are helpful in initiatives aimed at improving the care. Although this review mentioned that homeless people get minimal access to palliative care, primary care and/or preventive services, no details are known about homeless people who completely avoid care. If healthcare providers want to provide tailored palliative care to the entire target group, more research is needed into palliative care for homeless people who avoid care. Because the homeless people who avoid care are hard to reach, it is advisable to do participatory observation or to interview people who use successful methods to reach them, such as street pastors. Finally, more information is needed about healthcare providers who provide palliative care to homeless people. The studies included mostly concerned characteristics of homeless people, but little is known about the background characteristics in terms of the experience and preferences of healthcare providers. Future studies can study the healthcare professionals. This can help provide tailored training, education and knowledge for healthcare providers.

Our review also included intervention studies that provide information about interventions for tailoring palliative care to the needs of homeless people. Several studies indicated advance care planning and documentation as a potentially effective way of encountering the concerns and needs of homeless people, such as a fear of death, anonymity, estrangement, maintaining control and discussions with significant others. These studies were also included in the review by Sumalinog et al. that focused on interventions.[73] In that review, the methodology of these studies was rated at between poor and fair, which is lower than our methodological ratings. This can be explained by the fact that we used an assessment tool that can be used for various types of studies, while Sumalinog et al. used a tool that was appropriate for assessing whether intervention studies provide strong evidence for the intervention being effective. While this shows that there is no strong evidence for the interventions being effective, the results of these studies can provide pointers to help develop new interventions and study them thoroughly.

Strengths and limitations

One strength of this systematic review is that it looks at the concerns, care needs and preferences, barriers and facilitators and recommendations for practice, thereby providing a broad overview of topics that are relevant to palliative care for homeless people. In addition, the broad inclusion criteria resulted in a large number of studies being included (given the limited size of the field being researched). Moreover, this review combines both qualitative and quantitative studies. Finally, another strength of this systematic review is that doing a grey literature search meant that we also included studies by organizations working in the field, such as Simon Communities and St. Mungo's.

An initial limitation of this study is that the definition and terminology of palliative and/or end-of-life care differ according to the study. Studies may therefore include other aspects of palliative or end-of-life care while using the same definition and terminology. A second limitation is that both studies of seriously ill homeless people and studies of homeless people who expressed their expectations about being seriously ill have been included. Expectations about the end of life in advance may differ from the reality later. Another limitation was that, although we aimed only to summarize the recommendations from the studies' results, it is was not always certain that the recommendations were not also reflections of the author's opinions. As a fourth limitation, this systematic review lacks studies in published in languages other than English. Finally, a methodological limitation was that in some studies it was difficult to assess the methodological quality because some information was missing. It is possible that in those cases the actual study was conducted in a more thorough way than reported on in the article.

CONCLUSIONS

Homeless people at the end of life experience a range of problems and barriers concerning access to palliative care. A tailored, flexible and low-threshold approach consisting of awareness about the fear of death among homeless people (as well as priorities and needs of homeless people other than those assessed by healthcare professionals) can be used to help provide appropriate care in good time. This tailored, flexible and low-threshold approach should at least involve awareness of the concerns of homeless people (fear of death and negative experiences with healthcare providers). This requires sensitivity and patience of healthcare professionals. In addition, awareness about the meaning of dignity and respect to the homeless patient is important when it comes to understanding the needs of homeless people, as well as recognizing important components such as religiosity and documentation of future preferences. Finally, healthcare professionals need to be aware that future preferences may be different for homeless patients compared to a non-homeless patient, and therefore ask specific questions about it. Training, education and experience of healthcare providers can help accomplish this.

Kan ik iets voor je zijn
In je grote gemis
Omdat wie je zo liefhad
Er nu niet meer is?

De Dijk

CHAPTER 3

Care avoidance among homeless people and access to care: an interview study among spiritual caregivers, street pastors, homeless outreach workers and formerly homeless people

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ABSTRACT

Background. Because of their poor health and social vulnerability, homeless people require specific care. However, due to care avoidance, homeless people are often not involved in care. This study aims to get insights into reasons for and kinds of care avoidance among homeless people and to provide suggestions to reach this target group.

Methods. Semi-structured individual interviews were conducted among street pastors (n=9), spiritual caregivers (n=9), homeless outreach workers (n=7) and formerly homeless people (n=3). Participants were recruited by purposive sampling in the four major cities in the Netherlands (Amsterdam, Utrecht, Rotterdam, The Hague). The verbatim transcripts were analysed using thematic analysis.

Results. The term *care avoidance* was perceived as stigmatizing. Care avoidance is found to be related to characteristics of the homeless person (e.g. having complex problems, other priorities) as well as of the system (e.g. complex system, conditions and requirements of organizations). The person-related characteristics suggestions to involve homeless persons include tailoring care and building relationships, which might even be prioritised over starting care interventions. Setting limits on behaviour without rejecting the person, and an attitude reflecting humanity, dignity and equality were also important factors in making care more accessible and lasting. As regards system-related characteristics, the suggestions include clear information and communication to homeless people who avoid care as being crucial in order to make care more accessible. Other suggestions include quiet and less busy shelters, a non-threatening attitude and treatment by professionals, self-reflection by professionals and finally a change of policy and legislation regarding available time.

Conclusions. Reasons for care avoidance can be found in the interplay between both the individual and the system; measures to reduce care avoidance should be taken at both levels. These measures are centred on lowering the barriers to care *inter alia* by incorporating building trust and understanding into the care provided.

BACKGROUND

Because of their poor health and social vulnerability, people who are homeless require specific care. In this paper, we refer to homeless people as those who have unstable housing. They may use social day or night shelters including hostels, or avoid these accommodations and stay on the street. People living and sleeping on the streets or without fixed addresses also belong to this group. Unhealthy lifestyles, addiction and somatic morbidities such as lung diseases or cancer are common among the homeless[4, 97, 98] and morbidity rates are high.[17, 70, 99, 100] Moreover, intellectual disabilities and mental health problems are more prevalent in this group when compared to the general population and many homeless people face financial problems.[7, 10, 101, 102] Homeless people therefore need complex, multidimensional care. However, several studies have shown that homeless people have unmet care needs and poor access to care, and (partially) avoid or underuse this care.[11-16, 103, 104] Care avoidance is defined as partly or completely turning away from threat-related cues, which results in not being able or willing to be involved in care that is necessary.[13, 105] Care avoidance can be experienced as a problem by the homeless person (e.g. incomprehension or unmet needs) or the professionals (e.g. refusing necessary care or cancelling appointments). In this article, we use the term '*care avoidance*', by which we mean 'no access to care due to unwillingness or inability of homeless people or professionals, or the interaction between them'.

Care for the homeless can be divided in two types: i) social care for day and night shelters, housing, income and (social) activities on the one hand, and ii) medical care for addiction, mental and physical health issues on the other hand,[106] which we call 'healthcare'. Until now, most studies have focused on care avoidance in the context of healthcare. However, care avoidance can occur in broader areas, such as social issues, financial issues and housing issues. It is therefore crucial to cover all these areas by focusing on care avoidance in the context of both social and healthcare.

Although some evidence is available on unmet care needs of homeless people, poor access to care, and avoidance or underuse of care,[11-16, 103, 104] studies into the nature of their care avoidance are scarce. This might be explained by the fact that it is hard to include homeless people who avoid care as a participant due to unfamiliarity with the care system.[9, 107] In the Netherlands, there is anecdotal evidence that spiritual caregivers and street pastors are better able to reach homeless people who avoid care than other professionals, due to activities such as establishing contact by visiting homeless people on the streets, and by providing help with practical matters. The nature of the contact between the homeless and both spiritual caregivers and street pastors is often characterized by low-threshold conversations and respectful relations without the consequence of being referred to care. Including them in a study could provide more insights into homeless people's perspectives as well as those of care and healthcare professionals.

This study aims to get insight into the reasons for care avoidance, ways in which it occurs and how to deal with it by interviewing spiritual caregivers and street pastors. This provides more insight into the phenomenon of care avoidance according to people close to them, while at the same time more insight into methods is given for reaching this target group. The research questions were:

1. Why do spiritual caregivers and street pastors think homeless people avoid social care or healthcare?
2. Based on their experiences with reaching care avoiders, what suggestions do spiritual caregivers and street pastors have for making care accessible for homeless people who avoid care?

METHODS

Design and participants

This study was designed as a qualitative study using in-depth interviews with spiritual caregivers and street pastors. A qualitative design was used to better understand the unexplored field of care avoidance, and for exploring the nature and context of care avoidance among the homeless. Differences between street pastors and spiritual caregivers concern religious background (street pastors have a religious background, spiritual caregivers not necessarily), aim (street pastors are specifically aimed at homeless people and spiritual caregivers can also be aimed at people in other contexts) and employment (street pastors are often employed by a church, spiritual caregivers often work within or for a healthcare organization). Participants were recruited using purposive sampling in the four major cities in the Netherlands (Amsterdam, Rotterdam, The Hague and Utrecht). We tried to ensure as much variation as possible in characteristics such as sex, age, religious beliefs, and city and recruited through the existing professional networks of the project team using the snowball method. Potential participants were contacted by telephone and informed by a letter about the topic and procedure. Beforehand, we intended to interview only spiritual caregivers and street pastors. During data collection, however, we found that besides spiritual caregivers and street pastors, some other homeless outreach workers such as street doctors or people who provide food also had very useful information on the topic. The information provided by these other homeless outreach workers corresponded with that of the street pastors and spiritual caretakers. This can be explained by the fact that they all use a similar working method: i.e. low-threshold contact. We therefore decided to include seven of them as well. In addition, we were given the opportunity to include former homeless people. In the first interviews with street pastors and spiritual caregivers, the researcher was told that interviewing former homeless perspective would enrich the perspective of street pastors and spiritual caregivers. We therefore decided to include three of them. In the end, 40 people were invited for interviews and 28 actually participated. Seven people did not respond, three were ineligible because they did not have contact with the target group, and two were not interested. In-depth interviews were held with nine spiritual caregivers, nine street pastors, seven other homeless outreach workers and three formerly homeless people. Characteristics of the participants are shown in Table 1. The number of street pastors that participated was high compared to the number of spiritual caregivers, especially considering the fact that the population of street pastors in the Netherlands is considerably smaller than the population of spiritual caregivers and the population of other homeless outreach workers. All participants were experienced in approaching people who avoid formal care, or were themselves formerly homeless persons who avoided (parts of) care. We followed the consolidated criteria guidelines for reporting qualitative studies (COREQ).[108] This checklist consisted of three domains: (1) research team and reflexivity (among which personal characteristics and relationship with participants), (2) study design (among which theoretical framework, participant selection, setting, data collection), and (3) analysis and findings (among which data analysis and reporting). We took account of all items from the checklist when designing the study and article.

Ethics

Participants signed a consent form prior to the interview. This form contained information about the aim of the research and interview, global information about the interview topics, the confidentiality of the information provided and the guarantee of anonymity of quotes in publications. All participants received a gift voucher for their participation. Transcripts were anonymized after transcription to ensure anonymity of participants. Access to the data was limited to three researchers.

Data collection

Data was collected from April 10 to October 6, 2017. All interviews were performed by the same researcher (HK), who was formerly employed by a homeless shelter and the Salvation Army, and is currently involved in palliative care for the homeless. Affinity with the topic of care avoidance arose when the researcher noted in previous studies that due to care avoidance a part of the homeless population is not involved in palliative care.[109, 110] All interviews were conducted at the participant's location of choice, which was often the organization where the participant was employed, and in some cases at the participant's home. The length of the interviews varied between 45 minutes and one hour. The interviews consisted of open questions and were guided by a semi-structured topic list, which was developed by two researchers (HK and BO) The topic list is shown in Table 2. This topic list evolved over time: some interview questions were deleted because they did not fit within the timeframe and the order of the subjects was slightly modified. Data saturation was discussed several times and after about 20 interviews no new information was found and no new themes emerged from the data.

Data analysis

All interviews were audio recorded and transcribed verbatim. Written summaries were sent by e-mail to participants to evaluate correctness and validity. We followed the principles of thematic analysis.[111] First, transcripts were read and reread before analysis by HK and BO.

Transcripts were then coded independently by two researchers (HK and KE) using Atlas.ti 7 and common themes were identified. Data from the first three interviews was analysed and discussed by HK and BO. After discussion, HK and BO decided that the themes already identified covered the important fragments from the transcripts, but that some codes had to be placed under other themes. Additionally, some topics needed to be highlighted more during the interviews that followed. Subsequently, all remaining transcripts were analysed and coded by HK. After that, codes were finally grouped into themes by HK and discussed with a second person (KE). Themes and interpretations were regularly and extensively discussed with BO, KE, JG, AV, HK through a draft report of the analysis and the themes identified.

Table 1. Characteristics of participants (n=28)

Participant	Profession	Sex	Age range (years)[a]	City[d]	Religious beliefs	Experience (years)[b, c]
#19	Spiritual caregiver	F	55-60	4	Catholic	1
#9	Spiritual caregiver	F	25-30	3	Humanist	3
#10	Spiritual caregiver	F	50-55	4	Protestant	7
#17	Spiritual caregiver	M	35-40	1	Humanist	8
#8	Spiritual caregiver	F	50-55	3	Protestant	9
#3	Spiritual caregiver	F	60-65	2	Protestant	10
#11	Spiritual caregiver	F	60-65	4	Protestant	10
#16	Spiritual caregiver	M	60-65	4	Protestant	15
#25	Spiritual caregiver	F	45-50	2	Protestant	15
#2	Street pastor	M	60-65	1	Protestant	3
#5	Street pastor	M	60-65	3	Catholic	5
#18	Street pastor	M	50-55	3	Protestant	6
#4	Street pastor	M	60-65	2	Protestant	9
#12	Street pastor	M	60-65	4	Protestant	9
#24	Street pastor	F	60-65	2	Protestant	11
#1	Street pastor	F	50-55	1	Protestant	13
#6	Street pastor	F	50-55	3	Protestant	14
#14	Street pastor	F	55-60	2	Catholic	14
#27	Formerly homeless person	M	50-55	1	None / NR[e]	1
#28	Formerly homeless person	M	45-50	2	None / NR	10
#22	Formerly homeless person	M	65-70	1	None / NR	10
#15	Homeless outreach worker	M	55-60	2	None / NR	1
#23	Homeless outreach worker	F	25-30	1	Protestant	8
#7	Homeless outreach worker	F	45-50	3	Catholic	11
#20	Homeless outreach worker	F	55-60	1	Protestant	12
#21	Homeless outreach worker	M	35-40	3	Protestant	13
#26	Homeless outreach worker	M	45-50	4	Protestant	14
#13	Homeless outreach worker	M	55-60	4	Protestant	26

[a] Mean age 52.8.

[b] Mean experience 9.8 years (formerly homeless people excluded).

[c] In case of formerly homeless people: years of living on the streets.

[d] Each number represents one of the four major cities in the Netherlands.

[e] NR = Not relevant (formerly homeless people were not asked about their religious beliefs).

Table 2. Topic list for semi-structured interviews.

Care avoidance by homeless people	Care provided by participants
• Current access to care and perceived problems	• Care or guidance to homeless people
• Extent of care avoidance	• Reaching care avoiders and required expertise
• Signs of care avoidance	• Identified needs of homeless people who avoid care
• Causes of care avoidance	• Accessibility of care for target group
• Characteristics of homeless people who avoid care	• Examples of good and bad practices
• Care and aspects of care avoided	

RESULTS

After rereading the manuscripts and three stages of coding, common themes were grouped together following the research questions: factors that hamper accessible and appropriate care and possible solutions as suggested by respondents. For both categories a clear distinction could be made between themes related to characteristics of homeless people and characteristics of the care system. Furthermore, as several respondents commented on the term care avoidance, we considered this as a separate theme. We will address this theme first.

Care avoidance – an ambiguous term

"*Care avoidance*" was considered to be stigmatizing by the participants, focussing primarily on the responsibility (or lack thereof) of homeless individuals rather than design issues of the care system related to care accessibility and usage. According to participants, several issues prevent homeless people from being involved in care including the way the care system functions and the fact that it can be difficult to access care. Participants therefore emphasized the importance of also looking at the inadequacy or inaccessibility of care.

> *"So we're building a system, and the homeless are left outside it because they either can't fit or won't fit in it – or both. And then we punish them by saying that they're avoiding care." (P15, homeless outreach worker)*

> *"They aren't care avoiders, they're just careful about what care they accept. Saying it's care avoidance is very negative. That says something about the person themselves, as if they don't want any care. What I often see is that people look for care that suits them, which may not exist." (P20, homeless outreach worker)*

It is therefore important to realize that care avoidance is about homeless people for whom care is not appropriate or inaccessible, and that it is not only a problem of homeless people. Participants gave many different reasons for care avoidance among the homeless, which we have divided into characteristics of homeless people and characteristics of the health system that hamper accessible or appropriate care. In reality, care avoidance is often a combination of these factors.

Characteristics of homeless people that hamper accessible or appropriate care

The analysis showed six themes relating to homeless people themselves that might play a role in care avoidance. The five themes are shown in Table 3 below, each theme is illustrated with a quote. As a first theme, the majority of the participants mentioned that this group is diverse and that no stereotype exists (Table 3, Q1). There are people from all sorts of cultures, ages, with different medical and social problems, and with several reasons to avoid care. Despite this diversity some common denominators related to care avoidance did emerge from the interviews. As a second theme, a common factor among homeless people who avoid care is the complexity of their problems and the number of diagnoses and labels (Table 3, Q2). Becoming homeless is often related to a variety of problems that are either medical or social in nature, such as a combination of psychiatric symptoms, addiction, intellectual disabilities, not having insurance, having debts, and housing deprivation. Also, being uninsured or undocumented was mentioned as a barrier to care. The stress and complexity of what is going on often make it difficult for homeless people to find solutions themselves. Besides, many homeless people have already been involved in healthcare for a long time, and have tried several social or medical services without success. They are often disappointed because they are not treated equally and they feel disparaged by professionals.

The third theme regarding care avoidance was that homeless people often have other priorities e.g. related to food or substance abuse due to their survival mode, which means living day to day and fulfilling basic needs (Table 3, Q3). Moreover, maintaining (self-)control in difficult circumstances (Table 3, Q4) was frequently mentioned as a fourth theme regarding reasons for avoiding care. As a fifth theme, it was stated that in cases of psychological or psychiatric problems homeless people might fear stigmatization and compulsory treatment and therefore stay away from care (Table 3, Q5).

System-related characteristics that impede accessible or appropriate care

The analysis showed seven themes that concerned the relation between care and healthcare systems and care avoidance. The seven themes are shown in Table 4 below, each theme is illustrated with a quote. Overall, participants mentioned that many homeless people experience ‘the healthcare system’ as inaccessible and inappropriate, i.e. not meeting their needs and – directly or indirectly – leading to care avoidance. According to participants, the inaccessibility of the system is caused by several factors listed below.

The first theme refers to the complexity of the system for homeless people (Table 4, Q7). Care for homeless people is, as was stated, complex, multifaceted and scattered in its organization with a wide range of shelters, hostels, psychiatric institutions and nursing homes. In addition, consultation hours vary and helpdesks have limited and different opening hours. This is especially difficult for homeless people because of their psychosocial vulnerability including their intellectual and mental disabilities. Some specific problems related to the system were reported including regional bonding (which means that someone who is homeless is taken care of in the region they come from, this implies that care cannot be provided in other region), arranging things via the Internet, different locations for arranging different things, limited opening hours, waiting lists, protocols, rules and bureaucracy.

Table 3. Quotes on characteristics of homeless people that hamper accessible or appropriate care.

Theme	No.	Quote
1. No stereotype	Q1	*"Care avoidance isn't a single big group you can tackle in one go. The pattern varies hugely from one person to the next." (P16, spiritual caregiver)*
2. Complexity of problems	Q2	*"I'd associate care avoidance with significant medical problems. They've also often been through a lot of psychotherapy and mental care already. They've seen it all before." (P24, street pastor)*
3. Other priorities	Q3	*"If you're homeless, you have to be ready to do things for your health that you don't actually like. If they'd had normal lives, it maybe wouldn't have been do difficult, but they don't think it's worth it. Scoring is often more important." (P22, formerly homeless person)*
4. Maintaining self-control	Q4	*"I don't think that they're afraid to go to a doctor. They're afraid that it'll end up restricting their lives, you know? Suppose the doctor says you've got to be admitted to hospital… well, there's no boozing or smoking in hospital. That lifestyle will be changed drastically – the doctor's restricting what you can do, because you've got to go to hospital. They don't want that. They don't want to be tied down; they want to be able to respond when they think they need to. Maybe they'll do nothing all day, but you never know – maybe the one time that they do have an appointment is just the moment when they could nick something or score or whatever. Yup, then they're stuck with the appointment and they don't think it's right" (P22, formerly homeless person)*
5. Fear of stigmatization and treatment related to psychological or psychiatric problems	Q5	*"For mental things in particular, I think that people do avoid care. So it's sometimes not so much care avoidance as denial and lack of an understanding of their illness as well. That's often the case with psychiatric conditions. People who hallucinate but have a lot of difficulty admitting they're hallucinations and who feel they're being pigeon-holed. But if it's a perception that you've got but they haven't, then they feel they're being accused of inventing things that they think are absolutely true. But, well, they don't think there's much point talking to a doctor anymore because they won't be taken seriously." (P6, street pastor)*

Secondly, participants reported that the conditions and requirements that people must adhere to in order to get access to care can be a reason for homeless people avoiding care (Table 4, Q8). These conditions are e.g. paying off debts in a certain way, detoxing, naming care needs and concrete questions, and going through processes quickly. Participants believed that enforcing such conditions and requirements meant care organizations were not sufficiently considering the needs or capabilities of homeless people.

Another theme that appeared from the interviews is that even when homeless people find access to the regular care system, the care they receive is often not appropriate, i.e. not adapted to their care needs. Their health problems often expand beyond the borders of individual somatic and psychiatric specialists, warranting a tailored and multidisciplinary approach in which interdisciplinary communication should be secured (Table 4, Q9).

Time pressure among professionals proved to be a recurrent barrier to providing appropriate care for the homeless. According to participants, current legislation and the way care is organized and financed contribute to heavy time pressure on professionals (Table 4, Q10). Professionals are bound to a specific amount of time, but as care for this population is more intensive and complex, it takes more time. As a result, there is little time for good conversations. Homeless people, however, generally consider real interest, attention and time for small talk and conversations to be very important. To achieve this, not only time but also the attitude of the professionals is important (Table 4, Q11). According to our participants, homeless people could experience professionals' attitude as suspicious, asking questions unpleasantly, an attitude of knowing better, and applying their own standards. A lack of patience and creativity hampering finding solutions was also reported to be a barrier.

Many participants mentioned that homeless people perceive the day and night shelters as busy and overcrowded. Often, there is unrest (fights, disputes and security), little privacy and they have to be very careful when it comes to property. Moreover, professionals intend to immediately start arranging things and setting goals, which can increase stress. Homeless people, however, are in need of rest (Table 4, Q12). Avoiding busy shelters is a way of reducing stress.

Finally, while engagement and equality are very important values for homeless people, they are often left out in decision-making. According to participants, homeless people feel inferior, patronized and not taken seriously by professionals (Table 4, Q13). Consequently, they tend to avoid care professionals. According to the respondents, homeless people should have the right to be involved in formulating their needs and making decisions together with the professional despite their psychosocial limitations or issues.

Recommendations for facilitating access to homeless people who avoid care

Our second research question concerned suggestions of spiritual caregivers, street pastors, homeless outreach workers and formerly homeless participants for how professionals can improve the accessibility of care for homeless people. As indicated in the previous section, care avoidance has no single cause but is caused by factors related to the homeless people, the health system, and the interaction between them. Recommendations are aimed at a wide variety of professionals working in medical care, social assistance or a combination of these. In addition, each organization and professional has other sources, possibilities and limitations. Thus, for each organization and professional, another combination of recommendations will be relevant. In addition, a number of recommendations aimed at policy makers are addressed below. The suggestions for improving accessibility are categorized similarly. Firstly, we will discuss the suggestions related to the characteristics of homeless people themselves. Secondly, we will discuss the system-related suggestions. All themes are mentioned in Table 5, and illustrated by quotes.

Table 4. Quotes on system-related characteristics that hamper accessible or appropriate care.

Theme	**No.**	**Quote**
System is complicated	Q7	*"It's complicated finding the right organization as well. There are several options for your dole money or day care, for instance. Then there are the people from different situations, or from prison, where the probation service gets involved. Or there are people with addictions, where the addiction care service gets involved. Or the housing corporation – evictions or whatever – where a district team will sometimes have had a role too. And then you've got to find your way. So where do you start?" (P20, homeless outreach worker)*
Conditions and requirements of organizations	Q8	*"They've already said to start with that you should kick the drugs and then maybe we can help you with the mental problems. People can't comply with those conditions – what's going to replace them? They aren't going to stop using because they're suffering from sweaty feet. They're going to keep using because they're got an issue that they have to resolve, i.e. coping with daily life and the problem of what's going on in their heads." (P15, homeless outreach worker)*
System is inappropriate	Q9	*"Maybe it's the level of education of the personal supervisors as well – that they're simply not qualified enough to be able to deal with the entire spectrum of both mental and physical complaints. Ordinary staff, supervisors, they're sitting there looking at a lump and wondering whether it means that a doctor is needed or not. They're not really the people who should be dealing with those issues." (P25, spiritual caregiver)*
Time pressure of professionals	Q10	*"The caregivers would also want to do more, but there simply isn't the time. They only come along to tackle the issues of the moment and dole out medication. The homeless see perfectly well that they're short of time too. They complain hugely about it, that the caregivers are often not really available." (P25, spiritual caregiver)*
Attitudes of professionals	Q11	*"Many homeless people's experience is that if they go anywhere – to a doctor or hospital or dentist – they get treated with a degree of suspicion." (P4)*
Noisy and busy shelters	Q12	*"Some people actually find sleeping on the streets quite peaceful, because they think the care places are much too unsettled and too busy and too many other people snoring and far too much stuff that they don't want." (P8, spiritual caregiver)*
Patronizing and lacking participation	Q13	*"And one of these caregivers will then think, 'I'm going to take you by the hand like a little kid and tell you how you have to do it.' And if you do that to a fifty-year-old bloke who may have fought in a war or whatever, you'll soon lose their respect. You mustn't lay down the law for people. You can give them advice, though." (P21, homeless outreach worker)*

Related to the interaction between homeless persons and professionals

Tailored care

To reach homeless people who avoid care, it is important to be able to offer personalized care. According to participants, tailored care means that professionals offer care that corresponds to the care needs of the homeless person. Additionally, tailored care implies that exceptions can be made when needed; professionals should be able to deviate from procedures or protocols, due to the complexity of needs and problems among people who are homeless (Table 5, Q1). A personal approach also involves attention to personal circumstances and capacity, e.g. coping skills or availability of time. Professionals have to understand that care cannot be limited to one discipline. In order to get a complete picture of the needs of homeless people avoiding care, it is important to explore the health, psyche, intellect, history, housing, finances, and other relevant social fields. According to participants, connecting all disciplines can provide tailored care. For this, it is important that professionals are well and specifically trained in the field of needs and preferences of homeless people, are able to find each other and ask each other for advice.

Building a trusting relationship

The most frequently mentioned theme in the interviews was that in order to reach care avoiding homeless people, building a relationship between professionals and the homeless person is crucial (Table 5, Q2). An important requirement for building relationships is that it does not focus on providing care, but on the quality of the relationship. Conditions for building a trusting relationship include a consistent professional, and a feeling of having a connection between the homeless person and the professional. The professional should be easily approachable, reliable, keep in touch and have patience and time, as building trusting relationships may take a long time. Besides this, a 'mediator' can be helpful such as a street pastor, spiritual caregiver or case manager who can act in the care avoider's interests during appointments.

Setting limits, but no rejection

According to participants, it regularly occurs that care-avoiding homeless people fail to comply with agreements, misbehave or become angry or aggressive (Table 5, Q3). Participants stated that in such situations, it is very important that professionals do not reject the person. Professionals can accomplish this by seeing the behaviour as only one aspect of the person, by setting limits to the behaviour of their client, but at the same time offering the possibility to start again afterwards.

Table 5. Quotes on suggestions for making care more accessible to homeless people who avoid care

Theme	Subtheme	No.	Quote
Characteristics of homeless people	Tailored care	Q1	*"Wouldn't it be nice if the care system could offer more tailored solutions, saying 'What would help you? And how can we work together so that here's a place where you can get it. Get what would help you.' Within reason, of course, but without saying it's our way or the highway. Instead, you say there's supervision but we'll take a look at things with you to see what's the best way of arranging it. So that it works for you." (P1, street pastor)*
	Building relationships	Q2	*"Suppose I've found you and you very often sit at a particular time on a certain bench in the part, 'cos that's where you are with your two bags. Well, then you've not got to start by saying, 'Come along with me.' No, I think you've first got to ask if you can sit there with them. And maybe you don't say anything else to start with. Getting someone to come and do what you want is still a long way down the road at that point." (P19, spiritual caregiver)*
	Setting limits, but no rejection	Q3	*"We speak to people about their behaviour, we apply sanctions, but there's one thing that we always make clear: you can always come back again. So it's crucial that they know that the relationship will never be put under pressure. It can therefore mean that we ban people ten times, that they do something wrong ten times, but you can always come back again." (P13, homeless outreach worker)*
	Humanity, dignity and equality	Q4	*"It's pretty awkward for them; they're never normal. So, well, they need in some way or other to be able to give and get something back. And so that they've got lots of skills and things that they can use, even if they are care avoiders." (P23, homeless outreach worker)*
Characteristics of the system	Clear information, explanation and communication	Q5	*"Just be honest about it, like 'It's not possible right now with these waiting lists, but we'll see what steps we can take that will really help you.' And being straight up: 'I can make this or that agreement with you now that we'll take a look, because you want something to do. Right, I can call them now and see if there's a place and I'll call you, make an agreement with you, such and such a place and time, that's when you'll get the details from me.' Short timelines, clear communication and clear agreements." (P27, formerly homeless person)*
	Change of policy and legislation regarding to available time	Q6	*"My experience is that individual care providers are genuinely motivated, but that it's often the structures of the institutions – imposed by legislation and regulations and driven by costs above all – that make it tricky. So it's not the individual care providers, because they're people who are really trying [to make the process less complex, more accessible, working from a relationship of trust, looking to see what the person themselves needs, communicating in understandable terms]. But, well, we need to set up the legislation and regulations and the funding so that it's possible." (P3, spiritual caregiver)*

Table 5. Continued.

Theme	Subtheme	No.	Quote
	Quiet shelters	Q7	*"All the crisis shelters are in groups: several people sleeping in the same room. And it's difficult there, it's sometimes difficult to tailor the care there to suit… there's just too little money for it, actually. A crisis shelter like that, there are just two of them for sixty people, so there's no chance for any one-on-one supervision or whatever." (P21, homeless outreach worker)*
	Attitude and treatment by professionals	Q8	*"We go to the station at five in the morning, at the times and moments that really suit them and not just during office hours. Care avoiders are often up and about at night, and they'll sleep during the day, simply because sleeping in the daytime is safer. The other thing we do is start normal conversations with these people. So it's not like 'What do you need to get out of this situation', but 'How was your day? What are you going to do?' And don't think people won't appreciate it, that it's not part of the world they live in: it's very much in their kind of world, because all day long they've got a caregiver or a cop or a guard hassling them, and never a normal person with a normal conversation." (P15, homeless outreach worker)*

Humanity, dignity and equality

Respect, humanity, dignity and equality are essential aspects in the attitude of a professional towards a homeless person, in order to ensure non-threatening and appropriate care (Table 5, Q4). For people who are homeless, it is especially important to feel respected. Humanity features a (more or less) equivalent exchange of personal information. Professionals can give examples of their personal experiences. Dignity also implies looking at what is important for homeless people. Equality is mainly about freedom of choice and not looking down at a homeless person as a professional.

Related to characteristics of the system

Clear information, explanation and communication

Information, explanation and communication are key to increasing the accessibility of care. The system is often experienced as complicated and homeless people can be overwhelmed by the difficult language used by health providers. It is crucial that homeless people are familiar with the rules and functioning of the healthcare system. They should be empowered to stand up for themselves (Table 5, Q5). This can be done concretely by providing information in simple and clear langue. Professionals must communicate clearly about the possibilities and impossibilities of their services and time schedule

Less busy day and night shelters

In order to improve accessibility of care, shelters should be more inviting. Day and night shelters are usually overcrowded and noisy and there is a lack of privacy: all reasons why homeless people tend to avoid care. To make day and night shelters more accessible, it is recommended for policy makers and managers in organizations that organizations offer smaller rooms and quieter geographical locations, even in urban environments (Table 5, Q7).

Attitude and treatment: more patience, time and understanding

According to the participants, an open and friendly attitude of professionals towards homeless care avoiders is essential to improving accessibility (Table 5, Q8). Professionals should be aware that when dealing with care avoiders, more patience, time and understanding are needed than with the average person. In practice it is important that care providers create rest during appointments and treatment pathways, e.g. to start an appointment or treatment without too much pressure on commitment, engaging in small talk without providing care or to familiarize themselves with the background of their client. For doctors, this implies e.g. that several appointments are needed to fully map the problem and the history of the person. Given the limited time of doctors and high costs, it might be more feasible to deploy nurses to do these extensive intakes and let them mediate the doctor's appointment, or to engage another mediator who joins homeless people to the appointment, for example a street pastor, spiritual caregiver or other homeless outreach worker.

Self-reflection by professionals

Many participants stated that professionals need sufficient self-awareness and must be critical of their own actions (Table 5, Q9). The way a professional sees things can be very different to the care avoider. A professional must be aware of this and realize that their standards and expectations may not always be the same as those of the homeless person. An open attitude is crucial. Self-reflection also means acknowledging mistakes and being honest about their professional limitations.

Change of policy and legislation with regard to available time of professionals

Finally, participants indicated that the time available for care is too limited (Table 5, Q6). This is mainly due to current legislation and regulations and the policies of organizations. In order to provide effective and appropriate care, more intensive care is needed, which takes more time.

DISCUSSION

Spiritual caregivers, street pastors, homeless outreach workers and formerly homeless people, experienced the term 'care avoidance' to be stigmatizing. Care avoidance seemed to focus only on the homeless and not on the system, while inaccessibility of the system is a barrier to involvement in care. This study shows that care avoidance was not only related to the characteristics of homeless people (e.g. complex problems, other priorities), but also to system-related characteristics (e.g. complicated system, conditions and requirements of organizations), both impeding care involvement. This supports the findings of Schout et al.,[112] who introduced the term 'care paralysis', meaning the inability of professionals in social services to help people with multiple and complex problems. By using both terms simultaneously, i.e. care avoidance and care paralysis, it is more clear that not only characteristics of the homeless but also from the system must be addressed in order to improve care avoidance. Moreover, this might be experienced as less stigmatizing.

