The quality of palliative care for patients with cancer in Indonesia
All studies described in this thesis have been performed at the Scientific Institute for Quality of Healthcare (IQ healthcare), in close cooperation with the department of Anesthesiology, Pain and Palliative Medicine. These are part of the Radboud Institute for Health Sciences (RIHS), one of the research institutes of the Radboud university medical center.

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

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The quality of palliative care for patients with cancer in Indonesia

Proefschrift

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maandag 23 februari 2015 om 14.30 uur precies

door Christantie Effendy

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# Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prologue</td>
<td>7</td>
</tr>
<tr>
<td>Chapter 1</td>
<td>Introduction</td>
<td>9</td>
</tr>
<tr>
<td><strong>Part I</strong></td>
<td><strong>Problems and unmet needs of patients with cancer</strong></td>
<td>19</td>
</tr>
</tbody>
</table>
| Chapter 2 | Comparison problems and unmet needs of patients with advanced cancer in a European Country and an Asian Country.  
_Pain Practice; Epub ahead of print 26 March 2014._ | 21   |
| Chapter 3 | Dealing with symptoms and issues of hospitalised patients with cancer in Indonesia: the role of families, nurses and physicians.  
_Pain Practice; Epub ahead of print 2 May 2014._ | 33   |
| **Part II** | **The role of family caregivers in caring for patients with cancer and their quality of life** | 45   |
| Chapter 4 | Family caregivers' involvement in caring for a hospitalized patient with cancer and their quality of life in a country with strong family bonds.  
_Psycho-Oncology; Epub ahead of print 7 October 2014._ | 47   |
| **Part III** | **Developing a set of quality indicators of the organization of palliative care for patients with cancer in Indonesia** | 61   |
| Chapter 5 | Face-validation of quality indicators for the organization of palliative care in hospitals in Indonesia: a contribution to quality improvement  
_Supportive Care in Cancer 2014; 22(12):3301-3310._ | 63   |
| Chapter 6 | Discussion                                                          | 83   |
|         | Summary                                                             | 99   |
|         | Samenvatting                                                        | 103  |
|         | Intisari                                                            | 107  |
|         | Acknowledgement                                                     | 111  |
|         | Curriculum Vitae                                                    | 119  |
Prologue

The case scenario below illustrates the themes I studied in this thesis: firstly patient-centered care by focusing on the needs of the patient and his/her family when facing a palliative trajectory and benefitting from the culture of family care. Secondly, the quality improvement with the help of development and testing of a set of quality indicators (QIs) for palliative care in hospitals settings.

Mrs M (56 years), who lives in a small town 65 kilometres from Yogyakarta, Indonesia, has been diagnosed with breast cancer with metastasis. She has had a mastectomy, for which she had to stay in hospital for 2 weeks. Her daughter accompanied her as a family caregiver during hospitalisation. She stayed in a second class room and her daughter slept on the chair beside her every night. The nurses documented Mrs M's pain intensity using a visual analogue scale (VAS). Besides, when she suffered from pain or other physical symptoms, her daughter reported it to a nurse. Mrs. M received pain medication, and every 2 days wound care. Her daughter took care of bathing, toileting and positioning and tried to make her as comfortable as possible.

When Mrs M was allowed to go home, the nurse gave her and her daughter some information about what she should do and should not do at home and a consultation schedule to follow up her condition and chemotherapy.

The case scenario above features a common condition of a hospitalized patient in an Indonesian hospital and the provision of good quality of care in the Indonesian context. However, this is a description of what can ideally be achieved, not of usual care.

Having worked as a clinical nurse for 15 years and as a researcher for more than 10 years, I experienced that most patients came to the hospitals in bad condition. Not only patients but also families suffer a lot. Furthermore, I lost many friends and colleagues because of cancer. For those reasons, I performed the studies described in this thesis, aiming to contribute to better care for those who suffer from cancer.
Chapter 1

Introduction
Chapter 1

The World Health Organization stated palliative care as ‘...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness,...’\(^1\) According to this definition, palliative care should begin at the time of diagnosis and continue alongside treatment with curative intent, follow-up care, and at the end of life. Particularly when cure is no longer possible, palliative care is needed. The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, which include psychological, social, and spiritual problems.\(^1\)

The healthcare system in Indonesia is shaped by both traditional and modern components. In some rural areas, patients still depend on traditional healers, partly as a result of limited access to, and high costs of, medical care, and partly because of cultural beliefs and distrust of the health care services.\(^2\) They go to the hospital when traditional or alternative therapy fail.

In Indonesia, about 60\% of the patients with cancer seek medical care when the disease is already in an advanced stage.\(^3\) In line with the WHO’s definition of palliative care\(^1\) we assumed that most hospitalized patients with cancer are palliative patients. Therefore, not only curative treatment but also palliative care should be an important focus in Indonesian hospitals.

The Indonesian palliative care service began in 1992,\(^4\) and has been on the agenda of the Indonesian government since 2007.\(^5\) The Indonesian government, through the Minister of Health, enacted the Regulation No 812/Menkes/SK/VII/2007 on Palliative Care.\(^6\) There are five provinces (Jakarta, Yogyakarta, Surabaya, Denpasar, and Makassar) that have been appointed to conduct palliative care.\(^6\) However, there is no standardised operating procedure for the provision of palliative care in Indonesia and no quality indicators guiding the organization of palliative care in hospitals, in order to allow evaluation of the implementation of palliative care in Indonesian hospitals.

Culture, religion and beliefs influence integrated palliative care implementation in the Indonesian community.\(^7\) In contrast to Western countries and similar to other Asian countries, in Indonesia it is considered a family obligation to care for a family member who is ill, wherever this patient stays, including during hospitalization.\(^8\) For example, when a husband gets ill and is hospitalized, his wife will accompany him 24/7 in the hospital and one of the grandparents will take care of the children. Culture also influences the patient’s response to the disease and the treatment. For example, a patient from Sumatra who suffers from pain will respond to the pain differently from patients from Java.\(^9\) Culture provides opportunities and sets boundaries to the organization of care, patient approach, and care by families. Improvement of care needs to take these cultural norms into account.
Religion and beliefs also play an important role in patients' attitudes towards health behaviour and seeking health care. For example, Advent Christians reject receiving blood transfusions. They have more faith in fate, destiny and God than in medical interventions. Some patients also believe that having surgery on Saturday will bring them bad luck.

I want to contribute to a better quality of palliative care in Indonesia by using methodology and research evidence developed in other parts of the world, while considering the Indonesian context.

In this introduction chapter, first the cancer epidemiology will be described, followed by a description of evidence on problems and needs experienced by Western cancer patients. Furthermore the theoretical background of the thesis will be explained: I will describe how patient-centered care can contribute to good quality of palliative care of patients with cancer in Indonesian hospitals. In addition I will describe how quality indicators can contribute to the improvement of palliative cancer care, and the urgency to validate the quality indicators for the organization of palliative care in hospital settings in Indonesia. Finally, the aims for research contributing to improvement of Indonesian palliative care will be presented.

Cancer epidemiology
Cancer is, and will be, a major cause of morbidity and mortality in the next few decades in every region of the world. Cancer is also one of the most burdensome and expensive non-communicable diseases facing healthcare systems globally.

The global population was 7 billion in 2012 and the United Nations Population Division forecast that this will rise to 8.3 billion by 2030. A global burden of 20.3 million new cancer cases by 2030 has been predicted, while in 2008 this figure was about 12.7 million. It is predicted that in 2030 about 13.2 million persons will die of cancer worldwide, while this number was 7.6 million in 2008.

In Indonesia, an archipelagic country of 17.508 islands, cancer is one of the main public health problems. The prevalence of cancer is 4.3 per 1,000 inhabitants. Based on Basic Health Research 2007, cancer is the 7th cause of death among all causes of deaths. Cervical cancer, breast cancer, lymph cancer, skin cancer, and rectal colon cancer all have high mortality rates in this country. Accurate data on cancer incidence is still unattainable due to administrative, financial and geographical constraints.

