Chapter 8

General discussion
In this thesis several issues and methodological challenges related to palliative care research are described, and special attention is paid to measuring important concepts in this field i.e. quality of life and personal dignity. The studies described in this thesis all contribute to a better understanding of the current state-of-the-art in outcome measurement in palliative care research. The findings of these studies provide helpful information about the difficulties of measuring the complex concepts of quality of life and personal dignity in research on palliative care and can help to direct future research in this field.

This final chapter will discuss the findings of the studies described in the previous chapters. First, some methodological considerations will be addressed. Subsequently, the discussion is divided into three parts corresponding to those presented in the introduction. The main findings and the interpretation of the results will be discussed per part. Implications for research policy and suggestions for further research will also be considered separately per part following on from the discussion of the main findings. Part I addresses the main results and the interpretation of the results concerning the first research question i.e. what is the methodological rigour of palliative care research in long-term care facilities in Europe? The findings related to the feasibility and clinimetric quality of measurement instruments to measure quality of life in palliative care patients will be discussed in Part II. The following paragraphs included in Part III address the findings related to the concept of personal dignity at the end of life and the influence of health status, sociodemographics and the role of caregivers. The final paragraph draws some overall conclusions.

Methodological considerations of the studies
This thesis is based on four different studies: two systematic literature reviews, a survey among people with an advance directive and a survey among caregivers involved in the care for terminally ill patients.

The systematic reviews
The process of systematic review refers to locating, appraising and synthesizing the evidence from all individual studies relevant to a specific research question. Chapter 2 described how a systematic review of the literature was used to explore the field of research on palliative care in long-term care facilities. In this way a comprehensive summary of all European studies on palliative care in long-term care facilities could be given. Recent and adequate information is needed to propose a future research agenda on palliative care research in long-term care facilities in Europe. Since long-term care facilities are increasingly responsible for palliative care the systematic review described in Chapter 2 is useful to provide those professionals with information about state-of-the-art research in this field. Policy makers and even researchers can benefit from an overview of the literature as they often have a lack of time and knowledge to provide themselves with all the latest information. Since palliative care has mainly been associated with patients with specific diseases such as cancer, it might be that study populations in studies on long-term care facilities were not specifically described as palliative care or end-of-life care population in particular because patients residing in long-term care facilities do not often have specific terminal illnesses. Accordingly, a previous study found that there is little similarity between patient groups that were defined as 'end-of-life' patients, and showed the difficulty of defining groups in palliative care research. A consequence might be that not all studies on palliative care populations were indexed as palliative or end-of-life care related studies on the medical databases such as PubMed. Therefore, any relevant studies may not have been found by the search strategy we used in the review study described in Chapter 2.

Chapter 3 and 4 are based on another systematic review that brought together all different measurement instruments to assess quality of life for use in palliative care. This review can be characterised as a clinimetric review as the content and measurement properties of measurement instruments were critically appraised and compared. The clinimetric review on quality-of-life measures can be very helpful for selecting an instrument for a certain purpose, and to identify instruments that need further testing.

Despite the possibility of missing any important studies, frequently mentioned in relation to systematic reviews, it is unlikely that any relevant articles have been missed here. Some experts were consulted in order to develop an adequate search strategy, and a clinimetric search filter with a sensitivity of 90-97% was included. Restriction the search to the English and Dutch languages in both review studies might have limited the results. In addition, as the amount of literature is growing rapidly it might be that from the time our systematic reviews were submitted to a journal new studies were published. In general, systematic reviews are not completely up-to-date at the moment of publication.

The survey studies
Survey research represents one of the most common types of quantitative research in health and social science research. Cross-sectional surveys gather data to make inferences about a population of interest at one moment in time. We used a survey design as a cost-effective and efficient way of gathering information from a large and specific study population and to find relationships between population characteristics and other variables. Data used in the studies described in Chapter 5 and 6 were collected from a large cohort study consisting of more than 6,000 people with an advance directive. An important strength of this large-scale cohort study is that we could divide the cohort into sub-groups that included enough people to perform meaningful statistical analyses of the sub-group. Consequently, we could adequately assess the content validity of the Patient Dignity Inventory since we split the cohort in one group who completed the Patient Dignity Inventory and another group who completed an open-ended question on dignity (Chapter 5). In addition, we were able to define three health status groups in order to investigate the effect of health status on perceptions of factors influencing personal dignity (Chapter 6).