Previous studies in the field of care avoidance, although carried out among other populations, show similar reasons for care avoidance, such as mistrust or a lack of confidence, negative evaluations of the quality of care and previous negative experiences with care providers' communication styles and seeking healthcare.[113-117] Additionally, several studies also reported a low perceived need to seek medical care as a reason to avoid care.[114, 116] However, existing literature also provides some reasons for avoiding care that were indeed confirmed by our study but were less evident such as a fear of serious illness or of thinking about dying,[114, 117, 118] insured lack of (health) insurance and being illegal.[115, 116] This was most likely due to the focus of the interviews which was more on the complexity of various problems among the homeless, as a result of which a lack of health insurance and illegality appear less prominently as reasons for care avoidance. Since the reasons for care avoidance identified by this study are similar to the reasons previously reported for other populations, the question can be raised whether care avoidance among the homeless is essentially different from care avoidance among other populations. Nevertheless, the multifaceted nature of the problems, the focus on psychosocial barriers, and the need for a multidisciplinary approach, respect, understanding and trust do distinguish this group from other populations. Ye, Shim & Rust provide evidence for the focus on psychosocial barriers to care among this target group. They mentioned that people with serious psychological distress were more likely to report psychosocial barriers to care.[118]

Participants made suggestions that could help reach care avoiders, related to characteristics of both the homeless and the system. The person-related characteristics include tailoring care and building relationships at an early stage. It is often necessary to build a trustful relationship before care can be provided. Meeting the practical needs of the homeless person is key in building this relationship. When care is provided, the needs of homeless must be leading.[119, 120] Furthermore, setting limits to behaviour without rejecting the person, and an attitude reflecting humanity, dignity and equality were also important factors in making care more accessible and long-lasting. Regarding system-related characteristics, clear information and communication to homeless people who avoid care are important for making care more accessible. Other system-related suggestions include quiet and less busy shelters, unthreatening attitudes and treatment by professionals, self-reflection by professionals and finally a change of policy and legislation regarding available time. Other studies in care for the homeless have also reported the need for respect, understanding, trust and easier access to health services.[121-123] Not being able or willing to be involved in care has several reasons, which are mainly "demands, thresholds and fragmentation of services, which hinder the accessibility of healthcare", and more specifically "disputes, conflicts, suspicions about the intentions of healthcare professionals and a mismatch between expectations and provision of care".[13] Our findings confirm a previous study on care avoidance in psychological care by amongst others homeless people, which highlighted the importance of establishing contact and winning trust[13] and reported that care avoidance is often caused by the interplay between characteristics of both the clients and the system. It is important to notice that many of the solutions can only be successful if healthcare professionals realize that they have agency and have an important role in achieving improvements. Thinking beyond the individual causes of care avoidance, i.e. either related to the homeless person or the system, but also having attention for the interplay between those causes is crucial.

While several respondents of our study reported the term care avoidance to be problematic, respondents of another study did not report this.[14] This does raise the question whether we should discard the term 'care avoidance' and use more neutral terminology related to the accessibility of care for different target groups, or at least emphasize that care avoidance can be rooted in both personal and system characteristics.

To our knowledge, this study is the first to explore the reasons for avoiding care and the way to overcome this from the perspective of spiritual caregivers, street pastors and homeless outreach workers, and is supported by experiences of formerly homeless people. It is a strength of our study that we were able to expand the respondent group, i.e. including also homeless outreach workers and formerly homeless people. Together, the participants interviewed were people who view both the perspective of the target group and the world of professional care. It therefore gives practical suggestions for improving accessibility of care based on the non-threatening working methods used by these participants. This was confirmed in the interviews with the formerly homeless participants, who stated that the spiritual caregivers and street pastors were the people who were most closely attached and committed to them, and who understood them well. A limitation of our study was the different nature of care that street pastors and spiritual caregivers provided in comparison with other care providers in medical and social care, who often experience more obligations and more time pressure. This might make it difficult for the latter to implement the suggestions for improvement. However, several of the recommendations can be implemented in any event, e.g. attitude. Moreover, although building relationships might require an investment at first, this may strengthen relationships and contributes to providing more appropriate and more accessible care.

CONCLUSIONS

Reasons for care avoidance turned out to be a combination of characteristics of homeless individuals as well as characteristics of the system and the competences of the professionals working with homeless people. Measures to reduce care avoidance should be taken at both levels. While changes in the organization of healthcare need measures from policy makers, medical and social care professionals can also help reduce care avoidance. A low-barrier method such as that of street pastors, spiritual caregivers and homeless outreach workers, involves building relationships by building trust, showing understanding and being with the homeless person. By paying attention, the professional can discover what these values mean for the homeless and what this implies for providing care and starting a care pathway.

PART 2

Current palliative care provision and future improvements

Kan ik iets voor je doen?
Met een blik met een woord
Dat doet denken aan toen
Dat je even weer voort?

De Dijk

CHAPTER 4

End-of-life care for homeless people in shelter-based nursing care settings: A retrospective record study

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ABSTRACT

Background. Homeless people experience multiple health problems and early mortality. In the Netherlands, they can get shelter-based end-of-life care, but shelters are predominantly focused on temporary accommodation and recovery.

Aim. To examine the characteristics of homeless people who reside at the end-of-life in shelter-based nursing care settings and the challenges in the end-of-life care provided to them.

Design. A retrospective record study using both quantitative and qualitative analysis methods.

Setting and participants. Two Dutch shelter-based nursing care settings. We included 61 homeless patients who died between 2009 and 2016.

Results. Most patients had somatic (98%), psychiatric (84%) and addiction problems (90%). For 75% of the patients, the end of life was recognised and documented; this occurred 0–1253 days before death. For 26%, a palliative care team was consulted in the year before death. In the three months before death, 45% had at least three transitions, mainly to hospitals. Sixty-five percent of the patients died in the shelter, 27% in a hospital and three percent in a hospice. A quarter of all patients were known to have died alone. Documented care difficulties concerned continuity of care, social and environmental safety, patient–professional communication and medical-pharmacological alleviation of suffering.

Conclusions. End-of-life care for homeless persons residing in shelter-based nursing care settings is characterised and challenged by comorbidities, uncertain prognoses, complicated social circumstances and many transitions to other settings. Multilevel end-of life care improvements, including increased interdisciplinary collaboration, are needed to reduce transitions and suffering of this vulnerable population at the end of life.

BACKGROUND

People experiencing homelessness are a special, yet understudied population in the field of palliative care. Compared to the general population, they have high rates of early mortality, with average ages of death varying between 40 and 65 years in different Western population-based studies.[22, 24-26, 29, 124-128] Also in the Netherlands, homeless people have a substantially reduced life expectancy: a 10-year follow-up study demonstrated that the average remaining life expectancy at age 30 was 11.0 (95% confidence interval (CI): 9.1–12.9) years shorter for homeless men and 15.9 (95% CI: 10.3–21.5) years shorter for homeless women than for men and women in the general population, respectively.[28]

Besides dying at a younger age, homeless people generally also spend more years in poor health than housed individuals. Research has shown a disproportionally high prevalence of somatic and psychiatric problems, addiction, intellectual disabilities and other psychosocial issues.[4, 5, 10, 29, 129] These problems prevail at the end of life, resulting in challenges for palliative care provision.

Indeed, various studies suggest that end-of-life care for homeless people is highly complex, among other things because of their harsh living conditions and frequent lack of social support networks and health insurance.[6, 30-32, 58, 86, 109, 110, 130, 131] However, many of these studies have been conducted in countries where the majority of homeless people die on the streets, in hostels or in acute care hospitals, such as the United States and the United Kingdom. [27, 31, 32, 58, 86, 130] In several countries, including the Netherlands, some social relief shelters provide 24/7 in-patient nursing care.[69] These shelters accommodate a significant proportion of the homeless people at the end of life, but little is known about these people's sociodemographic and health-related characteristics. In addition, as the Dutch shelter-based nursing care settings are primarily focused on temporary accommodation and recovery,[30, 69] it is unclear to what extent they are capable of providing end-of-life care. Therefore, this retrospective record study aimed to describe the characteristics of homeless people who reside at the end of life in Dutch shelter-based nursing care settings and to examine the end-of-life care provided to them as well as the documented difficulties in end-of-life care.

METHODS

Design and setting

We performed a retrospective record study at two Dutch shelter-based nursing care settings. Both settings are social relief shelters that provide 24/7 in-patient nursing care and at least biweekly consultations with either a general practitioner specialised in street medicine (one shelter) or a municipal public health service physician (the other shelter). They have limited capacity (20 and 60 beds, respectively) and are officially intended at providing short-term care and accommodation (for a maximum of three months).[69]

Study population

We included all persons who were known to have died (either expectedly or unexpectedly) between 2009 and 2016 and to have resided in one of the shelter-based nursing care settings for at least one night in the three months prior to death. To be admitted, people had to be diagnosed with severe somatic problems, combined with psychiatric and/or psychosocial problems. They had to be dependent on social relief and have a history of homelessness, that is, lacking housing or residing primarily in transitional housing or supervised facilities that provide temporary living accommodations (e.g. shelters).[66] For the ease of reading, in this paper, we will refer to them as 'homeless people' or 'homeless patients'.

Data collection

Data were obtained between September 2016 and February 2017. Medical and nursing records were collected and provided by shelter staff, who verified that patients had died based on autopsy reports, death certificates or death notifications from the institutions where death had occurred.

Measurements

To systematically extract relevant data, we developed a data extraction form.[132] This form included pre-categorised as well as open items about (1) availability and comprehensiveness of records, (2) patients' characteristics and diagnoses upon their last shelter admission, (3) recognition and discussion of the end of life, (4) care provision and symptoms at the end of life, (5) medical decision-making and transitions between settings at the end of life, (6) informal social contact at the end of life and sociodemographic characteristics of death, and (7) difficulties in care provision at the end of life.

We operationalised the end of life as the year prior to death.[133] However, to get more specific information about the circumstances surrounding death, for some variables, data were only collected for the three months (i.e. symptoms, transitions between settings) or month (i.e. informal social contact) before death.

A transition was defined as a change of setting for at least one night. The end of life was considered to have been recognised and documented if the medical record included an explicit statement expressing that the patient (1) had a limited life expectancy or an unfavourable prognosis of a life-threatening disease or was in the palliative or terminal phase of life; (2) had no more curative treatment options or received palliative care; or (3) was transferred to a hospice. If the record contained more than one such statement, the first statement was used. Care difficulties were registered if the researcher identified descriptions of situations perceived to impede quality or provision of care. A palliative care team or consultant was considered to have been involved if the record included a statement describing consultation about palliation (either face-to-face or by phone, fax or email) with one or more experts of a palliative care team or service (e.g. a hospice).[134]

Data extraction

Two researchers (SD and HK) independently pilot-tested the data extraction form on the records of five patients from both settings. They concluded that it worked well and did not require any further adjustments. Records of the remaining 51 patients were extracted and analysed by one researcher (SD); a random sample of 10 records were checked by another researcher (HK). Cases of disagreement and uncertainty were discussed and resolved with members of the project team.

Data analysis

Data were entered in SPSS version 24.0 and Excel 2016. Open answers were categorised using both empirical approaches (i.e. categorisation guided by the data) and theoretical approaches (i.e. categorisation based on expert opinion and classification systems commonly used) approaches. Subsequently, for each of the quantitative variables, descriptive statistics were computed. Missing data were treated as a distinct category if a variable had missing data for ≥10% of the patients.[150] Qualitative information was analysed following the principles of thematic analysis (i.e. coded, classified into themes and discussed within the project team).[111]

Ethical approval

The Medical Research Ethics Committee of the Amsterdam UMC (VU University Medical Centre) declared that this study was exempt from formal review because it was not subject to the Medical Research Involving Human Subjects Act (registration number: 2016.308).

RESULTS

Availability and comprehensiveness of medical and nursing records

Records of 61 homeless people were included. Thirty-six (59%) of these records were derived from one shelter and 25 (41%) from the other. For all but two patients (97%), both medical and nursing records were available, and results were obtained for all variables of interest.

Patients' characteristics and diagnoses upon their last shelter admission

The majority of homeless patients were male (85%) and either had a Dutch (56%) or Surinamese/Antillean (28%) cultural background (see Table 1). Seven percent of the patients did not have legal status in the Netherlands; a quarter did not have health insurance. Over half of them came from another social relief facility (i.e. outreach services, supportive housing/rooming-house or night shelter). Most patients had a combination of somatic (98%), psychiatric (84%) and addiction problems (90%). The duration of stay at the shelter-based nursing care setting varied between patients from one day to more than ten years.

Recognition and discussion of the end of life

For 75% of the patients, the record contained a statement indicating that the end of life was recognised (see Table 2). Patient–professional end-of-life discussions were reported for 59% of the patients.

Table 1. Characteristics and diagnoses at the end of life among homeless people in shelter-based nursing care settings (n=61)

	n (%)
Age in years upon shelter admission, mean (*SD*); (min – max)	55 (10); (31 – 79)
Duration of last shelter stay in days, median [IQR]; (min – max)	123 [31 – 302]; (1 – 4491)
Sex: male	52 (85)
Cultural background:	
Dutch	34 (56)
Surinamese/Antillean	17 (28)
Turkish/Moroccan	2 (3)
East European	1 (2)
Other, Western	2 (3)
Other, non-Western	5 (8)
Legal residential status: no	4 (7)
Health insurance: no	15 (25)
Housing status prior to last shelter admission:	
Independent, private or public housing	3 (5)
Temporary address at friends' or family members' place	6 (10)
Independent, outreach services	12 (20)
Supportive housing/ Rooming-house	21 (34)
Night shelter	4 (7)
Street/sleeping rough	5 (8)
Other (e.g. detention, drug rehabilitation centre, nursing home)	10 (16)
Somatic diagnoses[a]: yes, i.e. *(more than one option possible)*	60 (98)
Cancer	30 (49)
Respiratory disease	44 (72)
Cardiovascular disease	35 (57)
Diabetes mellitus II	7 (11)
Infectious disease	31 (51)
Liver disease	19 (31)
Injury	25 (41)
Musculoskeletal disease	18 (30)
Dental problems	16 (26)
Psychiatric diagnoses[b]: yes, i.e. *(more than one option possible)*	51 (84)
Psychotic disorder	20 (33)
Depression and anxiety disorder	22 (36)
Personality disorder	12 (20)
Psycho-organic syndrome	34 (56)
Intellectual disability	13 (21)
Other (e.g. suicidal thoughts or attempts, autism spectrum disorder)	19 (31)
Addiction diagnoses (excluding tobacco)[c]: yes, i.e. *(more than one option possible)*	55 (90)
Alcohol	34 (56)
Cannabis	21 (34)
Cocaine	36 (59)
Heroin	34 (56)
Methadone	31 (51)

SD: standard deviation; Min: minimum; Max: maximum; IQR: interquartile range.

[a] No/Not in record: n(%)=1(2).

[b] No/Not in record: n(%)=10(16).

[c] No/Not in record: n(%)=6(10).

Table 2. Recognition and discussion of the end of life and care provision and symptoms at the end of life among homeless patients in shelter-based nursing care settings (n=61)

	n (%)
End of life recognised and documented in record: yes	46 (75)
End of life discussed with patient[a]: yes	36 (59)
Moment at which recognition of the end of life was first stated (number of days before death)[b], median [IQR]; (min – max)	67 [18 – 170]; (0 – 1253)
Care discipline involved in *the year before death:* yes, i.e. *(more than one option possible)*	61 (100)
Social work	61 (100)
General practicioner care	61 (100)
Nursing care	61 (100)
Mental healthcare (e.g. addiction care, psychiatric care)	43 (71)
Medical specialist care	60 (98)
General internal medicine	36 (59)
Pulmonology	26 (43)
Surgery	20 (33)
Radiology	16 (26)
Cardiology	14 (23)
Gastroenterology	14 (23)
Neurology	12 (20)
Oncology	10 (16)
Dental surgery	9 (15)
Other (e.g. rehabilitation care, infectious diseases)	26 (43)
Dietic care	15 (25)
Physiotherapy	20 (33)
Spiritual care	10 (16)
Volunteer services/Buddy care	2 (3)
Pedicure	13 (21)
Palliative care team or consultant	16 (26)
Symptoms in *the three months before death*[c]*:* yes, i.e. *(more than one option possible)*	59 (97)
Pain	55 (90)
Fatigue/Drowsiness	52 (85)
Restlessness/Confusion	44 (72)
Shortness of breath	43 (70)
Diarrhoea/Constipation	35 (57)
Nausea/Vomiting	30 (49)
Cachexia/Sarcopenia	37 (61)
Fall accidents or increased fall risk	15 (25)
Peripheral oedema	25 (41)
Ascites	6 (10)
Icterus	6 (10)
Skin problems	22 (36)

IQR: interquartile range; Min: minimum; Max: maximum.

[a] No/Not in record: n(%)=10(16); Not applicable: n(%)=15(25).

[b] n=46 (i.e. patients for whom the end of life was recognised and documented in the record).

[c] No/Not in record: n(%)=2(3).

The moment at which recognition of the end of life was first stated ranged from almost three and a half years before death to the day of death. The content of the statements varied as well (see examples in Box 1): whereas some statements explicitly mentioned palliative care interventions (e.g. involvement of chaplain; P50) or end-of-life decisions taken (e.g. new or updated resuscitation policies; P12 and P50), others were less explicit about care and treatment implications (e.g. P37). Furthermore, actual end-of-life trajectories could be very different from the initial expectations of care professionals, as was the case for this patient:

> *P09 – Last year, patient had ended up in a terminal situation, which was partly due to his frequent cocaine use. Apparently, however, he has somehow gotten out of it again. (180 Days prior to death.)*

P01 – Patient declared to his internist that he wants to quit chemotherapy. Oncologist: life expectancy of two months. (77 Days prior to death.)
P12 – Conversation about the end of life. Patient was admitted to shelter-based nursing ward with a crack lung, chronic obstructive pulmonary disease, and heart failure. Previously, care professionals barely managed to get him off ventilator. Although patient hopes everything will still be done, his general practitioner, internist, pulmonologist and I together decided that resuscitation and hospitalisation are medically useless. (36 Days prior to death.)
P037 – Current somatic problems: patient is extremely tired, feels already exhausted when waking up. Terminal renal failure, human immunodeficiency virus, heart failure, hepatitis C, chronic obstructive pulmonary disease. Patient should have had an appointment with his cardiologist and internist this month, but did not show up. (40 Days prior to death.)
P50 – Incurable adenocarcinoma. Patient does not want any more invasive treatments; do not resuscitate policy, no hospital admissions unless not burdensome and with favourable prognosis for comorbid diseases. Involve a chaplain. (699 Days prior to death.)

Box 1: Examples of statements describing recognition of the end of life in medical records of homeless patients in shelter-based nursing care settings

Care provision and symptoms at the end of life

In the year prior to death, the majority of the patients received a combination of social care (100%), nursing care (100%), general practitioner care (100%), medical specialist care (98%) and mental healthcare (70%; see Table 2). For 26% of the patients, a palliative care team or consultant was involved. The most frequently stated reasons for involving palliative care experts were pain and symptom management (e.g. medication management or palliative sedation), behavioural and psychosocial problems and care transitions (results not shown in Table 2). Symptoms reported for over 70% of the patients in the three months before death were pain (90%), fatigue/drowsiness (85%), restlessness/confusion (72%) and shortness of breath (70%). The following example shows the complexity of many palliative care consultation requests:

> *P36 – Please help to assess potential preferences and options to alleviate suffering of a patient with malignancy, Cushing’s syndrome, multiple drug addictions and a long history of*

> *psychiatric problems. Pain is not under control. However, this also seems to be affected by a psychiatric component, i.e. anxiety and confusion. Gradually, an unmanageable situation of refractory symptoms is arising. Patient indicated to take an overdose of methadone in case of ongoing unbearable suffering. After mentioning the consequences and the options for better supportive care, we (care professionals) could talk her out of this idea. We need to combine hospital care, primary healthcare and addiction care. (304 Days prior to death.)*

Medical decision-making and transitions between settings at the end of life

Records of 67% of the patients contained a resuscitation policy, which mostly (62% of the patients) indicated that the patient would not be resuscitated (see Table 3). For 39% of the patients, physicians had established a hospital admission policy, which predominantly (36% of the patients) concerned a non-admission decision. In the final three months before death, 77% of the patients were transferred at least once to another setting and 45% of the patients had three or more such transitions. This mainly involved transitions to acute care hospitals and intensive care units of acute care hospitals (70% and 23% of the patients, respectively, including patients with a hospital non-admission policy), and to a lesser extent to mental healthcare institutions (10%), hospices/nursing homes (8%) and detention (7%) (see Table 3). Patient–professional discussions about euthanasia were reported for 16% of the patients; in two patients, euthanasia was performed.

Table 3. Medical decision-making and transitions between settings at the end of life among homeless patients in shelter-based nursing care settings (n=61)

	n (%)
Resuscitation policy documented in record: yes, i.e.	41 (67)
No resuscitation	38 (62)
Resuscitation	3 (5)
Resuscitation carried out[a]: yes	6 (10)
Hospital admission policy documented in record: yes, i.e.	24 (39)
No hospital admission	22 (36)
Hospital admission	2 (3)
Transitions between settings in the three months before death b: yes, i.e.	46 (77)
One transitions	9 (15)
Two transitions	10 (17)
Three or more transitions	27 (45)
Types of transitions between settings in the three months before death; at least one transition to (more than one option possible)[b]:	
Acute care hospital	42 (70)
Intensive care unit of acute care hospital	14 (23)
Mental healthcare institution	6 (10)
Hospice/nursing home	5 (8)
Detention	4 (7)
Euthanasia discussed with patient[c]: yes	10 (16)
Euthanasia performed: yes	2 (3)

[a] No/Not in record: n(%)=55(90).

[b] n=60 (the record of 1 patient did not contain sufficient information to examine transitions).

[c] No/Not in record: n(%)=51(84).

Informal social contact at the end of life and sociodemographic characteristics of death

Records of 88% of the patients provided information about informal social contact in the month before death (see Table 4). Two-thirds (67%) of the patients had received some sort of social support, mainly from family (66%). Several patients had increased or even restored contact with loved ones, sometimes with the help of shelter staff. This is shown by the following extract:

> *P11 – Patient is single and has one little son who has been placed in custody care recently. Today, foster father came with this son to visit patient. Patient is happy about this and has started writing a little book for his son. He would like to get in touch with his family in Turkey. Possibly, we can arrange contact by emailing the town hall of his hometown.*

Table 4. Informal social contact at the end of life and sociodemographic characteristics of death among homeless patients in shelter-based nursing care settings (n=61)

	n (%)
Informal social contact in the month before death:	
Yes, i.e. with *(more than one option possible)*	41 (67)
Family/partner	40 (66)
Friend/acquaintance	16 (26)
No	13 (21)
Not in record	7 (12)
Cause of death[a]:	
Natural	55 (93)
Non-natural[b]	4 (7)
Place of death[c]:	
Shelter-based nursing care setting	39 (65)
Hospital	16 (27)
Hospice	2 (3)
Other: street, psychiatric hospital, detention, general practice	3 (5)
Presence of others *at the moment of death:*	
Yes, i.e. *(more than one option possible)*	26 (43)
Care professional	17 (28)
Family/partner	11 (18)
Friend/acquaintance	2 (3)
No	15 (25)
Not in record	20 (32)
Age at years *at the moment of death,*[b] mean (*SD*); (min-max)	56 (9); (38-79)

SD: standard deviation; Min: minimum; Max: maximum.

[a] n=59 (records of 2 patients did not contain information about the cause of death).

[b] Injury: n(%)=2(3); Euthanasia: n(%)=2(3).

[c] *n*=60 (the record of one patient did not contain information about the place of death).

About one-fifth of the patients did not see anyone other than care professionals or fellow patients in the month before death. Some records included an explicit statement that the patient did not want or appreciate informal social contact, like the following extract:

> *P51 – Patient has two children. He tried to stay in touch after divorce, but did not get any response. His mother died and patient does not know whether his father is still alive. His sorrow about this has faded. He has no wish to get in contact with his family.*

For both patients with and without informal social contact at the end of life, social circumstances were often pictured as complicated. This sometimes invoked feelings of loneliness and regret:

> *P60 – Patient feels lonely. On some days, he gets little attention from staff. [. . .] Today, he used the following words: 'taken the wrong path in life', 'having disappointed loved ones', 'becoming increasingly aware that I am really all alone now'.*

Table 4 shows that patients died at the average (SD) age of 56 (9) years. Except for 7% who died from euthanasia (3%) or due to injury (3%), almost all patients (93%) died from a natural cause. Most patients died in the shelter (65%), others in a hospital (27%) or a hospice (3%). According to 43% of the records, patients died in the presence of someone else, mostly a care professional (28%). A quarter (25%) of the patients were known to have died alone.

Difficulties in care provision to homeless people at the end of life

Examples of documented difficulties in end-of-life care are displayed in Table 5. A recurrent issue concerned the continuity of care, which was considered to be impeded by insufficient and fragmented facilities and expertise, but also by inadequate coordination of tasks and responsibilities between care providers (P05, P39, P48) and gaps in care policies and legislations for certain subgroups, such as uninsured (P38) and psychiatric patients (P01). In addition, records contained frequent accounts of social and environmental safety problems, such as rude (P04), unhygienic (P31) and hazardous behaviours (P10, P37). Another challenge to end-of-life care provision was constituted by patient–professional communication difficulties, which were mostly attributed to characteristics of the homeless population, such as language barriers (P39), somatic functional impairments (P42) and psychiatric and behavioural problems, including care denial (P50) and lack of openness towards care professionals (P36). Finally, many records included remarks expressing persistent medical-pharmacological difficulties to alleviate suffering of homeless patients at the end of life (P11).

DISCUSSION

Summary of findings

Our study confirms previous findings that compared to the general population, homeless people die younger[22, 24-26, 28, 29, 124-128] and have complex comorbidities and a high symptom burden at the end of life.[30, 32, 34, 35, 71, 110, 130, 135] Although the end of life was recognised for three-quarters of the homeless persons in our study, it was difficult to specifically predict prognoses and identify palliative care needs: whereas some patients revived prodigiously, others deteriorated rapidly once admitted to the shelter-based nursing care setting. This finding corroborates qualitative studies indicating that healthcare professionals experience end-of life trajectories of homeless people to be especially capricious.[30-32, 109, 110]

In the year prior to death, almost all patients received care from multiple social work, medical specialist and mental healthcare services. For a quarter of them, a palliative care team was consulted, which is twice the proportion observed in the general Dutch population.[134] Almost two-thirds died in the often familiar shelter-based nursing care setting. Nevertheless, in most cases, it seemed unfeasible to continuously organise and integrate end-of-life care in the shelters: 75% of the patients in our study were transferred more than once to another institution, with almost 50% experiencing at least three such transitions. This is a lot compared to the general Dutch people, who mostly experience no more than one transition in the three months before death.[136] Moreover, these figures largely outnumber estimates obtained in other vulnerable populations.[137-139] Among institutionalised people with dementia, for example, less than ten percent had multiple transitions in the three months before death.[137, 138]

Most records contained multiple explicit examples of discontinuity of care, social and environmental safety issues, complex communication and medical-pharmacological issues. Partially, these difficulties are inherent to the complex problems of the population. Yet, they may also be attributed to external, systemic factors. For example, unwanted hospital admissions and extended stay in the not always sufficiently equipped shelters could be explained by a lack of specialised, long-term available end-of-life care facilities for homeless people and policies hampering their placement in regular care facilities. Also, these placement issues may have deeper causes, such as a tendency among professionals in medical disciplines to shift responsibility to other care disciplines (e.g. social care) when confronted with serious psychiatric and psychosocial symptoms.[135, 140, 141] Together with statements about, for instance, reimbursement issues for uninsured patients and insufficient coordination between care providers, these results elucidate pressing and ubiquitous issues of uncertainty, confusion and conflicting ideas regarding roles and responsibilities in end-of-life care for homeless people.

Although we observed some sort of informal social support among two-thirds of this shelter population, consistent with other studies,[30, 34, 71, 83, 141-143] social circumstances at the end of life were often described as complicated. In addition, 25% of the patients were known to have died alone, and in reality, this percentage is probably higher, as information about the presence of others at the moment of death was unavailable for most of the patients who died in the hospital. Previous studies among homeless people have pointed out unmet needs for personal attention, understanding and family-like relationships as well as a common fear of dying alone.[32, 71, 83, 86, 87, 144-146] Hence, carefully assessing social networks and needs of homeless people is important to anticipate and reduce emotional suffering at the end of life.[147]

Implications for practice, research and policy-making

Our findings suggest that continuity of end-of-life care for homeless people at the end of life could be improved by more comprehensive collaboration between the various care disciplines involved. The current difficulties in continuity of end-of-life care and the complex problems of the population highlight the challenges, but also the importance of individualised advance care planning.[73, 76] Furthermore, system-level changes in organisation of end-of-life care for homeless people, which take into account uncertain prognoses, are required to address structural shortages in expertise and facilities and increase end-of-life care options in shelter-based nursing care settings.[64, 148] For patients with unmet social support needs, volunteer or buddy support might be a valuable alternative, which could possibly also reduce the strain on care professionals.[58, 59, 146] In research and policy-making, it is important to identify needs and self-management strategies of homeless people themselves, including those who do not seek professional care.[149] Future studies might utilise local and international differences in care models to draw comparisons and identify successful elements of end-of-life care provision to homeless people.

Strengths and limitations

To our knowledge, this is the first European study that provides a thorough overview of shelter-based care for homeless people at the end of life. While most studies have used cross-sectional data from interviews and focus groups, we examined real-world medical and nursing record data that were documented during the full end-of-life period. We included two of the largest shelter-based nursing care settings in the Netherlands. Still, generalisability of our results remains limited to homeless people who use such facilities. Compared to two previous, North American studies on shelter-based end-of-life care for homeless people, our study included more patients and adds quantitative findings on the number of care transitions in the months before death.[34, 71] Unfortunately, however, data collection was confined to shelter records and therefore only included information about care provision elsewhere if communicated to the shelters and put in the record. Also, data might have been prone to other types of recording bias, which may, for example, have occurred due to changes in documentation over time.[132, 150] Nevertheless, records seemed rather complete with respect to most of the variables of interest.

CONCLUSION

This retrospective record study shows that at the end of life, homeless people have multiple somatic, psychiatric, addiction and social problems, for which those residing in shelter-based nursing care settings receive care from a variety of healthcare and social care disciplines. Yet, their end-of-life trajectories are uncertain and end-of-life care is fragmented, with transitions to other institutions being rather the rule than the exception. Overall, our findings paint a worrisome picture of acute and structural shortages in capacity to serve this vulnerable population at the end of life. Multilevel end-of-life care improvements, including increased interdisciplinary collaboration and more palliative care facilities and expertise within shelter-based nursing care settings, are needed to reduce unwanted transitions and suffering among homeless people at the end of life.

Is er iets wat je wilt
Wat je stilte verstoort
In het kaal en het kil
Wat je graag van me hoort

Is er iets wat ik doen kan
Wat je helpt in de pijn?
Wat iets voor je betekent
Wil ik graag voor je zijn

De Dijk

CHAPTER 5

The views of homeless people and healthcare professionals on palliative care and the desirability of setting up a consultation service: a focus group study

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ABSTRACT

Context. Palliative care for homeless people is often given late, if provided at all. Professionals in both palliative care and shelter care are often insufficiently equipped to provide this complex care.

Objectives. To provide insights into the palliative care experiences of professionals and homeless people, including barriers and facilitators to care, and to investigate whether a consultative function can help improve palliative care for homeless people.

Methods. Six focus groups were included; four with professionals (n=19) and two with severely ill homeless people (n=15). Professionals were sampled purposively in organizations providing (palliative) care to the homeless. Homeless people were recruited by opportunity sampling.

Results. Palliative care for homeless people is especially complex and differs substantially from regular palliative care. It differs greatly among professionals, institutions, and cities. Homeless people get less autonomy than they would like. Homeless people and professionals have different perceptions of the care provided. Trusting relationships between professionals and homeless people is essential and easily accessible, and flexible care is needed. Consultation, in particular involving exchange of expertise between professionals, can provide added value to professionals. Homeless people consider consultation primarily as an opportunity to train professionals to show more understanding, provide tailored palliative care, and enhance professional collaboration. The local situation, characteristics of a consultant, and role of a consultant in providing information and education must be considered when developing the consultation process.

Conclusion. Consultation can play an important role in improving palliative care by linking disciplines, providing support to professionals and appropriate palliative care to homeless people.

BACKGROUND

People who are homeless often have psychiatric disorders and alcohol and drug dependency, as well as intellectual disorder.[4, 151] Their lifestyles and living conditions are accompanied by multiple comorbidities and a significantly lower life expectancy than the nonhomeless population.[4, 10, 35, 152]. Defining homeless people as those known to the Dutch social shelter system, about 30,000 people in the Netherlands are currently estimated to use that, and this number is thought to be growing.[1, 153] Almost 80% are males, 16% are aged between 50 and 65 years, and they mainly live in the four major cities.[1] Because of the low life expectancy and multiple comorbidities at the end of life, palliative care is often needed.[69] However, more and more international studies are showing that homeless people's access to palliative care is still minimal for several reasons. First, there are factors related to the homeless themselves, for example, competing priorities and not complying with procedures. Second, there are factors related to the healthcare professionals caring for them, for example, limited knowledge of the specific needs of homeless people. Finally, there are factors related to the organization of services such as the system's nonadherence to harm reduction strategies.[11, 35-37, 57, 84-86, 90, 94]

When looking for strategies to overcome the problems mentioned previously, many studies recommend multidisciplinary collaboration between professionals and staff training to improve the access and quality of palliative care for homeless individuals.[32, 34-37] Because consultation proved to be an effective way of getting different disciplines working together and increasing knowledge of palliative care in The Netherlands,[154] consultation might also be effective in homelessness and palliative care. We define consultation as the process in which healthcare professionals can consult somebody with more expertise in a particular field or situation, with the aim of providing appropriate care. This consultation approach largely corresponds to a multiagency approach as mentioned by Hudson et al.,[146] where meetings are arranged in which professionals with different expertise get together to consider the care of a homeless individual with advanced ill health and work together to form care plans for that patient who meet both their immediate and potentially future care needs and wishes. In addition, our approach to consultation specifically concerns professionals in social care who consult palliative care experts (e.g., hospice nurses) and vice versa. In practice, this implies that when a social worker suspects or knows that a homeless person is nearing the end of life, a hospice nurse or another palliative care expert is approached for palliative care advice when the homeless person stays in the shelter. Where the homeless person later requires admission to a palliative setting, the social worker can give advice on treatment, challenging behaviour and contact with the patient. To understand whether reciprocal consultation between social workers and palliative care experts would be helpful in providing appropriate and timely palliative care to the homeless, more insights are also needed into current care and the problems experienced by both professionals and homeless individuals. Our study therefore aimed:

1. To explore the experiences and perceptions of professionals and severely ill homeless people regarding care and support provided to such people, including barriers and facilitators within that care.
2. To explore whether reciprocal consultations between professionals in social and palliative care would be appropriate for improving palliative care for homeless people.