Problems of patients with cancer
Many patients with advanced cancer suffer from physical, psychosocial, spiritual, or other problems. Five symptoms: fatigue, pain, lack of energy, weakness, and loss of appetite all occur in more than 50% of the patients with advanced cancer; the suffering of these
patients is determined to a large degree by the presence and intensity of these symptoms.\textsuperscript{19}

In an advanced stage of cancer, when being cured is no longer possible, improving or maintaining the quality of life of the patient becomes the primary aim. A multidimensional focus on the patient, his disease, his social environment, his wishes and needs now and in future to prevent crisis is needed; with particular attention to physical, social, spiritual and psychological problems and needs.\textsuperscript{20}

Ideally, the care of patients with advanced cancer is consistent with the principles of palliative care and includes an assessment of patients' values and goals throughout the course of the illness, with consideration of disease-directed therapy, symptom management, and quality of life.\textsuperscript{21}

It is crucial to ensure that patients understand their prognosis and treatment options and have the opportunity to express their preferences, as well as their physical, psychosocial, and spiritual concerns.\textsuperscript{21,22}

Knowledge of symptom prevalence is important for clinical practice as it enables physicians and nurses to focus on the more prevalent symptoms. This focus may help to anticipate problems and plan better care for the individual patient, to educate clinical staff, to direct assessments of health care needs, and to plan services.\textsuperscript{23}

Proper attention to symptom burden and suffering should be the basis for individually tailored treatment aimed at improving or maintaining the quality of life of patients.\textsuperscript{19}

Assessment of problems and needs that patients experience is an important aspect of appropriate palliative care as a basis of intervention.\textsuperscript{24}

Yet, for patients with cancer, facing problems is not the same as desiring or needing more professional care or attention for each of them. In order to optimise the patient's well-being, it is essential to tailor professional care to each patient's personal needs.\textsuperscript{25}

An assessment instrument to identify problems and needs of patients with cancer has been developed in the Netherlands: the Problems and Needs in Palliative Care Questionnaire (PNPC).\textsuperscript{26}

As part of my PhD project I aim to identify the problems and unmet needs of patients with cancer in Indonesia, using the PNPC questionnaire. The results of this study can be used to guide physicians and nurses in symptoms and needs management.

\textbf{Theoretical background: a patient-centered cancer care approach}

Traditionally, patients have been placed in the role of passive recipients of care delivered by healthcare professionals who know what is best for the patients.\textsuperscript{27} It is now widely recognized for all healthcare providers that patient-centered care is important\textsuperscript{28} and that the patient is a part of a care team. Patients' values and perceptions should be considered as an important element to meet the demands of quality improvement.
To reach the goal of palliative care, it is crucial to understand what patients' personal needs are. Patient-centered care is care that is 'respectful of and responsive to individual patients' preferences, needs and values, and ensures that patients' values guide all clinical decisions'. Like palliative care, patient-centered care addresses the physical, psychological, social and spiritual needs of patients.

To implement patient-centered care, all health care providers should work together as a team and involve the patient and their family. Appropriate palliative care depends upon the formation of a caring collaboration between physicians, nurses and patients. This collaboration will ensure that resources are not wasted on unnecessary treatments, that patient autonomy is respected and professionals are better equipped to avoid burn-out. With the implementation of patient-centered care, the cost of palliative care might be reduced, and satisfaction of healthcare providers and patients might increase by strengthening professional practice and maintaining the values of the patient and healthcare providers.

Regarding caring for hospitalized patients with cancer in Indonesia, nurses take care of the patient by using the Indonesian nursing care concept. The Indonesian National Nurse Association/Persatuan Perawat Nasional Indonesia (PPNI) mentioned that nursing care is a professional service that is an integral part of health care based on nursing science and troubleshooting. It uses the comprehensive approach of the bio-psycho-socio-spiritual model to individuals, groups and communities, to both sick and healthy persons. This nursing care concept derived from the theory of human caring of Watson. It is clearly recognized that the nursing care concept in Indonesia is in line with the principle of palliative care, as well as with those of patient-centered care.

For the above-mentioned reasons, patient-centered care can be the backbone of the efforts to describe and improve the quality of Indonesian palliative care. Identifying patients' personal problems and unmet needs should be the first step in improving their quality of life.

**Quality improvement and quality indicators (QIs) in palliative cancer care**

Patients with cancer often need hospitalization. Hospitals are considered very important to enhance the quality of life of patients. In Indonesia, most patients with cancer are hospitalized in their advanced stage of cancer.

Although the 2002 WHO definition of palliative care has also been recognized in Indonesia, palliative care is still in its infancy. More efforts and resources need to be directed to establishing higher numbers of qualified palliative care services, to support an effective and efficient palliative care programme embedded in cancer care which enables it to reach the great majority of those patients that could benefit from it.
The quality of care can be improved by using evidence or consensus-based interventions. In order to improve the quality of care, quality indicators (QIs) have been developed. A QI is 'a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality, and hence measure changes in the quality of care provided over time'.\textsuperscript{40} A QI measures the quality of the performance of professional practice.\textsuperscript{41} QIs for the organization of care can be an important tool in providing guidance in complex care.\textsuperscript{42} These indicators can contribute to quality improvement of palliative care by providing the key elements of an adequate organization.\textsuperscript{43} Using QIs can provide valuable information on outcomes, processes and structures that need improvement.\textsuperscript{44,45}

Hardly any evidence-based palliative care guidelines or QIs are available. The search for QIs fits into the Indonesian policy that aims to develop and improve the quality of palliative care in hospital settings. Therefore, I considered it important to adapt a set of QIs for the organization of palliative care for patients with cancer in Indonesian hospitals. A European set of QIs has been developed in the past few years. Yet, because Indonesia has different health care system, culture, and economic situation than Europe, translating this European set of structure and process indicators is not enough. For that reason I performed a modified RAND Delphi process.

In order to improve the quality of palliative care, it is crucial to validate the existing QIs for the organization of palliative care in hospital settings in an Indonesian context, to add missing QIs and to pilot test them.

The research questions and outline of the thesis

The present thesis consists of three main parts. The first part of the thesis explores the problems and unmet needs of patients with advanced cancer in Indonesia compared with the same group in the Netherlands and explores how the Indonesian patients deal with their problems.(chapter 2 and 3) The second part explores the involvement of family caregivers in caring for hospitalized patients with cancer and their quality of life.(chapter 4) The third part explores the adaptation and face validation of a set European quality indicators (QIs) relating to the organization of palliative care in the Indonesian context.(chapter 5)
The research questions of this thesis are as follows:
1. Do patients with advanced cancer in Indonesia have more problems and needs than a similar group of patients in the Netherlands? (Chapter 2)
2. What kind of symptoms and issues do hospitalized patients with cancer in Indonesia have and how and by whom are they addressed? (Chapter 3)
3. What kind of factors influence the quality of life of family caregivers of hospitalized cancer patients in Indonesia? (Chapter 4)
4. Is it possible to validate a set of quality indicators for the organisation of palliative care, previously developed in Europe, for use in Indonesian hospitals? (Chapter 5)

Outline of this thesis
The scientific work addressing these three component parts will be presented in the subsequent chapters of this thesis. Chapter 1 is the introduction of the thesis. In chapter 2, we determined what the problems and unmet needs are in patients with advanced cancer in Indonesia, and compared this to a similar group of patients in the Netherlands. In chapter 3, we determined what kind of symptoms and issues Indonesian patients with cancer have, whether they are addressed during hospitalization, and by whom. In chapter 4, we identified how family caregivers are involved in caring for hospitalized patients with cancer, and how the different types of caring, as well as their demographic characteristics, influence the quality of life of the family caregivers in Indonesia. In chapter 5 we face-validated a set of quality indicators (QIs) for the organisation of palliative care in Indonesian hospitals. This set of QIs was based on a European set. Both sets were compared and the applicability of the Indonesian set was pilot tested in five Indonesian hospitals. This thesis concludes with chapter 6, which provides a general discussion of the findings in the previous chapters.
Chapter 1

References


Introduction

Part I

Problems and unmet needs of patients with cancer
Chapter 2

Comparison of problems and unmet needs of patients with advanced cancer in a European country and an Asian country

Christantie Effendy
Kris Vissers
Bart Osse
Sunaryadi Tejawinata
Myrrha Vernooij-Dassen
Yvonne Engels

Pain Practice; Epub ahead of print 26 March 2014.
ABSTRACT

Background: Patients with advanced cancer experience problems and unmet needs. However, we assume that patients with advanced cancer will have more problems and unmet needs in a country with a lower economic status than in an economically stronger country. We studied whether patients with advanced cancer in Indonesia have more problems and unmet needs than a similar group of patients in the Netherlands.