Main concerns about survey research relate to sampling, representativeness and generalizability. The advance directives cohort study was set up by taking random samples from the membership files of the Right to Die-NL and the Dutch patient association. The cohort is representative for the part of the Dutch population who formulated an advance directive, although it has to be considered that people who do not have a standard advance directive but draw one up for themselves were not included in the cohort. In addition, comparing the two groups of the cohort to the Dutch population showed several differences regarding background characteristics. The Right to Die-NL respondents were more often single, more highly educated and non-religious. The majority of respondents who were members of the Dutch patient association were from a Protestant background. It might be argued that the results of our survey studies cannot be generalised to other populations because people who formulated an advance directive may be considered as people having...
exceptional views on issues concerning the end of life. Nevertheless, concern about loss of dignity is one of the most common reasons to formulate an advance directive; the respondents may have thought more profoundly about life values and end-of-life issues which makes the advance directives cohort a relevant group for the study of personal dignity.

The generalizability of the results described in Chapter 7 can also be criticised. Data for this study was collected in two groups of caregivers, trained volunteer members of the National Organisation of Volunteers in Palliative Terminal Care and Support and Consultation on Euthanasia (SCEN) physicians, with much experience of the issues involved in care at the end of life. Other caregiver respondents may have produced different results. However, we assumed that experience with palliative care made our study population better able to imagine which factors influence the sense of dignity in a patient’s final phase of life compared to caregivers in general, which enhances the quality of the data.

Another possible source of bias frequently mentioned in relation to survey studies is the inflexibility of questionnaires that may provide responses that may not accurately reflect how the respondents exactly feel. We used a written questionnaire including the Patient Dignity Inventory consisting of standardised questions. As one of our study aims was to investigate whether the Patient Dignity Inventory comprehensively reflect the construct of personal dignity at the end of life, we created a semi-structured questionnaire by giving the respondents the possibility to indicate what aspects they missed in the Patient Dignity Inventory by an open-ended question. In addition, one half of the cohort received a questionnaire including open-ended questions concerning dignity which demonstrated that open-ended questions provided more detailed information on how the respondents understand dignity at the end of life as they could use more specific phrasing compared to the information gathered from the Patient Dignity Inventory with structured response options provided.

Part I
Research methodology in research on palliative care in long-term care facilities

Life expectancy has been increasing and more people are becoming very old, and will get frail and/or suffer from chronic long-term illnesses. Health care services are facing challenges to provide good care for these frail older people. Moreover, increasingly more people live their final phase of life in long-term care settings and die in these settings. Therefore, exploring and studying the opportunities to provide appropriate palliative care services in long-term care facilities is important.

Key findings and interpretation of the results regarding the methodological rigour of palliative care research in long-term care facilities

Little attention has been paid to research on palliative care in long-term care facilities in Europe, and the majority of the studies of them are descriptive. This can be related to the relatively newness of research on patients receiving palliative care in long-term care facilities, and the methodological difficulties hampering the use of interventions and randomized clinical trials in studies investigating palliative care. Another explanation might be that the care given in long-term care facilities is not always considered as palliative care. Residents of long-term care facilities do not usually die from cancer but are more likely to die at an older age from complications associated with multiple chronic diseases. Murray and colleagues described the illness trajectory for people with progressive chronic illness as ‘prolonged dwindling.’ The illness trajectory typical of frail elderly people or people with dementia entails a short period of evident decline subsequent to a rather stable period with progression. The illness trajectory of cancer is reasonably predictable and usually characterised by a clear terminal phase. The traditional palliative care services concentrated on providing comprehensive services in the last weeks or months of life, and consequently, palliative care has mainly been associated with cancer patients. However, it has been recognised that palliative care should be provided on the basis of needs rather than prognosis or diagnosis. The palliative care approach should be offered increasingly alongside curative treatment to support people with chronic progressive illnesses over many years. As long-term care residents have multidimensional care needs the palliative care approach including psychological and spiritual care would also be an appropriate care approach in long-term care settings.