METHODS

Design and participants

We held four multidisciplinary focus groups with professionals working with homeless people needing palliative care and two focus groups with severely ill homeless people. Professionals were recruited by telephone and electronic mail using purposive sampling, ensuring as much variation as possible in characteristics, such as organization (homeless shelter for day care, respite care, night shelters, nursing home wards, or palliative care facilities), city, and profession (physicians, nurses, social workers, policy makers). Inclusion and exclusion criteria are shown in Table 1. Recruitment was through relevant healthcare organizations and existing professional networks of the project team using the snowball method. Of all professionals approached for participation, 31 agreed to participate in one of the four focus groups. Finally, 19 professionals participated. Participants who failed to take part mostly did so at short notice because of illness, work-related emergencies, and public transport problems. As a consequence, two focus groups with professionals were smaller than expected (both n=3). Homeless people were recruited using opportunity sampling. In a specialized nursing home for homeless people and a homeless shelter providing medical respite care, staff were asked to distribute an information letter to all homeless residents who were admitted in the nursing home and the homeless shelter or being cared for by outreach home care provided by the nursing home because of severe illness (defined as having one or more life-limiting illnesses, such as chronic obstructive pulmonary disease, cancer, liver problems, or infections). Severe illness and the corresponding definition were chosen because a recent systematic review showed that determining whether a patient is nearing the dying phase and observing palliative care needs is very difficult for healthcare providers, particularly in this target group.[109] Residents who did not respond (e.g., low-literacy people or non-native speakers) received explanations from staff or were asked later on by staff whether they were willing to participate; no pressure was exerted. Of 70 homeless people approached, eight agreed to participate in advance, ten agreed as a result of last-minute recruitment, and fifteen actually participated. Not wanting to take part was mostly at very short notice and because of not wanting to talk in a group or sudden other activities. We followed the consolidated criteria for reporting qualitative studies guidelines (COREQ).[108]

Table 1. Inclusion and exclusion criteria for healthcare professionals and homeless participants.

Healthcare professionals	**Homeless participants**
Inclusion • Participant is currently working in a shelter for homeless people (day or night care), respite care, nursing home ward, other facility aimed at homeless people, or palliative care facility • Participant works in one of the four major Dutch cities, which are Amsterdam, Rotterdam, The Hague, and Utrecht • Participant is a physician, nurse, social worker, and policy maker or has a related profession • Participant is available on selected moments for the focus groups	*Inclusion:* • Participant is currently homeless • Patient is currently seriously ill • Participant is being cared for in the nursing unit, nursing home, or outreach home care provided by the nursing home • Participant is willing to talk about palliative care or care when being seriously ill • Participant is older than eighteen years
Exclusion • Participant is not currently working in a facility for (care for) the homeless	*Exclusion* • Participant is not able to talk or is not understandable • Participant does not understand Dutch or English and/ or is not able to communicate in one of those languages • Participant is younger than eighteen years

Ethics

Both homeless participants and professionals provided written informed consent before the focus groups. All participants received a gift voucher for their participation. Transcripts were anonymized to ensure the participants' anonymity. Access to the data was limited to three researchers. On July 27, 2016, the Ethics Review Committee of VU University Medical Center provided a waiver as ethical approval was not needed under Dutch law.

Data collection and topics

Data was collected from October 11 to November 30, 2016. All focus groups were conducted and moderated by the same female researcher, trained in both qualitative and quantitative research. She was assisted by another female researcher who also made field notes. Focus groups (duration one and a half hours) with professionals were held at a central location. Focus groups (duration one hour) with homeless people were conducted in the nursing homes where they were staying at that time. Well-being of the homeless participants was ensured by the availability of a staff member who was informed about the research and was willing to assist the homeless participants during or after the focus group. An interview guide was developed for the focus groups (Figure 1).

Interview guide for focus groups with professionals

- Introducing the subject, programme and discussing rules and topics
- 'Consultation intervention' was introduced as follows. *'A consultation function for healthcare providers employed in the medical or social care for homeless people, which can be consulted by a broad population of healthcare professionals who need knowledge or advice about palliative care for homeless people. The purpose of this consultation is to provide appropriate palliative care in good time when needed. Specialists in particular fields (e.g., shelter workers or palliative care nurses) are thus assisted by exchanging knowledge and experience with other disciplines.'*
- Short participant introduction
- Introductory, general question
- Care provided
    - pain and physical symptoms
    - psychosocial
    - spiritual
    - contact with medical specialists
    - cooperation with different organizations
- Care needs

severely ill homeless people
involvement in decisions and care
communication about health situation
individual wishes of homeless people at the end of life

- Consultation intervention
    - existing interventions
    - need for consultation
    - requirements for good consultation
    - resolving problems in current care
- Summary and member check

Interview guide focus groups with homeless participants

- Introducing the subject, programme and discussing rules and topics
- 'Consultation intervention' was introduced as follows. *'A consultation function for healthcare providers employed in the medical or social care for homeless people, which can be consulted by a broad population of healthcare professionals who need knowledge or advice about palliative care for homeless people. The purpose of this consultation is to provide appropriate palliative care in good time when needed. Specialists in particular fields (e.g,. shelter workers or palliative care nurses) are thus assisted by exchanging knowledge and experience with other disciplines.'*
- Short participant introduction
- Introductory, general question
- Care received
    - at the end of life
    - problems experienced
- Care needs
    - when severely ill
    - involvement in decisions and care
    - communication about health situation with professionals
- Consultation intervention
    - need for consultation
    - requirements for good consultation
    - resolving problems in current care
- Summary and member check

Figure 1. Interview guide for focus groups with professionals and homeless participants.

When talking about care needs, some homeless participants recognized that they might be at the end of life, whereas others discussed experiences of other homeless people with advanced ill health. Demographic data as shown in Table 2 were collected by brief paper questionnaires before the focus group. Data saturation was discussed frequently. All focus groups were audio recorded and transcribed verbatim.

Table 2. Characteristics of participants

Group	**Number and gender of participants**	**Age range (mean)**	**Occupation**[a]	**Range of years' experience in occupation (mean)**[a]	**Health status (self-reported)**[b]
Homeless participants (1)	8 (7 M, 1 F)	40-64 (55.5)			Moderate: n=5 Good: n=2
Homeless participants (2)	7 (4 M, 3 F)	42-82 (63.1)			Poor: n=1 Moderate: n=3 Good: n=3
Healthcare professionals (1)	7 (3 M, 4 F)	44-58 (53.3)	Two outreach nurses, nurse, elderly care physician, physician specialized in addiction, spiritual caretaker, street pastor.	13-32 (19.3)	
Healthcare professionals (2)	3 (3 M, 0 F)	36-68 (56.3)	Pharmacist specialized in medication for homeless people, physician specialized in addiction, GP working in a nursing home for homeless people	3-25 (12.7)	
Healthcare professionals (3)	6 (1 M, 5 F)	48-60 (52.3)	Social worker, hospice coordinator, spiritual caretaker, nurse, street pastor, nursing specialist	10-24 (17.3)	
Policy makers and peer workers	3 (2 M, 1 F)	55-69 (60.7)	Policy advisor, client board advisor of an organization involved in care to homeless people, peer worker with experience of homelessness and addiction	4-42 (17.3)	

M = male; F = female; n = number

[a] Only applicable to healthcare professionals.

[b] Only applicable to homeless participants.

Analysis

Data from the first two focus groups were discussed by two researchers, who decided that the interview guide worked well and needed no adjustment for the remaining focus groups. Transcripts were analysed following the principles of thematic analysis.[111] Before analyzing, the transcripts were read and reread by two researchers for familiarization with the data. Codes were assigned to meaningful text and then grouped into themes by one researcher and checked by a second, using Atlas.ti 7. The codes and themes were discussed with three researchers after initially coding five transcripts and then after coding all transcripts. In addition, themes and interpretations were regularly discussed in the project team.

RESULTS

Experiences and perceptions of care and support for severely ill homeless people

Characteristics of the participants are shown in Table 2. Several themes emerged from the data that gave insights into how severely ill homeless people and professionals experience the care given. A brief overview of these themes is provided in Table 3.

Table 3. Summary of themes regarding experiences and perceptions of care and support

Themes and subthemes
• Complexity of palliative care for the homeless
• *Behavior of homeless people*
• *Lack of expertise among professionals*
• *Sharing of knowledge*
• Variety of palliative care
• Self-determination
• Different perceptions on care
• Trusting relationship
• Less barriers
• Flexible care

Palliative care for homeless people is especially complex

According to both the professionals and homeless people interviewed, needs of homeless people who may benefit from palliative care differ greatly from those of regular palliative patients (Table 4, Q1). The disease course is often unpredictable, making it difficult to recognize the palliative phase and address problems adequately. This is largely related to the frequent (somatic and psychiatric) multimorbidity, often combined with addiction to alcohol and/ or drugs and intellectual disabilities.

Related to this, services are often unable to meet the homeless person's needs. According to homeless participants, palliative care in nursing home departments now focuses mainly on providing physical care, whereas social and psychosocial care is very important to them.

In concrete terms, psychosocial care, for example, taking time for small talk, attention to the life story, and building trust is essential for the target group. In addition, the challenging behavior of homeless people can be distressing to the healthcare providers, which complicates the care (Table 4, Q2).

Given the various problems homeless people experience, it is almost impossible for professionals or even specialists to have sufficient expertise in all aspects. Both professionals (Table 4, Q3) and homeless people (Table 4, Q4) brought this up. Professionals also expressed a desire to share existing knowledge with professionals from different disciplines and cities (Table 4, Q5). This was a recurring theme in all focus groups.

Table 4. Quotes on experiences and perceptions of care and support for severely ill homeless people.

Theme	No.	Quote
Complexity of palliative care	Q1	*"I regularly have contact with homeless people who are extremely ill and highly vulnerable, and increasing numbers are dying when with us. Then you come up against all kinds of things that are never in the picture for a GP, because you aren't familiar with the severe psychiatric issues and you don't see the addiction either." (professional, FG 2)*
Behaviour of homeless people	Q2	*"It's often awkward enough already for ordinary people in society to deal with the palliative phase properly, but with a target group like this it's even more so, because if they are admitted to whatever setting, they start behaving in highly inappropriate ways." (professional, FG 1*
Lack of expertise	Q3	*"If people are sedated at the last, and if they're heavy users you have to watch out very carefully that you have to begin with roughly a double dose, because apparently – well, you see it a lot with alcohol and morphine abuse – it doesn't work so well then. And yes, that means you need to know more about it." (professional, FG 3)*
	Q4	*"I needed a sedative, but they were afraid that I'd change my day-night rhythm around. I had to get rid of the stimuli. The people who work here don't have enough of an all-round thought pattern to be able to understand someone with that kind of weird problems." (homeless participant, FG 2)*
Sharing of knowledge	Q5	*"If it was left to our management, we'd be allowed to do minor operations as well, so then you have to be able to do everything. But there's a real lack of knowledge about palliative care. I know a fair bit about pain and addiction." (professional, FG 1)*
Variety of palliative care	Q6	*"It's pioneering, it's finding everything out for yourself. It's actually also the lack of a doctor at our place who's well familiar with it and able to assist us a little as well. I sometimes speak to a GP who has some experience with palliative care and euthanasia. But she often has to look things up as well." (professional, FG 1)*
	Q7	*"I work in a hospice and we occasionally get homeless people, off the streets. We have a sort of cooperative link with the homeless shelter so that they can stay there as long as possible and so that a nurse from the hospice will go and take a look there, do an intake, get to know the person a bit. And once it's no longer possible to stay there, the idea is that they then come to us." (professional, FG 3)*

Table 4. Continued.

Theme	No.	Quote
Self-determination	Q8	*"I'd like to have more influence over my own situation. It's not like the other person can decide what you should be doing. There are even rules about how late we should be going to sleep. Come on now, I'm fifty-six…" (homeless participant, FG 1)*
	Q9	*"I have one patient now who can put it beautifully: more rest and less condescension, fewer rules. Something simple – controlling their own medication, being able to drink a beer, rest, that there aren't other residents in particular knocking on the door all the time for a light or tobacco." (professional, FG 1)*
	Q10	*"So it's about their pills and the benzos and the methadone and you sometimes end up in, well, an awkward area, because they sometimes want things that are medically irresponsible." (professional, FG 2)*
Different perceptions	Q11	*"Have a look at what's coming to the fore with a person. Take a look at the dreams that they still have, for instance what they still want." (professional, FG 1)*
	Q12	*"And if they do come in, or if she comes in saying she's in a hurry because there are two more patients after me, then as far as I'm concerned there's no point talking. So then I keep quiet. I say, do your work, dole out your medicines, give me the injection and bugger off." (homeless participant, FG 3)*
Trusting relationship	Q13	*"Trust is often needed, but tricky because there's already a past history in which a lot of stuff has happened, and then at the end you have to build up that trust again. Sometimes you do have time, fortunately, because that relationship of trust has to be there. A lot of these people off the street have in fact lost that trust hugely – in the people around then, in humanity as a whole and in family relationships, because of all the circumstances." (professional, FG 3)*
Less barriers	Q14	*"I couldn't sit in my room, because they never came there. So I had to go and sit in the living room, go and eat with them, and then at one point somebody just fell forward with their face in a plate, and I thought, right I'll go and have a chat with him and find out what's up. And so they gradually get to know your face and then trust does start to appear, and then you start hearing the stories." (professionals, FG 3)*
	Q15	*"There's nothing agreed, no discussions, nothing about reducing anything if I say that I've stopped taking my meds. It's tricky to talk to the doctor. Look – they should be starting the process. They're the doctors, not me." (homeless participant, FG 1)*
Flexible care	Q16	*"Well, that comes from us but it's something the target group would say too, that's my experience. It's very important that they can just pop in and out. You actually need to be a bit more flexible." (professional, FG 3)*
	Q17	*"Without you making an appointment on Monday that they'll let you sit there for quarter of an hour on the Thursday three weeks later. People just have to be accessible, able to make time quickly. And I'd like a bit of privacy too." (homeless participant, FG 1)*

Q (number) = Quote number, FG = Focus group

Palliative care varies widely between professionals, institutions and cities

Although participants indicated that palliative care for homeless people has received more attention during the last few years, most pointed out that the quality and knowledge of palliative care still varies greatly among professionals, organizations, and cities (Table 4, Q6). Opportunities for professionals to consult someone often appear to depend on available knowledge, experience, and funding regarding palliative care for homeless people (Table 4, Q7).

Homeless people get to determine less than they would like

Both homeless participants and professionals saw self-determination as an important need of homeless people, especially in palliative care (Table 4, Q8). They also identified tension between homeless people's wishes when it comes to self-determination in care (e.g., wanting to be more autonomous) and the role of the professional regarding decisions about care (e.g., wanting to be more involved). Homeless participants wanted to become more involved in decisions about health or treatment, even in cases of limited mental capacity (Table 4, Q9). This tension often creates conflicts between professionals and homeless individuals, affecting the relationship negatively. Professionals often make decisions because (according to them) homeless people often make irresponsible or inappropriate decisions such as refusing medication (Table 4, Q10).

Homeless people and professionals have different perceptions of the care provided

According to professionals, their approach to palliative care consists mainly of being involved in the daily life of a homeless person, making patients feel at home, being available for small talk, offering flexibility, knowing the homeless personally, asking about spiritual needs, discussing the last wishes and giving love and attention (Table 4, Q11).

According to homeless participants, however, the focus on palliative care in their residence is mainly on somatic care, whereas psychosocial care matters more to them. This is related to homeless participants' perceptions that there is too little staff time available, among nurses in particular. This is in turn related to the limited availability and frequently changing staff. They mentioned that professionals need to pay attention to, for example, their life story and psychological needs (without immediately referring them to a psychologist), and need to be more open about palliative care (Table 4, Q12).

Trusting relationships are essential for providing palliative care to homeless people

To discuss palliative care with homeless people and/ or determine their wishes, a trusting relationship between professionals and homeless patients is essential. This is especially the case because fear of death and not wanting to die are common among homeless people, according to professionals. According to both professionals and homeless participants, homeless people are often distrustful and need time and attention to build a trusting relationship (Table 4, Q13).

Homeless participants provided specific suggestions for establishing trusting relationships: they are more positive about professionals who pay attention and have more time available, and who have sincere interest in them.

Fewer barriers and flexible care are needed in palliative care for homeless people

Both professionals and homeless participants mentioned that severely ill homeless people often perceive barriers to palliative care and will often not approach professionals spontaneously (Table 4, Q14 and Q15). Professionals can overcome this barrier by regularly visiting where a homeless person stays and by taking the initiative. In addition, homeless people mentioned a need for care beyond the usual opening hours and possibilities (Table 4, Q16 and Q17).

Views on designing a consultation function to improve palliative care for homeless people

Relevance of consultation

In this part of the focus groups, the primary question was whether and how consultation specifically might be helpful. In all four groups, most professionals saw added value in consultations. A number of professionals mentioned that since palliative care for homeless people is so complex, existing palliative care consultation is often not specific enough. Professionals see the added value of consultation for sharing, bundling and developing knowledge and expertise. This supports professionals with knowledge and experience in disciplines where they have less knowledge (Table 5, Q1). Additionally, increasing awareness about palliative care can be part of consultation (Table 35, Q2).

Reciprocity seemed important for the added value of a consultation function (Table 5, Q3). On the one hand, professionals employed in social services, mental healthcare or psychiatry should be able to consult a medical consultant so that the homeless person can stay in a familiar place as long as possible. On the other hand, professionals employed in medical services could consult a consultant in social services to find out more about someone's background. In addition, consultation can be seen in a wider perspective according to the professionals. Consultation does not only have to be limited to social care and hospice or nursing home care but can also concern generalist professionals who work in hospitals, home care, or nursing homes and would like to receive advice from an expert in social care or palliative care for the homeless.

A small proportion of the participants were employed in organizations where consultations about palliative care for homeless people have already been used by professionals. Participants felt these consultations were very useful. In the focus groups with homeless participants, homeless participants were more likely to talk about current care and the problems they experienced than about consultation. Homeless people often gave practical suggestions for consultations, such as a social worker or a peer worker to help them express their needs (Table 5, Q4). When asked about consultation, homeless people considered a consultation function as a good option, as it could provide training for professionals in showing understanding and paying attention to homeless people at the end of life.

Considerations on designing consultation

Professionals described several issues that should be considered when developing a consultation function. First, a consultation function should fit the regional situation. It is important to take account of varying expertise and the organizations already available. In any event, consultation for palliative care for homeless people must be integrated into existing consultation services (Table 5, Q5).

Secondly, it is important to consider which characteristics a consultant should have. Aspects mentioned were knowledge in multiple disciplines, experience with homeless people and their characteristics, being able to connect different disciplines, taking initiative, and representing several organizations. A consultant should be approachable for professionals and be flexible because of the lifestyle of homeless people (Table 5, Q6). Professionals mentioned that double consultations should not occur, consultation should ideally be available in a wide range of fields such as illnesses or combinations thereof that are typical for homeless people in the palliative phase and diversity among homeless people (including cultural and religious differences), symptom management (including cases of drug tolerance), behavioral problems of homeless people, addiction and drug use, practical issues such as insurance, and rituals and commemorations.

Thirdly, in addition to consultation in individual cases, consultants should also have a role in providing information and education. Participants said that there may be a barrier to approaching a consultant. A proactive approach could improve awareness that appropriate palliative care can be provided (Table 5, Q7). Professionals said that knowledge and information would make them feel more capable and self-confident when providing palliative care.

Homeless participants also made suggestions that may be important in developing consultation. Suggestions were that professionals should individually tailor palliative care, take homeless people seriously, take time and pay attention, respect their need for control, care in a familiar environment, and understand and implement the patient's vision of palliative care (Table 5, Q8).

Table 5. Quotes on views on developing a consultation function.

Theme	No.	Quote
Relevance of consultation	Q1	*"I think that consultations can give security – that you know where you have to go with your questions, that you can ask targeted questions and you'll get specific answers. So that you don't have to start investigating things yourself and you know what the situation is. That keeps things calmer." (Professional, FG 1)*
	Q2	*"A consultant can give information, provide extra knowledge to people, bring other parties on board who are needed at that moment, as well as working on a process for improving awareness." (Professional, FG 3)*
Reciprocity	Q3	*"I think that consultations by bringing the social shelters and the hospice together, transferring knowledge from one to the other, can help make sure that someone can stay for as long as possible in their own familiar place. Which is often a care placement." (Professional, FG 3)*
Views of the homeless	Q4	*"Someone who knows the situation from the inside and knows how they can help me further. Someone who will look out for me a bit, who will get things pointed out to the nursing staff and tell them that they really have to listen to me." (Homeless participant, FG 1)*
Considerations: *regional situation*	Q5	*"Consultation… the municipality: if you look at the consultations for social assistance, our policy for addresses for letters is very different than what Amsterdam does. So don't ask me how someone in Amsterdam gets a letter drop address; if you want to ask me how things are arranged in Rotterdam, then I'm a great consultant for that." (Professional, FG 4)*
Characteristics of a consultant	Q6	*"A consultant has to know where palliative care can be offered… in fact they need to know everything that someone in that safety net role should know. That's one. And he has to know about how to arrange practical things – a letter drop, care insurance, income, financial management. And practical experience too." (Professional, FG 4)*
Information and education	Q7	*"Consultation is important, but so are awareness and training and things like that, I'd say. And you can keep on about that, I reckon, because I think you can give training from the palliative care sector to people in the homeless care circuit, the care providers. But the care providers in the homeless care sector can also give the people from palliative care training about the target group, the homeless and the people on the streets." (Professional, FG 3)*
View of the homeless	Q8	*"There simply needs to be more knowledge. They need to know more about these people as a whole, before they immediately start trying to respond. More understanding needs to be created about how you should deal with these people." (Homeless participant, FG 1)*

Quote (number) = Quote number, FG = Focus group

DISCUSSION

Main findings

Views of professionals and homeless people about palliative care are often influenced by its complexity for this target group, the wide variation in palliative care between professionals, institutions, and cities, self-determination of homeless people, differing perceptions of professionals and homeless people about the care provided, trusting relationships between homeless and professionals when providing palliative care, and easily accessible flexible care. Almost all participants saw a consultative role for helping caregivers care for individual patients as a good way of addressing those themes and providing appropriate palliative care to the homeless. Professionals supported this idea because of the complexity of problems and the need for sharing, bundling and developing knowledge and expertise from different disciplines. Homeless people saw consultation as a way of training professionals to show understanding and pay attention as they feel that there is room for improvement in the care given. It is noteworthy that the two groups emphasize different important aspects: professionals emphasize the need of exchange of knowledge and skills to respond to complex care needs and homeless people emphasize that consultation services have to result in person-centeredness. The regional situation, the characteristics of a consultant, and their role in providing information and/ or education must also be considered when developing consultative processes.

This study is the first qualitative study that explores whether a consultative function can be used to provide timely and tailored palliative care for homeless people. It combines the views and experiences of professionals and homeless participants about palliative care. The fact that the homeless people included in our study were severely ill, but not necessarily in the palliative phase, can be seen as a limitation of this study. However, we think this is not necessarily a limitation, given the challenges of identifying who might be palliative in this population. However, their responses should be regarded as a combination of views on preferences for current care and palliative care. Another limitation is related to the opportunity sampling of homeless participants; they all were residents in nursing home wards for homeless people. They are not representative of for instance homeless people who avoid care.

The complexity of homeless people's problems at the end of life was also noted in other recent studies conducted in other countries, as was the need for easily accessible flexible care and the need for trusting relationships between professionals and homeless people in the palliative phase.[11, 31, 32, 37, 85, 91] In addition, our study revealed that professionals and homeless people have different perceptions about the meaning and content of palliative care, the actual or perceived roles of the homeless patient and of professionals; homeless people expressed a need for time, attention, and being taken seriously. Furthermore, this study highlights new insights about the need and use of a consultative function to provide timely, appropriate, and high-quality palliative care to homeless people, especially by providing specific knowledge, reciprocal exchange of skills and knowledge, and a broader vision of the homeless patient. Finally, it became clear that consultation was not the only option for providing more appropriate and on-time palliative care to homeless people. Homeless people expressed a need for support when severely ill. An intervention in which experts with practical experience help the homeless understand and communicate their needs better could perhaps be developed.

In order to realize a consultative function, more attention needs to be paid to the policy for financing palliative care for homeless people. The funding (and knowledge about the options for funding) was seen to vary greatly, so it seems that a regional structure needs to be provided so that every homeless person will have the same opportunities and quality of care at the end of life. In addition, consultations about palliative care for homeless people should be embedded in existing care and consultation structures.

CONCLUSIONS

In conclusion, given the fragmented and complex nature of palliative care for homeless people, multidisciplinary cooperation between professionals is necessary to improve palliative care for this group. Consultation can play an important role in improving palliative care by linking disciplines, supporting professionals, and providing appropriate palliative care to homeless people and exchanging knowledge between disciplines. In addition to consultation, other ways to improve palliative care for the homeless are training and knowledge sharing, as well deploying of experts by experience to support the homeless.

PART 3

A threefold intervention: evaluation of added value and process

Kan ik iets voor je doen?
Misschien een lied een gedicht
Dat je wanhoop benoemt
En je last iets verlicht?
Waar je droevig van wordt
Maar toch huilend om lacht
Dat je dagen verkort
Dat je nachten verzacht

De Dijk

CHAPTER 6

Evaluating the use and added value of a threefold intervention to improve palliative care for persons experiencing homelessness: a mixed-method study

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ABSTRACT

Background. Palliative care for persons experiencing homelessness who reside in social service facilities is often late or lacking. A threefold intervention was implemented to improve palliative care for this population by increasing knowledge and collaboration between professionals. This consultation service comprised: 1) consultations between social service professionals and palliative care professionals; 2) multidisciplinary meetings involving these professionals; and 3) training of these professionals. This study aims to evaluate the perceived added value of this threefold consultation service in three regions in the Netherlands.

Methods. A mixed-methods evaluation study using structured questionnaires for consultants, requesting consultants, and attendees of multidisciplinary meetings, semi-structured group and individual interviews with the professionals involved, weekly diaries filled out by consultants, and an implementation diary. Qualitative data were analyzed following the principles of thematic analysis. Quantitative data were analyzed descriptively.

Results. 34 consultations, 22 multidisciplinary meetings and nine training sessions were studied during the implementation period of 21 months. Social service professionals made up the majority of professionals reached by the intervention. In all regions the intervention was perceived to have added value for collaboration and networks of professionals (connecting disciplines reciprocally and strengthening collaborations), the competences of the professionals involved (competency in palliative care provision, feeling emotionally supported in complex situations), and the quality and timing of palliative care (more focus on quality of life and dying, advance care planning and looking ahead, and greater awareness of death and palliative care).

Conclusions. The threefold consultation service particularly helps social service professionals connect with palliative care professionals. It helps them to identify palliative care needs in good time and to provide qualitatively better palliative care to persons experiencing homelessness.

BACKGROUND

Persons experiencing homelessness often live lives characterized by poor health, frequently in combination with psychiatric diseases, intellectual disabilities, behavioral issues, and/or substance use.[155-157] The official number of persons experiencing homelessness in the Netherlands—defined as persons living rough, in emergency accommodation, or in special accommodation for persons experiencing homelessness or housing instability—has risen from almost 18,000 in 2009 to almost 32,000 in 2021.[1, 39] Persons experiencing homelessness often suffer from infectious diseases, cancer, psychiatric disorders, or cardiovascular disease[70, 93, 158, 159] and have a higher risk of health problems as they grow older.[155, 160] If their health condition worsens, they often live in shelters for day care, night shelters, or respite care,[69] which we refer to here as 'social service facilities'. We term the professionals working at these services "social service professionals"; they include social service workers and street nurses working on in-shelter nursing wards. The age at death of the homeless population is approximately 10 to 30 years younger than for the housed population.[4, 20-22, 28, 29, 161] However, palliative care is often lacking, late or of poor quality.[31, 109, 162] Therefore, timely palliative care is of great importance. We define "timely palliative care" as recognizing the palliative phase in good time and implementing palliative care, as early palliative care is an important pillar of palliative care and closely related to quality of life in the last phase of life.[50, 52]

Several international studies and commentaries have shown a need to strengthen multidisciplinary collaboration between palliative care professionals and social service professionals in order to improve the access and quality of palliative care for persons experiencing homelessness.[32, 34-37] A multidisciplinary approach to palliative care for persons experiencing homelessness is especially important due to the complex and multi-problem nature of their needs. In addition, the care in many shelters focuses on practical issues with little consideration for medical issues, illness, and death.[31, 32] Evidence on methods using multidisciplinary collaboration or staff training for professionals serving this population shows perceived positive effects on the quality of palliative care.[64, 65, 163] However, multidisciplinary collaboration between social service and palliative care professionals using a threefold intervention has not been studied yet within social service and healthcare professionals caring for persons experiencing homelessness.

In our previous focus-group study, we explored the need for a consultation service intervention in which professionals of different disciplines work together in order to increase collaboration and the exchange of knowledge between social service professionals and palliative care professionals. Participants who experienced homelessness indicated that professionals serving them need to be trained more in palliative care knowledge and skills, interdisciplinary collaboration, tailored care provision, and an attitude showing understanding and respect. They expected a consultation function supplemented by training and interdisciplinary collaboration to contribute to better palliative care for them.[110]

In the Netherlands, palliative care is generally delivered by generalists who are supported by healthcare professionals specialized in palliative care. Consultation with a palliative care consultant is a commonly used method to increase palliative care knowledge among healthcare professionals, and it has been shown to lead to the delivery of palliative care starting earlier.[53, 54] Our focus-group study showed that reciprocal consultation was expected to be of added value in providing timely and appropriate care to persons experiencing homelessness who have palliative care needs. Additionally, we found that training and multidisciplinary meetings should be part of this approach as well. A context-sensitive development of this intervention was considered important in view of the differences between services and regions.[110, 164]

Therefore, over a period of 21 months a threefold intervention involving consultation, multidisciplinary meetings, and training sessions was developed and implemented in three Dutch regions and the added value evaluated. The intervention was aimed at both professionals working in the field of social services for people experiencing homelessness and healthcare professionals working in the field of palliative care. We aimed to improve the quality of care by increasing collaboration and knowledge, and ensuring that palliative care starts earlier for people who are homeless.

In this evaluation study, we aim to provide insights into the intervention's added value. The research questions were:

1. How was the threefold consultation service received by social service professionals and palliative care professionals, and which professionals and patients did the intervention reach?
2. What is the perceived added value of the threefold consultation service for collaboration between professionals, professionals' competences, and the timing and quality of palliative care for persons experiencing homelessness, according to the social service professionals and palliative care professionals?

METHODS

Intervention

The intervention is described in Box 1.

Design and Data Collection

The mixed-methods evaluation study consisted of structured questionnaires, semi-structured topic-list guided interviews, and diaries. Table 1 shows an overview of methods used for data collection. Participants were sampled purposively based on their participation in the intervention activities. They were then contacted by phone or via the consultant. Almost all interviews were audio-recorded and performed by phone by one researcher (HK) trained in qualitative research; there were also two audio-recorded face-to-face interviews. The eighteen-month evaluation started in September 2019 and ran simultaneously with the implementation.

Elements of the threefold consultation service

The intervention comprised three activities. These were: (1) regular reciprocal bedside consultations between social service professionals and palliative care professionals (seeing the patient and talking with them) concerning patients experiencing homelessness who are eligible for palliative care. Involved are professionals working in the field of social services for this population, and palliative-care professionals working, for instance, in hospices and General Practices (2) multidisciplinary meetings between social-service professionals and palliative-care professionals to discuss patients eligible for palliative care; and (3) training and education on both palliative care and homelessness, whereby the frequency and content were determined by the professionals concerned. Also 'strategic partnerships' were created with one consultant in palliative care and one consultant in services for the homeless. This pair of consultants formed the basis for the intervention; the consultants initiated the consultations, multidisciplinary meetings, training sessions, and the involvement of other organizations. Group meetings with all the consultants were scheduled every six months in each region.

Intervention duration

The implementation of the threefold consultation service and process evaluation started with a preparatory phase for all three regions from June to September 2019. Implementation plans were made, followed by an execution phase lasting eighteen months. From March 2020, the COVID-19 pandemic affected the evaluation. Professionals had less time and had additional tasks, while visiting restrictions meant interviews had to be conducted by phone or video call.

Context-sensitive approach and implementation plans

This intervention was designed to be context-sensitive in order to fit local needs and tie in with existing collaboration efforts and/or further develop them. The regions of Amsterdam, Rotterdam, and Utrecht (three large cities in the Netherlands) participated in this intervention. Part of the context-sensitive design involved working out strategies drawn up in implementation plans by the participating organizations in each of the three regions. These implementation plans covered: the details of organizing the consultations, existing initiatives for consultation, collaboration, knowledge exchange, training, the organization of multidisciplinary meetings and potential for improvement, the organization of training and additional educational requirements, barriers and facilitators for all three elements, characteristics specific to each region, and possibilities for future financing and the continuation and embedding of the intervention. The implementation plans were updated every six months on the initiative of the researchers.

Small-scale intervention

The intervention aimed to start on a small scale and to expand further amongst professionals in the region once the consultations, multidisciplinary meetings, and training sessions were well established.

Box 1. Description of the threefold consultation service

The data consisted of: 216 structured weekly digital diaries recorded by the consultants; 34 questionnaires filled out by consultants after consultations; 14 questionnaires completed by professionals who had requested a consultation; 22 questionnaires about multidisciplinary meetings (MDMs) filled out by the palliative care consultant; eight semi-structured individual interviews with managers at organizations involved in the intervention; two semi-structured group interviews about MDMs (n=10, one face to face and one by video call); two semi-structured group interviews about the training (n=10, one face to face and one by video call); five telephone interviews with consultants; and one implementation diary.

Ethics

Participants were informed verbally by the researcher about the research goals. Written informed consent was provided by all the professionals involved in interviews prior to the interview. Completed questionnaires and transcripts were anonymized to ensure the participants' anonymity. Access to the data was limited to three researchers. On July 24, 2019, the Ethics Review Committee of VU University Medical Center provided a waiver as ethical approval was not needed under Dutch law.

Data analysis

Quantitative data were analyzed descriptively using SPSS 26.0. Answers to open questions were categorized by one researcher (HK) and checked by a second researcher (BO). Qualitative data collected in the interviews and the implementation diary were analyzed using the RE-AIM framework to structure analysis, and subsequently searching openly for themes within these RE-AIM elements, following the principles of thematic analysis.[111] Using MAXQDA2020, analysis started after conducting the first five interviews. After an initial analysis of these interviews, topic lists appeared to have some overlap, and the topic lists were shortened slightly. Three researchers (HK, BO, AV) independently coded four transcripts and then discussed their codes together until agreement was reached. Afterwards, all other data were coded by one researcher (HK). This researcher specifically looked for information on the reach of the intervention, collaboration between professionals, professionals' competences, and the quality and timing of palliative care. In addition, an open and inductive search was made for new themes that emerged from the data, until no more new themes were found. All codes were grouped into themes, which were discussed in the research team until no more new themes appeared.

In total, 60 palliative care professionals and 106 social service professionals were involved in the intervention. In the three regions combined, 34 consultations were held with social service professionals and palliative care professionals. All consultations were requested by social service professionals. A total of 22 multidisciplinary meetings were organized, as well as nine training sessions in the field of palliative care or in the field of social services for professionals serving people experiencing homelessness.