Methods: We performed a cross-sectional survey. We compared the data for 180 Indonesian and 94 Dutch patients relating to 24 items of the Problems and Needs in Palliative Care-short version questionnaire. We performed descriptive and $\chi^2$ analysis with Bonferroni correction.

Results: The prevalence of most physical problems, including pain, was similar in the 2 groups. In Indonesia, financial problems were the most common: 70 to 80% vs. 30 to 42% in the Netherlands. In Indonesia, 25 to 50% of the patients reported psychological and autonomy problems versus 55 to 86% in the Netherlands. The Indonesian group had many more unmet needs for each problem (> 54%) than the Dutch group (< 35%).

Conclusion: Apparently, economic and cultural differences hardly influence physical problems. Nonetheless, fewer Indonesian patients reported psychological and autonomy problems than Dutch patients. This difference contradicts our hypothesis. However, we found more unmet needs for professional attention in Indonesia than in the Netherlands, which is compatible with our hypothesis. These simple comparative data provide interesting insights into problems and unmet needs and give rise to our new hypothesis about cultural influences. This hypothesis should be studied in more depth.
INTRODUCTION
Cancer is a huge problem throughout the world. The World Health Organization (WHO) estimates that by 2020, over 15 million people worldwide will have cancer, and about 10 million people will die of this disease every year. In Indonesia, an archipelago with more than 215 million inhabitants, cancer is the 17th most common cause of death. Cancer prevalence in this country with limited economic opportunities is about 4.3 cases per 1,000 inhabitants. Although there is no national cancer register, the Health Department of the Republic of Indonesia estimates that approximately 65% of the patients with cancer are already in an advanced stage when they seek medical treatment. In the Netherlands, a European country with 16 million inhabitants, cancer is the primary cause of death, although the prevalence (4.9 to 5.3 per 1,000 inhabitants) is about the same as in Indonesia.

Cancer, particularly in the advanced stages, has severe consequences for quality of life. Many patients with advanced cancer suffer from physical, psychosocial, spiritual, or other problems. More than 75% of them suffer from fatigue, and 2 of 3 patients suffer from pain. Patients' problems might differ between countries due to culture, personal values, and economics. Facing problems is not the same as desiring or needing more professional care or attention for each of them. It is essential to tailor professional care to the patient's personal needs in order to optimize quality of life. To achieve this, assessment of the problems and needs that a patient experiences is crucial.

About 10 years ago, a questionnaire to assess problems and needs in patients with advanced cancer has been developed in the Netherlands. The valid and reliable Problems and Needs in Palliative Care-short version (PNPC-sv) questionnaire was developed to support the provision of care tailored to the specific demands of patients, which only can be provided when their needs are clearly identified. In contrast to other quality of life instruments, the PNPC-sv not only addresses symptoms and problems, but also addresses needs for more professional attention of care. It was built as a comprehensive checklist to be used in clinical practice.

We assumed that patients with advanced cancer in Indonesia, a country with a lower economic status, fewer treatment facilities, and the tendency of patients not to seek professional help before they are in an advanced stage of cancer, will perceive more problems and unmet needs than in the Netherlands, a well resourced country. Therefore, the aim of this study was to determine whether patients with advanced cancer in Indonesia have more problems and unmet needs than a similar group of patients in the Netherlands.
Methods
Setting and population
A cross-sectional survey was conducted between November 12, 2009 and June 5, 2010. Nurses recruited patients with advanced cancer from the outpatient oncology clinics or the day care centers of 5 hospitals in Indonesia (in Yogyakarta, Surabaya, Jakarta, Denpasar, and Makassar). We chose these hospitals because the Indonesian Ministry of Health obliges them to provide palliative care. Previously, collected and published data of 94 patients with advanced cancer living at home were used for the Dutch sample. Physicians and medical oncologists selected some of these patients, and the Dutch federation of organizations for patients with cancer recruited others. The inclusion and exclusion criteria were the same in the 2 countries. The inclusion criteria were (1) having an advanced stage of cancer (as checked in the medical record by the researcher), regardless of the type of cancer, and (2) being able to fill in the PNPC-sv questionnaire. The exclusion criteria consisted of (1) having a physical or mental condition that makes the use of a questionnaire impossible and (2) being too ill to be able to complete the questionnaire (as determined by the physician or medical specialist). The local medical ethics committees in Indonesia approved the study. On the basis of this approval, the participating hospitals gave their permission for the study.

Instrument
The PNPC-sv was used to assess cancer-related problems and needs. This self-report valid and reliable questionnaire for patients contains symptoms and problems that cover all dimensions of palliative care in the WHO definition, namely activities of daily living (ADL), physical symptoms and social, psychological and spiritual problems, as well as 2 additional domains: autonomy and finances. For this study, the English version of the questionnaire was translated into Indonesian in a forward–backward translation. Twenty-four of the 33 items in the original version were used. A pilot test showed that the deleted ones (9 items) were inapplicable in Indonesia due to differences in infrastructure (1 item), daily activities (1 item), autonomy perception (2 items), social aspects (2 items), psychological aspects (1 item), spirituality (1 item), and information needs (1 item). For example, in the autonomy domain, "difficulties handing over tasks to others" is not an autonomy issue in Indonesia, with its extended family culture.

In the Indonesian version, the patient answered yes or no to the questions of whether each topic was an existing problem. Four answering categories for the needs questions were used, namely no; as much as until now; yes, a little; and yes, a lot, as it appeared from the pilot testing in Indonesia that a "yes, a little" category was missing. In the Dutch version, a patient could indicate whether he/she felt each item was a problem with
Comparison of problems and unmet needs of patients with cancer

yes, somewhat, or no and whether he/she needed professional attention for it with no; as much as until now; yes, more.

**Data collection**

After having provided their informed consent, respondents were asked to complete the adapted PNPC-sv during their stay at the outpatient clinic or day care center, which took them about 20 to 25 minutes. If patients were unable to fill in the questionnaire by themselves, the family or the research assistant assisted them. Respondents did not receive financial or other compensations for taking part in the study.

**Data analysis**

Descriptive analyses (frequencies and means) were used for the demographic characteristics of the patient groups and to determine the frequencies of the answers of both groups for each question in each domain of ‘problems’ as well as ‘needs’. The answers to the questions about problems were recoded to elicit dichotomous ‘yes/no’ answers by combining ‘yes’ and ‘somewhat’ to ‘yes’.16 The answers to the ‘needs’ questions were dichotomized to ‘yes/no’ by adding ‘as much as now’ to ‘no’.16 We used chi-square tests with *Bonferroni* correction (because of multiple testing) to identify differences between the ‘problems’ and ‘unmet needs’ of the respondents in Indonesia and the Netherlands. Based on this *Bonferroni* correction, we used *p* < 0.0002 to determine the significance of each problem and unmet need. We used the statistical software program SPSS version 20 (IBM SPSS Statistics, Armonk, NY, U.S.A.).

**RESULTS**

**Demographics of the patients**

The data of 180 (72%) patients with advanced cancer collected in 5 Indonesian hospitals were compared with the data of 94 patients with advanced cancer in the Netherlands.16 Table 1 shows demographics of both groups (age, sex, and educational level).