More research on palliative or end-of-life care in long-term care facilities has been performed in the Netherlands compared with other European countries. A reason may be that the Netherlands is unique with regard to the existence of nursing home medicine as an independent medical specialism. In the Netherlands a nursing home physician is part of the staff in every nursing home. The long tradition of developing the system of long-term care in the Netherlands went along with the involvement of long-term care facilities in various scientific research projects in the past two decades.

Symptoms and symptom management were found to be the most frequently measured outcome in the studies. A previous study that examined the status of palliative care research in Europe also concluded that they were the main area of content of research. However, this may not be surprising as pain and other physical symptoms are more clearly defined and therefore easier to measure compared with psychosocial and spiritual issues. This seems to be reflected by the content of the quality-of-life instruments as the domain of physical comfort was more often included than the other domains of quality of life. Measuring psychosocial or spiritual wellbeing is rather more complicated than measuring the presence of symptoms, though increasing the understanding of psychosocial and spiritual issues in long-term care facilities is of importance to improving research and care in long-term care facilities. For instance, due to lack of agreement on a clear definition and consensus about appropriate outcomes on spirituality, researchers and caregivers are given little guidance on how to assess spiritual needs at the end of life, which is a barrier to the provision of adequate spiritual care at the end of life.

Many different measurement instruments were used in studies on palliative care in long-term care facilities. This may be due to the lack of knowledge about which instruments are valid and most appropriate for use in long-term care facilities. Furthermore, many residents are cognitively impaired, which makes using most instruments very complicated. Consequently, many self-report questionnaires are not useful in these settings. Although studies investigating the agreement between patient and proxy ratings report inconsistent findings the use of proxy ratings is of utmost importance in research in these settings because of the high prevalence of dementia.
Suggestions for research policy and practice regarding the methodological rigour of palliative care research in long-term care facilities

In order to develop more evidence and to improve research on palliative care in long-term care facilities more uniformity in defining palliative care in these settings needs to be developed. As we described in the introduction, conceptual clarity and clearly defined study populations are of significant importance to operationalizing concepts. Therefore, the development of well-defined and more standardised descriptions concerning the quality of palliative care is needed. In addition, the identification of appropriate outcomes reflecting the concerns of patients receiving palliative care, like for instance, quality of life and dignity, and how these outcomes can best be measured is important. Special attention should be paid to the identification of outcomes and the development and validation of measurement instruments that can be used for proxy assessments. In order to improve palliative care nationally and internationally, organizations for the promotion and development of palliative care, such as the European Association for Palliative Care (EAPC) or the International Association for Hospice & Palliative Care (IAHPC), should support further development and identification of concepts, definitions and outcomes for palliative care research. These organisations should stimulate their use and help to implement the use of more standardised concepts, definitions and outcomes as this would make research more comparable and benefit all researchers working in the field. In addition, clear definitions and valid outcome measures are needed to adequately evaluate interventions in the palliative care setting. Moreover, organisations for research funding should also be aware of the importance of conceptual clarity and adequate and valid measures in order to perform high quality research and evaluate interventions. In order to improve research and to develop adequate evidence-based palliative care, more prospective and longitudinal studies, such as trials and intervention studies to verify hypotheses defined by the descriptive studies conducted in the field, should be developed, although retrospective studies can also provide relevant information and have many practical advantages considering the frailty and short life expectancy of patients receiving palliative care. Furthermore, duplicating or expanding national research projects can be an efficient way to provide more robust evidence, to achieve international collaboration and to make research more comparable across countries in order to facilitate international guideline development, evidence-based care, and policy making.