Table 3 shows that 54 patients were discussed in the consultations (n=22) and multidisciplinary meetings (n=32). Most of them were male (80%). Almost all patients (93%) were 70 years of age or younger. A majority of patients had Dutch nationality (59%) and resided in long-term shelters (57%). The most common diagnoses were cancer or lung disease (including COPD) and severe substance use.

Table 1. Overview of methods used, topics and content, respondents, and measurement moments

Methods	Topics and content	Respondents	Measurement moments
Structured questionnaires on consultations, including the perceived added value	Nature of care request, patient diagnosis, advice provided or received (broken down into the physical, psychological, social, and spiritual domains of palliative care, plus addiction), consultant's knowledge, consultation timing, facilitating and impeding factors regarding consultation, consultation quality, concreteness and usefulness of advice, effect on quality of palliative care, and added value of consultations.	Consultant Professional who requested consultation Requesting consultant	After each consultation
Structured questionnaires about the multidisciplinary meetings	Professional background of attendees, diagnosis, and details of the patients and domains discussed.	Consultant	After each multidisciplinary meeting
Structured digital diary recording activities and experiences with these activities	Type and number of activities performed, reason for activity, experiences with activity. The activities were: consultations, multidisciplinary meetings, training (given or received), and project team meetings.	Consultant	Weekly
Semi-structured group interviews about the perceived added value of multidisciplinary meetings and training activities	Process of getting involved in multidisciplinary meetings and training activities, appreciation of collaboration and discussions, discussed topics, added value of meetings, effect on knowledge and competences, effect on timing and quality of palliative care, suggestions for improvement.	Attendees of multidisciplinary meetings and training activities	After 12 multidisciplinary meetings and training activities
Semi-structured individual interviews about activities, process, added value, and maintenance	Activities, process, added value, and maintenance.	Managers at participating organizations	Shortly after consultation
Semi-structured individual interviews about activities, implementation, and added value	Current activities, collaboration, implementation and effort required, useful elements, missing aspects, perceived benefits of the three elements, perceived added value for collaboration, competences, quality and timing of palliative care.	Consultant	Mid-intervention period
Implementation diary with observations on added value and factors affecting this	Observations on the intervention: activities performed, steps taken to accomplish this, and evaluations and difficulties in this process. Observations on implementation: support for this process, strategies.	Researchers	Every week

RESULTS

The threefold consultation service during the intervention period

Table 2 shows the number of professionals who took part and the activities within the three regions.

Table 2. Overview of involved professionals and activities

	n of unique involved palliative care or health-care professionals involved	n of unique social service professionals[a] involved	n of consultations	n of MDMs[b]	n of training/ education sessions
Region 1	19	40	5	11	3
Region 2	18	19	5	7	3
Region 3	33	47	24	4	3
Total N	*60*	*106*	*34*	*22*	*9*

[a] Including in-shelter nursing staff

[b] Multidisciplinary Meetings (MDMs). The meetings involved the individuals referred to in columns 1 and 2

Consultations between social service professionals and palliative care professionals lasted on average 56 minutes (range 10-120) and were mostly held at the bedside (59%). For practical reasons or due to COVID-19 restrictions, some consultations were by phone (32%). On average, 3.23 symptoms (range 1-6) were mentioned in a consultation request; these were mainly fatigue, pain, and weight loss. On average 1.79 domains (range 1-4) were covered in the consultation requests per patient. These requests mostly concerned somatic aspects (30/34) and the patient's future well-being, pain treatment, or support and comfort in daily life. To a lesser extent, consultation requests concerned the psychological domain (7/34), for example patients being withdrawn or defensive. Some consultation requests were in the social domain (6/34), concerning the involvement of family members, isolation, or behavior. Lastly, consultation requests were in the existential domain (5/34), concerning future wishes, how to discuss incurability with the patient, isolation, and suffering. Consultants reported on average 2.23 (range 1-4) advice per consultation; these were mostly somatic care advice (29/34), and to a lesser extent advice on substance use (10/34), psychosocial aspects (19/34), and existential aspects (9/34).

Table 3. General characteristics of patients discussed in consultations and MDMs

		n of patients in consultations (%)	n of patients discussed in MDM (%)	Total n (%)
Unique patients		22	32	54
Region	Region 1	4 (18)	14 (44)	18 (33)
	Region 2	4 (18)	15 (47)	19 (35)
	Region 3	14 (64)	3 (9)	17 (32)
Sex	Male	17[a] (77)	26[b] (82)	43 (80)
Age range	30-40 years	0 (0)[a]	3 (9)	3 (6)
	41-50 years	3 (14)	2 (6)	5 (9)
	51-60 years	8 (36)	9 (28)	17 (32)
	61-70 years	9 (41)	10 (32)	19 (35)
	70 and older	2 (9)	2 (6)	4 (7)
Nationality	Dutch	13[a] (59)	n/a[e]	
	European (other)	1 (5)	n/a[e]	
	Non-Western	8 (36)	n/a[e]	
Residence	24-hour shelter (long term)	14 (64)[a]	17 (53)	31 (57)
	Assisted living	3 (14)		3 (6)
	In-shelter nursing ward	5 (22)	15 (47)	20 (37)
Diagnoses[c, d]				
Somatic		21[a]	26[b]	47 (87)
	Cancer (metastatic)	9	15	24
	Lung disease / COPD	4	5	9
	Rheumatism	3	0	3
	Heart failure	1	5	6
	HIV	0	3	3
	Other	4	5	9
Substance use		17	19	36 (67)
	Tobacco	5	n/a[e]	5
	Combination of substances	5	2	7
	Cocaine and/or heroine	5	6	11
	Alcohol	2	2	4
	Methadone	1	n/a[e]	1
	Unspecified		9	
Mental health		12	4	16 (30)
	Schizophrenia	6	0	6
	Personality disorder	3	3	6
	Other	3	1	4

[a] Missing values for consultation data were < 5% for sex, age, nationality, residence and diagnoses. Missing values are not included in the numbers and percentages.

[b] Missing values for MDM data were 19% for age and 13% for diagnoses. Missing values are not included in the numbers and percentages.

[c] As reported in the first consultation.

[d] Combination of diagnoses possible.

[e] Not included as a question or a checkbox in the evaluation questionnaire after MDMs.

On average MDMs lasted 75 minutes (range 30-90) and were attended by an average of 6.86 persons (range 4-9). In terms of disciplines, most attendees were general practitioners (GPs) and practicing or trainee medical specialists (34%), nurses and social workers in social services (21%) and to a lesser extent, in-shelter care coordinators (11%), nurses specialized in palliative care or psychiatric care (20%), or professionals of other disciplines (14%). The training sessions as part of the threefold consultation service lasted on average 132 minutes (range 30-300) and were attended by an average of 12.43 persons (range 7-16). Training sessions were provided on an introduction to palliative care, palliative sedation, handling complicated behavior, and taking care of caretakers.

Added value of the threefold consultation service

The use of the intervention differed per region and strongly depended on what options for consultation, MDMs, and training were already available within the region and whether there were needs within the region. Table 2 shows use of the intervention elements by region. Although the three regions used elements of the intervention differently due to the tailored nature of the intervention, there was homogeneity in the perceived added value of the intervention.

The intervention mainly had perceived added value for collaboration between social service professionals and palliative care professionals and the competences of these professionals, which in turn was thought to improve the timing and quality of palliative care. The data revealed seven themes reflecting the added value of the intervention.

Collaboration and Professionals' Networks

Reciprocity helps connect social services and palliative care

The intervention resulted in reciprocity between healthcare professionals and social service professionals. For all intervention elements, reciprocity was of added value in equipping professionals as caregivers to provide palliative care in the physical, psychological, social, and spiritual domains to a complex population. Reciprocity provided them with additional knowledge, skills, and understanding that helped them take care of this population. They gained options for palliative care provision that they had not been aware of before. Reciprocity resulted in particular in social service professionals having more palliative care competences (Table 4, Q1). Although palliative care professionals did not request consultations with social service professionals, reciprocity in the exchange of knowledge resulted in them having better insight into a complex population, and more flexible and creative ways of dealing with this population and their behavior.

Table 4. Quotes on collaboration, competences, and quality and timing of palliative care.

Theme and sub-theme	**Quote number**	**Quote**
Collaboration and networks		
Reciprocity	Q1	But for me it's the other way about, because of course I wasn't familiar with the whole homeless world. I knew something through the addiction services because of the multidisciplinary meetings [MDMs, which the participant took part in before the intervention]. But I take things from that and I think that we... (I'm repeating myself, aren't I? Great)... well, that we got to know more and... well, that we learned from one another. [...] So not just more breadth, but also getting the nursing perspective more involved [...] (Region 1, palliative care consultant)
Creating and strengthening collaborations	Q2	I think that we can find one another, and there comes a point that we're in one another's networks. And if we had a patient here with really complex behavior, then even if they came from another homeless center and not from [the homeless center with nursing facilities], for example, then you can still just call [the homeless center with nursing facilities] and ask them what we ought to do, or what route we need to take to get help with this. (Region 1, palliative care consultant)
Competences of professionals involved		
Feeling equipped and competent in palliative care provision	Q3	P: Well, she was real good at tying in with the medical aspects, I'd say. So yes, she has a different view of the residents than we do as sheltered housing supervisors. Yeah, we mainly focus on the supervisory aspect but we don't know so much about the medical, physical aspect. She helps us think about that and asks us critical questions. She also does that with the psychiatrist and the family doctor. She also looks at what alternative solutions there are and how we can get an even better picture of a resident in terms of their physical condition.(Region 1, care coordinator in social services)
Support in complex and emotional situations	Q4	P: I know she was involved at [location 2] with someone who was really in the terminal stage... and also behaviorally... I'm not going to the nursing home. And she was really good there at helping think up solutions, whereas the family doctor said, 'Just go to a nursing home.' And we thought, that's not always how it works. It's different behavior, another culture, not wanting to leave your safe environment, not having any family. She gave real support — what can you do as a team? [...] She could act as an intermediary more, say this is what the team can do, these are their areas of expertise, but that only goes so far and after that, we need to bring in other people. She brings those different worlds together. You really need that with a specific group, especially here with aging people and addiction and Lord alone knows what diseases. Yes, the whole package is broader, more complex perhaps. She's better at that. I don't have a nursing background at all. But the ultimate responsibility for the processes is mine, so I thought, 'Oh great, someone who's helping find solutions, that can only be positive.' (Region 3, social service professionals in MDM)

Table 4. Continued.

Theme and sub-theme	Quote number	Quote
Quality and timing of palliative care		
Focus on quality of life and dying	Q5	P: She is also doing a bit better now thanks to this [dietary advice]. You can have a bit more of a conversation with her, and she's slightly more cheerful and less at risk of falls. So at first it's like, yeah, she's getting so thin, we can't communicate with her, everything's getting worse, one function after another stops working. Not caring properly for herself. And now you see her becoming more stable purely thanks to a good diet. And that it could be a few years yet. But then you prioritize… you prioritize comfort rather than active treatment. Then you can say it's a palliative process because if this woman doesn't want to go any further we need to accept it, or if she starts to feel a bit better again we could raise the topic again. That's the great thing about this; they arranged an Italian interpreter and now she has agreed to an operation, a cataract operation. Well, that'll also improve her quality of life because she'll be able to see things a lot better then, she will be able to watch TV, all that kind of thing. Those are things she enjoys doing. (Region 3, palliative care consultant)
Advance care planning and looking ahead	Q6	P: Right. And if I can add to what both [the social care consultant] and [the street doctor] have said, I reckon – and that's what [the street doctor] said at the start too –, that it's mainly the proactive aspect: thinking ahead, let's say. So not saying, 'We'll do this now and take another look in two days' time.' More a case of well, we'll do this and supposing that… then we'll take this route instead of that route. You can do that as a nurse, of course. So let's suppose someone becomes bedridden, well, you could consider a height-adjustable bed, just to give an example, I don't even know if you have that, but that kind of thing. It's kind of like testing out ideas with one another. As I said before to you [researcher], I reckon that's also largely because you know one another. That removes any obstacles, especially as you've been working with each other for several years by now. (Region 2, social service professionals and palliative care professionals, MDM)
Awareness of death and palliative care	Q7	P: Um, well, it [the advice in consultations and the MDMs] gives you a better understanding anyway if you know someone's in the final stage. Including stuff about how you can keep up their quality of life. Um, also the fact that you can discuss it with the actual resident. Just like when someone has poor liver function and you can tell them: look, if you carry on like this, it will eventually be too late. And your liver is functioning really badly. P2: It's terminal… P3: Yes. (Region 3, MDM)

Quote (number) = Quote number, P = participant, MDM = multidisciplinary meeting

The intervention creates and strengthens networks and collaborations
Particularly MDMs and training sessions resulted in new formal networks and collaborations. Mainly because of the MDMs and training sessions, the intervention resulted in new formal networks and new forms of teamwork encompassing professionals in social services and palliative care. The main added value of these networks and this teamwork was in knowing how to find one another, the 'strategic partnerships' (Box 1), and familiarity, which makes it easy to consult one another. Other perceived benefits were the new options for patient transfers, contacts with new categories of professionals such as spiritual caregivers, and being able to integrate the two 'worlds' of healthcare and social services. On the other hand, some social service professionals said they felt no need for more collaboration as they already felt committed to in-house palliative care for their patients due to the involvement of a GP. Also, some professionals reported that they were not yet able to assess the added value of the intervention due to a delayed start, the small number of activities, or only briefly being engaged as a consultant in the intervention (Table 4, Q2).

Professionals' Competences

Professionals feel better equipped and more competent in palliative care provision
Both social service professionals and palliative care professionals felt better supported in providing palliative care to patients coping with complex issues in all domains of palliative care. Advice in consultations and MDMs on medication, and symptom management provided in consultations by palliative care professionals helped social service professionals feel more competent in detailed, early and comfortable palliative care provision. Training helped them feel better equipped in applying knowledge, guidelines, and protocols and in signaling deterioration in the patient. Trained professionals felt that they could bring in 'fresh' expertise within their team, that they were better able to consider the situation from multiple perspectives, had easier access to palliative care services, and could request a consultation more easily. These benefits of the intervention were experienced in particular by social service professionals whose organizations did not have palliative care expertise or who previously felt ill equipped to provide palliative care to this patient population (Table 4, Q3).

Professionals feel supported in complex and emotional situations
Being able to request a consultation or ask for a second opinion on suspicions or actions that had been taken was perceived as of great importance for the professionals involved in the intervention. Social service professionals in particular reported that being able to consult a palliative care specialist whom they already knew helped them feel emotionally supported, gave them self-confidence and let them provide tailored care to the patient. Another perceived benefit was self-efficacy due to feeling better equipped, feeling supported when making decisions, and being able to ask for help. Some consultants, however, had ambiguous feelings about the added value of the intervention as it increased their workload and caused stress as well (Table 4, Q4).

Quality and Timing of Palliative Care

More focus on quality of life and quality of dying

Social service professionals and palliative care professionals saw added value for the quality of life and quality of death of patients from the regular use of all three elements of the intervention. They felt that the involvement of a palliative care consultant, the knowledge gained or refreshed in training, and the discussions of patients in MDMs with other professionals helped them offer patients more comfort, better symptom management and monitoring, and more humanity, with a greater focus on the patients' needs and wishes, and on somatic aspects of palliative care for patients residing in social service facilities (Table 4, Q5).

Focus on palliative care encourages advance care planning and looking ahead

In line with the previous theme, the training sessions and consultations in particular helped social service professionals use advance care planning and look ahead. As many deaths seemed to occur suddenly, social service professionals perceived added value in spending effort on looking ahead and thinking about what could be expected in the future. The consultant's questions during MDMs or consultations made them feel more alert to the possible deterioration in patients and made them more aware of early, tailored palliative care (Table 4, Q6).

Awareness of death and palliative care

As a recovery-oriented approach is common among social service professionals, they often fail to focus on the possibility of death. Therefore, the role of the training sessions in particular in raising awareness of death and palliative care among social service professionals was also of perceived value. Social service professionals often felt too busy with day-to-day ad hoc issues. In addition, it was difficult for them to recognize whether a resident's health was worsening. Because they often saw the resident on a daily basis, minor deteriorations in health went undetected. Training sessions, MDMs, and consultations made them realize that life is finite, and what consequences this has for daily care (Table 4, Q7).

DISCUSSION

All three elements of the threefold consultation service were used by all three regions. The intervention reached a comparable population of patients and professionals: mainly older, seriously ill male patients residing in long-term social service facilities and social service professionals. Regions varied in numbers of consultations, MDMs, and training sessions. Consultations mainly involved palliative care professionals advising social service professionals. Regarding the patients reached, the majority were male, of Dutch nationality, aged between 50 and 70, and residing in 24-hour shelter facilities or nursing wards. Consultation requests were mainly about somatic issues; advice often covered both somatic and psychosocial aspects. MDMs were mainly attended by GPs and nurses from both social services and healthcare services. The training sessions varied widely in duration and content.

Perceived added value was found for the collaboration and networks of professionals, especially in reciprocally connecting professionals with different disciplines and creating and strengthening collaborations. Added value was also found in strengthening competences in palliative care provision, and offering emotional support in complex situations. Lastly, the intervention was perceived as improving the quality and timing of palliative care for this population, especially through the focus on quality of life and dying, advance care planning when discussing patients, and awareness of death.

Our findings reveal that the intervention is of perceived added value regarding the detection of possible palliative care needs and quality of palliative care. All three elements of the three-faceted intervention contributed to the perceived added value of the intervention as a whole, combining equipping social service professionals with knowledge, raising awareness, and facilitating collaboration. In terms of improving the quality of palliative care, our study revealed several aspects that have been identified as determining quality in palliative care by the Dutch Quality Framework for palliative care, namely recognition, proactive care planning, coordination and continuity, expertise, and personal balance of the professional.[52] Therefore, we consider this intervention as contributing to an improvement in palliative care for this population, whereby the training, MDMs, and consultations increase professionals' (conscious) competence.

Our study shows that collaboration between different organizations helps social services to deliver palliative care covering the somatic, spiritual, social, and psychological domains as defined by the WHO,[50] rather than mainly from the social perspective as social services are used to doing. Several studies confirm the added value of interventions aimed at training or interdisciplinary collaboration between social service and palliative care professionals,[64, 65, 165] resulting in more knowledge, skills, collaboration, and confidence when providing palliative care to this population. Other international studies confirm the need for palliative care in the place where persons experiencing homelessness reside, all the more because of this population's poor access to palliative care.[30, 31, 109, 166]

In addition to our findings on collaboration, timing and quality, and competences, our study highlights the emotional support needed by professionals when providing palliative care to this population. This is also found in other studies,[56-58, 166] which indicate a need for emotional support among social service professionals in demanding situations, such as the imminent death, extreme suffering or sudden death of patients with whom they have established a bond during the patient's stay in the social service facility. Our study demonstrates the added value of the palliative care consultant in providing emotional support to social service professionals.

The diversity in use of the intervention but comparable perceived added value confirms the importance of a context-sensitive approach. Moreover, a context-specific approach using the basic elements of collaboration, competences, and quality and timing of palliative care is relevant in other contexts and countries. However, the success of implementing an intervention is also highly dependent on the process of implementation. Implementation of the intervention took time and effort, and some professionals involved said that it was too early to assess the efficacy of the intervention or that more time was needed for better implementation. The COVID-19 pandemic made it particularly difficult to build new collaborations. A process evaluation is needed to gain more insight.

Strengths and limitations

An important strength of this study is that it evaluates a new, regionally tailored intervention aimed at improving the quality and timeliness of palliative care for persons experiencing homelessness. Another strength of this study is the intervention explored and designed in close collaboration with persons experiencing homelessness, guided by our previous focus group study in which persons experiencing homelessness indicated that professionals serving them needed more knowledge, training and collaboration when providing palliative care.[110] The design of this intervention and the project were supervised by an expert by experience who participated in the advisory board. Also, in this study professionals were involved from both social services and health services, including palliative care professionals and their managers.

A limitation of this study is that persons experiencing homelessness who were the subject of consultations were not interviewed themselves due to COVID-19 visiting restrictions, although this had been intended in the study protocol. We recommend to conduct research into evaluation of this intervention from the perspective of those who experienced the intervention while measuring patient-centered outcomes. Another limitation can be seen in the use of the intervention within social services, which might have resulted in a relatively old, mainly Dutch patient population receiving care. Our study population is probably not generalizable to the entire homeless population in need of palliative care in the Netherlands, because a small number of seriously ill people live on the streets, are undocumented or do not use social services.[1, 39]

CONCLUSIONS

A threefold consultation service can help especially professionals in social services to connect with palliative care professionals. It is perceived to help professionals in social services better identify palliative care needs, and collaboratively provide timely palliative care of better quality. It is recommended to further study future use of the intervention in other regions and countries.

Is er iets wat ik doen kan
Wat troost in je verdriet?
Want straks moet je weer verder
Ook al wil je nog niet
Is er iets wat ik doen kan
Wat je helpt in de pijn?
Wat iets voor je betekent
Zou ik graag voor je zijn

De Dijk

CHAPTER 7

Implementation of a threefold intervention to improve palliative care for persons experiencing homelessness: a mixed-method process evaluation using the RE-AIM framework

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Submitted

ABSTRACT

Background. Palliative care provision for persons experiencing homelessness is often poor. A threefold consultation service intervention was expected to increase knowledge of palliative care and multidisciplinary collaboration, and improve palliative care for this population. This intervention comprised: 1) consultation of social service professionals by palliative care specialists and vice versa; 2) multidisciplinary meetings with these professionals; and 3) training and education of these professionals. We aimed to evaluate the implementation process and its barriers and facilitators of this service implemented within social services and healthcare organizations in three Dutch regions.

Methods. A mixed-method evaluation study using structured questionnaires among consultants, semi-structured individual and group interviews among professionals involved, and (research) diaries. Qualitative data were analysed using thematic analysis. The process was structured using the Reach, Adoption, Implementation and Maintenance dimensions of the RE-AIM framework.

Results. All three regions adopted all three activities of the intervention, with differences between the three regions in the start, timing and frequency. During the 21-month implementation period there were 34 consultations, 22 multidisciplinary meetings and nine training sessions. The professionals reached were mainly social service professionals. Facilitators for adoption of the service were a perceived need for improving palliative care provision and previous acquaintance with other professionals involved, while professionals' limited skills in recognizing, discussing and prioritizing palliative care hindered adoption. Implementation was facilitated by a consultant's expertise in advising professionals and working with persons experiencing homelessness, and hindered by COVID-19 circumstances, staff shortages and lack of knowledge of palliative care in social service facilities. Embedding the service in regular, properly funded meetings was expected to facilitate maintenance, while the limited number of persons involved in this small-scale service was expected to be an obstacle.

Conclusions. A threefold intervention aimed at improving palliative care for persons experiencing homelessness is evaluated as being most usable when tailored to specific regions, with bedside and telephone consultations and a combination of palliative care consultants and teams of social service professionals. It is recommended to further implement this region-tailored intervention with palliative care consultants in the lead, and to raise awareness and to remove fear of palliative care provision.

BACKGROUND

Persons experiencing homelessness often suffer from varying combinations of problems such as intellectual disabilities, a high burden of somatic and psychiatric problems, substance use, high symptom burden and high rates of early morbidity compared to the general population.[4, 5, 9, 10, 29] In the Netherlands, about 32,000 persons are officially registered as using the Dutch social services system for persons experiencing homelessness.[1] Given the high morbidity and mortality in this group, some of them will need palliative care.[28]

Palliative care is often provided late or not at all to this population, and the provision is characterized by many impediments such as lack of expertise and knowledge and training among staff. Persons experiencing homelessness typically have chaotic lifestyles and an unpredictable course of illness, with unexpected improvements in their health if they are cared for in social services.[30-32] Examples of impediments in care provision to this population are: a lack of criteria pertaining to when a patient is eligible for referral to palliative care or hospice care; what is often perceived to be the patronizing and stigmatizing attitude of healthcare staff towards persons experiencing homelessness; a large number of different social service professionals involved in the delivery of daily care; and inflexibility in mainstream healthcare systems in adapting the care to the specific needs of a person experiencing homelessness.[6, 31, 73, 109] Moreover, improving palliative care for this population is complex because of the decentralized organization, with individual municipalities or regions consequently taking an individual approach.[110] Also, existing regulations and financing systems hinder improvements to palliative care, as we found in our focus group study of barriers and needs regarding the provision of palliative care to persons experiencing homelessness.[110] In this study, we also found that many disciplines are involved when a person experiencing homelessness is at the end of life. Good quality palliative care is focused on improving the quality of life of patients and their families and on prevention and relief of suffering by the early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems,[50] as defined by the WHO. However, palliative care is often not provided for persons experiencing homelessness, or only to an insufficient degree. Moreover, the provision of palliative care is complicated by the characteristics of this population.[31, 109, 162, 167]

In this paper, ‘persons experiencing homelessness’ are defined as persons without housing, who reside in emergency accommodation or accommodation for persons experiencing homelessness or who reside temporarily at a friend’s or relative’s place, as officially defined by Statistics Netherlands (CBS).[1, 39] In the Netherlands, these persons often reside in social service facilities that provide daytime or overnight stays or temporary housing. Palliative care for people experiencing homelessness is delivered in various settings, such as in-shelter nursing care, outreach home care, or hospices,[110, 168] and by various healthcare professionals. In addition, these settings vary across towns and cities. Previously, we explored if professionals employed in social services, healthcare and palliative care would benefit from a reciprocal consultation service in order to foster appropriate and timely palliative care.

This consultation service was based on a practice-based, small-scaled intervention using a consultation service in Amsterdam. Participating professionals saw added value in an adapted version of this consultation service, which takes the form of a threefold reciprocal intervention. The threefold intervention comprises: (1) consultations between social service professionals in the field of services for persons experiencing homelessness and palliative care professionals; (2) multidisciplinary meetings (MDMs) between these and other professionals in social and palliative care services on a regular basis in which homeless patients eligible for palliative care are discussed; and (3) training and education on subjects related to palliative care and homelessness, whereby the frequency and content are determined by local professionals. This intervention was expected to work best when developed regionally and tailored to the regional situation.[110]

During 21 months, this threefold consultation service was implemented in three regions in Dutch healthcare and social service settings. By implementing this service, we aimed to increase collaboration and knowledge as well as improve the quality and timeliness of palliative care delivered to persons experiencing homelessness. As this threefold intervention is a new phenomenon, a process evaluation was embedded in the implementation process. This process evaluation was based on the Reach, Adoption, Implementation and Maintenance dimensions of the RE-AIM framework used to structure these different implementation factors.[169] The perceived added value was described in our study on the added value of this intervention.[170] Perceived added value was found in all three regions for the collaboration and networks of the professionals involved (connecting disciplines reciprocally and strengthening collaboration), the competences of the professionals involved (competency in palliative care provision and feeling emotionally supported in complex situations), and the quality and timing of palliative care (focus on quality of life and dying, advance care planning, and awareness of death and palliative care).

The study was guided by the following research questions:

1. What is the Reach, Adoption, Implementation and Maintenance of a threefold consultation function according to the social service and palliative care professionals involved in the threefold intervention?
2. What are the perceived barriers and facilitators during this implementation process?

METHODS

Intervention design

Elements of the intervention

The intervention consisted of three activities, which were: (1) regular consultations about patients experiencing homelessness and eligible for palliative care, between social service professionals working in the field of services for this population and palliative service providers, such as hospices and GPs; (2) multidisciplinary meetings between social service professionals and palliative care professionals to discuss homeless patients eligible for palliative care; and (3) training and education on both palliative care and homelessness, whereby the frequency and content were determined by local professionals. Another aspect of the intervention was the creation of 'strategic partnerships' consisting of one consultant in palliative care and one consultant in services for the homeless. This duo of consultants formed the basis for the intervention; the consultants took charge of the practical implementation of consultations, multidisciplinary meetings, training and involvement of other organizations.

Duration of intervention

The threefold intervention and process evaluation started with a preparatory phase for all three regions from June until September 2019. Implementation plans were made, followed by an eighteen month execution phase.

Context-sensitive approach and implementation plans

Because previous explorative research on the development of this consultation intervention had shown that local initiatives, collaboration and resources differ widely among regions,[110] this intervention was designed as context-sensitive, in order to fit local needs and to tie in with existing collaboration efforts and/or further develop them. The regions of Amsterdam, Rotterdam and Utrecht participated in this intervention. Part of the context-sensitive design was working strategies written down in detailed implementation plans. These implementation plans concerned details of the organization of consultations; existing initiatives for consultation, collaboration, knowledge exchange, and training; the organization of multidisciplinary meetings and potential for improvement; the organization of training and additional educational requirements; needs barriers and facilitators for all three elements; characteristics specific for each region; and possibilities for future financing and future continuation and embedding of the intervention. Implementation plans were updated every six months on the initiative of the researcher.

Small-scale intervention

This intervention aimed to start on a small scale. Once the consultations, multidisciplinary meetings and training were well established, the aim was to expand this further amongst the professionals in each region.

The RE-AIM framework

This mixed-methods process evaluation was designed to systematically monitor and evaluate the implementation of the threefold consultation service approach in three regions in the Netherlands, according to the RE-AIM framework. RE-AIM is an appropriate framework to evaluate the process and added value of interventions in practice at both the individual level (e.g. healthcare professionals) and the organizational level (e.g. institution, policy), and to provide useful starting points for improvement in the further implementation and future maintenance. Table 1 shows the operationalization for all dimensions of the RE-AIM framework. As we reported on Effectiveness, operationalized as added value in another study,[170] effectiveness was not part of this process evaluation. We evaluated Reach on an individual level, and Adoption, Implementation and Maintenance on an organizational level. The process evaluation started during the preparatory phase for all three regions from June until September 2019, and was followed by an evaluation of 18 months of practice, in which the professionals in the regions worked with the intervention. The intervention was implemented just before the start of the COVID-19 pandemic.

Ethical approval

Written or verbal informed consent was provided by all professionals involved in group and individual interviews prior to the interview. Transcripts were anonymized to ensure the participants' anonymity. Access to the data was limited to two researchers. On 24 July 2019, the Ethics Review Committee of VU University Medical Center provided a waiver as ethical approval was not needed under Dutch law.

Data collection

This mixed-methods evaluation study consisted of structured questionnaires filled in by (requesting and advising) consultants, semi-structured topic-list-guided interviews in which managers, multidisciplinary meeting (MDM) members and consultants participated, structured diaries kept by consultants and an implementation diary kept by the lead author. The topics covered in each data source are listed per RE-AIM dimension in Table 1. Table 1 also shows the measurements for the data collected for all RE-AIM dimensions and the timing and specifications of the measurements. All RE-AIM dimensions were measured in each data source. Topic lists used during interviews are shown in Appendix 5 and included topics on organizing activities and the process, maintenance, implementation and current activities. Results are based on data from 216 structured weekly digital diaries, 34 questionnaires filled in by consultants and fourteen questionnaires filled in by requesting consultants, 22 questionnaires completed by MDM attendees, eight semi-structured individual interviews with managers in organizations involved in the intervention, two semi-structured group interviews on MDMs and two semi-structured group interviews on training, five interviews with consultants, and one implementation diary.

Data analysis

Qualitative data collected in semi-structured individual and group interviews and the implementation diary and structured diaries were analysed following the principles of thematic analysis to identify important themes,[111] using the RE-AIM framework[169] to structure the analysis of reach, adoption, implementation and maintenance. Using MaxQDA (version 2020), analysis started after conducting the first five interviews. After that, topic lists were adjusted slightly as some topics overlapped. Three researchers (HK, BDO, AJEV) independently coded four transcripts and then discussed themes until agreement was achieved. After that, all other data were coded by one researcher (HK). All data were coded using the RE-AIM dimensions. Subsequently, we searched openly for themes concerning barriers and facilitators within each of the RE-AIM dimensions. Then barriers and facilitators within the

RE-AIM dimensions were further categorized using predefined constructs of the Consolidated Framework for Implementation Research (CFIR),[171] as operationalized in Table 1. All themes, constructs, quotes and categorizations were discussed in the research team. Answers to open questions were categorized by one researcher (HK) and checked by a second researcher (BDO). Descriptive analyses took place for the quantitative data using SPSS 26.0.

RESULTS

Reach of the intervention

Regarding persons experiencing homelessness at the end of life, the intervention mainly reached sick residents of social service facilities (long-term or short-term care); no persons living on the street were reached. Patients discussed in consultations and MDMs were often older persons (42% aged 61 and over) where a need for palliative care was recognized. The professionals reached by the intervention were mainly the colleagues of consultants and/or the team to which the consultant was connected. Prior to the implementation period, the professionals involved estimated the number of social service professionals and palliative care professionals who could be reached by the intervention initially and potentially. Table 2 shows an estimated 400 professionals could potentially be reached by the intervention, and 166 professionals were ultimately reached by the intervention in practice.

Table 3 shows intervention activities per region. There were a total number of 34 consultations, 22 MDMs and nine training sessions. The participants were mainly social service professionals and nurses employed in social service provision. Home-care professionals, hospice nurses, practice nurses and general practitioners were also involved to a lesser extent. During the implementation period, some external professionals other than the initial participants became involved in the intervention, such as professionals working in other social service organizations on the possible extension of the intervention, and professionals in hospitals such as anaesthetists and surgeons.

Table 1. Operationalization of RE-AIM dimensions and CFIR constructs

RE-AIM dimension	Conceptualization of RE-AIM dimension	Operationalization
Reach	Extent to which the target population is reached by the initiatives	Extent, type and setting of professionals in social, hostel and palliative care services, and homeless persons who were (or were not) involved in consultation, multidisciplinary meetings and training during the study
Adoption	Degree to which the initiatives are adopted or used by organizations and settings	Extent to which consultation, multidisciplinary meetings and training were adopted and used by organizations, standardization of use, and factors affecting this
Implementation	Extent to which the initiatives have been implemented according to plan, including barriers and facilitators	Extent to which the threefold consultation services are implemented according to original plans, including barriers and facilitators
Maintenance	Extent to which the initiatives are future-proof	Extent to which the threefold consultation services are (or are expected to be) used, supported and sustained over time by healthcare professionals and management
Data sources	**Detailed description of measurement type**	
	1. Weekly structured digital diary for the consultants, questions on type and number of activities performed, reason for activity, experiences with activity. The activities were: consultations, multidisciplinary meetings, training (given or received), and project team meetings.	
	2. Structured questionnaire for advising consultant and requesting consultant after each consultation; nature of care request, patient diagnosis, advice provided or received (broken down into the physical, psychological, social, and spiritual domains of palliative care, plus addiction), consultant's knowledge, consultation timing, facilitating and impeding factors regarding consultation, consultation quality, concreteness and usefulness of advice, effect on quality of palliative care, and added value of consultations.	
	3. Structured questionnaire after each multidisciplinary meeting filled in by the consultant involved; questions on professional background of attendees, diagnosis, and details of the patients and domains discussed.	
	4. Semi-structured group interviews with attendees of multidisciplinary meetings and training activities, guided by a topic list with topics on the process of getting involved in multidisciplinary meetings and training activities, appreciation of collaboration and discussions, topics discussed, added value of meetings, effect on knowledge and competences, effect on timing and quality of palliative care, suggestions for improvement.	
	5. Semi-structured individual and group interviews with managers, guided by a topic list with topics on activities, process, added value, and maintenance of intervention activities.	
	6. Semi-structured short individual interviews with consultants on current activities, collaboration, implementation and effort required, useful elements, missing aspects, perceived benefits of the three elements, perceived added value for collaboration, competences, quality and timing of palliative care.	
	7. Implementation diary, filled in weekly by the researcher with observations on the intervention: activities performed, steps taken to accomplish this, and evaluations and difficulties in this process. Observations on implementation: support for this process, strategies.	