The Indonesian patients were generally younger than the Dutch ones (mean age respectively 49 and 58 years). In both countries, more women than men (> 70%) took part. Of the Indonesian patients, 8.4% had no education at all. Slightly fewer Indonesian patients than Dutch had a high level of education.
Table 1. Characteristics of the respondents

<table>
<thead>
<tr>
<th></th>
<th>Indonesia n = 180 (%)</th>
<th>The Netherlands * n = 94 (%)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (in years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 30</td>
<td>3.4</td>
<td>0</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>30-45</td>
<td>32</td>
<td>11.7</td>
<td></td>
</tr>
<tr>
<td>46-60</td>
<td>50</td>
<td>55.3</td>
<td></td>
</tr>
<tr>
<td>&gt;60</td>
<td>14.9</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>(mean ±SD), range</td>
<td>(49.3 ±10.7) 21 - 77</td>
<td>(58±12.3) 30 - 87</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>26.1</td>
<td>29.8</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>73.9</td>
<td>70.2</td>
<td></td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
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<td></td>
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</tr>
<tr>
<td>No schooling</td>
<td>8.4</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>23.5</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Junior high school</td>
<td>17.3</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Senior high school</td>
<td>28.8</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>College and University level</td>
<td>22</td>
<td>31</td>
<td></td>
</tr>
</tbody>
</table>

* Osse 16

Comparing problems and unmet needs in the 2 countries

Table 2 shows comparisons of all 24 problems for the 2 patient groups. Four of 5 Indonesian patients had financial problems, as did 2 of 5 Dutch patients (p=0.000). Each physical problem had about the same prevalence in each country except for fatigue (67% in Indonesia and 93% in the Netherlands, p=0.000). Autonomy (48% vs. 71%, p=0.000), psychological (25 to 50% vs. 55 to 86%, p=0.000), social (10 to 22% vs. 28 to 51%, p=0.000), and spiritual problems (23 to 79% vs. 42 to 69%, p=0.000) were mentioned more often in the Netherlands. The Indonesian patients more often mentioned having problems with daily activities than did the Dutch patients (55% vs. 36%, p=0.004). Loss of control over one's life (p=0.016), difficulties in finding someone to confidentially talk to (p=0.003), and difficulties with being available for others (p=0.003) did not differ significantly between the 2 groups. Except for financial problems, all nonphysical problems were mentioned more often in the Netherlands than in Indonesia.

Regarding each problem, at least 50% of the Indonesian patients answered that they needed more professional attention. In the Dutch study group, this proportion was always < 35%. In Indonesia, patients with extra expenses caused by the disease had most need for professional attention (72%), while Dutch patients with difficulties coping with the unpredictability of the future most often had this need (29%; Table 2).
Table 2. Problems and needs for more professional attention per problem of patients with cancer

<table>
<thead>
<tr>
<th>Domain</th>
<th>% Patients with problems</th>
<th>% Patient with unmet needs</th>
<th>Significance</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=180 IND</td>
<td>n=180 NL</td>
<td>n=94 IND</td>
<td>n=94 NL</td>
</tr>
<tr>
<td>Daily activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body care, washing, dressing, or toileting</td>
<td>53.9</td>
<td>35.5</td>
<td>n varies</td>
<td></td>
</tr>
<tr>
<td>Physical symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>71.1</td>
<td>67.0</td>
<td>0.380</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>66.7</td>
<td><strong>92.5</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Sleeping problems</td>
<td>53.3</td>
<td>51.1</td>
<td>0.721</td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>30.6</td>
<td>45.7</td>
<td>0.013</td>
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</tr>
<tr>
<td>Cough</td>
<td>42.2</td>
<td>34.0</td>
<td>0.188</td>
<td></td>
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<td>Itch</td>
<td>26.1</td>
<td>22.3</td>
<td>0.493</td>
<td></td>
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<td>Sexual dysfunction</td>
<td>37.8</td>
<td>36.7</td>
<td>0.859</td>
<td></td>
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<td>Numb sensation</td>
<td>40.0</td>
<td>46.0</td>
<td>0.167</td>
<td></td>
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<tr>
<td>Sweating (nightly)</td>
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<td>50.0</td>
<td>0.264</td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being dependent on others</td>
<td>47.8</td>
<td><strong>71.1</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Loss of control over one's life</td>
<td>50.6</td>
<td>63.8</td>
<td>0.016</td>
<td></td>
</tr>
<tr>
<td>Social issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems in the relationship with life companion</td>
<td>10.6</td>
<td><strong>27.6</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Difficulties talking about the disease because of not wanting to burden others</td>
<td>22.2</td>
<td><strong>51.1</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Difficulties in finding someone to talk to (confidant)</td>
<td>16.2</td>
<td><strong>31.9</strong></td>
<td>0.003</td>
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</tr>
<tr>
<td>Psychological issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Depressed mood</td>
<td>34.4</td>
<td><strong>72.0</strong></td>
<td>0.000*</td>
<td></td>
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<tr>
<td>Fear of physical suffering and the disease</td>
<td>50.0</td>
<td><strong>75.3</strong></td>
<td>0.000*</td>
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<tr>
<td>Difficulties coping with the unpredictability of the future</td>
<td>48.3</td>
<td><strong>86.0</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Difficulties showing emotions</td>
<td>25.1</td>
<td><strong>53.2</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Spiritual issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulties being available for others</td>
<td>32.2</td>
<td>50.5</td>
<td>0.003</td>
<td></td>
</tr>
<tr>
<td>Difficulties about the meaning of death</td>
<td>22.8</td>
<td><strong>52.9</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Difficulties accepting the disease</td>
<td>37.2</td>
<td><strong>69.2</strong></td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Financial problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extra expenses because of the disease</td>
<td>79.4</td>
<td>42.4</td>
<td>0.000*</td>
<td></td>
</tr>
<tr>
<td>Loss of income because of the disease</td>
<td>71.7</td>
<td>29.7</td>
<td>0.000*</td>
<td></td>
</tr>
</tbody>
</table>

*a The percentages of patients who need more professional attention refer only to the patients who experience the topic as a problem, not to the whole population (n varies)

*b Significance of the problems and the needs: chi-square tests with Bonferroni correction were performed with (p < 0.0002)

* Significantly different (p < 0.0002); IND= Indonesia; NL= the Netherlands
DISCUSSION
We performed a comparative self-reporting study of problems and unmet needs of Indonesian and Dutch patients with advanced cancer to answer our hypothesis. We assumed that patients with advanced cancer in a country with a lower economic status like Indonesia will have more problems and unmet needs than in an economically stronger country like the Netherlands.

We found that prevalence of most physical problems, including pain, was similar in both groups. In Indonesia, financial problems were the most common problems, while in the Netherlands, psychological and autonomy problems were most often reported. The Indonesian patients had much more unmet needs for each problem than the Dutch patients. In comparison with a systematic literature review on symptoms in patients with advanced cancer, pain prevalence in our populations was about the same, but many other symptoms had higher prevalences. Yet, none of the studies included in the systematic review used the PNPC-sv, which makes interpretation difficult.10

The fact that many Indonesian patients experienced financial problems is not a surprise, as about 3/4 of the Indonesian population has no health insurance. Therefore, most patients have to pay for their hospital stay, transportation, food, and medication.21 In the Netherlands, almost everyone has health insurance that completely covers hospital stay, as well as most other health costs.22,23

Our results show that, even though Indonesia and the Netherlands are different in culture and economics, most physical problems were comparable, and about the same as in other studies. In both countries, fatigue and pain were most prevalent. Walsh24 found similar figures regarding pain and fatigue, as did Van den Beuken and colleagues25 for pain; yet, fewer Indonesian than Dutch respondents were fatigued (67% vs. 92%). These data confirm findings in other western studies on patients with an advanced stage of cancer.26,27 Cancer-related fatigue is not only a physical symptom. It is also a subjective and multidimensional symptom with physical, emotional, and mental components.28-30 This might partly explain why this "physical" symptom results in different figures in the 2 countries with different cultures. Cancer type, stage, treatment differences31,32 and a different perception about the meaning of fatigue might also have influenced these figures.