Part II

Measuring quality of life in palliative care

The primary goal of palliative care is to improve the quality of life of patients and their families. According to the WHO definition of palliative care this means that in addition to physical pain and symptoms attention need to be paid to patients’ psychosocial and spiritual concerns.20 Palliative care may entail any form of medical care or treatment that concentrates on the prevention and relief of suffering. Any combination of pain and symptom management, psychological care and spiritual care, and social support can be applied to improve the quality of life of patients for whom there are no longer any curative treatment options.21 Quality-of-life measurement is an important aspect of palliative care, given that maximizing the quality of life in terminally ill patients is the main aim of this type of care. Four principal goals supporting the importance of measuring the quality of life and outcomes of care have been described by Hearn and Higginson.22 First, detailed information about the patient obtained by outcome measurement can be used for clinical monitoring to aid and improve patient care, and to help in decision making.23 Second, the care provided can be audited by determining whether standards are being achieved and by identifying potential areas for improvement. Third, quality-of-life outcome measures can be used to compare services, or to compare care before and after the introduction of a service in order to assess the efficacy and cost-effectiveness of care services. Finally, analysis of data generated by the use of outcome measures can be used to inform purchasers and thereby secure resources for future services. According to these goals the use of instruments to measure quality of life and care outcomes should be encouraged. A large variety of measurement instruments have been developed and used to measure quality of life in palliative care. However, there is a lack of consensus on what is the most appropriate outcome measure.

Key findings and interpretation of the results regarding the content of the quality-of-life instruments

A first step in the evaluation of the quality-of-life instruments was the development of a quality-of-life framework including domains identified as important to people for whom there are no curative treatment options. Physical comfort, physical functioning, cognitive functioning, psychological, social and spiritual wellbeing and perceived quality of care were identified as the most important domains. Most quality-of-life instruments suitable for use in palliative care covered only one or two of these domains, and none of the instruments covered all quality-of-life domains included in the framework. The domain of physical comfort was the most often included in the quality-of-life instruments. However, it is generally recommended that health-related quality-of-life should be assessed using a multidimensional instrument rather than by using one or more unidimensional instruments assessing one particular domain of quality of life.24 Thus, the outcome measures should be comprehensive and reflect the specific goals of palliative care. Dame Cicely Saunders advocated that people are indivisible physical and spiritual beings.25 In addition, several studies showed that spiritual and existential issues become more and more important at the end of life.26-30 and the existential or spiritual domain has also been found to be an important determinant of quality of life in palliative care settings.21 However, many health-related quality-of-life measures may be criticised for being too narrow by mainly focusing on physical, psychological and social aspects of a patient’s life. Since the concept of spirituality has not been very well defined, we hypothesised that the domain of spirituality was rarely included in the quality-of-life instruments. We found that half of the quality-of-life instruments identified in our study contained items related to spirituality. Most of these items were related to meaning or purpose of life and are possibly phrased in such universal terms to develop an item that make sense to all respondents, and not only to people adhering to a belief or religion. A recent study on the conceptualization of measurable aspects of spirituality identified the following dimensions of spirituality as the most important: spiritual beliefs, spiritual activities, and spiritual relationships, and spiritual coping.14 Spirituality or
existential issues can offer patients a way that may help to cope with illness and illness-related difficulties and therefore, conceptualization of spiritual aspects requires further attention. Understanding a patient's quality of life and whether a patient has any spiritual distress can also help to assist caregivers in planning palliative care.

**Key findings and interpretation of the results regarding the quality of the instruments**

Twenty-nine questionnaires were found to be appropriate to assess the quality of life of palliative care patients. The previous paragraph discussed the content of the instruments and demonstrated that some only included one or two quality-of-life domains. These instruments can be considered as domain-specific measures. We also identified measures that were disease-specific, e.g. specifically developed for cancer patients, setting-specific measures such as those specifically developed for use in a hospice setting, and more generic measures, targeted on palliative care populations in general. The advantage of the more generic measures is that they are suitable for use in patients with different conditions, and they make comparisons across different palliative care populations and settings possible. Domain-specific measures and disease-specific measures are intended to provide more information or more specific information. However, whether more information will be gained by use of a domain-specific instrument is clearly dependent on the measurement properties of the instrument.