Table 1. Continued.

RE-AIM dimension	Conceptualization of RE-AIM dimension	Operationalization
CFIR Construct	**Operationalization**	
Intervention characteristics	The intervention as referred to in the project proposal with consultations, MDMs and training activities aimed at palliative care for this population specifically, characteristics of the intervention (reciprocity, duos, bedside consultations), and the activities and perspectives of the professionals involved in this	
Outer setting	The characteristics of organizations and networks that are involved later on and are complementary to the initial collaboration as described in the work plan.	
Inner setting	The characteristics and culture of the organizations that were involved in the project from the start and the implementation climate within these organizations.	
Characteristics of individuals	Characteristics of individuals involved in the project from the start and later on in the project in consultations, MDMs and training.	
Process	Process of preparing, planning and executing the intervention.	

Table 2. Reach in terms of numbers and professionals.

	n Actual organizations involved	n of Professionals who could potentially be reached (estimated)[b]	n of Palliative care and healthcare professionals involved	n of Social service professionals involved
Region 1	3	115	19	40
Region 2	4	110	18	19
Region 3	2[a]	175	33	47
Total N	9	400	60	106

[a] This involved two different branches of one large organization: a social services branch and a general district nursing branch that had not previously worked together

[b] Estimated numbers are based on a survey before the start of the intervention among the participating consultants.

Table 3. Number of consultations, MDMs and training sessions per region.

	n Consultations	n MDM's	n Training/education
Region 1	5	11	3
Region 2	5	7	3
Region 3	24	4	3
Total n	34	22	9

The main facilitators in reaching professionals were *intervention characteristics* and the *characteristics of individuals,* respectively homeless individuals already known to the social services involved in the intervention and s having an enthusiastic and proactive consultant (Table 4). Reported barriers to reaching persons experiencing homelessness at the end of life were mainly in the field of *intervention characteristics*. Telephone consultations and consultations during MDMs were considered to be barriers, as the consultant was not personally able to assess the symptoms and patients. Another barrier in reaching this population was that not all seriously ill persons experiencing homelessness for whom a palliative care approach could be beneficial resided in social services or on a nursing ward. Barriers to reaching more social service professionals in the intervention were in the *outer setting*, and concerned difficulties in getting other social service professionals involved because new contacts had to be made and developed. *Intervention characteristics* also formed a barrier because starting the intervention required time and preparatory work. Regarding the *process*, COVID-19 restrictions formed a barrier to reaching persons experiencing homelessness and to professionals providing palliative care to them because of visiting restrictions and the high workload of social service professionals.

Table 4. Overview of facilitators and barriers in the RE-AIM Reach dimension

CFIR domain[a]	Facilitators	Barriers
Intervention characteristics	• Persons experiencing homelessness are known to the social services so that the intervention can be potentially beneficial for them	• Telephone consultations and indirect consultations may have hindered the assessment of symptoms and the patients themselves by the consultant • Intervention is aimed at social services, while some persons experiencing homelessness do not reside within these services • Starting the intervention requires time and preparatory work, making it hard to involve new parties as well
Outer setting		• Expanding and reaching additional social service professionals with the intervention is hard to accomplish
Characteristics of individuals	• An enthusiastic and proactive consultant helps in reaching out to social service professionals and establishing intervention activities	
Process		• COVID-19 visiting restrictions and the heavy workload may have hindered efforts to reach persons experiencing homelessness and professionals providing palliative care to them

[a] For Reach, we did not find factors for the inner setting

Adoption of the intervention

All three intervention activities —consultations, multidisciplinary meetings and training — were adopted in all three regions. However, the start, timing and frequency of these activities differed greatly from region to region. Figure 1 shows when and how often a region used each of the three activities. The course of activities shows that regular use of the activities required time and effort in preliminary work. The activities were mainly taken up by organizations involved from the start, and occasionally spread to new organizations during the implementation period. Activity growth was mostly gradual. However, in one region there was a sudden big increase in consultations due to the regular planned visits of the consultant to the linked social service professionals and their facility. All regions provided three training sessions during the intervention period at a similar pace.

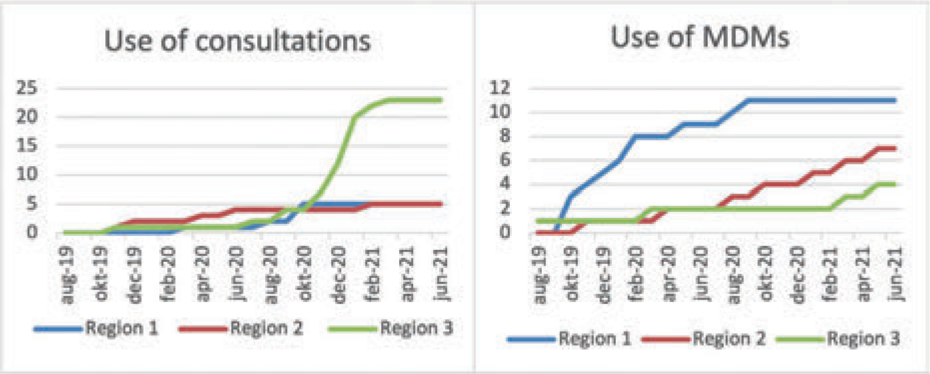

Figure 1. Cumulative numbers of intervention activities in three regions.

Facilitators in adopting all or parts of the intervention were mainly found in *characteristics of individuals*, specifically in having a committed and enthusiastic consultant in palliative care who is medically skilled and familiar with the homeless population (Table 5, illustrated with quotes in Appendix 6). The intervention is more likely to be adopted if there is a palliative care consultant who is approachable and proactive in offering consultations, training sessions or participation in MDMs. The consultant's independence in managing their available time also helps, as does an open mindset. Awareness among social service professionals of skill shortcomings in palliative care makes them open to reflecting and learning, which facilitates adoption of the intervention, while trust between the consultants providing and requesting assistance encourages collaboration and adoption. *Intervention characteristics* that facilitated adoption were having professionals who perceived a need for palliative care support and saw it as a priority, tools in palliative care for social service professionals, and an intervention tailored to local collaborations and working structures. In line with this, in the *outer setting*, having pre-existing regular meetings in the networks of the professionals who were involved facilitated the adoption of intervention activities. Facilitating factors identified in the *inner setting* were the intervention being compatible with current working structures in the organization and a shared vision among collaborating professionals on good healthcare and equal and reciprocal collaboration.

Barriers in adopting the intervention were predominantly found in the CFIR domain of the *inner setting*. Adoption of the intervention was hindered by norms and values within social services focusing on social care with a focus on recovery, thereby underexposing somatic (palliative) care. Furthermore, adoption of the intervention was sometimes hindered by the limited skills of social service professionals in recognizing, discussing and prioritizing palliative care. Staff changes, insecure future prospects for some departments of the social services in question, such as uncertain prospects for nursing beds, and a lack of apparent engagement among managers were also perceived as hindering adoption. As regards hindering *intervention characteristics*, the intended bedside consultations were sometimes not perceived as valuable. The relative advantage of the threefold intervention for such a small population was also questioned. Also, low self-efficacy in palliative care skills and different views on the need for a consultation request hindered *individuals* in adopting the intervention. In the *outer setting*, unclear policies on the responsibilities of the organizations involved complicated adoption of the intervention. Lastly, *process-related* issues hindered adoption of the intervention; these concerned the difficulty of converting the work plan and intentions into concrete actions and an unclear implementation route for the intervention in the organization.

Table 5. Overview of all reported facilitators and barriers of the RE-AIM Adoption dimension.

CFIR domain	Facilitators	Barriers
Intervention characteristics	• Professionals perceive a need and priority for additional support which makes them feel the need for collaboration (QA1.1)[a]	• Benefit of consultations not recognized by all the professionals involved as not everyone feels the need to engage the consultant in bedside consultations (QA1.4)
	• Provision of palliative care tools helps consultants concretize palliative care in intervention activities (QA1.2)	• Concerns about the relative advantage of the intervention as palliative care concerns a small population and narrow topic (QA1.5)
	• An intervention tailored to local collaborations and structures facilitates easy adoption of intervention (QA1.3)	
Outer setting	• Pre-existing regular meetings in professionals' network means that professionals who already have a network among other organizations can easily adopt the intervention (QA1.6)	• Unclear policies on responsibilities. due to too many external parties involved in care for homeless people. may hinder adoption of the intervention (QA1.7)
Inner setting	• Intervention is compatible within existing workflow due to a clear route of palliative care (and responsibilities) within the organization participating in the intervention (QA1.8) • Shared vision on good healthcare among colleagues within the participating organization makes collaboration easier (QA1.9) • Shared views of involved professionals regarding equal and reciprocal cooperation (QA1.10)	• Norms and values within the organization for social service provision are often focused on social care, while somatic care gets less attention (QA1.11) • Limited skills in recognizing, discussing and providing palliative care within social services hinder adequate care at the end of life (QA1.12) • Many staff changes and insecure future prospects for organization make organizational commitment hard (QA1.13) • Limited support and engagement of management makes consultants feel they are getting little support (QA1.14)
Characteristics of individuals	• Commitment and enthusiasm of the professionals involved regarding the intervention and palliative care (QA1.15)	• Low self-efficacy in palliative care skills may hinder identification of palliative care and use of the intervention (QA1.23)

Table 5. Continued.

CFIR domain	Facilitators	Barriers
	• Medical skills and knowledge of individual consultant makes professionals feel the consultant is competent (QA1.16) • An approachable consultant without their own agenda helps the professionals to adapt the intervention according to their needs (QA1.17) • Adoption is facilitated by consultants who proactively initiate consultations, organize training or participate in multidisciplinary meetings, which makes it easier for professionals to adapt to the involvement of the consultant (QA1.18) • A consultant who is familiar with the homeless population makes the intervention easier to adopt for social professionals (QA1.19) • Open mindset and attitude of professionals helps make them more motivated for palliative care (QA1.20) • Awareness of skill shortcomings makes individuals open to reflecting and learning (QA1.21) • Individuals who trust each other cooperate better in using the intervention (QA1.22)	• Professionals' differences in their views when a consultation is requested could hinder use of the intervention (QA1.24)
Process		• Issues with converting the work plan and intentions into actions impedes planning and engaging appropriate individuals (QA1.25) • Unclear implementation route for intervention within organization (QA1.26)

[a] QA refers to quotes on Adoption by facilitating and hindering factors, shown in Appendix 6.

Implementation of the threefold intervention

The 'consultation' element of the threefold intervention was partly implemented according to plan. Initially, bedside consultations were planned with fixed duos of consultants who consulted each other reciprocally. In practice, 59% of the consultations were held at the bedside and two of the three regions had no fixed duo of consultants, but rather one palliative care consultant and a requesting team of social service professionals. The 'multidisciplinary meetings' element was implemented according to plan, resulting in multidisciplinary meetings that varied in the disciplines involved and the frequency. The 'training' element was implemented according to plan. However, few training sessions were given even though there was a perceived shortage of knowledge and skills. Regarding the reciprocity of the duos as originally intended, there was a particular need among professionals in social services for advice and knowledge from the professionals in a palliative setting, because they felt that homeless people were dying more in social services nowadays, with fewer transfers to hospitals or hospices.

Facilitators in the implementation of the intervention were most often mentioned in *intervention characteristics* and *characteristics of individuals* (Table 6). *Intervention characteristics* facilitating implementation were frequent physical intervention activities, consultants' structured questioning, writing down notes and appointments in patient files, and discussing patient cases in training. The fact that the three intervention activities complement one another was also perceived as a facilitator. Regarding the *characteristics of individuals,* having a predictable consultant who has extensive experience with the population and who is assessed as highly competent in giving advice was also found to be a facilitating factor. Other facilitating factors for the implementation were consultants who get on well, colleagues who share tasks in organizing intervention activities, and a strong relationship between social service professionals and patients. Lastly, in the *outer setting*, familiarity with other professionals originating from other regular meetings helps in implementing the intervention, as do clear financial structures and regulations regarding palliative care indication for patients and financing this care.

Barriers in the implementation of the intervention were mainly perceived in *intervention characteristics* and *inner settings* of the organizations involved. Barriers in *intervention characteristics* were a lack of clarity about the role of the consultant in the intervention, consultants not feeling able to assess the situation themselves due to the lack of bedside consultations when consulted by phone or when COVID-19 restrictions applied, and a lack of follow-up consultations. No perceived necessity among social service professionals for embedding palliative care patients in MDMs, and limited time for discussing patients in MDMs and training were also perceived as hampering the implementation of the intervention. In the *inner setting* of the organizations, staff shortages in social services, unexpected situations and ad hoc activities in the day-to-day business of social services, and late consultation requests sometimes hindered implementation of the intervention. Furthermore, unfamiliarity among the social service professionals with palliative care consultants in general may have hindered implementation of the intervention. Also in the category of *characteristics of individuals*, resistance and fear of the end of life and death hindered social service professionals in requesting consultations, MDMs and training. Lastly, regarding the *process* of implementation, COVID-19 had an effect that could of course not have been predicted. Implementing the threefold intervention was probably particularly difficult due to COVID-19 restrictions and the scaling down of healthcare during the intervention. This might have been an obstacle to planning and using of the intervention, mainly because more time was required for regular tasks, but also because of restrictions on visiting patients and attending meetings in person.

Table 6. Overview of all reported facilitators and barriers of the RE-AIM Implementation dimension.

CFIR domain	Facilitators	Barriers
Intervention characteristics	• Frequent physical meetings (consultations, MDMs, training) normalize collaboration between palliative care professionals and social service professionals (QI1.1)[a] • Consultants' structured questioning helps in implementing consultations (QI1.2) • The three intervention activities complement each other, making implementation of the intervention easier (QI1.3) • Discussing patient cases in training helps participants to see the advantage of training (QI1.4) • Making notes of conversations and appointments in patient files contributes to clear agreements (QI1.5)	• Unclear role of consultant increases the perceived complexity of the intervention (QI1.6) • Making limited use of bedside consultation possibilities prevents the consultant from making their own assessments as intended in the intervention (QI1.7) • Discussion of patients in MDMs is too short/limited, which hampers implementation of advice in MDM (QI1.9) • Limited time for patient discussion in training hampers implementation of knowledge and skills in training (QI1.10) • A follow-up consultation was not always possible (QI1.11)
Outer setting	• Familiarity with other professionals (not participating in the intervention) through pre-existing regular meetings helps in implementing the intervention (QI1.12) • A policy of clear incentives and regulations regarding palliative care indication and associated (existing) funding helps in implementing the intervention (QI1.13)	
Inner setting	• Available time of consultant supports adaptability of the intervention (QI1.14)	• Staff shortages hinder implementation of the intervention (QI1.15) • Many unexpected events and therefore ad hoc activities within social service organizations distracts from focusing on implementing the intervention (QI1.16) • Implementation can be difficult when social service professionals do not know the consultant yet (QI1.17) • Lack of knowledge on how to recognize palliative care needs frequently led to consultations that were too late in the illness trajectory (QI1.18)

Table 6. Continued.

CFIR domain	Facilitators	Barriers
Characteristics of individuals	• Consultant is experienced in advising professionals about this patient population, which helps in introducing implementation activities (QI1.19) • Predictability of the consultants' presence helps to normalize implementation of intervention activities (QI1.20) • Sharing tasks with colleague helps familiarization with implementing the intervention (QI1.21) • Getting on as consultants helps in implementing consultations (QI1.22) • A personal bond between social service provider and patient helps in ensuring proper use of the intervention (QI1.23) • Professionals perceiving the consultant as highly competent (QI1.24)	• Resistance and fear of end of life and death hinders implementation (QI1.25)
Process		• COVID-19 restrictions and the scaling down of healthcare made planning and implementing intervention activities more difficult (QI1.25)

[a] QI refers to quotes on Implementation by facilitating and hindering factors, shown in Appendix 6.

Maintenance of the intervention

All regions expected to continue with the use of one or more activities of the intervention in the future, although the three regions differed in the expected continuation of activities of the threefold intervention. Region 1 preferred MDMs as the activity that was most commonly used, while Region 2 preferred to use all three activities interacting together, and Region 3 preferred the consultations and training. MDMs were expected to be an effective way for palliative care professionals and social service professionals to meet and exchange advice. Consultations were seen as helpful with specific questions about a patient, but also highly dependent on having consultation funding in place for this population. Training was seen as something that could be used to raise awareness of where advice could be sought about palliative care in consultations or MDMs. Expected facilitators and barriers illustrate how sustainability of the intervention can be realized.

Facilitating factors for maintenance of the intervention were mainly found in the inner setting of the organizations involved (Table 7). The social and financial support of the consultant's manager and colleagues were considered as facilitating, as was the openness of other professionals to teamwork with disciplines other than their own. Other facilitating factors in maintenance were a mindset geared to a need for change within organizations and a mindset among professionals in social service organizations that not only focuses on social and psychosocial care but also pays attention to somatic care needs. Maintenance was also facilitated by concrete actions that helped prevent the drop-out of consultants, like sharing information with colleagues on the intervention activities performed. Intervention characteristics that helped maintenance of the intervention were the availability of the consultant, frequent evaluation of intervention activities, and use of MDMs in which a palliative care professional is involved on a regular basis. Also, use of the threefold consultation service was expected to be most sustainable over time when ownership is assigned to organizations in palliative care. Structural discussion of patients initiated by the palliative care consultant, e.g. once a month, could also contribute to sustainable, early, future-focused consultations. In the outer setting, a clear policy of financial support and clear regulations regarding indications concerning ageing and serious illness of the homeless would help in maintaining the intervention over time.

The factors mentioned as barriers for maintenance of the intervention were mainly in the inner setting of organizations. Unfamiliarity within organizations with death in the population could hamper the willingness to continue the intervention, as well as the fact that unpaid medical tasks are not taken seriously within social services. In addition, staff shortages within the social services could hamper further maintenance of the intervention. So could drop-out and the vulnerability of the consultants' position due to the dependency on a one-person position. Also, different perceptions between organizations on ethical issues such as euthanasia may hamper future collaboration between the organizations. Furthermore, an organization with many layers of management needs time to arrange financing and hours, which could hamper continuation of the intervention by leading to a temporary suspension of intervention activities. Intervention characteristics mentioned as hampering maintenance of the intervention were unclear mutual responsibilities of the parties involved and the consultation being small-scale and very specific. Besides, a shift in non-intervention-related tasks of the palliative care consultant could hamper future collaboration, which was based on a small number of individuals. In the outer setting, a lack of clear policy, funding and regulations regarding care for seriously ill homeless patients on the part of the government and health insurers was considered as a barrier. Lastly, a process-related barrier was found in the dependency of the intervention on local champions participating in the intervention.

DISCUSSION

The patients reached by the intervention were mostly seriously ill homeless patients in the last days of life residing in social service facilities. The reach of the intervention was mainly accomplished by involving social service professionals who were working in the organizations that initiated the intervention. While adoption of the three activities of the intervention was achieved in all regions, there were differences in the start, timing and frequency of the three activities in each region. Implementation of the intervention was partly accomplished according to plan. Half of the consultations were bedside consultations and half were telephone consultations instead of the planned bedsides consultations. Also, instead of the planned duos of consultants, two of the three regions had collaboration between a palliative care consultant and a team of social service professionals. Also, the consultations were mainly in one direction, with palliative care consultants advising social service professionals. Finally, regarding maintenance, all regions expected to use one or more activities of the intervention in the future, although they differed in which activities they expected to use. Facilitators and barriers were found for all the RE-AIM dimensions; the facilitators were mainly found in the inner setting of the organizations, in characteristics of individuals, and in intervention characteristics. Barriers were mainly identified in the inner setting of the organizations and in intervention characteristics.

The three activities of the intervention are closely related

Our study shows that the consultations, MDMs and training are interrelated and that all three elements are important in improving palliative care. Moreover, the elements reinforce each other as by working together the professionals know more easily how to find each other and know how to formulate a request for advice. Our study also shows that participants get to know one another through the recurring meetings in person, such as on training sessions, at bedside consultations or in MDMs. Thus, training sessions and multidisciplinary meetings might be especially relevant when starting a similar intervention, as they nurture a collaboration in which consultations can then be requested. Other interventions aimed at collaborations between palliative care and social services for this population are still scarce. Two British studies evaluated one intervention focused on palliative care specialists training, supporting and advising shelter staff; they also found that training, structural connections and advice reinforce each other.[64, 65]

Table 7. Overview of all reported facilitators and barriers of the RE-AIM Maintenance dimension

CFIR domain	Facilitators	Barriers
Intervention characteristics	• Refining the intervention regarding availability of consultant, frequent evaluation of intervention activities, and MDMs as standard practice may contribute to sustained use over time (QM1.1)[a] • Ownership of the intervention by organizations in palliative care in order to transfer palliative care knowledge to social service professionals (QM1.2) • Structural discussion of patients initiated by the palliative care consultant may contribute to sustainable, early, future-focused consultations (QM1.3)	• Unclear mutual responsibilities hamper sustained use over time due to complexity (QM1.4) • A shift in non-intervention-related tasks of the palliative care consultant could hamper collaboration as this could hamper availability and participation in intervention activities (QM1.5) • Small-scale and specific consultations may negatively affect maintenance and expansion of the intervention over time (QM1.6)
Outer setting	• A policy of clear incentives and regulations regarding patient indication and associated existing funding help in maintaining the intervention over time (QM1.7)	• Lack of clear policy and regulations regarding proper/structural palliative care indications and funding for care (QM1.8)
Inner setting	• Mental and financial support from manager and colleagues for consultants within the organization helps prioritize intervention for consultants in future (QM1.9) • Professionals' openness to teamwork helps use of the intervention over time (QM1.10) • Organizations' recognition of a need for change contributes to a culture that is more open to change over time (QM1.11) • A mindset within social services that focuses on more domains such as the somatic domain (QM1.12) • Concrete actions, like sharing information on the intervention activities performed, to prevent loss of consultants' position, helps embed intervention over time (QM1.13)	• As long as organizations are unfamiliar with death and dying among this population, maintaining the intervention will be hampered by these assumptions. (QM1.14) • Staff shortages hamper use of the intervention over time (QM1.15) • Unpaid medical tasks not being taken seriously within organization may hamper the implementation climate in future (QM1.16) • Different views on ethical issues may hamper future collaboration (QM1.17) • Many layers of management in an organization mean it takes a long time to arrange financing and hours for consultants; this threatens continuation of the intervention (QM1.18) • Drop-out and vulnerability of consultants' position threaten use of the intervention over time (QM1.19)
Process		• Maintenance is highly dependent on local champions, which might threaten future collaborations and maintenance of the intervention over time (QM1.20)

[a] QM refers to quotes on Maintenance by facilitating and hindering factor, shown in Appendix 6.

The threefold intervention takes time and effort to adopt

Our study reveals that the threefold intervention takes time to adopt, and that this is determined mainly by factors in the inner setting, or organizations. Awareness-raising, a shortage of skills in recognizing and discussing serious illness and the end of life, norms and values about palliative care and death, the many changes among staff in social services hindering sustainable collaborations, and insufficient recognition and support from managers were factors that needed time and effort to tackle. Also, the COVID-19 pandemic limited the amount of time and effort professionals could spend on the adoption of the intervention. This process evaluation reveals that implementation of an intervention focusing on palliative care provision requires time to create awareness and break down resistance and lack of knowledge about palliative care and dying; this is also found in one other study.[65] Although this study indicates that time and effort is needed for adoption and implementation, our study suggests that added value can already be achieved in this phase of adoption and implementation.[170] Further, this process evaluation also shows that efforts must also be made in the financial field: multidisciplinary care also needs multidisciplinary, structural funding to achieve long-term improvements in the palliative care for this population.

The importance of a competent consultant

Our study shows that characteristics of individuals appear to be highly relevant to the reach, adoption and implementation of the intervention. Therefore, this should be considered when connecting palliative care consultants and social service professionals. Our results indicate that the palliative care consultant should be carefully selected. The selection should consider their commitment and enthusiasm for the intervention and palliative care, their medical skills and knowledge, approachability, ability to be proactive, and familiarity with an underserved population as important factors. A predefined number of hours without overlap with other tasks, support from managers and a lot of control over their own diary were found to be important as well. Considering the complexity of care needs in the homeless population at the end of life, it is recommended to match medically skilled, proactive, flexible palliative care consultants with social service professionals who have a great deal of expertise.

The challenge of connecting two worlds

Our findings show that the inner setting is a determining factor and potentially a barrier in the process of adopting, implementing and maintaining the intervention. The settings of social services and palliative care differ substantially, e.g. in attitudes towards death and dying, skills in this area, organizational structures and recognition of the relevance of palliative care. The results of our study indicate that a consultation service like our threefold intervention could be best implemented within social service providers, and palliative care professionals should have a proactive role in the provision of consultations and training and participation in MDMs. When implementing a similar intervention focusing on increasing competences, knowledge and collaboration, it is important to be aware of unfamiliarity and resistance to the idea of death and dying in social services. A gap between social services and palliative care services as well as unfamiliarity with palliative care in social services is also found in other studies.[166, 172]

The importance of tailoring the intervention to the regional situation

A need for a context-sensitive intervention tailored to participating regions was already indicated in our focus group study.[110] The implementation of this intervention reveals that the three regions differed in their use of the intervention activities and preference for the different intervention activities. Also, the regions varied in resources for collaboration and knowledge regarding palliative care. Both this study and our study on the added value for all three regions[170] confirm that tailoring the intervention to a regional situation and regionally available resources is important. This indicates that using working strategies and implementation plans, as applied in the preparatory phase of this study, are essential when further expanding the intervention to other regions and settings.

Strengths and limitations

Our study is the first study to combine consultations, multidisciplinary meetings and training, with palliative care professionals and social service professionals in an intervention. Another strength of this study is the process evaluation using RE-AIM and CFIR sequentially, resulting in structured domains of facilitators and barriers. Also, our mixed-method design resulted in a broad scope covering different dimensions of RE-AIM. A strength of this study is that this intervention is based on the needs and wishes expressed by persons experiencing homelessness. They indicated that professionals needed more knowledge, training and collaboration in palliative care.[110] The design of this intervention and the evaluation of the intervention were supervised by an advisory board, in which people who are homeless were also represented. However, a limitation is that we did not interview homeless persons who received palliative care; this study therefore gives the professionals' views on their situation rather than their own perspective.

CONCLUSION

A threefold consultation service aimed at improving palliative care provision to persons experiencing homelessness was implemented, with consultations, joint multidisciplinary meetings and training initiated by palliative care professionals. It proved possible to implement the intervention, especially when sufficient time for adoption and implementation was allowed and barriers and facilitators were taken into account. The intervention works best when it is tailored to fit the specific region, with both bedside consultations and telephone consultations and with a palliative care consultant connected to a team of social service professionals rather than to an individual social service professional. Facilitators for the reach, adoption, implementation and maintenance were mainly found in the characteristics of individuals, the inner setting and intervention characteristics. Barriers for the reach, adoption, implementation and maintenance were mainly found in the fields of the inner setting and intervention characteristics. We recommend further implementing this region-tailored intervention within social service teams, with competent and enthusiastic palliative care consultants in the lead. The intervention can start with training to raise awareness of possible palliative care needs and reduce fear of palliative care provision among social service professionals.

Kan ik iets voor je zijn
Een soort arm om je heen?
Zodat het iets minder schrijnt
En je niet zo alleen?

De Dijk

CHAPTER 8

General discussion

INTRODUCTION

The aims of this thesis were to provide insight into:

1. important aspects of palliative care for persons experiencing homelessness and important elements for reaching persons experiencing homelessness (**Chapters 2 and 3**);
2. the current provision of palliative care for persons experiencing homelessness in the Netherlands, and to explore future needs for improving palliative care provision (**Chapters 4 and 5**);
3. how a threefold intervention to improve palliative care for this population was evaluated regarding the added value and implementation (**Chapters 6 and 7**).

This final chapter provides an overview of the main findings in relation to the literature. It also reflects on the research methodologies used and on important themes addressed in this thesis, and it provides recommendations for practice, policy and future research.

MAIN FINDINGS IN RELATION TO THE LITERATURE

Important aspects of palliative care and reaching persons experiencing homelessness

The first aim was to get insight into important aspects of palliative care for persons experiencing homelessness and important elements when trying to reach this population. First, specific aspects and challenges for palliative care provision to this population emerged from a comprehensive overview of many aspects. Attention to the fear of dying and suffering among persons experiencing homelessness, the importance of professionals addressing spiritual issues, a strong desire for professionals to show dignity, a trusted and non-stigmatizing relationship with professionals, room for patients to express their concerns, and a wish for a natural death were found to be important points to consider in caring for persons experiencing homelessness with palliative care needs (Chapter 2). These aspects fit well with the core principles of palliative care, which is aimed at the individual as a whole and their environment and involves physical, psychological, social and spiritual care.[50] Furthermore, our findings addressed the importance of training for professionals and collaboration between multiple disciplines involved in the care for persons experiencing homelessness. Training for professionals, establishing a patient-centred approach with trustful relationships, providing proper accommodation, and better organization of care were recommended in the study (Chapter 2). Reflecting the complex, multi-problem issues in the lives of persons experiencing homelessness, our findings emphasized both the importance and challenges of palliative care in the somatic, psychological, social and spiritual domains. Our findings highlighted a need for an approach that includes dignity, respect, and spirituality and religiosity for this population at the end of life (Chapters 2 and 3). However, other studies found that while psychosocial and spiritual care is particularly important for persons experiencing homelessness, it is perceived as difficult as well.[30, 173] This could be explained by our findings of a fear of death and suffering among persons experiencing homelessness, which might complicate palliative care provision in all domains.

Second, palliative care for people experiencing homelessness was found to be hampered by interfering day-to-day needs, resulting in a lack of priority for palliative care and distrust towards professionals among persons experiencing homelessness. Also, palliative care provision was found to be hampered by poor access to healthcare services and a lack of hospice-like facilities, and limited palliative care skills among staff (Chapter 2). In addition, our findings showed that people experiencing homelessness often felt stigmatized (Chapter 3), which might be closely related to the findings reported in other studies of feelings of being ignored, discriminated against and disrespected, resulting in a suspicious and distrustful attitude towards receiving care.[35, 56, 58, 59, 84, 94] Palliative care provision for persons experiencing homelessness was found to be facilitated by professionals acknowledging their spiritual needs and building trustful relationships between the professional and the patient. Other facilitating factors were professionals treating the person experiencing homelessness with dignity, pragmatism in tailored palliative care, and compassion for lived lives (Chapters 2 and 3). Other facilitators included personalized care without stigmatization, professionals who set limits on misbehaviour but do not reject the individual, and professionals who realize that their values might differ from those of the persons experiencing homelessness (Chapter 3).

A third finding was that similar challenges in palliative care provision were reported in other special needs groups, such as people with intellectual disabilities and people with severe mental illness. The challenges described in the palliative care for people with intellectual disabilities residing in intellectual disability services are mainly: understanding the patients' perspectives, referrals and collaboration between professionals in different disciplines, training professionals in providing palliative care, and empowering professionals' confidence in their ability to provide palliative care.[174-176] Challenges in palliative care provision to patients with severe mental illness are mainly found in the lack of attention for palliative care among mental-health professionals, lack of education in palliative care among professionals and the lack of collaboration between healthcare professionals and professionals in mental care.[141] Our findings add that persons experiencing homelessness suffer from multiple problems that often affect multiple areas, such as intellectual disabilities, substance use, complex comorbidities, lack of housing, and dying at a relatively young age. It can be concluded that serving persons experiencing homelessness at the end of life involves even more challenges than for other patient populations, and that it is challenging for professionals to cover all the domains of palliative care.

Fourth, our findings highlighted that the multi-level issues of persons experiencing homelessness and a complicated care system are underlying factors behind the underuse of care. We found that changes in the healthcare and support system are necessary in order to provide adequate, accessible palliative care to a population dealing with many challenges

(Chapter 3). This indicates that in order to provide multidisciplinary care at the end of life, collaboration between social and healthcare services is of great importance. We found that access to the care system must be accompanied by clear information provision and communication between professionals of different organizations and with persons experiencing homelessness (Chapter 3). This is also found by another recent study of homelessness.[177]

Current palliative care provision for persons experiencing homelessness and future improvements

The second aim was to get insight into the current provision of palliative care for persons experiencing homelessness and to explore future needs for improving palliative care provision. First, regarding the current provision of palliative care for this population, we found that this palliative care provision is perceived by professionals as complex and the provision varies widely between professionals, institutions and cities (Chapter 5).

Second, regarding the characteristics of persons experiencing homelessness who are eligible for palliative care in the Netherlands, our results showed a young age at death, multi-level and complex somatic, psychiatric, addiction and social issues, and a high symptom burden at the end of life in the year before death. We found that the end of life of persons experiencing homelessness and residing at in-shelter nursing wards was characterized by uncertain prognoses and unexpected revival or deterioration. In addition, it appeared difficult to recognize whether the end of life is near. Other characteristics were complicated social circumstances and frequent transitions to other settings such as the acute care hospital (Chapter 4). Difficulties with uncertain prognoses, identification of palliative care needs, recognition of the dying phase, and recognizing palliative care needs among multiple other problems are also addressed in other studies and commentaries about homelessness and mental illnesses.[11, 30, 58, 178]

Third, our medical record study revealed that organizing and integrating palliative care in Dutch social services during the final phase of life is challenging. At the same time, two-thirds of the study population eventually died in this setting (Chapter 4). This raises the question whether social services are an appropriate place for palliative care, or whether professionals within social services should be given more support in providing palliative care. Literature shows that residents wish to die in a home-like setting such as a hostel or home community,[65, 85] that residents prefer being somewhere comfortable where they are known to others,[173] and that persons experiencing homelessness consider family-like and trusting relationships with social service professionals to be important.[58, 59, 63]

Fourth, potential areas of improvement were found in multidisciplinary collaboration, more palliative care facilities for this population, and palliative care expertise within social services (Chapter 4). A consultation intervention between palliative care and social service professionals was expected to contribute to multidisciplinary collaboration and palliative care knowledge, and to be of added value for both patients and professionals. Besides consultation, training on palliative care topics and skills, and multidisciplinary meetings attended by palliative care professionals and social service professionals were expected to be necessary as well. Consultation, training, and multidisciplinary meetings could be developed best regionally and tailored, and guided by an experienced consultant (Chapter 5). Our findings suggest that it is desirable to strive for in-shelter palliative care beds, supported by palliative care expertise and multidisciplinary collaboration. This is in line with studies in other countries advocating for appropriate respite or hospice facilities for this population.[36, 63, 86, 91, 93]

Fifth, regarding the involvement of palliative care consultants, the number of consultations observed in our study population was twice the proportion for the general Dutch population (Chapter 4). This higher involvement of palliative care consultants is probably a reflection of results from our studies that highlight the importance of support from palliative care specialists given the complexities, complications and place of residence before death. However, our studies also indicated that there is need for even more support from palliative care specialists (Chapters 4 and 5).