Problems related to issues of autonomy appeared less prevalent in Indonesia than in the Netherlands. Being independent is greatly valued in the Netherlands,33 while in Indonesia, a country with an extended family structure, family ties are much stronger. Being dependent on the family during illness is more in line with the Indonesian culture and therefore more accepted in Indonesia than in the Netherlands.21,34 The Indonesian patients less often mentioned to have psychological or social problems than the Dutch patients. In Indonesia, the family has a key role in taking care of the
Comparison of problems and unmet needs of patients with cancer

patient and in making treatment decisions. Even when hospitalized, almost always a family member accompanies the patient 24 hours a day.\textsuperscript{21} This may have positively influenced their psychological status. Yet, reluctance of Indonesian respondents to discuss their psychological and social concerns with healthcare providers may also have contributed to these figures.\textsuperscript{35-39} Particularly in the Netherlands, many patients mentioned that they have spiritual problems. Pearce and colleagues described that patients with unmet spiritual needs will have a reduced sense of spiritual meaning and peacefulness.\textsuperscript{40} Other studies also found that many patients with advanced cancer have spiritual needs.\textsuperscript{41-43} Significantly, fewer patients in the Indonesian study's population had difficulties with accepting their disease. This is not a surprise, as spirituality is strongly influenced by culture.\textsuperscript{44-46} The majority of Indonesians are Muslim, and religion plays an important role in their daily lives. A major illness is considered God's will, and death is predestined by God, which makes it easier for them to accept their illness and limited life expectancy. In Indonesia, almost all hospitals have spiritual caregivers to support patients, which might have contributed to relieving or preventing spiritual problems. Besides, it explains the higher need for professional attention; patients in Indonesia know that there are specific professionals to manage their spiritual needs. In the Netherlands, patients will not expect that the healthcare professional will relieve spiritual needs. Besides, in the Netherlands, 42% of the population does not have a religion or spiritual background,\textsuperscript{43} which may explain why the Dutch respondents had less need for professional attention for this problem. Patients in Indonesia reported fewer problems than in the Netherlands. Yet, they experienced more unmet needs (for professional attention) for almost all problems. Besides fewer treatment facilities in Indonesia, no national standard of caring for patients with cancer and inadequate training for nurses might have contributed to these figures in Indonesia.\textsuperscript{47} A study on terminal cancer patients in Italy supports our findings that particularly physical symptoms need more professional attention.\textsuperscript{48}

**Strengths and limitations**

These comparative data provide new insights into problems and unmet needs of patients with advanced cancer in a European and an Asian country, and sheds more light on this topic.

Originally, the PNPC questionnaire was developed to help individual patients prepare and structure consultations with their physician,\textsuperscript{16,18} but the instrument appeared also useful to measure differences and similarities in problems and needs between 2 countries. Yet, differences in problems and needs may also be influenced by differences in sample size, cancer type and stage, and treatment. We did not study these aspects.
In this study, we used existing Dutch data\textsuperscript{16} that were collected a few years earlier. Yet, it is arguable that symptoms and needs do not change much overtime. Prevalence of pain in patients with cancer, for example, has not changed at all in the last 40 years.\textsuperscript{25} The advantages of using an existing database were that no new frail patients in the Netherlands needed to participate for this comparison and that the inclusion criteria in Indonesia could be adapted to the Dutch criteria.

**Conclusion**

Apparently, economic and cultural differences hardly influence physical problems, as these are widely determined by the disease. Nonetheless, fewer Indonesian patients reported psychological and autonomy problems than Dutch patients. This difference contradicts our hypothesis. Cultural differences such as strong family ties in Indonesia and a more individualistic culture in the Netherlands might overrule economic differences. However, we found more unmet needs for professional attention in Indonesia than in the Netherlands, which is compatible with our hypothesis. These simple comparative data provide interesting insights into problems and unmet needs and give rise to our new hypothesis about cultural influences. This hypothesis should be studied in more depth.

**Implication for practice**

To provide personalized patient care, identifying patients' personal problems and unmet needs should be the first step in improving the quality of care and the quality of life. The Indonesian culture, where family members are involved in caring for their frail beloved ones, may have positively influenced the psychological status of the patient. European countries might learn from Indonesia about the way of caring, but more research is needed on consequences for the patient, the family caregiver, and the professional caregivers.

This study is a result of collaboration between Indonesian and Dutch researchers, aiming to improve the quality of palliative care in both countries.\textsuperscript{49} The findings will be used for next steps in this collaboration, for example, for starting quality improvement projects in hospitals in Indonesia. Finally, we recommend more in-depth comparison studies, in which factors that influence problems and needs such as sample size, cancer type and stage, and treatment will be taken into account.
REFERENCES

22. de Jong JD, van den Brink-Muinen A, Groenewegen PP. The Dutch health insurance reform: switching between insurers, a comparison between the general population and the chronically ill and disabled. BMC Health Serv Res 2008:8:58.
Chapter 2

Chapter 3

Dealing with symptoms and issues of hospitalised patients with cancer in Indonesia: the role of families, nurses and physicians

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Kris Vissers
Sunaryadi Tejawinata
Myrra Vernooij-Dassen
Yvonne Engels

Pain Practice; Epub ahead of print 2 May 2014.
ABSTRACT

Objective: Patients with cancer often face physical, psychological, social, spiritual, and emotional symptoms. Our aim was to study symptoms and issues of hospitalized patients with cancer in Indonesia, a country with strong family ties, and how family members, nurses, and physicians deal with them.

Methods: In 2011, 150 hospitalized cancer patients in 3 general hospitals in Indonesia were invited to fill in a questionnaire, which was based on the validated Problems and Needs of Palliative Care (short version) questionnaire. Descriptive statistics were performed.

Results: Of 119 patients (79%) who completed the questionnaire, 85% stated that their symptoms and issues were addressed. According to these patients, financial (56%), autonomy (36%), and psychosocial (34%) issues were most often addressed by the family alone. Physical symptoms (52%) and spiritual issues (33%) were addressed mainly by a combination of family, nurses, and physicians.

Conclusions: Hospitalized patients with cancer in Indonesia felt that most of their symptoms and issues had been addressed, and the family was highly involved. The strong family ties in Indonesian culture may have contributed to this family role. More research is needed to clarify how this influences patient outcome, quality of care, and quality of life of both the patients and their families, along with the degree of partnership between families and professionals. This information might help answer the question what advantages and disadvantages the family role in caring for a hospitalized patient with cancer generates for the patient, the family, and professional caregivers.
INTRODUCTION

Patients suffering from cancer are frequently hospitalized. This can be a stressful experience and a time of intense distress for both the patients and their families. In Indonesia, the incidence of cancer is 170 to 190 per 100,000 people. Many patients with cancer face physical and psychosocial symptoms. For example, in advanced stages, over 70% of them suffer from fatigue and pain, 39% of depressed mood, and 30% of anxiety. Besides, 91% patients with advanced cancer have spiritual needs, and 28% felt their spiritual needs were not met. According to the WHO definition of palliative care, all kinds of symptoms and issues of palliative patients need to be addressed to enhance the quality of life. At present, it is unknown whether and by whom symptoms and issues of patients with cancer are addressed in Indonesian hospitals. In contrast to Western countries, in Asian countries, it is considered a family obligation to care for a family member who is ill, wherever this patient stays, including during hospitalization. In Indonesia, nearly all hospitals allow a family member to accompany their loved one in an inpatient care setting 24 hours a day and to be involved in caring for the patient. Particularly in first-class rooms, an extra bed beside the patient's bed is available for a family member. Therefore, the aim of this study was to determine what kind of symptoms and issues of Indonesian patients with cancer are addressed during hospitalization and how family members, nurses, and physicians contribute to this.