The majority of the 29 quality-of-life instruments that were identified had not yet been adequately evaluated with regard to their measurement properties. Consequently, none of them achieved satisfactory ratings for all the measurement properties. This is probably due to the strictness of the criteria we used to assess whether the measurement properties were adequately evaluated and if the instrument showed satisfactory results with regard to the measurement properties. Seven of the 29 questionnaires identified in our review study were revised versions. In other words, researchers tried to improve the original instrument, mostly by excluding the least relevant items, resulting in a shorter questionnaire. Revision can improve the practical feasibility of the instrument but it does not automatically mean that the clinimetric quality has improved.

The number of measurement instruments designed to assess quality of life is rapidly increasing but have not yet been adequately evaluated. Consequently, selecting an instrument has become a big challenge for researchers and clinicians. The choice of a measurement method is a crucial part of research and imperative to the evaluation of outcomes since it determines the quality of data. Apart from the clinimetric quality of the instrument the purpose of measurement also plays a role in the choice. Understanding of the strengths and limitations with regard to the clinimetric quality of an instrument is of crucial importance to the adequate choice of one suiting the purpose of the study. For instance, if the purpose of measurement is evaluation, testing for responsiveness is important, and if the aim of the study is discrimination, reliability testing is of significance. The instrument must fit the measurement goal, but also the feasibility of an instrument is important. Information on the length of the questionnaire, the time needed to complete the questionnaire and the method of administration of a measure varies widely over the instruments, and could also help clinicians and researchers to decide which instruments may be appropriate and/or feasible for a particular study or setting. However, the amount and quality of information gained by the use of one or more instruments should be balanced with the burden they place on the respondents and the costs of data collection. Self-report questionnaires are generally preferred over the use of caregivers or significant others as raters. Inconsistent findings exist with regard to the use of proxy raters while the use of self-report questionnaires refers to assessment directly from the patient which can be considered as the most valid way of collecting subjective data such as that on quality-of-life. However, proxies may be considered an alternative or complementary source of information since patients receiving palliative care are not always able to complete a questionnaire themselves.

**Suggestions for research policy and practice regarding quality-of-life measures**

Since most of the instruments that were identified had not yet been adequately evaluated it was not possible to provide an explicit recommendation for one specific quality-of-life instrument for use in palliative care. However, it is useful to make researchers and clinicians aware of the state of the art in quality-of-life measures for use in palliative and end-of-life care. A clear overview of the current level of development regarding the availability and appropriateness of the quality-of-life measures for palliative care can help researchers and clinicians to select an instrument. No specific instrument have been shown to be the best to assess quality of life and therefore the use of the instruments that received the best ratings for their measurement properties MQOL, followed by the QUAL-E and the QODD, can be recommended. In addition we would recommend evaluation of existing multi-dimensional instruments with a good content validity over developing new instruments as there already exists a wide variety of instruments intended to assess the construct of quality of life. The use of comprehensive quality-of-life measures could help caregivers to plan palliative care services and to set priorities in order to achieve the best possible quality of life for patients in the last phase of life. Thus, the outcome measures should be comprehensive and reflect the specific goals of palliative care. A first step in selecting a quality-of-life instrument for use in a study in palliative care is to specify the aims of the study or clinical problems of interest and to compare these with the content of the instrument. If quality of life will be measured to evaluate an intervention, it is important to consider in which domains change is expected and to select an instrument that includes these domains. Second, it is important to be aware of how the instrument was developed and the strengths and weaknesses of an instrument to interpret the results adequately.