Sixth, current provision of palliative care to persons experiencing homelessness showed that person-centred palliative care is essential and involves a specific approach. Both persons experiencing homelessness and professionals perceived this as challenging. Identified factors of particular importance were respecting the need for autonomy of the homeless patient, trusting relationships between them and professionals, which might take time and effort to establish, and pragmatism on the part of professionals in providing palliative care. Although patients having control over their own care is generally known to be one of the pillars of good quality palliative care,[52] the autonomy specifically mentioned by this population goes further than this, and is related to less access to care and the fact that not all care is accepted. There is a great need to live life without (much) interference by others. Also, we found that individuals experiencing homelessness and professionals have different perceptions on what care should be provided (Chapter 5); this was also found in Chapter 2.

Seventh, potential areas of improvement that were identified were more multidisciplinary collaboration, more palliative care facilities for this population, and palliative care expertise within social services (Chapter 4). To achieve these improvements, a threefold intervention was designed and implemented between palliative care professionals and social service professionals was expected to boost multidisciplinary collaboration and palliative care competences, and to be of added value for both patients and professionals. In addition, training in palliative care knowledge and skills, and multidisciplinary meetings attended by palliative care professionals and social service professionals were expected to be necessary as well. Consultation, training and multidisciplinary meetings could best be developed regionally, tailored to fit local requirements, and guided by an experienced consultant (Chapter 5). Our findings suggested that it is desirable to strive for in-shelter palliative care beds, supported by palliative care expertise and multidisciplinary collaboration. This is in line with studies in other countries advocating appropriate respite or hospice facilities for this population.[36, 63, 86, 91, 93]

A threefold intervention: evaluation of added value and process

The third aim was to provide insight into a threefold intervention to improve palliative care for this population and the evaluation of its added value and implementation process. The RE-AIM evaluation framework was used; RE-AIM is an acronym for the framework's five components: Reach, Effectiveness, Adoption, Implementation and Maintenance.

First, in the three participating regions, all three activities of the intervention — consultations, multidisciplinary meetings and training sessions — were implemented. All three intervention activities were considered useful. At the same time, use of the different activities was tailored to the needs and resources of each region. We found that mainly social service professionals were reached by the intervention. This focus on integrating a palliative care approach into social services with a major role for social service professionals in ensuring access to palliative care is also found by Canadian and British studies.[64, 65, 135, 166] Patients who were reached via consultations and multidisciplinary meetings were often males, born in the Netherlands, aged between 50 and 70 and residing in 24-hour shelter facilities or nursing wards (Chapter 6).

Second, perceived added value was found in all three regions in improvements to the quality of life and dying, and the timing of palliative care. In addition, added value was found in reciprocal collaboration and stronger connections and networks for the professionals involved. Also the professionals' competences improved and professionals felt better equipped to support patients emotionally. The importance of and need for emotional support from social service professionals is also addressed by a recent Canadian study.[166]

Third, regarding evaluation of the Reach, Adoption, Implementation and Maintenance, the reach of the intervention was mainly accomplished by involving social service professionals in the intervention who were working in the organizations that initiated the intervention. While all three activities of the intervention were adopted in all regions, there were differences in the start, timing and frequency of the three activities in each region. Implementation of the intervention went partly according to plan. While the intention was that all the consultations would be bedside consultations, half the consultations took place at the patient's bedside, and half were by telephone. Also, a palliative care consultant was linked to a team of social service professionals (rather than a single social service professional), and the consultations mainly involved palliative care professionals advising social service professionals. Regarding maintenance, all regions expected to use one or more activities of the intervention in the future, although the three activities were expected to be used differently between regions (Chapter 7).

Fourth, many facilitators and barriers influenced the use of the intervention. Facilitators were most often found in characteristics of individuals, the inner setting of organizations and the characteristics of the intervention itself. Barriers were most often found in the inner settings of organizations and in the intervention itself (Chapter 7). The importance of individuals in the role of 'local champions' is recognized in another study.[64] Barriers in the inner settings of organizations are also found in other studies of palliative care and homelessness, which show that workload, limited capacity and staff changes put high pressure on social service professionals.[91, 166, 172] In addition, studies into palliative care for persons with intellectual disabilities and psychiatric issues show that somatic and palliative care is barely integrated into daily care.[175, 179]

METHODOLOGICAL CONSIDERATIONS

The data for this thesis were derived from five studies: a systematic review of concerns, care needs and preferences, and barriers and facilitators for providing palliative care to persons experiencing homelessness (Chapter 2); a semi-structured interview study on homeless persons with less access to care (Chapter 3); a retrospective medical-record study on end-of-life care for persons experiencing homelessness in shelter settings (Chapter 4); a focus group study of palliative care provision for persons experiencing homelessness and the desirability of setting up a consultation service (Chapter 5); and a mixed-method study on the evaluation of the added value and implementation process of a threefold consultation intervention (Chapters 6 and 7).The strengths and limitations of the individual studies were discussed in the respective chapters already. Here we reflect on the overall way in which the aims of the study have been reached.

A mixed-method design enables a broad exploration

Of the five studies included in this thesis, three studies had a mixed-method design involving qualitative and quantitative data (Chapters 2, 4, 6 and 7), and two studies had a qualitative design (Chapters 3 and 5). Because palliative care for persons experiencing homelessness is a yet understudied and the population of persons experiencing homelessness is relatively small, the aims of the study were of an explorative nature. Varying research methods were used, such as a systematic review, semi-structured interviews, focus groups, a study in which medical records were analysed, and research diaries. These mixed methods helped give a comprehensive and detailed overview of core elements of palliative care, the current provision and areas for the future improvement of palliative care for persons experiencing homelessness.

Specifically for this population, a strength can be found in collecting data using a focus group study (Chapter 5). This method is eminently suitable for a marginalized, underserved group expressing their feelings around such precarious subjects as illness and mortality. It is a strength that while different designs were used, there is overlap in the findings of the various studies. Examples are the findings on the importance of dignity for this population, a need for trustful relationships between persons experiencing homelessness and professionals, and issues with integrating end-of-life care in shelter settings. Realizing the risk of bias in these types of studies, we tried to avoid bias as much as possible during data collection and interpretation by making joint decisions, coding independently and in varying compositions, and jointly discussing and interpreting data. A limitation can be found in a potential interview bias and selection bias as the coordination of the intervention and the data collection were conducted by the same researcher and performed with participants interested in the intervention. This might have resulted in participants giving socially desirable answers and a positive distortion of the perceived added value.

Perspective of persons experiencing homelessness themselves

Another strength of the study is that the perspectives of persons experiencing homelessness themselves were explored in several chapters. As palliative care is person-centred care, including their perspective is essential when studying important aspects of palliative care for this population. The interview study on homeless persons with less access to care included the perspectives of formerly homeless persons (Chapter 3), and the focus group study (Chapter 5) included two groups of participants experiencing homelessness. Chapters 6 and 7 only consider the perspectives of professionals and do not include the perspectives of persons experiencing homelessness regarding the care received. We did not succeed in including the perspectives of the population of persons experiencing homelessness in these studies as visitation restrictions around COVID-19 and the high work pressure for professionals as a result of the pandemic meant that it was not possible to conduct interviews with persons who were the subject of consultations. The implementation and the research project were supervised by an advisory board, in which people who were homeless were also represented so that their perspective was included in all phases of the research. However, it is a limitation that the data presented in Chapters 6 and 7 was only collected among social service and palliative care professionals. These chapters therefore, only discuss the views of social service and palliative care professionals rather than the patient perspective. Perspectives of persons experiencing homelessness on the intervention and its added value therefore have not been extensively researched and compared with the perspectives of care providers.

Generalizability of intervention and study population

A strength of this study is that the research presented in Chapters 6 and 7 was conducted in three of the four major cities (G4) in the Netherlands. Because 37% of all homeless people in the Netherlands reside in these cities, the exploration of the use, added value and process of implementation of the intervention was most effective in its reach in these cities. However, 63% of the Dutch persons experiencing homelessness resides outside the G4 cities.[1] It is unknown whether our results also apply to persons experiencing homelessness in The Hague (not covered in Chapters 6 and 7) and other cities. In addition to having focused on three cities, our intervention also mainly reached people who were already receiving care e.g. in social service facilities. Therefore our results are probably not generalizable to seriously ill people experiencing homelessness who do not receive care. Compared to the data of Statistics Netherlands (CBS), the findings in Chapters 4 and Chapter 6 might under-represent persons of non-Dutch origin (CBS: 62% of persons experiencing homelessness of non-Dutch origin, Chapter 4: 44% of non-Dutch origin, Chapter 6: 41% of non-Dutch origin). Characteristics regarding the sex of participants experiencing homelessness (male: 85% in Chapter 4 and male: 80% in Chapter 6) are in line with CBS data (male: 83%).

Another strength was that our threefold intervention was expected to be context-sensitive for each region, and was found indeed to be best implemented by tailoring the intervention activities to the needs and resources of each region (Chapters 5, 6 and 7). Thus, this intervention is expected to work well in other contexts due to the possibility of tailoring it to suit requirements, but good monitoring is needed to see whether it is useful in other regions and on a larger and nationwide scale.

Added value of the intervention

A strength of this thesis is that the added value of a new intervention aimed at serving persons experiencing homelessness in the last phase of life is explored. It reveals that especially social service professionals perceive added value for their palliative care competences, the interdisciplinary collaboration and the quality and timing of palliative care. However, a quantitatively measurable effect of the intervention was not determined due to the small study population and the explorative nature of the use of the new intervention. This was the first step of providing evidence on use, added value and implementation process, and indicates possibilities for future studies that could make use of a pre-test and post-test, large-scale evaluation study.

Using RE-AIM and CFIR in the process evaluation

The RE-AIM framework was developed to help evaluate the impact of interventions on several dimensions,[169] and was used in this thesis to structure the process evaluation (Chapter 7). A strength of this study is that an existing model with multiple dimensions has been used to structure the process evaluation. This resulted in a detailed overview of the reach, adoption, implementation and maintenance of the intervention in practice. The Consolidated Framework for Implementation Research (CFIR) was used to further structure analysis of the barriers and facilitators within each RE-AIM dimension. This combination of RE-AIM and CFIR provided insight and structure in a large number of facilitators and barriers within the RE-AIM dimensions. Furthermore, we consider that the conceptualization and operationalization of the RE-AIM framework is a strength of our study. After all, the RE-AIM authors emphasize that application of the framework should be done pragmatically, as we did e.g. when measuring added value instead of effectiveness as this better fits the aims of our studies; and by using and identifying contextual factors such as the norms and values of persons involved in the intervention.[180] Some limitations can be found in how we assessed the reach, implementation and maintenance. We did not discuss the representativeness of non-participants. Also, professionals who did not use the intervention were not questioned about their reasons for not doing so (reach). No costs were evaluated (implementation) and no distinction was made between the expected maintenance in the shorter term and longer term (maintenance) (Chapters 6 and 7).

REFLECTIONS ON THE FINDINGS

We found several recurring themes in our findings that particularly characterize palliative care provision for persons experiencing homelessness and efforts to improve their palliative care.

Bringing palliative care and social services together

This thesis shows that healthcare services and social services are separate worlds that often have little or no contact. We found that somatic care within social services is often considered as subordinate to the other domains of care. Working together with psychiatrists, mental health nurses and addiction doctors is often self-evident for social service professionals. However, multidisciplinary collaboration with palliative care professionals is much less obvious, despite the high comorbidities and high mortality among this population. Other studies reflect on this as well, emphasizing that end-of-life care should be an important element integrated into social care for the homeless, starting with the integration of primary care practice within social services as standard practice in daily personal care.[33, 58, 166, 172, 173] It is also indicated that multidisciplinary collaboration helps give emotional support to social service professionals.[146] This thesis reveals that during the intervention period, consultations and advice in the somatic domain in particular are provided in social services. However, this thesis (Chapters 2 and 4) and other evidence also shows that older persons experiencing homelessness have a high prevalence of symptoms and needs in all domains.[18] Therefore, consultations, meetings and training sessions involving both palliative care and social services should not be limited to the integration of somatic care for patients, but also extend to the integration of social, psychological and spiritual care into standard palliative care practice.

Holistic care and a person-centred approach

Palliative care is eminently holistic, including multidisciplinary care involving various disciplines, and facilitating a good quality of life for as long as possible.[51] We found that accomplishment of multidisciplinary care was hampered by the inner settings of the organizations involved (Chapter 7). At the same time, a person-centred approach by social service professionals was a huge facilitator for palliative care provision. A person-centred approach is already part of the recovery-oriented perspective that social service professionals are used to having. While learning how to deal with death, dying and the increasing dependence of loved residents, social service professionals’ norms and values of person-centred care make a strong foundation for providing person-centred palliative care based on a trustful relationship and familiarity with the resident, as also highlighted by other studies.[135, 166, 181]

Importance of advance care planning and parallel planning

This thesis reveals that the death of persons experiencing homelessness is often experienced as unexpected, and that professionals find it difficult to recognize and determine palliative care needs. Moreover, persons experiencing homelessness have a need to discuss their concerns and future wishes. It is considered crucial for professionals to have more knowledge and skills in order to provide tailored palliative care to persons experiencing homelessness (Chapters 2, 3, 4 and 5). Given the early age of death, persons aged 50 and older can be classified as 'old people', as advocated by a recent study.[182] Discussing values, goals and preferences for future care in good time can thus be considered as extremely relevant. Advance care planning, which is "a process that supports adults at any stage or state in health in understanding their personal values, life goals, and preferences regarding future care", can help ensure early discussion of the person in question's values, goals and preferences.[183] Several studies already showed the importance of integrating advance care planning into routine primary care.[73, 184-186] However, this also requires timely identification of a need for palliative care. We showed several difficulties that professionals have with recognizing this need (Chapters 6 and 7). Therefore, we emphasize the necessity of incorporating uncertainty and using parallel planning for people aged 50 and older as a standard practice in social service facilities.[146] Such planning should be embedded in a trustful relationship with a familiar professional (Chapters 2 and 5). Parallel planning involves a "hope for the best, prepare for the worst" approach, emphasizing that the person in question is not necessarily at the end of life but at the same time discussing values, goals and preferences should their condition start deteriorating or become life-threatening.

Perspectives on a good final phase of life

Evidence shows that life circumstances influence the perspective on a good death, and emphasizes that these perspectives differ across groups and individuals.[187] It is known that for non-homeless patients, a good death includes good symptom and pain control, clear decision-making, a feeling of closure, acceptance and inner peace, being seen as a person and having one's wishes respected, and the presence of loved ones.[187, 188] Our findings highlight that for persons experiencing homelessness other themes also play a role in a good death. A good death for persons experiencing homelessness often means a natural death avoiding heroic treatments, no suffering, not dying alone, and resolving inner conflicts and restoring connections with loved ones. Other aspects considered as important for a good death are time and attention for life stories and psychosocial issues, being treated with dignity and respect, attention to religious and spiritual experiences, and being respected and memorialized after death (Chapters 2 and 5). Our findings on a good death reflect the (past) lifestyles of persons experiencing homelessness and indicate that their perspectives on death and palliative care differ from those of non-homeless patients. Given the number of persons experiencing homelessness who ended up dying alone (Chapter 4), more effort is needed to ensure a good death for persons experiencing homelessness.

Unequal access to palliative care provision

The WHO states that "Palliative care needs to be provided in accordance with the principles of universal health coverage. All people, irrespective of income, disease type or age, should have access to a nationally- determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups."[51] However, palliative care services are known to vary widely between organizations and regions and in terms of professionals' skills and resources. Given their poor access to health services in general,[11, 30, 72, 143, 145] a lack of family or social support, and the frequently unexpected nature of their death, it can be concluded that persons experiencing homelessness are affected by their unhoused status and corresponding problems when it comes to availability of palliative care provision. This thesis suggests that dying with dignity for people experiencing homelessness involves at least a respectful approach, peace, acknowledgement of their fear of dying and suffering, high-quality care at the end of life, attentiveness for spirituality, room for the patient to express their concerns, pragmatism and compassion. In addition, persons experiencing homelessness regularly have no choice in where they die[58] and often experience more transfers in the final phase of their lives compared to other vulnerable populations (Chapter 4). To achieve equal access to palliative care for this underserved population, system-related structural changes are needed to integrate palliative care into the social service facilities that are the home-like residence of persons experiencing homelessness.[33, 145]

Urgency of structural and tailored funding

This thesis reveals a lack of structural, countrywide funding of palliative care provision for this population. Extra funding is needed to encourage interdisciplinary collaboration to improve the quality of palliative care provision (Chapters 5 and 7). Other international studies endorse structural funding for palliative care provision to persons experiencing homelessness and clear funding policies. [65, 72, 143, 172] Funding for palliative care provision has proven to be challenging because persons experiencing homelessness deal with multiple problems and a lack of housing, and financing is often geared to the care concerning a single problem (such as psychiatric care, somatic care, or housing counselling). In addition, compared to the general population, a high number of transitions occur within the last phase of life of persons experiencing homelessness. In the Netherlands, difficulties exist in the regular lack of indications for palliative care because life expectancy in this population is very difficult to determine (Chapter 4). Persons experiencing homelessness are often ill long before their death and do not always have recognized palliative care needs, they sometimes experience unexpected improvements in their health situation once they start receiving care, they cannot live independently, they have indications in several domains, and they do not have a home where they can receive care (Chapters 2 and 4). There is a gap in the funding options for the situation when highly complex (palliative) care is needed when someone is seriously ill or when curative treatment is no longer possible. The Social Support Act (*Wmo*) covers funding for stays in social services and shelter facilities. The funding for primary-care residence and highly complex care (*ELV Hoogcomplex*) can be used for 42 days in the first instance and is intended, for example, for rehabilitation and people who return home afterwards. The options and conditions for extending this *ELV Hoogcomplex* funding differ greatly between health insurers. The indication for primary-care palliative care (*ELV Palliatief*) can rarely be used for longer than six months. The Long-term Care Act (*WLZ*) funding is subject to the condition that no further improvement is possible and that nursing care is provided 24/7, which is often not feasible in residential facilities. Under the Health Insurance Act (*ZVW*), only specific treatments are reimbursed, such as hospice care or wound care. Thus, within the social service facilities and nursing wards, there is a lack of proper funding for people with multi-level problems and highly complex care. Lastly, when we developed a regional threefold intervention that encourages interdisciplinary collaboration and improves the quality of health and palliative care provision (Chapters 6 and 7), another area lacking funding was revealed, namely regarding the specific combination of consultations, multidisciplinary meetings, and training, which could contribute to better palliative care provision for this population.

RECOMMENDATIONS

Practice

This thesis shows that persons experiencing homelessness prefer to die in a home-like environment and to receive care from professionals whom they know well. Therefore, we recommend that social service facilities facilitate a resident's wish to die in the social service facility.

Providing palliative care within social service facilities requires structural multidisciplinary collaboration with palliative care professionals, as this thesis shows that social service professionals are often not fully equipped to provide the necessary palliative care. This multidisciplinary collaboration requires structural funding for all activities. We recommend that the multidisciplinary collaboration should be tailored regionally, using consultations, multidisciplinary meetings and training sessions. Also, regarding multidisciplinary teams, we recommend a greater mix of competencies in teams within social service facilities, such as the standard deployment of nursing assistants, nurses and GPs. This could encourage interdisciplinary care. Besides these efforts, we recommend integration of palliative care practices into the care for all persons with comorbidities and 'older' homeless persons.

Lastly, it is recommended that social service professionals should be trained in palliative care knowledge and skills. We recommend at least training to enhance awareness of palliative care principles and the vulnerability of the population. Besides, in order to anticipate unexpected deaths, we recommend an approach involving "hope for the best, prepare to the worst" in order to integrate parallel planning and advance care planning into the standard practice of care in social service facilities and on nursing wards. This could be facilitated by a trusting and familiar bond between professionals and residents and not discussing end-of-life issues directly during intake. Furthermore, social service professionals should be trained in discussing needs, wishes and preferences with residents. Within these conversations, the end of life does not necessarily need to be addressed specifically as it may scare people, but a potentially serious illness and deterioration can be the starting point for the discussion. Taken together, enhancing these competencies can positively affect the wellbeing and quality of life of persons experiencing homelessness.

Research

As we studied the homeless population in three of the four largest cities in the Netherlands (the G4), we recommend conducting further research also among professionals and persons experiencing homelessness outside Rotterdam, Utrecht and Amsterdam. Specifically, when conducting research outside these highly urban areas, results in smaller cities and rural areas could be compared with the preferred approach in the highly urban areas already studied, which have many facilities for this population. Furthermore, regarding the intervention and patient-measured outcomes for added value, we recommend conducting further research into the perspectives of homeless people regarding the practice of palliative care within social service facilities and their opinion of the threefold intervention. Lastly, once the intervention is being used on a large scale and by many organizations, we recommend studying the effects of the intervention on the quality of care, timing of care, competences of professionals, and quality of collaboration.

Policy and legislations

This thesis indicated that palliative care professionals had a very active role in this intervention. They gave the consultations and training sessions. They also attended multidisciplinary meetings in social service facilities. Therefore, we recommend that funding should be arranged for the palliative care professionals' activities as this is essential for a future-proof intervention focused on accessible and good palliative care for the homeless. Also, the three intervention activities reinforce each other and the need for tailoring the activities to the regional situation implies that financial resources must be made available for all those activities on a regional level. As current funding of direct patient care does not cover these additional activities, we recommend extra, structural funding for the combination of consultations, multidisciplinary meetings and training sessions. In addition, concerning the funding for direct patient care, we recommend that health insurers and social service facilities should facilitate a residential or home-care setting for non-urgent, long-term care for persons with a life-threatening condition, who are in relative good health but in need of daily somatic care. Ideally, this would be comprehensive primary care stays (ELVs) especially for the homeless and spread across the country. Furthermore, we recommend that health insurers and municipalities responsible for budgets become involved in financing the consultations, multidisciplinary meetings and training sessions specifically for this population.

Regarding the organizational policies of social service facilities, we strongly recommend including criteria on the quality and provision of palliative care and minimal requirements for good-quality palliative care provision within their facility. Further, we advise social service facilities in which homeless people are ageing and living in the final stages of life to acknowledge that people may see this ‘home’ as their ‘last home’, and consequently to reduce the number of transitions, such as avoidable hospitalizations. For this it is necessary to improve palliative care provision in social service facilities. Finally, we recommend that both social service facilities and healthcare organizations such as hospices reflect on person-oriented palliative care and the prerequisites for such care, even if the lifestyles of persons experiencing homelessness are different to other patients when they reside in hospice settings, such as their smoking, substance use, complicated behaviour, and sometimes differences in hygiene. That is why we recommend both social service facilities and healthcare organizations to deal pragmatically with rules and standards, so that people experiencing homelessness have access to palliative care.

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APPENDICES

Appendix 1. Search Strategies

Search strategy for Embase.com (April 1, 2016)
/exp = EMtree keyword with explosion, :ab,ti = words in title or abstract, NEAR/3 = words near to each other, 3 places apart

Search	Query	Items found
#3	#1 AND #2	899
#2	'terminal care'/de OR 'hospice care'/exp OR 'palliative therapy'/de OR 'palliative nursing'/exp OR 'hospice'/exp OR 'hospice nursing'/exp OR 'death'/de OR 'dying'/exp OR 'attitude to death'/exp OR 'mortality'/de OR terminal*:ab,ti OR 'end of life':ab,ti OR 'life care end':ab,ti OR hospice*:ab,ti OR (bereavement NEAR/3 car*) :ab,ti OR palliati*:ab,ti OR (limited NEAR/3 life*):ab,ti OR death*:ab,ti OR dying*:ab,ti OR die:ab,ti OR mortal*:ab,ti OR 'advanced car*':ab,ti OR 'advance car*':ab,ti	2,358,671
#1	'homelessness'/exp OR homeless*:ab,ti OR 'street people*':ab,ti	11,028

Search strategy for Ebsco/PsycInfo (April 1, 2016)
DE = descriptors, keywordsTI = words in title, AB = words in abstract, N3 = words near to each other, 3 places apart

Search	Query	Items found
S3	S1 AND S2	332
S2	(DE "Terminally Ill Patients" OR DE "Advance Directives" OR DE "Death and Dying" OR DE "Hospice" OR DE "Palliative Care" OR DE "Death Attitudes") OR TI (terminal* OR "end of life" OR "life care end" OR hospice* OR (bereavement N3 car*) OR palliati* OR (limited N3 life*) OR death* OR dying* OR die OR mortal* OR "advanced car*" OR "advance car*") OR AB (terminal* OR "end of life" OR "life care end" OR hospice* OR (bereavement N3 car*) OR palliati* OR (limited N3 life*) OR death* OR dying* OR die OR mortal* OR "advanced car*" OR "advance car*")	145,273
S1	DE "Homeless" OR TI (homeless* OR "street people*") OR AB (homeless* OR "street people*")	8,750

Search strategy for Ebsco/CINAHL (April 5, 2016)
MH = keywords, TI = words in title, AB = words in abstract, N3 = words near to each other, 3 places apart

Search	Query	Items found
S3	S1 AND S2	283
S2	((MH "Terminal Care (Saba CCC)") OR (MH "Terminal Care") OR (MH "Palliative Care") OR (MH "Hospice and Palliative Nursing") OR (MH "Hospice Care") OR (MH "Death") OR (MH	170,379

	"Dying Care (Iowa NIC)") OR (MH "Attitude to Death") OR (MH "Advance Care Planning")) OR TI (terminal* OR "end of life" OR "life care end" OR hospice* OR (bereavement N3 car*) OR palliati* OR (limited N3 life*) OR death* OR dying* OR die OR mortal* OR "advanced car*" OR "advance car*") OR AB (terminal* OR "end of life" OR "life care end" OR hospice* OR (bereavement N3 car*) OR palliati* OR (limited N3 life*) OR death* OR dying* OR die OR mortal* OR "advanced car*" OR "advance car*")	
S1	((MH "Homeless Persons") OR (MH "Homelessness")) OR TI (homeless* OR "street people*") OR AB (homeless* OR "street people*")	6,233

Search strategy for Thomson Reuters/Web of Science (May 3, 2016)
TOPIC = words in title, abstract or keywords, NEAR/3 = words near to each other, 3 places apart, Indexes=SCI-EXPANDED, SSCI, A&HCI, ESCI; Timespan=All years

Search	**Query**	**Items found**
#3	#2 AND #1	1,116
#2	TOPIC: (terminal* OR "end of life" OR "life care end" OR hospice* OR (bereavement NEAR/3 car*) OR palliati* OR (limited NEAR/3 life*) OR death* OR dying* OR die OR mortal* OR "advanced car*" OR "advance car*")	4,071,753
#1	TOPIC: (homeless* OR "street people*")	21,929

Search strategy for PubMed (May 10, 2016)
(Mesh) = Medical subject headings (MeSH), (Mesh:NoExp) = Medical subject headings (MeSH) without explosion, (Subheading) = qualifier to MeSH term, (tiab) = words in title or abstract

Search	**Query**	**Items found**
#3	#1 AND #2	614
#2	"Terminal Care"[Mesh] OR "Palliative Care"[Mesh] OR "Palliative Medicine"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Death"[Mesh:NoExp] OR "mortality"[Subheading] OR terminal*[tiab] OR end of life[tiab] OR life care end[tiab] OR hospice*[tiab] OR bereavement car*[tiab] OR palliati*[tiab] OR limited life*[tiab] OR death*[tiab] OR dying*[tiab] OR die[tiab] OR "Advance Care Planning"[Mesh] OR "Attitude to death"[Mesh] OR mortal*[tiab] OR advanced car*[tiab] OR advance car*[tiab]	1,797,180
#1	"Homeless Persons"[Mesh:NoExp] OR homeless*[tiab] OR street people*[tiab]	9,277

Appendix 2. Details of assessments of studies by using the Critical Appraisal Tool

Study	Reviewer 1 (HTK)	Reviewer 2 (AJEV)
Bartels et al. [89]	Abstract and title: very poor (1) Introduction and aims: fair (3) Method and data: good (4) Sampling: fair (3) Data-analysis: poor (2) Ethics and bias: poor (2) Findings/results: fair (3) Transferability/generalizability: fair (3) Implications and usefulness: fair (3) Total = 24 (moderate)	Abstract and title: very poor (1) Introduction and aims: fair (3) Method and data: fair (3) Sampling: fair (3) Data-analysis: poor (2) Ethics and bias: very poor (1) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: poor (2) Total = 20 (moderate)
Davis et al. [57]	Abstract and title: very poor (1) Introduction and aims: fair (3) Method and data: good (4) Sampling: fair (3) Data-analysis: poor (2) Ethics and bias: very poor (1) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 22 (moderate)	Abstract and title: poor (2) Introduction and aims: poor (2) Method and data: fair (3) Sampling: good (4) Data-analysis: poor (2) Ethics and bias: very poor (1) Findings/results: poor (2) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 21 (moderate)
Hakanson et al.[59]	Abstract and title: good (4) Introduction and aims: good (4) Method and data: good (4) Sampling: good (4) Data-analysis: fair (3) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: good (4) Implications and usefulness: good (4) Total = 34 (good)	Abstract and title: fair (3) Introduction and aims: good (4) Method and data: fair (3) Sampling: good (4) Data-analysis: fair (3) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 31
Hutt et al.[36]	Abstract and title: good (4) Introduction and aims: fair (3) Method and data: fair (3) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: poor (2) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 28 (moderate)	Abstract and title: fair (3) Introduction and aims: fair (3) Method and data: poor (2) Sampling: poor (2) Data-analysis: fair (3) Ethics and bias: fair (3) Findings/results: poor (2) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 23 (moderate)
Hwang et al.[11]	Abstract and title: poor (2) Introduction and aims: fair (3) Method and data: fair (3) Sampling: good (4) Data-analysis: fair (3) Ethics and bias: very poor (1) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (3) Total = 27 (moderate)	Abstract and title: poor (2) Introduction and aims: poor (2) Method and data: poor (2) Sampling: good (4) Data-analysis: good (4) Ethics and bias: very poor (1) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: fair (3) Total = 25 (moderate)

Appendix 2. Continued.

Study	Reviewer 1 (HTK)	Reviewer 2 (AJEV)
Ko et al.[82]	Abstract and title: fair (3) Introduction and aims: fair (3) Method and data: fair (3) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: good (4) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 30 (good)	Abstract and title: poor (2) Introduction and aims: fair (3) Method and data: good (4) Sampling: good (4) Data-analysis: good (4) Ethics and bias: poor (2) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 29 (good)
Ko et al.[83]	Abstract and title: poor (2) Introduction and aims: good (4) Method and data: fair (3) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: good (4) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 30 (good)	Abstract and title: fair (3) Introduction and aims: good (4) Method and data: good (4) Sampling: good (4) Data-analysis: good (4) Ethics and bias: good (4) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 33 (good)
Krakowsky et al.[35]	Abstract and title: fair (3) Introduction and aims: poor (2) Method and data: poor (2) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: poor (2) Findings/results: poor (2) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 19 (poor)	Abstract and title: fair (3) Introduction and aims: poor (2) Method and data: poor (2) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: poor (2) Findings/results: poor (2) Transferability/generalizability: very poor (1) Implications and usefulness: fair (3) Total = 18 (poor)
Leung et al.[62]	Abstract and title: good (4) Introduction and aims: good (4) Method and data: fair (3) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 31 (good)	Abstract and title: good (4) Introduction and aims: good (4) Method and data: fair (3) Sampling: good (4) Data-analysis: good (4) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 33 (good)
Mac Williams et al.[90]	Abstract and title: fair (3) Introduction and aims: good (4) Method and data: fair (3) Sampling: fair (4) Data-analysis: poor (2) Ethics and bias: fair (3) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 27 (moderate)	Abstract and title: fair (3) Introduction and aims: good (4) Method and data: poor (2) Sampling: poor (2) Data-analysis: poor (2) Ethics and bias: poor (2) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 23 (moderate)

Appendix 2. Continued.

Study	Reviewer 1 (HTK)	Reviewer 2 (AJEV)
McGrath[88]	Abstract and title: poor (2) Introduction and aims: good (4) Method and data: good (4) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: very poor (1) Findings/results: fair (3) Transferability/generalizability: very poor (1) Implications and usefulness: fair (3) Total = 21 (moderate)	Abstract and title: fair (3) Introduction and aims: good (4) Method and data: poor (2) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: very poor (1) Findings/results: very poor (1) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 19 (moderate)
McNeil & Guirguis-Yonger[63]	Abstract and title: fair (3) Introduction and aims: good (4) Method and data: good (4) Sampling: poor (2) Data-analysis: good (4) Ethics and bias: poor (2) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 29 (good)	Abstract and title: poor (2) Introduction and aims: good (4) Method and data: fair (3) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: good (4) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 31 (good)
McNeil et al.[84]	Abstract and title: good (4) Introduction and aims: fair (3) Method and data: good (4) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 32 (good)	Abstract and title: good (4) Introduction and aims: good (4) Method and data: good (4) Sampling: good (4) Data-analysis: good (4) Ethics and bias: good (4) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 35 (good)
McNeil et al.[83]	Abstract and title: good (4 Introduction and aims: fair (3) Method and data: good (4) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 32 (good)	Abstract and title: good (4) Introduction and aims: good (4) Method and data: fair (3) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: good (4) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 33 (good)
Nikouline & Dosani[91]	Abstract and title: very poor (1) Introduction and aims: fair (3) Method and data: fair (3) Sampling: poor (2) Data-analysis: fair (3) Ethics and bias: very poor (1) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 23 (moderate)	Abstract and title: very poor (1) Introduction and aims: poor (2) Method and data: poor (2) Sampling: poor (2) Data-analysis: poor (2) Ethics and bias: poor (2) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 19 (moderate)

Appendix 2. Continued.