Methods

Setting and population

A cross-sectional survey was performed in 3 general hospitals (in Yogyakarta, Denpasar, and Makassar) from August 10, 2011 to November 25, 2011. One hundred and fifty hospitalized patients were invited to participate. The inclusion criteria were as follows: (a) having any type of cancer; (b) being 18 years or older; (c) being hospitalized for at least 5 days; (d) being able to fill in a questionnaire; and (e) having provided informed consent. There were no exclusion criteria. All eligible patients were included.

Ethical permission

The university medical ethics committee approved the study. On the basis of this approval, the participating hospitals gave us their local permission to perform the study.

Instruments

The domains of the validated Problems and Needs of Palliative Care - short version (PNPC-sv) questionnaire were used to develop the questionnaire in this study. These domains, based on the World Health Organization (WHO) definition of palliative care,
are as follows: activities of daily living (ADL); physical symptoms; social and psychological issues; and spiritual issues; with additional topics relevant to autonomy and financial issues. The questions of each domain in the PNPC-sv questionnaire were used as examples to describe the patient's symptoms. For example, when we asked whether patients had physical symptoms, the question was, "Do you have physical symptoms such as pain, fatigue, cough, etc."

To identify which symptoms or issues of hospitalized patients with cancer were being addressed, they were asked whether they had symptoms or issues. For each domain in which they had symptoms, they answered 2 questions: Has anyone addressed or dealt with the symptom(s)? (yes/no) and Who addressed the symptom(s): family; nurse; physician; social worker; and/or volunteer? (multiple answers possible). The entire questionnaire consisted of 14 questions.

**Data collection**

After having provided their informed consent, patients were asked to fill in the questionnaire on the basis of their own experience during hospitalization. If patients were unable to fill in the questionnaire by themselves, the family or the research assistant assisted them.

**Data analysis**

Descriptive analysis (frequency, mean, and median) was used for the demographic characteristics of respondents. It was also used to determine the frequencies of the answers for each question in each domain. For each symptom or issue category, we calculated who or which combination of professionals and family addressed the symptom. We used SPSS version 20 (IBM, SPSS Statistics, Armonk, NY, U.S.A.) for these calculations.

**Results**

**Patient demographics**

Of the 150 invited patients, 119 (79%) completed and returned the questionnaire to the research assistant. Table 1 shows the demographics, educational level, and profession of the respondents.
Table 1. Demographics

<table>
<thead>
<tr>
<th>Patient characteristics (n=119)</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td>39</td>
</tr>
<tr>
<td>Female</td>
<td>73</td>
<td>61</td>
</tr>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>11</td>
<td>9.2</td>
</tr>
<tr>
<td>31–50</td>
<td>65</td>
<td>54.6</td>
</tr>
<tr>
<td>51–65</td>
<td>33</td>
<td>27.8</td>
</tr>
<tr>
<td>&gt;65</td>
<td>10</td>
<td>8.4</td>
</tr>
<tr>
<td><strong>Median, range</strong></td>
<td>47, 20–80</td>
<td></td>
</tr>
<tr>
<td><strong>Stage of cancer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>42</td>
<td>35.3</td>
</tr>
<tr>
<td>3</td>
<td>58</td>
<td>48.7</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
<td>12.6</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Time since diagnosis (in months)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–6</td>
<td>40</td>
<td>33.6</td>
</tr>
<tr>
<td>7–12</td>
<td>43</td>
<td>36.1</td>
</tr>
<tr>
<td>&gt;12</td>
<td>36</td>
<td>30.3</td>
</tr>
<tr>
<td><strong>Education</strong></td>
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<td></td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>13.4</td>
</tr>
<tr>
<td>Elementary school</td>
<td>46</td>
<td>38.7</td>
</tr>
<tr>
<td>Junior high school</td>
<td>23</td>
<td>19.3</td>
</tr>
<tr>
<td>Senior high school</td>
<td>21</td>
<td>17.6</td>
</tr>
<tr>
<td>University/college</td>
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<td>8.5</td>
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<td>Other</td>
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<td>2.5</td>
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<td><strong>Profession</strong></td>
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<td></td>
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<tr>
<td>Government employee</td>
<td>13</td>
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<td>Private</td>
<td>34</td>
<td>27.3</td>
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<tr>
<td>Retired</td>
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<td>7.3</td>
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<td>Farmer</td>
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<td>16.3</td>
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<td>Laborer</td>
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<td>20.0</td>
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<tr>
<td>Housewife</td>
<td>8</td>
<td>14.5</td>
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<tr>
<td>Other</td>
<td>3</td>
<td>5.4</td>
</tr>
<tr>
<td><strong>Family caregiver</strong></td>
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<td></td>
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<tr>
<td>Spouse</td>
<td>69</td>
<td>57.8</td>
</tr>
<tr>
<td>Child</td>
<td>39</td>
<td>32.8</td>
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<tr>
<td>Relative</td>
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<td>3.4</td>
</tr>
<tr>
<td>Parent</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Hospitalized patients’ perception of symptoms or issues being addressed and by whom

Table 2 shows that most patients suffered from physical symptoms (82%) and financial issues (75%), and many had psychological issues (59%). For all domains, 85% or more of the patients who had a symptom or issue in a given domain stated that it was addressed. Very often, the family addressed symptoms with activities of daily living (ADL; 89%), and financial (89%), autonomy (83%), and spiritual issues (81%). According to many patients, nurses addressed their restrictions in ADL (80%), physical symptoms (73%), and their spiritual (63%), social (54%), psychological (50%), autonomy (49%), and financial issues (28%).
Table 2. Hospitalized patients’ (n=119) perception of symptoms and issues being addressed and by whom

<table>
<thead>
<tr>
<th>Domain</th>
<th>Symptoms / issues</th>
<th>Symptoms / issues addressed</th>
<th>Caregivers that addresses patients’ symptoms / issues **</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Doctor</td>
</tr>
<tr>
<td>Activities of daily living</td>
<td>61 (51.3)</td>
<td>59 (96.7)</td>
<td>5 (8.2)</td>
</tr>
<tr>
<td>Physical</td>
<td>98 (82.4)</td>
<td>96 (97.9)</td>
<td>76 (77.5)</td>
</tr>
<tr>
<td>Social</td>
<td>33 (27.7)</td>
<td>29 (87.8)</td>
<td>7 (21.2)</td>
</tr>
<tr>
<td>Psychological</td>
<td>70 (58.8)</td>
<td>65 (92.8)</td>
<td>19 (27.1)</td>
</tr>
<tr>
<td>Spiritual</td>
<td>52 (43.7)</td>
<td>46 (88.4)</td>
<td>20 (38.4)</td>
</tr>
<tr>
<td>Autonomy</td>
<td>47 (39.5)</td>
<td>42 (89.3)</td>
<td>8 (17.0)</td>
</tr>
<tr>
<td>Financial</td>
<td>89 (74.8)</td>
<td>80 (89.9)</td>
<td>2 (2.2)</td>
</tr>
</tbody>
</table>

* Number (percentage) of patients with a symptom or an issue (n vary)
** The symptoms and issues could be addressed by more than one person and per person more than one symptom/issue can exist

Three of 4 patients (78%) stated that also the physician addressed their physical symptoms. Only a small number of patients mentioned that the physician addressed nonphysical issues (range: 2% to 38%). Sometimes, the social worker appeared to be involved in taking care of spiritual (25%) and financial issues (11%). Volunteers were seldom involved in addressing patients’ symptoms and issues (3% or fewer).

Table 3 shows who or which combination of professionals and family addressed patients’ symptoms and issues. Patients reported that only their families were involved in addressing financial (56%), autonomy (36%), psychological (34%), and social issues (33%). The combination of family and nurse mainly addressed their restrictions in ADL (62%). Patients also reported that the combination of family, nurse, and physician addressed their physical symptoms (52%) and spiritual issues (33%). Between 2% (physical) and 12% (social) of the symptoms and issues were not addressed by anyone.