In accordance with what we described earlier, organisations like the EAPC and IAHPC should take the initiative in mobilising international palliative care organisations to develop a network and infrastructure to share, distribute and integrate knowledge and expertise internationally. Coordinated actions should encourage and foster international collaboration to create international agreement on instruments to measure outcomes for palliative care. In addition, EAPC and IAHPC should guide the coordination to stimulate further development and testing and promotion of the use of one or a few well-developed and adequately tested instruments. Furthermore, the translation of instruments should be coordinated to stimulate appropriate translation in order to enable cross-cultural comparison between studies. Moreover, standardization and repetitive use of measurement instruments creates better understanding of the meaning of scores and changes in scores on a specific instrument, so that the score can be translated into information that is meaningful to the patient, clinician or researcher. An important advantage of the use of one or a few high-quality instruments is the comparability of research results providing more robust evidence to facilitate guideline development, evidence-based care, and policy making. An important recommendation for research funders is that they should create research programmes in the field of palliative care focusing on conceptual, methodological and clinimetric research.
Part III

Measuring dignity at the end of life

While improvement of quality of life has been considered as the main purpose of palliative care, patients frequently speak about the importance of preserving their personal dignity when considering the end of life. As a consequence dignity has been seen as a central goal of palliative care but is still a relatively new concept in research. In line with the growing interest of the concept of personal dignity, measuring dignity in palliative care research has become of significant importance. Especially with regard to studies investigating the patient perspective, dignity can be a very useful outcome in order to provide a comprehensive understanding of the patient’s wellbeing. Therefore, our studies make an important contribution to the better understanding of the concept of dignity at the end of life.

Key findings and interpretation of the results regarding measuring dignity

Investigating the construct of personal dignity and the content validity of the Patient Dignity Inventory showed that independence, incontinence, pain, mental clarity, dementia, the ability to communicate and adequate care have important influence on personal dignity at the end of life. The majority of the items in the Patient Dignity Inventory were also found to be relevant to the sense of dignity at the end of life by people with an advance directive; however, the items did not comprehensively reflect the construct of dignity as items on communication and care-related aspects were not included in the instrument. In view of these findings, the way caregivers approach patients and communicate with them can be seen to have great influence on dignity at the end of life. Considering that physical and mental independence which influence a patient’s sense of dignity cannot be changed, relatives and caregivers should aim to preserve dignity in a patient’s last phase of life. A new measurement instrument was developed in accordance with the findings from our study that evaluated the construct of personal dignity and the content validity of the Patient Dignity Inventory prototype.35 This instrument can be used to measure the influence as well as the presence of factors that influence self-perceived dignity, and consists of four domains: evaluation of self in relation to others, functional status, mental status, and care and situational aspects.

The results from the study described in Chapter 6 showed that the perceptions of factors maintaining personal dignity at the end of life of people in good health were not substantially different from the perceptions of people who suffer from any disease and/or disability except for three physical factors related to symptoms, roles and routines. Those items were considered significantly more influential on dignity for people with poor health status. This would suggest that healthy people tend to underestimate the physical aspects that were found to be influential on dignity at the end of life. The results also suggest that people do not change their mind about the influence of psychological, social and existential factors on personal dignity at the end of life when their health status changes. Socio-demographic characteristics such as gender, age, having a partner and having a belief or religion rather than health status affect the perception of factors influencing dignity at the end of life. Although patients need to adjust continuously during the illness trajectory to find a way to cope with their changing health condition, the data suggest that the understanding of dignity will not substantially change as health status changes. The understanding of personal dignity and especially the psychological, social and existential factors covered by this construct seem to be reasonably stable. Although several authors45,47 have expressed concerns about patients who may change their minds about life values and preferences for care when confronted with a serious illness or in an illness trajectory, an important implication followed from the study (Chapter 6) might be that personal dignity can already be discussed in good health or in an early stage of a disease. Discussing a patient’s understanding of dignity can be part of advance care planning and help to develop value-based preferences about future care. However, we need to be cautious in suggesting that people’s views on dignity remain stable during the trajectory of illness as our study was not a longitudinal research study.