Study	Reviewer 1 (HTK)	Reviewer 2 (AJEV)
Norris et al.[92]	Abstract and title: good (4) Introduction and aims: good (4) Method and data: fair (3) Sampling: good (4) Data-analysis: good (4) Ethics and bias: poor (2) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: fair (3) Total = 31 (good)	Abstract and title: good (4) Introduction and aims: good (4) Method and data: fair (3) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: good (4) Total = 32 (good)
O'Connell et al.[93]	Abstract and title: fair (3) Introduction and aims: very poor (1) Method and data: very poor (1) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: very poor (1) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: very poor (1) Total = 15 (poor)	Abstract and title: poor (2) Introduction and aims: very poor (1) Method and data: very poor (1) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: very poor (1) Findings/results: fair (3) Transferability/generalizability: very poor (1) Implications and usefulness: very poor (1) Total = 13
Podymow et al.[34]	Abstract and title: good (4) Introduction and aims: good (4) Method and data: good (4) Sampling: good (4) Data-analysis: good (4) Ethics and bias: poor (2) Findings/results: good (4) Transferability/generalizability: good (4) Implications and usefulness: poor (2) Total = 32 (good)	Abstract and title: good (4) Introduction and aims: poor (2) Method and data: fair (3) Sampling: good (4) Data-analysis: good (4) Ethics and bias: poor (2) Findings/results: good (4) Transferability/generalizability: good (4) Implications and usefulness: fair (3) Total = 30 (good)
Ratner et al.[94]	Abstract and title: poor (2) Introduction and aims: poor (2) Method and data: poor (2) Sampling: fair (3) Data-analysis: poor (2) Ethics and bias: very poor (1) Findings/results: poor (2) Transferability/generalizability: poor (2) Implications and usefulness: poor (2) Total = 18 (poor)	Abstract and title: poor (2) Introduction and aims: fair (3) Method and data: poor (2) Sampling: fair (3) Data-analysis: very poor (1) Ethics and bias: very poor (1) Findings/results: poor (2) Transferability/generalizability: poor (2) Implications and usefulness: poor (2) Total = 18 (poor)
Song et al.[56]	Abstract and title: very poor (1) Introduction and aims: fair (3) Method and data: fair (3) Sampling: poor (2) Data-analysis: fair (3) Ethics and bias: poor (2) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 23 (moderate)	Abstract and title: very poor (1) Introduction and aims: poor (2) Method and data: fair (3) Sampling: poor (2) Data-analysis: fair (3) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: poor (2) Implications and usefulness: good (4) Total = 24 (moderate)

Appendix 2. Continued.

Study	Reviewer 1 (HTK)	Reviewer 2 (AJEV)
Song et al.[87]	Abstract and title: good (4)	Abstract and title: good (4)
	Introduction and aims: good (4)	Introduction and aims: good (4)
	Method and data: fair (3)	Method and data: good (4)
	Sampling: fair (3)	Sampling: good (4)
	Data-analysis: fair (3)	Data-analysis: good (4)
	Ethics and bias: fair (3)	Ethics and bias: good (4)
	Findings/results: fair (3)	Findings/results: good (4)
	Transferability/generalizability: fair (3)	Transferability/generalizability: fair (3)
	Implications and usefulness: good (4)	Implications and usefulness: good (4)
	Total = 30 (good)	Total = 35 (good)
Song et al.[86]	Abstract and title: good (4)	Abstract and title: good (4)
	Introduction and aims: good (4)	Introduction and aims: good (4)
	Method and data: fair (3)	Method and data: fair (3)
	Sampling: fair (3)	Sampling: good (4)
	Data-analysis: fair (3)	Data-analysis: good (4)
	Ethics and bias: fair (3)	Ethics and bias: fair (3)
	Findings/results: fair (3)	Findings/results: fair (3)
	Transferability/generalizability: fair (3)	Transferability/generalizability: fair (3)
	Implications and usefulness: fair (3)	Implications and usefulness: good (4)
	Total = 29 (good)	Total = 32 (good)
Song et al.[60]	Abstract and title: good (4)	Abstract and title: good (4)
	Introduction and aims: good (4)	Introduction and aims: good (4)
	Method and data: good (4)	Method and data: good (4)
	Sampling: fair (3)	Sampling: good (4)
	Data-analysis: fair (3)	Data-analysis: good (4)
	Ethics and bias: good (4)	Ethics and bias: good (4)
	Findings/results: fair (3)	Findings/results: good (4)
	Transferability/generalizability: fair (3)	Transferability/generalizability: fair (3)
	Implications and usefulness: good (4)	Implications and usefulness: good (4)
	Total = 32 (good)	Total = 35 (good)
Song et al.[61]	Abstract and title: good (4)	Abstract and title: good (4)
	Introduction and aims: fair (3)	Introduction and aims: good (4)
	Method and data: good (4)	Method and data: good (4)
	Sampling: good (4)	Sampling: fair (3)
	Data-analysis: fair (3)	Data-analysis: good (4)
	Ethics and bias: poor (2)	Ethics and bias: good (4)
	Findings/results: good (4)	Findings/results: good (4)
	Transferability/generalizability: fair (3)	Transferability/generalizability: good (4)
	Implications and usefulness: good (4)	Implications and usefulness: good (4)
	Total = 31 (good)	Total = 35 (good)
Tarzian et al.[95]	Abstract and title: good (4)	Abstract and title: good (4)
	Introduction and aims: fair (3)	Introduction and aims: fair (3)
	Method and data: good (4)	Method and data: good (4)
	Sampling: good (4)	Sampling: fair (3)
	Data-analysis: poor (2)	Data-analysis: fair (3)
	Ethics and bias: fair (3)	Ethics and bias: fair (3)
	Findings/results: good (4)	Findings/results: good (4)
	Transferability/generalizability: fair (3)	Transferability/generalizability: good (4)
	Implications and usefulness: good (4)	Implications and usefulness: good (4)
	Total = 31 (good)	Total = 28 (good)

Appendix 2. Continued.

Study	Reviewer 1 (HTK)	Reviewer 2 (AJEV)
Walsh[96]	Abstract and title: very poor (1) Introduction and aims: good (4) Method and data: poor (2) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: good (4) Findings/results: fair (3) Transferability/generalizability: very poor (1) Implications and usefulness: good (4) Total = 22 (moderate)	Abstract and title: very poor (1) Introduction and aims: good (4) Method and data: fair (3) Sampling: poor (2) Data-analysis: very poor (1) Ethics and bias: fair (3) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 22 (moderate)
Webb[58]	Abstract and title: good (4) Introduction and aims: fair (3) Method and data: good (4) Sampling: poor (2) Data-analysis: good (4) Ethics and bias: fair (3) Findings/results: fair (3) Transferability/generalizability: poor (2) Implications and usefulness: fair (3) Total = 28 (good)	Abstract and title: good (4) Introduction and aims: good (4) Method and data: good (4) Sampling: fair (3) Data-analysis: good (4) Ethics and bias: fair (3) Findings/results: good (4) Transferability/generalizability: fair (3) Implications and usefulness: poor (2) Total = 33 (good)

HTK = Hanna Klop, AJEV = Anke de Veer

Appendix 3. Characteristics of study populations (categorization as used in original studies)

Reference	Type of participants	Sex (% male)	Age (m)	Cultural background	Health status	Education
[86]	Homeless people	82%	NA	64.7% Black 23.5% Non-Hispanic White 11.8% Native American	NA	41.2% Finished college 35.3% High school graduates 23.5% No answer
[82, 83]	Homeless people	86%	65	52.4% White 23.8% Black 14.3% Latino/Hispanics 9.5% Other	57.1% (Very) good 23.8% Fair 19% Poor	57.1% College education 28.6% High school graduates 9.5% Less than high school 4.8% Post graduate
[62]	Homeless people	100%	55	70.2% White 8.8% Black 6.8% Aboriginal 11.2% Asian 2.9% Other	7.8% Excellent 15.7% Very good 32.8% Good 25.5% Fair 18.1% Poor	12.2% 8th grade or lower 38% High school 21.5% High school diploma 16.1% College or university 12.2% Bachelor's degree
[90]	Homeless people	NA	NA	NA	NA	NA
[57]	Homeless people	100%	62	75% Caucasian 13% Black 13% Hispanic		25% Started college 75% Unknown(
[94]	Homeless people	NA	48	40% American Indians 29% Black	NA	34% More than 12 years education
[86, 87]	Homeless people	66%	47	36% American Indian or Alaskan Native 27% Black 22% White 7% Not reported 2% Hispanic or Latino 2% Not Hispanic or Latino 2% Asian 2% Native African	NA	Years of education: 8% 5-8 39% 9-11 32% 12-15 8% >16 13% Not reported
[60]	Homeless people	75%	45	34% White 51% Black 7% Native American 3% Hispanic 2% Asian 3% Mixed	NA	11% <High School 48% High School 40% >High School

Appendix 3. Continued.

Reference	Type of participants	Sex (% male)	Age (m)	Cultural background	Health status	Education
[61]	Homeless people	74%	43	31.7% White 53.8% Black 6,9% Native American 0.8% Asian 97.3%Non-Hispanic 2.7% Hispanic	NA	30.6% Did not complete high school 69.4% High school or higher
[95]	Homeless people	60%	NA	80% African American 20% Caucasian	NA	NA
[96]	Homeless people	81%	61	NA	NA	NA
[34]	Homeless people	89%	49	89.3% Caucasian 7.9% African American 3.6% Aboriginal	NA	NA
[92]	Homeless people and healthcare professionals*	59%	51	40.7% White 37% African American 10.4% Hispanic 3.7% Asian 8.1% Native American	8.1% Excellent 15.6% Very good 31.1% Good 25.2% Fair	1.5% No formal education 3.7% <8th grade 14.7% High school 25.2% High school graduate 44.4% College/trade school 8.9% College degree 1.5% Graduate degree
[56]	Homeless people and healthcare professionals	NA	NA	NA	NA	NA
[63, 84, 85]	Healthcare professionals	NA	NA	NA	NA	NA
[11]	Healthcare professionals*, **	86%	47	59.1% White 30.3% Black 8.1% Hispanic 2.5% Other		
[93]	Healthcare professionals*, **	73%	67	NA	NA	NA

Appendix 3. Continued.

Reference	Type of participants	Sex (% male)	Age (m)	Cultural background	Health status	Education
[57]	Healthcare professionals*, **	96%	55	70.4% White British 14.8% Irish 7.4% Black 3.7% Portuguese 3.7% Afro Caribbean	NA	NA
[91]	Healthcare professionals	NA	NA	NA	NA	NA
[59]	Healthcare professionals	NA	NA	NA	NA	NA
[36]	Healthcare professionals	NA	NA	NA	NA	NA
[35]	Healthcare professionals	NA	NA	NA	NA	NA
[58]	Healthcare professionals	NA	NA	NA	NA	NA

NA = not applicable

*Only data available of homeless persons

** Data was collected by healthcare providers but provides information about homeless persons, e.g. a cohort or review of medical files

Appendix 4. Recommendations for practice

Training, education and knowledge	Delivering care	Overall organization
Training and education regarding providing palliative care to and specific needs of (older) homeless people • Training for staff working with homeless people to provide support as health deteriorates and death approaches, e.g. talking about death and dying, talking about the unique needs of the homeless population, pain and symptom management, substance use and recognition of health needs[35, 58, 84, 85, 91, 96]	*Patient-centred approach* • A patient-centered approach: respecting each persons' individual story, autonomy, dignity and own end-of-life priorities, wishes and desires[35, 58-61, 83, 89] • Harm reduction approaches and interventions that have minimal requirements for admission and care are needed to improve health equity and promote dignity for homeless persons who use illicit drugs at the end of life[34, 35, 63, 84, 85] • A non-judgmental, culturally sensitive and individually tailored approach, deviating from policies and guidelines should be more the rule rather than the exception[59, 66, 82, 84] • Decision-making for homeless persons by physicians should not be made based on assumptions or physicians' preferences[92, 94]	*Availability of accommodation* • Ensure that palliative care beds are accessible to people who are homeless, e.g. by a palliative care team that is able to make use of limited space, operate in many different locations and provide flexible treatment options or special accommodation to facilitate dying for homeless people[91, 96] • Provision of appropriate accommodation with healthcare support for homeless individuals who are too sick for hostels and not sick enough for hospital[96]
Training and education about addressing preferences, ACP, advance directives, after-death wishes and surrogate decision-makers • The importance of religion/spirituality in the participant's attitudes towards ACP needs to be recognized, a holistic approach that incorporates a religious/spiritual component as a part of ACP process will be necessary[82, 96] • Having some form of identification card with simple directives or contacts may also serve to preserve the dignity and autonomy of homeless persons at the end of life[56] • Homeless individuals' levels of motivation and perceived ability to engage in ACP might vary with their circumstances, so preparing them to consider death and dying might be an important first step to take. In doing so, engaging in EOL communication gradually and over time can help reach better future decisions[82]	*Trusting and respectful relationships* • Contextual, experience-based skills that go beyond palliative care education and should be based on trusting and respectful relationships between provider and patient and on previous encounters[11, 35, 59] • Healthcare professionals who help homeless people to rebuild and strengthen social support[83] • A "professional family member" for those estranged from their family can support patients who are homeless in their emotional, physical and social struggles[59]	*Involved expertise and coordination* • Having a Palliative Care Coordinator[57, 96] • A palliative care team that supports shelter staff and is able to make use of limited space, operate in many different locations and provide flexible treatment options[91] *Policies and guidelines* • Hospital discharge policies and establishment of a pathways model[96] • Guidelines of communication regarding communication on death and dying need reconsideration because communication needs to be sensitively weighted against the risk of harming the patient by exposing the social loneliness and intensifying feelings of anxiety and fear about the impending death[59]

Appendix 4. Continued.

Training, education and knowledge	Delivering care	Overall organization
Training and educational initiatives directed towards both providers and homeless clients • Educational initiatives directed towards both providers and homeless clients may be extremely beneficial, end-of-life service providers need to understand the end–of-life concerns of their clients, and toward hospice and other end-of-life care and healthcare providers who need to understand the special concerns and needs of homeless individuals[56, 66, 84, 85] *Access to support that acknowledges the challenges of professionals* • Access to bereavement support that acknowledges the challenges faced by staff and other residents in coming to terms with unanticipated deaths[57]	• Healthcare professionals or patient navigators might serve as an advocate for homeless persons as they try to navigate the end-of- life care system and help minimize the impact of discrimination and/or exclusionary policies[35, 66, 85] • Expand individuals' social networks (using volunteers/former service users) and community mobilization[96] *Reliability, experience and sensitivity of healthcare professionals* • Health practitioners needed with strong communication skills, this shows reliability and commitment to the homeless population[91] • Healthcare providers need to be sensitive and respond effectively to varying emotional responses that may stem from fear of pain, suffering, and losing control in EOL situations[83] *Attention for various areas of concern of homeless people* • Areas of concern of homeless people at the end of life are different to those of the general population and require a different approach; healthcare providers should be aware of a deep level of concern about morbidity, premature mortality, and decisions they might confront as they approach the end of their lives. Listening to patients' stories and exploring options in a collaborative way will increase empathy and the ability to provide care in the best way[83, 89, 95]	• Institutions should consider developing an explicit policy for involving additional persons, such as hospital ethics committees and/or advocates for homeless persons[92] *Partnering and exchange of knowledge between organizations* • Partnering social communities with the end-of-life care system. Trust developed between agencies and homeless populations can help mediate access to a range of other services and can provide accurate and up-to-date medical information and clearer lines of communication. Partnerships need to be developed[58, 63, 66, 85] • The community palliative care service should initiate discussions with hospital referrers and community nurses about ways to approach referrals and shared care of terminally ill homeless people, as well as about how best to provide information on the range of services available to homeless people[90] • There must be diversity in institutions and palliative services (hospital-based palliative care, shelter-based palliative care, street-based palliative care. Individuals have different levels of comfort[35] • The population needs to advocate the importance of palliative care in-shelter[91]

Appendix 4. Continued.

Training, education and knowledge	Delivering care	Overall organization
	• Planning for death with individuals who have spent so much energy surviving requires an understanding of their life experiences[95] *Flexible programmes and availability* • A mobile and flexible program and being available through multiple modalities (e-mail, phone etc.) improves communication[91] • Provide access to a range of activities to tackle the issue of boredom[96] *Advance care planning* • Every patient at the time of hospital admission should be asked who their surrogate decision-maker is and how to contact that person[92] • Primary care physicians should address preferences regarding end-of-life care with homeless patients in the primary setting, and (whenever possible) a primary care physician should be called to help hospital physicians make such decisions[92] • Addressing themes concerning dignity and asking questions about death and dying in advance directive formats[89] *Support after death* • Identification of proxies not only for medical decision-making (as traditionally identified) but also for witnessing and care of the body after death[56] • Support after death for both shelter occupants and staff, including bereavement groups and memorial services from friends and family[91]	• Primary and continuous care are possible for elderly homeless people if multidisciplinary teams of doctors working with nurse practitioners, physician assistants, nurses, social workers and benefits specialists based in hospitals and health centres are willing to venture out on the streets on a consistent basis to offer services directly[93]

ACP = Advance care planning, EOL = End of life

Appendix 5. Overview of topic-lists used for semi-structured (group) interviews

Semi-structured group interviews with attendees of MDMs and training activities

Process of organizing MDMs and training activities
- Start and progress
- Establishing contact and collaboration
- Role of consultant
- Appreciation of meetings attended

Perceived added value
- Of topics discussed
- Of MDM or training for professionals and patients
- For daily work and competences
- Contribution to identification of patients with palliative-care needs
- Contribution to quality and timing of palliative care

Maintenance and suggestions for improvement
- Advice for consultant/trainer
- Advice for other regions

Semi-structured individual interviews with managers of the organizations involved

Process of consultations, MDMs and training
- Start and progress
- Establishing contact and collaboration
- Facilitating the consultant
- Collaboration with other organizations

Perceived added value
- Of consultations, MDMs, and training activities for own organization
- Of consultations, MDMs, and training activities on palliative care for the homeless

Maintenance
- Future-proof financing of activities
- Ownership of activities

Semi-structured individual interviews with the consultants involved

Description of current activities
- Consultations, MDMs, training activities
- What works, what doesn't?
- Collaboration with other professionals in palliative-care provision
    - What helps, what doesn't?
    - Needs of care professionals
    - Strategies to involve other professionals

Implementing the intervention
- Minimal effort to let the intervention work
- Most useful elements of the intervention
- Missing elements

Appendix 5. Continued.

Added value and effectiveness

- Perceived achievements of the intervention
    - Through consultations, MDMs, training
    - On quality and timing of palliative care
    - On collaboration
    - On competences

Appendix 6. Overview of barriers and facilitators, organized by RE-AIM elements and main CFIR domains

Overview of barriers and facilitators, organized by RE-AIM elements and main CFIR domains

RE-AIM domain	CFIR domain	Facilitators	Barriers
Adoption	1. Intervention characteristics	Professionals perceive a need and priority for additional support which makes them feel the need for collaboration (QA1.1) *"I think that has become clear, that I definitely have little to no expertise when it comes to the homeless — that is really her area of expertise. But I do have expertise when it comes to palliative care. So I think that makes it work. Right, you need one another for that, yes." (Consultant 2)* Provision of palliative care tools helps consultants concretize palliative care in intervention activities (QA1.2) *"Sent [consultant] tools because she needed them: alert line, advance care planning form, Utrecht symptom diary, palliative performance scale, Leiden conversation aid." (Implementation logbook)* An intervention tailored to local collaborations and structures facilitates easy adoption of the intervention (QA1.3) *"Right, look, we already had a setup, of course; we had that practice of course where [street doctor] is the practice holder, we have MDM discussions and that MDM for the vulnerable elderly, which we have once every six weeks or two months. So we already had a structure." (Manager 2)*	Benefit of consultations not recognized by all the professionals involved as not everyone feels the need to engage the consultant in bedside consultations (QA1.4) *"Right, I can imagine it could grow more into something where you go and look at the patient at some point. At the moment, it's all advice on paper, as it were, because of course you only see the resident on paper. But there could come a point where that's perhaps at the patient's bedside."* (Consultant 1) Concerns about the relative advantage of the intervention as palliative care concerns a small population and narrow topic (QA1.5) *"I think it's the fact that the topic [palliative care] is quite limited in some way. It's such a small thing. [...] It's just difficult. You don't see it happen much." (Consultant 5)*
	2. Outer setting	Pre-existing regular meetings in professionals' network means that professionals who already have a network among other organizations can easily adopt the intervention (QA1.6) *"Because... so we'd been together because of [city]. So both [hospice] and [other shelter organization] and [shelter organization] take part in project meetings and that kind of thing, as well as representatives from [other shelter organization] and [shelter organization] and [hospice]. So that means you already know one another and well, basically, you meet one another everywhere." (Manager 3)*	Unclear policies on responsibilities. due to too many external parties involved in care for homeless people may hinder adoption of the intervention (QA1.7) *"But I think precisely because of all the many options and disciplines in [city], if you have a specific question you often get lost in all the possible options. And sometimes you get shunted from pillar to post as a result. And I think that you... yes, that absolutely does happen, that people say that's nothing to do with us, you should really go there. And then you go there and they say, well, no, we're referring you back to... It is easier for people here in [city] to pass the buck to someone else again." (Training 2)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
	3. Inner setting	Intervention is compatible within existing workflow due to a clear route of palliative care (and responsibilities) within the organization participating in the intervention (QA1.8) *“Well, that we have an embedded roadmap for residents who have been given the diagnosis [final phase of life] or a pre-diagnosis, that you say that you don’t know. That you can take a proper roadmap off the shelf as a carer or nurse, and immediately start delivering the care. And it also specifies using a consultant. Embedding the MDMs, which are important. And she [the consultant] doesn’t always have to attend; you can say, well we have this resident, we’ll call on you. Because that care too changes somewhat for us.” (Manager 8)*	Norms and values within the organization for social service provision are often focused on social care, while somatic care gets less attention (QA1.11) *“That whole aspect is simply… not in this business… They find it scary too. And you see too that when the moment comes — because I think that’s also part of it, they don’t want to see it — because when the moment comes that you see someone is getting dirty for example, you should do something about it. It’s also often a kind of mantra: no, it’s physical, it’s to do with the body, and I’m not going to do anything about that because it would be bad for my relationship with my client. Whereas I think that doesn’t have to be the case at all. It could enhance it.” (Manager 1)*
		Shared vision on good healthcare among colleagues within the participating organization makes collaboration easier (QA1.9) *I know she was involved at [location 2] with someone who was really in the terminal stage… and also behaviourally… I’m not going to the nursing home. […] She brings those different worlds together. You really need that with a specific group, especially here with ageing people and addiction and Lord alone knows what diseases. Yes, the whole package is broader, more complex perhaps. She’s better at that. I don’t have a nursing background at all. But the ultimate responsibility for the processes is mine, so I thought, ‘Oh great, someone who’s helping find solutions: that can only be positive.’” (MDM, U region)*	Limited skills in recognizing, discussing and providing palliative care within social services hinder adequate care at the end of life (QA1.12) *“I certainly don’t have the knowledge about palliative care because if you can’t put into words what you see, someone’s deteriorating but you can’t put into words exactly what you see and you don’t know what action to take, or you can’t explain it to a GP, well I can understand why people don’t get noticed, or they get noticed far too late. […] The problem is that sheltered housing supervisors don’t report… well, they report a deterioration but they can’t tell the GP exactly what it is they’re seeing. ‘The person’s a bit under the weather’. And right, that’s as much as you’re getting.” (Consultant 4)*
		Shared views of involved professionals regarding equal and reciprocal cooperation (QA1.10) *“It’s on an equal footing because I always say, ‘I know a bit about palliative care and you know a bit about homeless people and that’s how we complement one another’. I can also say ‘I know an awful lot and you know an awful lot, but we complement one another’.” (Consultant 2)*	Many staff changes and insecure future prospects for organization make organizational commitment hard (QA1.13) *“Because of all the changes in personnel and responsibilities, too. We really need to appoint a single person who can deal with it and take charge and who also makes sure it gets picked up in the team. Well, we did have someone but then our whole team got reorganized again. Then you have more new people so you really start from square one again at the start of this year.” (Manager 8)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
			Limited support and engagement of management makes consultants feel they are getting little support (QA1.14) *"Consultant feels manager is not giving much support or clarity, for example regarding time limits, available hours, a close colleague to work with, proper agreements, direct lines of communication." (Implementation logbook)*
	4. Characteristics of individuals	Commitment and enthusiasm of the professionals involved regarding the intervention and palliative care (QA1.15) *"He said, 'That we get listened to and noticed, that we get to tell our story'. He even said something I found quite funny: 'I'm getting enthusiastic about palliative care'." (Manager 1)* Medical skills and knowledge of individual consultant makes professionals feel the consultant is competent (QA1.16) *"And so I see in my partnership with [other consultant], they are genuinely saying hey, that person has even more of a medical perspective than me of course, my medical perspective has already become incredibly muddied by everything I've seen and she still sees someone's somatic condition and think hey, that's what's going on." (Consultant 5)* An approachable consultant without their own agenda helps the professionals to adapt the intervention according to their needs (QA1.17) *"Basically that you go round there with a fairly low profile. Of course I don't really have any particular status; I don't have to do anything. I think it becomes complex for them because, well, then they have to do something. [...] So if I take a serious stand there and say all kinds of things need to happen, then I think I would lose them." (Consultant 1)*	Low self-efficacy in palliative care skills may hinder identification of palliative care and use of the intervention (QA1.23) *"And if it [death or imminent death] happens, sometimes it feels as if it slips through your fingers, so you think: oh, it happened again and perhaps we should have paid it more attention." (Consultant 5)* Professionals' differences in their views when a consultation is requested could hinder use of the intervention (QA1.24) *"Tricky when a colleague asks for advice in a situation where we don't agree. The colleague doesn't see it as a problem." (Implementation logbook)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
		Adoption is facilitated by consultants who proactively initiate consultations, organize training or participate in multidisciplinary meetings, which makes it easier for professionals to adapt to the involvement of the consultant (QA1.18) *"Yes, that's simply keeping in easy contact with the locations. [...] And if I visit the location myself, I also like to pop in on the most vulnerable people, the ones I'm really worried about, let's say, who just aren't doing well. So I drop in on them, after agreeing it with the sheltered housing supervisor. She's always really pleased about that, or she comes along with me, right... Right, I find it goes very well like this. And I find that people really appreciate it. And if I phone them between times too, and ask how things are going, are there any new developments, can I help them with anything? Then I find that they really appreciate that a lot." (Consultant 5)* A consultant who is familiar with the homeless population makes the intervention easier to adopt for social professionals (QA1.19) *"You also have doctors who say well, if he's using cocaine... no, then you can't do this... or you can't do that. That isn't an issue. That's what makes it so difficult to explain what the problems are with our specific group in the regular health service. [...] She [consultant] does know that there's no point in questioning that. Sure, you can say it's not such a good idea for him to walk around outside drunk, that you should go and fetch him every time he's outside, you know. Sure, everyone realizes this. But that situation's not an issue for her." (Consultant 3)* Open mindset and attitude of professionals helps make them more motivated for palliative care (QA1.20) *"But also really the open mindset of our nurses; nothing is a standard, a protocol. Because we know that it's different for everybody. And I think we're different to the regular nursing-home care, where you base things more on a protocol, and that's just how you do that because you've been doing it that way for so long. Here you tend to take a tailored approach. And I think that helps a lot in that final stretch of care." (Consultant 3)*	

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
		Awareness of skill shortcomings makes individuals open to reflecting and learning (QA1.21) *"That too helps make you kind of… you find out: hey, perhaps I was unconsciously competent. That awareness has developed in me, there's this unconscious competence that makes me think: hey, that's also something other care providers have too to a certain degree for a particular case. It's good to develop that awareness so that you can also communicate that: hey, you might have more know-how than you realize." (Consultant 5)* Individuals who trust each other cooperate better in using the intervention (QA1.22) *"Right, I think a certain calm… you do see a lot of discontinuity in the care providers. And yes, trust in one another. Knowing that the team meetings have a really useful purpose at any rate. I think knowing one another a bit can definitely help. Sometimes you all kind of need to have a common enemy, shall we say." (Manager 7)*	
	5. Process		Issues with converting the work plan and intentions into actions impedes planning and engaging appropriate individuals (QA1.25) *"It's all still somewhat vague. Group members will think about their roles. Starting in September turns out to be too ambitious because of holidays and staff shortages." (Implementation logbook)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
			Unclear implementation route for intervention within organization (QA1.26) *"More than you thought… Ah, so that's what palliative care is. We had to learn that. We should have announced it differently beforehand, that's why there were some delays sometimes. […] She should have come along to the team meeting and explained publicly what we were going to do. And made a plan based on that. In the end, it was all a bit messy and people didn't know exactly what she was supposed to be doing. I didn't know either… are you going to bring her in for individual cases… I mean, who was in the terminal phase anyway, we thought? No one. We kind of went from Z to A instead of from A to Z." (MDM, U region)*
Implementation	1. Intervention characteristics	Frequent physical meetings (consultations, MDMs, training) normalize collaboration between palliative care professionals and social service professionals (QI1.1) *"And we have that now… Right, we see each other even more now, we are in contact even more often and so it's easier to take action, let's say." (MDM, R Region)* Consultants' structured questioning helps in implementing consultations (QI1.2) *"She writes it up in this very staccato way, so you really get a kind of prescription from her. Like this is an important point, this is an important point, did you calibrate this? And she does this by… she really interrogates me, I give a sketch of the situation, I tell her what we're doing and why we're doing it this way. Then she asks more and more questions, how are you doing that, did you do it like that, did you think of that? Did the doctor think of that medication? Then she always produces this really clear, compact report… which can go straight into the file as a guide for the nursing interventions, but the doctor can also look at it too, and maybe think 'OK, that medication could be an idea', or 'Oh, so that one isn't working so well'." (Consultant 3)*	Unclear role of consultant negatively increases the perceived complexity of the intervention (QI1.6) *"Well, at the beginning I remember it was a bit chaotic starting up the consultations; we didn't really know what we were going to do exactly and when." (MDM, U Region)* Making limited use of bedside consultation possibilities prevents the consultant from making their own assessments as intended in the intervention (QI1.7) *"Look, it's always nice, and I say this deliberately, nice to see a patient. […] [With a phone consultation] you are ever so aware that you are always dependent on the picture that the person requesting the consultation gives of the situation. So the challenge then is to ask the right questions so you can get as complete a picture as possible." (Consultant 2)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
		The three intervention activities complement each other, making implementation of the intervention easier (QI1.3) *"So you see that those three pillars [of the intervention]… they influence one another. And that is because you really… there is nothing complicated about that with meetings or so, of course there are a few meetings that are linked, but it really happens automatically. She knows what I do; I know what she does. That other person experiences various things and knows what I do in the MDM group, which she goes to as well." (Manager 2)* Discussing patient cases in training helps participants to see the advantage of training (QI1.4) *"Yes, I found it a nice set-up. First some general knowledge and then looking more at case studies together, plus we had a few who were also in the group and had personal experience and they could talk about this part or could ask questions, then finishing with case studies." (Training in region A)* Making notes of conversations and appointments in patient files contributes to clear agreements (QI1.5) *"And all the things I do during a peer-review session are recorded in the GP file. So [the street doctor] notes down the people who are discussed in the file." (Manager 2)*	Still no perceived necessity for MDMs in which palliative care is embedded (QI1.8) *"I think the middle element is the hardest because you need to systematically free up time for it and then you have that problem that the supervisors are often not aware of the somatic demands, let's say. So that's why it's really important that you're at these team meetings; then you can also give input and turn lack of awareness into awareness. But it isn't easy to get your voice heard in such a team meeting; people often don't honestly see the need." (Manager 1)* Discussion of patients in MDMs is too short/limited, which hampers implementation of advice in MDM (QI1.9) *"Then you discuss their caseload, let's say. But of course those palliative patients can be in anyone's caseload. Whereas if you discuss the palliative people specifically, then you would really need to have far more personal supervisors and nurses there because they all have a good picture of their own people." (Consultant 1)* Limited time for patient discussion in training hampers implementation of knowledge and skills in training (QI1.10) *"Too much time was… of course it's nice to know who's in the group, but too much time was spent on that. So now an entire case was skipped simply because we had run out of time, and I found that a real pity." (Training in region A)* A follow-up consultation was not always possible (QI1.11) *"The follow-up was tricky sometimes, but that was also familiar from the contact with [consultant on the homeless nursing ward], […] but it's difficult sometimes, just because of the work pressure, to find out in the short term whether the consultation or the advice worked or was suitable. I think that would complete your consultation properly, of course, if you do the follow-up too and hear whether it worked or whether you need to adjust the advice. That sometimes took a bit longer than you'd like." (Consultant 2)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
	2. Outer setting	Familiarity with other professionals (not participating in the intervention) through pre-existing regular meetings helps in implementing the intervention (QI1.12) *"Well, we already had regular meetings and so on. So we were already discussing homeless people with complicated stories. And I think that has become even more solid, let's say." (MDM, R region)* A policy of clear incentives and regulations regarding palliative care indication and associated (existing) funding helps in implementing the intervention (QI1.153) *"Yes, that's the mental healthcare under the Long-Term Care Act, that applies to these patients too, and that means… we're still figuring out… because it includes some personal care, so should that be delivered at the location where they live? That's a new aspect. Until recently, it was like, 'Oh no, this is to do with the body so that's someone else's business, something for the nursing staff.' Now you see a tendency to say, 'Hey, we should be organizing this ourselves' – but how are we going to do that actually?" (Manager 1)*	
	3. Inner setting	Available time of consultant supports adaptability of the intervention (QI1.14) *"Physical space and time, plus the prerequisites (a PC and phone), of course. But that's a bit basic — banal, I would almost say. But I'm the right person in that case, because I really am in charge of my own work." (Consultant 2)*	Staff shortages hinder implementation the intervention (QI1.15) *"Because if you don't free up someone and you tell them 'Do it on the side' or whatever, then it just doesn't work. The routes are always full, there is never any time. […] And people get completely taken up with the day-to-day business. So it's a good idea to schedule some free time for people, otherwise it doesn't work." (Manager 1)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
			Many unexpected events and therefore ad hoc activities within social service organizations distracts from focusing on implementing the intervention (QI1.16) *"Indeed, that aspect of yes, we need to look at this, we shouldn't skip it because it's already so hectic and busy. Right, pay a bit more attention to it. Right, and everyone does do that. The nurses working here all have their hearts in the right place. But it gets incredibly busy sometimes and then you do sometimes overlook things." (Manager 6)*
			Implementation can be difficult when social service professionals do not know the consultant yet (QI1.17) *"In December last year, we had an exploratory meeting for the first time about caring for the carers. That was very exploratory. That may have been disappointing for [consultant on the homeless nursing ward], but you can't do a peer intervention on caring for the carers straight off — first you need to know one another and know what you are dealing with." (Consultant 2)*
			Lack of knowledge on how to recognize palliative care needs frequently led to consultations that were too late in the illness trajectory (QI1.18) *"Consultant was brought in for a palliative case. He was brought in at a late stage: will the patient survive to the weekend?" (Implementation logbook)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
	4. Characteristics of individuals	Consultant is experienced in advising professionals about this patient population, which helps in introducing implementation activities (QI1.19) *"She is so at home with these kinds of problems that we can get a lot of help every time. You think to yourself that doctor knows it all, he knows what medication he should prescribe but he can still get ideas because she asks specifically about something, 'OK, nauseous and so on, well, did you think of that? Have they already tried that?' Terminal care, that final care delivery, is such a specialist field, you know, that you think, 'Oh yes, of course, yes, of course' when she says all this. Then I think, OK, of course. It's not a matter of course for me because it's something you do in addition to your own work." (Consultant 3)* Predictability on consultants' presence helps to normalize implementation of intervention activities (QI1.20) *"But what I've had in the past is, 'Oh, [consultant] is here this week, how nice.' So we weren't always particularly switched on to this. And of course that's because that person's there the one time, but not the next time. And sometimes she would have a course the next time so she would skip that time again. So there was a bit less continuity in that respect, for example. But fortunately [consultant] keeps that continuity up to scratch." (Manager 5)* Sharing tasks with a colleague helps familiarization with implementing the intervention (QI1.21) *P: "And if someone has taken that step [to deliver palliative care], then you'll need more time for that because you need to schedule those consultations, you'll want the geriatric specialist to have a look too, and there are other things that are needed too."* *I: "Right, so do I understand correctly that you simply do it in your normal working hours?"* *P: "Yes, I can easily manage that. That's because there's two of us. So if I have to spend time on something, it takes priority for the moment and my colleague simply does whatever else it is that needs doing." (Consultant 3)*	Resistance and fear of end of life and death hinders implementation (QI1.25) *"Consultant noticed resistance in the team: we have nothing to do with palliative care, why are we looking at this, we don't have that here (focused on short-term stays). In the course of the discussion, recognition that this [dying] did indeed happen, signals." (Implementation logbook)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
		Getting on as consultants helps in implementing consultations (QI1.22) *I: "What works well in these consultations, between you two as professionals?"* *P: "Well, to be very subjective, we like one another. It's accessible." (Consultant 2)* A personal bond between social service provider and patient helps in ensuring proper use of the intervention (QI1.23) *"But I do think that having the supervisors involved makes a really big difference in what a patient wants or doesn't want [regarding care] in the end. [...] What I see happening at the locations is incredibly positive. It makes me think: right, the supervisors have built up so much, when I see their dedication... Right, personal supervisors who have various patients and know absolutely everything about them and want the best for them and do their utmost, and also regularly have a bit of a one-to-one chat. The people there are incredibly good at the sheltered housing supervision side." (Consultant 4)* Professionals perceiving the consultant as highly competent (QI1.24) *"She [consultant] knows this target group. Our psychiatrist was a GP so that person also knows a lot. But they're basically a normal GP, so not part of the [organization]. And you see that [consultant] has experience with people with multiple diagnoses, so the addiction, the care avoidance, the smoking, the behaviour extremes that you don't come across that often as a normal GP. And she is better at making that link, which is what I hear from other people. [...] She knows the specific group very well and she knows about the medical side. That is indeed the area where she knows a bit more than what we know as sheltered housing supervisors." (MDM, U region)*	