Table 3. Hospitalized patients’ perception of combinations of caregivers who addressed their symptoms and issues (n=119)

<table>
<thead>
<tr>
<th>Domain</th>
<th>n*</th>
<th>Symptoms/ issues addressed **</th>
<th>unmet symptoms/ issues</th>
<th>unknown</th>
<th>Professional and family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>P</td>
<td>N</td>
</tr>
<tr>
<td>Activities of daily living</td>
<td>61</td>
<td>59 (96.7)</td>
<td>2 (3.3)</td>
<td>-</td>
<td>6(9.8)</td>
</tr>
<tr>
<td>Physical</td>
<td>98</td>
<td>96 (97.9)</td>
<td>2(2.2)</td>
<td>4(4.1)</td>
<td>7(7.1)</td>
</tr>
<tr>
<td>Social</td>
<td>33</td>
<td>29 (87.8)</td>
<td>4(12.1)</td>
<td>-</td>
<td>6(18.2)</td>
</tr>
<tr>
<td>Psychological</td>
<td>70</td>
<td>65 (92.8)</td>
<td>5(7.1)</td>
<td>2(2.9)</td>
<td>2(2.9)</td>
</tr>
<tr>
<td>Spiritual</td>
<td>52</td>
<td>46 (88.4)</td>
<td>6(11.5)</td>
<td>1(1.9)</td>
<td>-</td>
</tr>
<tr>
<td>Autonomy</td>
<td>47</td>
<td>42 (89.3)</td>
<td>5(10.6)</td>
<td>-</td>
<td>1(2.1)</td>
</tr>
<tr>
<td>Financial</td>
<td>89</td>
<td>80 (89.9)</td>
<td>9(10.1)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

P: Physician; N: Nurse; F: Family member; V: Volunteer; S: Social worker
* Number of patients with a symptom or an issue
** Number (percentage) of patients with a symptom/issue who reported that their symptoms and issues were addressed (n vary)
DISCUSSION
The participation rate of the invited Indonesian hospitalized patients was high (79%). Almost all respondents (93% to 98%) replied that their physical symptoms, their restrictions regarding ADL, and their psychological issues were addressed. Patients said that the family was involved in addressing almost every symptom and issue during hospitalization. Very often, only the family (not the professionals) was involved in addressing financial, autonomy, psychological, and social issues. This finding is consistent with another Indonesian study of family roles in caring for patients with breast cancer and a Malaysian study of terminally ill cancer patients in which both patients and their families perceived that the physical care during hospitalization was adequate, while professionals inadequately addressed the psychological and social aspects of care. The family gives psychological support by providing reinforcement or encouragement, love, and empathy for the patient, which is in line with family culture in Indonesia where the family feels a strong responsibility to care for their ill loved one.

Indonesian families are strong, cohesive groups that protect each other and demand loyalty throughout life. This is reflected in Hofstede’s ranking of individualism across cultures. Indonesia ranked 47th of the 53 countries, and regions assessed. Trandis et al. report that Indonesia had the least individualistic culture of the nine nations assessed. Although both studies derive from the 1980s, nowadays Indonesian people still have a culture of taking care of each other. If someone is in hospital, all close family members, relatives, friends, neighbors, and colleagues will visit and help the patient continuously. Particularly in Java, the importance of the family is reflected in the proverb: mangan ora mangan waton kumpul (even if there is no food to eat, being together is the most important thing).

<table>
<thead>
<tr>
<th></th>
<th>P+N</th>
<th>P+F</th>
<th>N+F</th>
<th>P+N+F</th>
<th>F+V</th>
<th>N+F+V</th>
<th>N+S</th>
<th>F+S</th>
<th>N+F+S</th>
</tr>
</thead>
<tbody>
<tr>
<td>16(16.2)</td>
<td>-</td>
<td>5(5.1)</td>
<td>38(62.3)</td>
<td>5(8.2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>4(5.7)</td>
<td>-</td>
<td>11(15.7)</td>
<td>13(18.6)</td>
<td>2(2.9)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>1(1.9)</td>
<td>2(3.8)</td>
<td>5(9.6)</td>
<td>17(32.7)</td>
<td>1(1.9)</td>
<td>-</td>
<td>2(3.8)</td>
<td>3(5.1)</td>
<td>8(15.4)</td>
<td>8(15.4)</td>
</tr>
</tbody>
</table>
Family members want to be with the patient to show their concern and attention and to stay as long as possible to provide care and encouragement. They also feel comfortable sharing their autonomy and psychosocial concerns with their own family. However, reluctance of patients to discuss their psychosocial concerns with their healthcare providers may also have contributed to these figures.

In a Finnish study, as an example of Western countries, family members often visited hospitalized elderly patients. Their role in ADL was limited to providing emotional support and helping the hospitalized patients to drink and to get in and out of bed. The family members considered their role easier if they received emotional and cognitive support from the nursing staff. In contrast to Asian findings, they did not consider such participation in inpatient care as an obligation.

We found that a combination of family, nurse, and physician care usually addresses physical symptoms and spiritual issues. This indicates that there might be a partnership between professionals and family in caring for a hospitalized patient, but they also might act independently of each other, each group not knowing what the other does. Most Indonesian patients are Muslim. They want to pray 5 times a day. Family members give support and assist the patient who is praying in bed. The spiritual field is multidimensional; spiritual issues are not restricted to religion only, but also include consideration of values and beliefs, such as culture, life itself, and relationships with family and friends. Visiting the patient or "being there" for the patient might also contribute to spiritual well-being. This might explain why patients reported that a combination of their family, nurses, and physicians addressed their spiritual issues.

The respondents in our study reported that the physicians focused mainly on physical symptoms, while nurses also took care of other disease-related symptoms and issues. This finding confirms the results of a German study of palliative care, where nurses appeared to provide more multidimensional care than physicians. Physicians focus on curing the patients rather than on caring for them. We found that nurses were involved in addressing most kinds of symptoms and issues, which is congruent with the nursing paradigm and the concept of caring in Indonesia.

Patients in Indonesia have to pay for their hospital stay, transportation, food, and medication. One quarter of the patients reported that nurses addressed their financial issues. As nurses do not have the resources to give financial support, this reporting probably refers to the nurse telling the patient how to apply for reduced hospital payment via the Jamkesmas program, which is a healthcare program for people with low incomes who need hospitalization. Nonetheless, most patients stated that the family took care of financial issues. This is not a surprise, as they need to pay the hospital fees.
medication, and solve other financial issues by helping the patients obtain funding from the Jamkesmas program.

**Conclusions**

This study gives a first impression of how symptoms and issues of hospitalized patients in Indonesia are addressed, the caregivers who address those issues, and of the crucial role of the family. Hospitalized patients with cancer stated that most of their symptoms and issues were addressed, and the family was very much involved. The strong family ties in the Indonesian culture may have influenced these findings. We did not study whether the patient and family were satisfied with the situation. More research is needed to get better insight into how the family role in caring for hospitalized patients with cancer influences patient outcomes, quality of care, quality of life for both the patients and the families, and the degree of partnership between the family and professionals. This information might help answer the question of what kind of advantages and disadvantages the family role in caring for a hospitalized cancer patient generates for the patient, family, and professional caregivers. The influence of economic status on the family role in caring for a hospitalized cancer patient needs to be studied too.
REFERENCES

Part II

The role of family caregivers in caring for patients with cancer and their quality of life
Chapter 4

Family caregivers' involvement in caring for a hospitalized patient with cancer and their quality of life in a country with strong family bonds

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Sri Setiyarini
Martina Sinta Kristanti
Sunaryadi Tejawinata
Kris Vissers
Yvonne Engels
ABSTRACT

**Background:** Being involved in caring for family members during illness is part of the Indonesian culture, even during hospitalization. It is unknown which factors influence the quality of life (QoL) of family members taking care of their loved ones. The present study aims to identify factors influencing the QoL of family caregivers of hospitalized patients with cancer in Indonesia.

**Methods:** A cross-sectional survey was performed. Data were collected in a general hospital in Yogyakarta from September to December 2011. Family caregivers of patients with cancer were invited to participate. Regression analysis was used to determine which aspects of caring and which demographic characteristics influenced their QoL. The Caregiver QoL Index-Cancer questionnaire was used to measure the QoL.