In Chapter 7 we showed that Dutch caregivers involved in caring for dying patients consider the same items as relevant to dignity as terminally ill patients. However, the trained volunteers included in this study indicated these items more frequently as influential to dignity, and as problematic in practice to maintaining dignity at the end of life than did SCEN (Support and Consultation on Euthanasia)-physicians. It seems that SCEN-physicians consider the physical aspects of suffering as most influential and problematic in practice to preserving dignity while volunteers think psychosocial aspects are most important. An explanation might be that volunteers are more often involved in someone’s personal life and are listening to what matters to the patient and his or her relatives. SCEN-physicians visit the people who explicitly request euthanasia in order to assess the their suffering and whether it is unbearable.47 This could explain why SCEN-physicians seem to focus more on physical suffering. A caregiver’s role in providing care for a terminally ill patient seems to affect their perception of the influence of factors that could maintain dignity.

Suggestions for research policy and practice regarding measuring dignity

Caregivers play an important role in the provision of care and support for terminally ill patients. With regard to future research, comparison of patient perceptions of dignity at the end of life and the perceptions of their caregivers in one study would be helpful to further explore understanding of and attitudes towards dignity, in particular because caregivers do have an important role in providing care for terminally ill patients, and communication and care-related aspects showed as important factors influencing sense of dignity at the end of life. Therefore, some of the results concerning the perceptions of dignity at the end of life are of particular interest for care providers involved in palliative care. Caregivers should be aware of the impact they may have in preserving dignity. This is in line with two previous studies that stressed the importance of the role of nursing staff in preserving dignity in elderly people.48,49 Anderberg et al. described that the concept of preserving dignity should be part of caregivers’ thinking in order to provide good care.49 Dignity should become a subject of education and training, especially for people providing palliative care. In palliative care practice, measuring dignity can be helpful for caregivers to identify which factors affect or have affected a patient’s sense of dignity in order to change focus of caregiving. The use of an instrument to measure factors that influence dignity can also be helpful to initiate and facilitate communication about values and preferences for care at the end of life.

This can be considered as even more important since a lack of understanding of a patient’s wishes about future care might result in loss of dignity, and additional distress for relatives and caregivers. Thus an outcome measure to assess personal dignity may be helpful in the
process of advance care planning, to discuss and evaluate patients’ preferences for future care, early in the illness trajectory or even before the issues arise due to disease or disabilities. An adequate and appropriate instrument is needed to identify factors that affect or have affected a patient’s sense of dignity. Therefore, more research regarding the feasibility and validity of the dignity-instrument we referred to in the previous paragraph 33 would be recommended. It would also be helpful to know whether this instrument can be used as a proxy assessment instrument. Future longitudinal research is needed to investigate whether peoples’ views on dignity remains stable during the trajectory of illness to verify or disprove the assumption that personal dignity might be a stable construct. Furthermore, it would be interesting to further explore what additional information would be gathered by measuring dignity in addition to quality of life considering that dignity and quality of life have some overlapping domains.

Conclusions

Much research has been done in the field of palliative care, with a main focus on cancer palliative care. As a growing number of people will be in need of palliative care over the coming years a lot more research is needed with a new focus on palliative care for non-cancer patients and palliative care in long-term care facilities. Research is very important to evaluate conceptual clarity and the development of well-defined and more standardized descriptions concerning quality of palliative care are needed to develop high-quality research. In addition, special attention should be paid to the identification of outcomes reflecting the concerns of patients receiving palliative care in these settings, and the development and validation of measurement instruments that can be used for proxy assessments.

Quality of life is a central concept and an important outcome measure in palliative care, and therefore measurement instruments to measure quality-of-life are of great importance. Personal dignity is increasingly considered as a goal of palliative care but is a relatively new concept in the field. Comparing the concepts of dignity and quality of life suggests that these concepts include some overlapping domains. Physical, socio-psychological and spiritual aspects are reflected in both concepts. The concept of personal dignity goes beyond the assessment of physical and psychological health status as it also includes one’s perception of worthiness. In addition to quality of life, personal dignity might be an important and comprehensive outcome in palliative care research, especially with regard to research on patient perspective in this field.

References