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
	5. Process		COVID-19 restrictions and the scaling down of healthcare made planning and implementing intervention activities more difficult (QI1.25) *"Right, and then there was Covid. We had a plan for training, with various peer group intervention sessions for care for the carers, then in addition to that training in palliative care, mainly pharmacological but also sedation, for example. That's still the intention." (Consultant 2)* *"But I'm waiting a bit with that [organizing MDM] in the hope that the coronavirus crisis lets up a bit. Because that's the tricky thing now: we always had a team meeting where we had invited speakers, and of course that lets you tell the whole team about things in one go in a nice, interactive way. But at the moment we're only allowed a maximum of ten people at a meeting. And that wouldn't even get me half my team." (Manager 5)* *"And right, I paid what I'd call a home visit on one occasion, so where I went to see the patient with [consultant on the homeless nursing ward] and I saw them. Of course that's become less now because of Covid. [...] I don't remember so well, I think it was the end of last year. This year, the consultations have mainly been by phone." (Consultant 2)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
Maintenance	1. Intervention characteristics	Refining the intervention regarding availability of consultant, frequent evaluation of intervention activities, and MDMs as standard practice may contribute to sustained use over time (QM1.1) *"According to the GP involved, prerequisites for palliative care delivery at a location where homeless people live are: an [advisory] team that is prepared to be available during evenings." (Implementation logbook)* *I: "What do you need to do to make sure it [the intervention] can take place?"* *P: "Well, to start with, have a chat soon with [consultant] to evaluate whether this use of her valuable time is something that she also sees as worthwhile, let's say. Also, towards the end of the year, when looking at the plan for 2021 and the training policy, have a look to see whether there are colleagues who could benefit from this training or that [palliative care] course." (Manager 5)* *"Right, what I'd like to work towards is not just having [social care consultant] responsible for this but getting the whole team involved. So in my ideal world you have an MDM with more people than just [social care consultant]. […] Well, in my previous job I was used to sitting down with the people involved around the table. So with a fixed MDM appointment where the duty nurse joins in and our social worker can join in too. That gives you the full picture. And you get a broader support base. Then you don't have to hand it over, that's not always what works." (Manager 6)*	Unclear mutual responsibilities hamper sustained use over time due to complexity (QM1.4) *"What I discovered last week is that there are collaborative agreements between [employer] and [nursing ward for homeless people] that I'm fairly sure I didn't know about and nor did [geriatric specialist, on call for palliative care consultation]. […] I said I would really like to know what those collaborative agreements are because then you could see whether you could pay a home visit based on those agreements, let's say. You know… But that's being looked into… We need to look into that because it could easily be for home help, to give a crazy example. That's not actually the case, of course, but as an example. So I need to look into that." (Consultant 2)* A shift in non-intervention related tasks of the palliative care consultant could hamper collaboration as this could hamper availability and participation in intervention activities (QM1.5) (Manager 1)

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
		Ownership of the intervention by organizations in palliative care in order to transfer palliative care knowledge to social service professionals (QM1.2) (Manager 1) Structural discussion of patients initiated by the palliative care consultant may contribute to sustainable, early, future-focused consultations (QM1.3) *“We are still doing it too much on an* ad hoc *basis, but perhaps it should be more preventive and anticipatory, so you make it even more of a useful instrument by saying we need to have a regular MDM once a month, just for the people on [homeless nursing ward]. Then everyone gets together and all the residents get discussed at the MDM.” (Manager 2)*	Small-scale and specific consultations may negatively affect maintenance and expansion of the intervention over time (QM1.6) *“Heard from both [region 2] and [region 3]: Is it actually possible to offer 24-hour consultations when you have a small-scale duo consultation function? How can we set up the availability?” (Implementation logbook)*
	2. Outer setting	A policy of clear incentives and regulations regarding patient indication and associated existing funding help in maintaining the intervention over time (QM1.7) *“Look, the best thing of course would be for the consultation function to be properly embedded in your… in your indication, so that you can simply make use of it and can have it as an indication, like community nursing. I think the most important thing is to have some kind of performance scheme with the insurers, in the future as well for all palliative care.” (Manager 8)*	Lack of clear policy and regulations regarding proper/structural palliative care indications and funding for care (QM1.8) *“Even all the divisions, whether or not there are nursing beds there… of course that’s… right, the insurer wanted to make huge cuts in our funding because they said we don’t have so many primary-care beds for the homeless in [another city]. And if that’s going to be the model, that we aren’t allowed to put people in primary-care beds because then they have to be paid through the social care funds, whereas they are simply lying there in the palliative stage, as it were.” (Manager 7)*
	3. Inner setting	Mental and financial support from manager and colleagues for consultants within the organization helps prioritize intervention for consultants in future (QM1.9) *“Well, look, what I could do is encourage her manager more so she frees up time for this. […] But it’s also more about giving support, prioritizing, that she needs more support in this from her manager.” (Manager 8)*	As long as organizations are unfamiliar with death and dying among this population, maintaining the intervention will be hampered by these assumptions (QM1.14) *“They find death and so on – people dying – that’s all a bit scary. It’s like putting people in the shower: they even find that scary. So someone who’s dying — well, of course that’s quite stressful. And we have [shelter organization] for this. Look, perhaps it will be needed more in the future, but I’ve really noticed in the past that it’s not yet… that it’s a difficult topic.” (Manager 4)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
		Professionals' openness to teamwork helps use of the intervention over time (QM1.10) *"Well, I think so after a year... I reckon everyone finds it ever so important to have [consultant] there and have her giving her input, yes, I would definitely say so. [...] Well, one example I can give of this is that [consultant] gets a phone call to tell her the MDM has been cancelled, let's say. If you really don't feel there's any kind of benefit to having [consultant] there, or if you're hardly aware of any benefit, then she wouldn't get a phone call about it being cancelled." (Manager 3)* Organizations' recognition of a need for change contributes to a culture that is more open to change over time (QM1.11) *"Because it seems there is... and that's how things work in [care organization]... there's suddenly a realization at the top that hey, something's going on, and that can lead to a change in the culture. Because our specific group is becoming sicker and sicker, older and older, and it's increasingly necessary. So I do see the organization doing something about this." (Consultant 5)* A mindset within social services that focuses on more domains such as the somatic domain (QM1.12) (Manager 2)	Staff shortages hamper use of the intervention over time (QM1.15) *"If it [the intervention] were used properly, I think we wouldn't have enough staff. Because I believe it [palliative care] is needed an awful lot but simply isn't given. I honestly believe that." (Manager 1)* Unpaid medical tasks not being taken seriously within organization may hamper the implementation climate in future (QM1.16) *"Well, I think that as managers at [organization with homeless shelter], we need to agree amongst ourselves much more that we should simply be paid for the work we do. That has really turned into a kind of chronic discussion, that we don't get paid for everything we do. [...] That's partly to do with our image: that you stick plasters on but it's not much more than that." (Manager 1)*

Appendix 6. Continued.

RE-AIM domain	CFIR domain	Facilitators	Barriers
		Concrete actions, like sharing information on the intervention activities performed, to prevent loss of consultants' position, helps embed intervention over time (QM1.13) "They [consultant and manager] don't see drop-out as a major problem because the consultant makes notes of the discussions she has, so her knowledge can easily be handed over." *(Implementation logbook)*	Different views on ethical issues may hamper future collaboration (QM1.17) *"But what we had occasionally in the period when we were working a bit more intensively with [hospice]… […] We also had some patients who had active wishes during the palliative process they were in to have euthanasia — what's the term for it? — applied. Right, and [hospice] didn't go along with that. So on the one hand that's a gap. […] So I can… who am I to judge the wishes of someone who feels their suffering is unbearable? And for us not to go along with that and not use that medication that I'm pretty sure is allowed by law in the Netherlands. So we need to think of a different option there if it's not possible via [hospice]." (Manager 5)*
			Many layers of management in an organization mean it takes a long time to arrange financing and hours for consultants; this threatens continuation of the intervention (QM1.18) (Manager 4)
			Drop-out and vulnerability of consultants' position threaten use of the intervention over time (QM1.19) *"Right, of course it's a problem that it depends so much on certain people. If [social care consultant] drops out for a while, that really doesn't help matters." (Manager 7)*
	4. Process		Maintenance is highly dependent on local champions, which might threaten future collaborations and maintenance of the intervention over time (QM1.20) *"That's right, you really rely on your network and on people being known. And that's a vulnerability: if a colleague leaves who people know well, you're left starting from scratch again. The infrastructure isn't yet up to it, let's say. […] Perhaps new things will be developed again gradually, I don't really know. But I have this idea, this feeling that perhaps there's some credit to be gained there." (Manager 1)*

SUMMARY

Introduction

The population of persons experiencing homelessness is generally associated with high morbidity, comorbidities, high mortality, a young age at death, and poor access to healthcare and palliative care. Palliative care is holistic, multidisciplinary, person-centred care for persons with a life-threatening illness, aimed at improving the quality of life by the prevention or alleviation of pain and symptoms. Palliative care encompasses physical, psychological, social and spiritual care. Provision of palliative care for persons experiencing homelessness is often deficient and challenging, in part due to the poor access to care of this population. Previous studies suggested that multidisciplinary collaboration between palliative care professionals and social service professionals could help improve the accessibility and quality of palliative care for persons experiencing homelessness. The aims of this thesis are: 1) to provide insight into important aspects of palliative care for persons experiencing homelessness and important elements for reaching them; 2) to obtain insight into the current provision of palliative care for persons experiencing homelessness in the Netherlands, and to explore future needs for improving palliative care provision; and 3) to provide insight into how a threefold intervention to improve palliative care for this population was evaluated regarding the added value and implementation process. This thesis is divided into three parts.

Part 1 | Important aspects of palliative care and reaching persons experiencing homelessness

The first part of this thesis examines aspects of palliative care that are particularly distinctive for persons experiencing homelessness and important elements for reaching persons experiencing homelessness. A systematic review of 23 studies (Chapter 2) provides an overview of the concerns and preferences of persons experiencing homelessness. Many concerns and preferences related to the attitudes and behaviour of healthcare professionals, such as a strong desire for professionals to show respect and treat them with dignity. Persons experiencing homelessness were most concerned about serious illness and physical distress, fear of death and dying, fear of being a burden to others, fear of the unknown, and fear of a ‘bad’ end of life. The care needs of persons experiencing homelessness often involved the attitude and behaviour of healthcare professionals, varying preferences for the involvement of family, addressing spirituality and religion, and worries about matters such as anonymity, estrangement and maintaining control. The future preferences of persons experiencing homelessness varied regarding resuscitation and life-sustaining treatment. A natural death was preferred by them, as well as naming a proxy for surrogate decision making. Furthermore, palliative care provision was often hampered by the interference of basic day-to-day needs of persons experiencing homelessness (such as a need for food and a place to sleep) and substance use, little support from family or networks, limited insight into their condition, and a lack of palliative care skills and knowledge among professionals. Palliative care for persons experiencing homelessness was facilitated by paying attention to spiritual needs, building trust, treating people with dignity, and a pragmatic, compassionate, patient-centred approach. Training professionals and enhancing their knowledge, empowerment of professionals using a patient-centred approach involving trustful relationships, and proper accommodation and better organization of palliative care were recommended to improve the delivery of palliative care for this population.

In a semi-structured interview study among 28 spiritual caregivers, street pastors, outreach workers and persons who had formerly experienced homelessness (Chapter 3), we show that stigmatization, characteristics of persons experiencing homelessness, and characteristics of a complex care system are underlying factors explaining the underutilization of care. On a person-related level, barriers to care can be lowered by ensuring personalized care and reciprocal trust between the professional and the person experiencing homelessness. Personalized care provided by professionals should at least involve setting limits on misbehaviour by persons experiencing homelessness without rejecting the person, and professionals should treat the person with dignity and respect. On a system-related level, barriers to care can be lowered by the provision of clear information, explanation and communication, quiet facilities, and self-reflecting professionals with patience and enough time. This can be facilitated by a change of policy and legislation.

Part 2 | Current palliative care provision for persons experiencing homelessness and future improvements

The second part of this thesis provides an overview of current palliative care for persons experiencing homelessness in the Netherlands, and an exploration of what is needed to improve palliative care. A retrospective medical record study of 61 deceased persons experiencing homelessness in two Dutch shelter-based nursing-care settings (Chapter 4) shows that they had a young age at death, multiple and complex somatic, psychiatric, addiction and social issues, and high symptom burden at the end of life. For 75% of the patients, the end of life was recognized and documented. For 26%, a palliative care team was consulted in the year before death. The study shows that the end of life was characterized by uncertain prognoses, often accompanied by sudden revival or deterioration, complicated social circumstances and a high number of transitions to other healthcare settings, most often hospitals. The study highlights the fact that organizing and integrating care for people in the final phase of their life is challenging. Two-thirds of the study population eventually died in the shelter setting; a quarter of all patients died alone within this setting. Difficulties in providing palliative care were found in the continuity of care, the social and environmental safety, patient-professional communication and medical-pharmacological alleviation of suffering. Potential areas for improvement concerned interdisciplinary collaboration, more dedicated palliative care facilities and corresponding expertise within shelter settings.

Furthermore, a focus group study among nineteen professionals and fifteen severely ill persons experiencing homelessness (Chapter 5) showed that palliative care is complex and that there are substantial differences between professionals, institutions and cities in the provision and organization of palliative care. Individuals experiencing homelessness and professionals had different perceptions of the care provided. According to the professionals and persons experiencing homelessness, palliative care should at least be characterized by respect for the autonomy of the patient, with trusting relationships between the patient and professional, flexible care, and professionals who take the initiative to visit the patient. A consultation intervention based on one local example, involving a fixed duo of a palliative care professional and a social service professional, who reciprocally provide each other with knowledge and expertise, could be a good way to address these issues. A consultation intervention was expected to be of added value for both patients and professionals, by training professionals in a respectful attitude, enhancing professional collaboration and bundling and empowering knowledge. Besides consultations, training of professionals and multidisciplinary meetings attended by both social service and palliative care professionals were expected to be necessary as well. The combination of consultation, training and multidisciplinary meetings is termed the 'threefold intervention'. It was expected that intervention is best developed regionally and tailored to regions and their resources, under the guidance of experienced consultants who have affinity with this population.

Part 3 | A threefold intervention: evaluation of added value and process

In the third part of this thesis, implementation of the threefold consultation intervention within three regions is evaluated in terms of the added value and process. Using a mixed-methods study with structured questionnaires and semi-structured individual and group interviews with professionals, consultants' diaries and an implementation diary (Chapter 6), we evaluated 34 consultations, 22 multidisciplinary meetings and nine training sessions held during the 21-month implementation period. All three activities of the intervention were implemented, while at the same time the intervention was tailored to the needs and resources of each region. Consultations mainly involved palliative care professionals advising social service professionals. Consultation requests were mainly about somatic issues; advice often covered both somatic and psychosocial issues. Multidisciplinary meetings were mainly attended by GPs and nurses from social services and healthcare services. Training sessions varied widely in duration and content. Persons experiencing homelessness who were discussed in consultations and multidisciplinary meetings were often males, of Dutch origin, and aged between 50 and 70. They were often seriously ill, and resided in 24-hour shelter facilities or nursing wards. The intervention was seen as having an added value by social service professionals, palliative care consultants, and the management of the organizations involved. The added value was seen specifically in the collaboration and networks of professionals, in particular in connecting professionals from different disciplines and the creation and strengthening of collaboration. Added value was also found in better competences in palliative care in general, and more specifically in palliative care professionals providing emotional support to social service professionals in complex situations. Lastly, the intervention was perceived as improving the timing and quality of palliative care, especially through its focus on the quality of life and dying, advance care planning when discussing patients, and awareness of death.

Using the same mixed-methods study, Chapter 7 describes the process evaluation of the threefold consultation intervention with respect to the RE-AIM dimensions of Reach, Adoption, Implementation and Maintenance. The RE-AIM framework is a tool that can be used to evaluate interventions. The reach of the intervention was mainly accomplished by involving social service professionals who worked in the organizations that initiated the intervention. While the three activities of the intervention were adopted in all three regions, there were differences between regions in the start, timing and frequency of the three activities. The intervention was only partly implemented according to plan. Half the consultations were bedside consultations and half were telephone consultations. Collaboration was often between a palliative care consultant and a social service team, and the consultations were mainly social service professionals consulting with and obtaining advice from palliative care consultants. Regarding maintenance, professionals in all regions expected to use one or more of the intervention activities in the future, although activities were expected to be used differently. For all RE-AIM dimensions, facilitators and barriers were identified using the Consolidated Framework for Implementation Research (CFIR) as a conceptual framework to categorize facilitators and barriers. Facilitators mainly lay in the inner setting of the organizations, in the characteristics of professionals, and in intervention characteristics. The main facilitators were: a perceived need to improve palliative care provision and previous acquaintance with other professionals involved (adoption), a consultant's expertise in advising professionals and the population of persons experiencing homelessness (implementation), and embedding the service in regular, properly funded meetings (maintenance). Barriers were mainly identified in the inner setting of the organizations and in intervention characteristics, specifically professionals' limited skills in recognizing, discussing and prioritizing palliative care (adoption), COVID-19 circumstances, staff shortages and lack of knowledge of palliative care in social service facilities (implementation) and the limited number of persons involved in the intervention (maintenance).

Discussion

The general discussion starts with a summary of the findings in relation to the literature, followed by a discussion of the methodological aspects. Strengths and limitations concern the mixed-method design, inclusion of the perspectives of persons experiencing homelessness, the generalizability of the intervention and study population, the measurement of the added value of the intervention, and the use of RE-AIM and CFIR and their operationalization. Reflections on the findings cover the themes: i) bringing palliative care and social services together; ii) a holistic care and person-centred approach; iii) the importance of advance care planning and parallel planning; iv) perspectives on a good final phase of life; v) unequal access to palliative care provision; and vi) the urgency of structural and tailored funding. Finally, recommendations for practice, research, and policy and legislation are given.

NEDERLANDSE SAMENVATTING

Introductie

De populatie van mensen die dakloos zijn wordt over het algemeen geassocieerd met slechte toegang tot gezondheidszorg en palliatieve zorg, hoge morbiditeit, comorbiditeiten, hoge mortaliteit en een jonge leeftijd van overlijden. Palliatieve zorg is holistische, multidisciplinaire, persoonsgerichte zorg voor mensen met een levensbedreigende ziekte, gericht op verbetering van de kwaliteit van leven door preventie of verlichting van pijn en symptomen. Palliatieve zorg omvat lichamelijke, psychische, sociale en spirituele zorg. Het aanbod van palliatieve zorg voor mensen die dak- of thuisloos zijn is vaak beperkt en kent uitdagingen, en gaat gepaard met een slechte toegang tot zorg. Eerdere studies suggereerden dat multidisciplinaire samenwerking tussen professionals in de palliatieve zorg en hulpverleners werkzaam in opvangvoorzieningen zou kunnen bijdragen aan toegankelijke en kwalitatief goede palliatieve zorg. De doelstellingen van dit proefschrift zijn het onderzoeken van belangrijke aspecten van palliatieve zorg voor mensen die dak- of thuisloos zijn en het bereiken van deze populatie, de huidige palliatieve zorgvoorziening voor deze populatie in Nederland en de behoefte aan verbetering van deze zorg, en het evalueren van het implementatieproces en de toegevoegde waarde van een driedelige interventie om de palliatieve zorgverlening te verbeteren. Dit proefschrift bestaat uit drie delen.

Deel 1 | Belangrijke aspecten van palliatieve zorg en het bereiken van deze populatie

Het eerste deel van dit proefschrift laat aspecten van palliatieve zorg zien die specifiek kenmerkend zijn voor mensen die dak- of thuisloos zijn, en belangrijke aspecten om mensen die dak- of thuisloos zijn te bereiken. Een systematische review van 23 studies (Hoofdstuk 2) laat zorgen en voorkeuren zien die vaak betrekking hebben op de houding en het gedrag van zorgprofessionals, zoals een sterk verlangen naar professionals die respect en waardigheid tonen. De meeste zorgen gaan over ernstig ziek worden en lichamelijk leed, angst voor het stervensproces en dood, angst om anderen tot last te zijn, angst voor het onbekende en angst voor een slecht levenseinde. Zorgbehoeften betreffen vaak de houding en het gedrag van zorgprofessionals, wisselende voorkeuren voor betrokkenheid van familie, het aan de orde stellen van spiritualiteit en religie en het uiten van zorgen als anonimiteit, vervreemding en het behouden van controle. Wat betreft toekomstige voorkeuren bestaan er verschillende voorkeuren met betrekking tot reanimatie en levensverlengende behandeling. Bovendien heeft een natuurlijke dood in veel gevallen de voorkeur, evenals het benoemen van een (wettelijk) vertegenwoordiger voor behandelbeslissingen. Palliatieve zorgverlening wordt vaak belemmerd door het voorop staan van dagelijkse basisbehoeften (zoals voedsel en een slaapplaats) en middelengebruik, weinig steun van familie of netwerken, beperkt inzicht in hun toestand en gebrek aan vaardigheden en kennis onder professionals. Palliatieve zorg kan worden gefaciliteerd door aandacht te schenken aan spirituele behoeften, het opbouwen van vertrouwen, mensen met waardigheid te behandelen en door een pragmatische, meelevende, patiëntgerichte benadering in te zetten. Training in en verbetering van kennis over palliatieve zorg, het aanmoedigen van een patiëntgerichte benadering waarin vertrouwensrelaties de basis zijn, een passende fysieke faciliteit voor palliatieve zorg aan deze doelgroep, en een betere organisatie van palliatieve zorg worden aanbevolen.

In een semigestructureerd interviewonderzoek onder 28 geestelijk verzorgers, straatpastores, veldwerkers en voormalige daklozen (Hoofdstuk 3) laten we zien dat stigmatisering, kenmerken van daklozen en kenmerken van een complex zorgsysteem onderliggende factoren zijn van het niet betrokken zijn in zorg. Wat betreft kenmerken van daklozen kunnen drempels voor zorg worden verlaagd door gepersonaliseerde zorg te bieden en te werken aan wederzijds vertrouwen tussen de professional en de dakloze. Gepersonaliseerde zorg moet in ieder geval het stellen van grenzen aan wangedrag inhouden zonder de persoon af te wijzen, evenals een houding van de professional die waardigheid, menselijkheid, gelijkheid en respect weerspiegelt. Op het niveau van het zorgsysteem kunnen drempels voor zorg worden verlaagd door het bieden van duidelijke informatie, uitleg en communicatie, rustige voorzieningen, zelf-reflecterende professionals met voldoende geduld en tijd beschikbaar, wat gefaciliteerd wordt door verandering van beleid en wetgeving.

Deel 2 | Huidige palliatieve zorgverlening en toekomstige verbeteringen

Het tweede deel van dit proefschrift geeft een overzicht van de huidige palliatieve zorg voor mensen die dakloos zijn in Nederland, en een verkenning van wat er nodig is om de palliatieve zorg te verbeteren. Een retrospectief medisch dossieronderzoek van 61 overleden daklozen in twee Nederlandse opvangvoorzieningen (Hoofdstuk 4) toont een jonge leeftijd van overlijden, meervoudige en complexe somatische, psychiatrische, verslavings- en sociale problemen, en een hoge symptoomlast in de laatste fase van hun leven. Bij 75% van de patiënten werd het levenseinde herkend en gedocumenteerd. Voor 26% werd in het jaar voor het overlijden een palliatief team geraadpleegd. Het laat zien dat het levenseinde wordt gekenmerkt door onzekere prognoses die vaak gepaard gaan met plotselinge opleving of verslechtering, gecompliceerde sociale omstandigheden en een groot aantal overplaatsingen naar andere zorginstellingen, meestal ziekenhuizen. Het benadrukt dat het organiseren en integreren van zorg voor deze populatie in de laatste fase van hun leven een uitdaging is, en dat twee derde van de onderzoekspopulatie uiteindelijk overlijdt in deze opvangvoorziening, een kwart van alle patiënten overlijdt alleen. Er worden problemen gerapporteerd met continuïteit van zorg, sociale veiligheid en veiligheid van de omgeving, patiënt-professionele communicatie en medisch-farmacologische verlichting van lijden. Een mogelijk verbeterpunt betreft interdisciplinaire samenwerking, meer en betere voorzieningen voor palliatieve zorg, en beschikbare bijbehorende expertise binnen opvangvoorzieningen. Verder blijkt uit een focusgroeponderzoek onder negentien professionals en vijftien ernstig zieke daklozen (Hoofdstuk 5) dat palliatieve zorg complex is en dat er grote verschillen zijn tussen professionals, instellingen en steden. Mensen die dakloos zijn en professionals hebben verschillende percepties op de gegeven zorg. Palliatieve zorg dient in ieder geval gekenmerkt te worden door respect voor de autonomie van de patiënt, vertrouwensrelaties tussen patiënt en professional, flexibele inzetbare zorg, en professionals die het initiatief nemen om de patiënt te bezoeken. Een consultatie-interventie met een vast duo van een palliatieve zorgprofessional en een maatschappelijke zorgprofessional, die elkaar wederzijds van kennis en kunde voorzien, kan een goede manier zijn om deze thema's aan te pakken. Deze consultatie-interventie zal naar verwachting van toegevoegde waarde zijn voor zowel patiënten als professionals door professionals te leren over een respectvolle houding, professionele samenwerking te versterken en kennis te bundelen en te versterken. Naast consultatie wordt verwacht dat ook training van professionals in palliatieve zorg en multidisciplinaire bijeenkomsten van zowel maatschappelijk hulpverleners als palliatieve zorgprofessionals nodig zijn. De combinatie van consultatie, training en multidisciplinair overleg, dat we een driedelige interventie noemden, kan het beste regionaal worden ontwikkeld en op maat gemaakt zijn voor regio's en hun voorzieningen, onder begeleiding van ervaren consulenten die affiniteit hebben met deze populatie.

Deel 3 | Een drievoudige interventie: evaluatie van meerwaarde en proces

In het derde deel van dit proefschrift wordt de implementatie van een drievoudige consultatie-interventie binnen drie regio's geëvalueerd op toegevoegde waarde en proces. Een mixed-methods-onderzoek met behulp van gestructureerde vragenlijsten en semigestructureerde (groeps)interviews met professionals, dagboeken van consulenten en een implementatiedagboek (Hoofdstuk 6) evalueerde 34 consultaties, 22 multidisciplinaire bijeenkomsten en negen trainingssessies die werden gehouden tijdens de implementatieperiode van 21 maanden. Alle drie de activiteiten van de interventie werden uitgevoerd, terwijl de interventie tegelijkertijd werd afgestemd op de behoeften en middelen van elke regio. Bij consulten gaat het vooral om palliatieve zorgprofessionals die maatschappelijke hulpverleners in opvangvoorzieningen adviseren. Consultatieverzoeken gaan vooral over somatische vraagstukken; advies betreft vaak zowel somatische als psychosociale vraagstukken. Multidisciplinaire bijeenkomsten worden voornamelijk bijgewoond door huisartsen en verpleegkundigen werkzaam in opvangvoorzieningen en de gezondheidszorg. Trainingen variëren sterk in duur en inhoud. Dakloze patiënten die in consulten en multidisciplinaire bijeenkomsten werden besproken, waren vaak mannen, van Nederlandse afkomst, en tussen de 50 en 70 jaar. Ze waren vaak ernstig ziek en verbleven in 24-uurs opvang of verpleegafdelingen. Meerwaarde werd door hulpverleners in de opvang, consulenten palliatieve zorg, en managers van betrokken organisaties ervaren in het samenwerken en netwerken tussen professionals, met name in het onderling verbinden van professionals uit verschillende disciplines en het creëren en versterken van samenwerkingsverbanden. Meerwaarde wordt ook gevonden in betere competenties in de palliatieve zorg in het algemeen, en meer specifiek in het bieden van emotionele steun in complexe situaties. Ten slotte wordt de interventie gezien als van meerwaarde op de verbetering van de timing en kwaliteit van palliatieve zorg, vooral door de focus op kwaliteit van leven en sterven, vroegtijdige zorgplanning bij het bespreken van patiënten, en bewustzijn van overlijden.

Op basis van dezelfde mixed-methods-studie beschrijft Hoofdstuk 7 de evaluatie van de drievoudige consultatie-interventie over het proces van RE-AIM-dimensies Bereik, Adoptie, Implementatie en Onderhoud. Het RE-AIM model is een hulpmiddel dat gebruikt kan worden om interventies te evalueren. Het bereik van de interventie betreft voornamelijk hulpverleners die werkzaam zijn in de organisaties die de interventie hebben geïnitieerd. Hoewel in alle regio's de drie activiteiten van de interventie werden uitgevoerd, zijn er verschillen in de start, timing en frequentie van de drie activiteiten tussen de drie regio's. Uitvoering van de interventie is deels volgens plan gegaan, wat in de helft van de gevallen resulteerde in consultaties aan het bed en in de andere helft van de gevallen telefonische consultaties. Er werd vaak samengewerkt tussen een palliatieve zorgconsulent en team in de opvangvoorziening, en de richting van consulten ging voornamelijk van de palliatieve zorgconsulenten naar de professionals in opvangvoorzieningen. Wat betreft het in stand houden van de interventie verwachten professionals in alle regio's in de toekomst een of meer activiteiten van de interventie te zullen gebruiken, hoewel de activiteiten naar verwachting anders zullen worden ingezet. Voor de RE-AIM dimensies worden bevorderende en belemmerende factoren gevonden met behulp van het Consolidated Framework for Implementation Research (CFIR) als conceptueel kader om bevorderende en belemmerende factoren te categoriseren. Bevorderende factoren waren vooral in de innerlijke setting van de organisaties, in de kenmerken van professionals en in de interventiekenmerken. Dit betrof vooral een ervaren behoefte aan verbetering van de palliatieve zorgverlening en al bekend zijn met de betrokken professionals vanuit eerdere samenwerkingen (adoptie), de expertise van een consulent in het adviseren van professionals en bekendheid met de populatie daklozen (implementatie), en het inbedden van interventie in regelmatige, goed gefinancierde bijeenkomsten (onderhoud). Belemmerende factoren zijn vooral genoemd in de innerlijke setting van de organisaties en in interventiekenmerken, met name de beperkte vaardigheden van professionals in het herkennen, bespreken en prioriteren van palliatieve zorg (adoptie), COVID-19 omstandigheden, personeelstekorten en gebrek aan kennis van palliatieve zorg in de maatschappelijke dienstverlening voorzieningen (uitvoering) en een beperkt aantal betrokken personen bij deze kleinschalige interventie (onderhoud).

Discussie

In de discussie worden, na een samenvatting van de bevindingen in relatie tot de literatuur, de methodologische overwegingen van dit proefschrift besproken. Sterkte punten en beperkingen van het onderzoek betreffen het mixed-methods design, de perspectieven van daklozen, de generaliseerbaarheid van de interventie- en studiepopulatie, het meten van de meerwaarde van de interventie, en het gebruik van RE-AIM en CFIR en de operationalisering daarvan. Reflecties op de bevindingen gaan over i) het samenbrengen van palliatieve zorg en opvangvoorzieningen; ii) een holistische zorg- en persoonsgerichte benadering; iii) het belang van vroegtijdige zorgplanning en parallelle planning; iv) perspectieven op een goede laatste levensfase; v) ongelijke toegang tot palliatieve zorgverlening; en vi) de urgentie van structurele financiering en financiering op maat. Tot slot worden aanbevelingen voor praktijk, onderzoek en beleid gegeven.

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ABOUT THE AUTHOR

Hanna Klop was born on November 20th in Vlissingen, the Netherlands. From 2009 until 2013, she studied Interdisciplinary Social Sciences at Utrecht University, where she focused on societal issues, policy and interventions. After obtaining her Bachelor's degree, she continued her studies with a master's in Social Psychology from 2013 to April 2014. As part of her research internship and Master's thesis, she conducted experiments and focus groups at the Netherlands Organization for Applied Scientific Research (TNO). Subject of the research was communication styles towards mothers of thirteen-year old girls with regard to governmental HPV-vaccination campaigns.

During her undergraduate and graduate studies, Hanna volunteered and worked at a day-care shelter for persons experiencing homelessness in Utrecht. From 2016 until 2018, she worked as a Junior Researcher at the end-of-life research group at Amsterdam UMC, location VUmc, focusing mainly on palliative care for people experiencing homelessness and care avoidance among this population. From June 2018 to September 2018, she worked as a social worker in several shelters of the Dutch Salvation Army.

In September 2018, she returned to the Amsterdam UMC, location VUmc as a Ph.D. student and Junior researcher. She continued research into palliative care for persons experiencing homelessness, focusing on evaluating a threefold consultation intervention. Simultaneously, she conducted research into the integration of spiritual into palliative care within Palliative Home Care (PaTz) groups (2018-2019), treatment goals of patients with metastatic lung cancer (2018-2019), and support for families of patients admitted at ICUs during COVID-19 pandemic (2020-2022). In March 2022, Hanna started working as a Health Care Lecturer at Viaa University of Applied Sciences in Zwolle and as a Senior Researcher within the Viaa Lectorate 'Zorg & Zingeving'.

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