**Results:** One hundred of 120 invited caregivers (83%) completed the questionnaire. Being involved in psychological issues in caring (β=0.374; p=0.000), younger age (β=-0.282; p=0.003), no previous caring experience (β=-0.301; p=0.001), and not being the spouse (β=-0.228; p=0.015) negatively influenced the QoL and explained 31% of the variation (adjusted R^2= 0.312; F=12.24; p=0.000). Gender, education level, and time spent on caring did not influence the QoL of family caregivers.

**Conclusions:** Our findings identified modifiable factors such as dealing with psychological issues and lack of experience in caring that negatively influenced the QoL of family caregivers. These factors are potential targets for intervention strategies. Education and intervention programs focusing on dealing with psychological problems in cancer care might improve the QoL of both patients and their families.
BACKGROUND
Cancer is one of the major health issues in Indonesia. No national cancer registration system exists, but the Department of Health estimated that cancer incidence is about 240,000 persons per year. The prevalence of cancer is about 4.3 per 1000 inhabitants. It has been estimated that two out of three patients are in an advanced stage when they visit the hospital for treatment. During hospitalization, family caregivers play an important role.

Family caregivers in cancer care are individuals who provide uncompensated care and health-related assistance to a family member who has cancer. Mostly, they are the spouse, child or parent of the patient and most of them are not trained in caring. They assist the patient in addressing his/her physical, emotional and medical problems; social issues; communicating with professional caregivers, and coordinating the care. However, care for patients with cancer exceeds usual family activities, such as household chores. Consequently, this implies that they have to rearrange the tasks and obligations that they usually perform, such as their own household activities, professional job, or care for others who depend on them, for example their children.

Particularly when the cancer is incurable and in an advanced stage, the role of the family caregivers increases, in a physical and an emotional way. In advanced stages of patients with cancer, the complex care required challenges the family caregivers' knowledge and skills, as well as their actions in caring for their loved ones. Caring for a family member who is chronically ill challenges the family caregivers' own quality of life (QoL), because of the fear of losing their loved one, the substantial impact of caring on the financial well-being and the restrictions placed on their social life. Therefore, not only the patient with advanced cancer but also the caregivers need attention. This is also reflected in the WHO definition of palliative care, in which caring for the family caregiver is mentioned as an essential part of palliative care.

A study in Europe found that family caregivers for patients with cancer experienced significant impairments in comparison with nonfamily caregivers. Many family caregivers become overburdened. Steel et al found that 38% of family caregivers reported symptoms of depression while caring for their loved one. Family caregivers' coping mechanisms are challenged by an ongoing involvement in complex personal and nursing care and confrontation with the suffering of and threat of losing their beloved one. Even though several studies have documented some positive effects of providing care to a family member such as enjoyment, meeting obligations, gaining a sense of meaning or fulfillment, QoL issues for patients and their families should be viewed as a priority for professional attention.

Norms, practices, expectations and also culture influence caring for a family member with cancer. In contrast to Western countries, in Indonesia, a country with strong family
bonds, being involved in caring for a family member during illness is part of the Indonesian culture.\textsuperscript{4,17} Such a strong family bond implies that family members protect each other and demand and provide loyalty throughout life.\textsuperscript{17,18} Even during hospitalization, the role of the family is obvious.\textsuperscript{4} Although family caregivers' experience in caring has been studied for terminally ill patients with cancer,\textsuperscript{5,6,11,13} there is little information on the type of care activities, and on its influence on the QoL of family caregivers, and none of these studies has been performed in Indonesia. Therefore, this study aims to identify factors influencing the QoL of family caregivers of hospitalized patients with cancer in Indonesia, a country with a strong culture of family care, particularly of modifiable factors as a potential target for intervention strategies.

\section*{METHODS}

\textbf{Setting and population}

From September to December 2011, data were collected by a research assistant in the adult inpatient ward in a general hospital in Yogyakarta, Indonesia, by means of a cross-sectional survey. Inclusion criteria for the caregivers were as follows: (a) taking care of a patient with advanced cancer (stadium 3 or 4) regardless of the type of cancer or whether the cancer was newly diagnosed or recurrent, (b) being 18 years of age or older, (c) having accompanied the patient during hospitalization for at least a week, (d) taking care of the patient's daily needs, (e) being able to fill in a questionnaire, and (f) having consented to take part in the study.

\textbf{Ethical permission}

The study was approved by the Medical Ethics committee of Universitas Gadjah Mada, Yogyakarta, Indonesia (Number: KE/FK/582/EC). All family caregivers gave their written informed consent to participate in the study.

\textbf{Measures}

\textbf{Demographic variables}

Information on the caregivers' gender, age, education level (none, elementary, junior high school, senior high school, or university/college), marital status (married, single, or widowed), the relationship with the patient (spouse, child, parent, or relative), time spent in caring (not every day; every day but <6 hours, 6-12 hours, or >12 hours), and having previous caring experience (yes/no) was collected.
Caregivers' involvement in caring for patients with cancer

We used the domains and problems of the validated Problems and Needs in Palliative Care–short version questionnaire to develop the Family Caregivers Involvement in Caring-Cancer (FCIC-C) questionnaire to identify family caregivers' involvement in caring for patients with cancer. The seven domains of this questionnaire are activities in daily living (ADLs), physical, social, psychological, autonomy, spiritual, and financial issues. To illustrate the type of caring per domain, we used the problems of the Problems and Needs of Palliative Care questionnaire to generate examples of caring to relieve these problems. For example, in the ADL domain, it is possible that a patient has problems with bathing, toileting and eating. To identify family caregivers' involvement in caring, we asked the family caregiver “Do you assist the patient with bathing, toileting and eating?” The questionnaire consisted of 29 questions with a four-point Likert scale ranging from 0 (never) to 3 (always) being involved, so the total score can range from 0 to 87. A higher score indicates a higher level of involvement in caring for a hospitalized patient with cancer. To examine the validity of the FCIC-C, Kaiser-Meyer-Olkin (KMO) and Bartlett tests were performed, and internal consistency was calculated. The KMO subscale appeared to be good (>0.75) and the Bartlett tests' value <0.001. Cronbach's alpha was good (>0.72) with (r= 0.3-0.8; Table 2).

Family satisfaction in cancer care during hospitalization

The FAMCARE questionnaire, measuring aspects of satisfaction and having a high internal consistency, test-retest reliability and mean inter-item correlation, was used to identify family satisfaction in cancer care during hospitalization. This questionnaire consists of 20 items about information giving (five items), availability of care (four items), physical care (seven items), and psychosocial care (four items). It consists of a five-point Likert scale from 1 (very satisfied) to 5 (very dissatisfied). The total score can range from 20 to 100. A higher score indicates a lower satisfaction of the family caregiver.

Quality of Life of family caregivers

The QoL of the family caregiver as a dependent variable was measured using the Caregiver QoL Index-Cancer (CQOLC) questionnaire. This questionnaire is multidimensional and a reliable tool that has been designed specifically for caregivers of patients with cancer and has been validated in many countries. Test-retest reliability was 0.95 and internal consistency 0.91. It consists of 35 items divided over four domains (burden, positive adaptation, disruptiveness, and financial concern) with a five-point Likert scale, ranging from 0 (not at all) to 4 (very much); the total score can range between 0 and 140. A high score indicates a low QoL.
Data analyses
We used descriptive analysis (frequencies, percentages, means, standard deviations and median) to describe sociodemographic characteristics of the respondents. The independent variables in this study were demographics, family satisfaction and family involvement in caring. The dependent variable was the QoL of the family caregiver. To more precisely identify those aspects of family caregiver involvement in caring for a hospitalized patient with cancer that influence the QoL of the family caregiver, we applied a two-step analysis. For the first step, we performed a bivariate analysis using Pearson correlations to measure the correlations between each separate independent variable (demographic, family satisfaction, and family involvement in caring) with the QoL of the family caregiver. In the second step, a multivariate analysis using stepwise linear regression analysis was performed with those independent variables that had a significant correlation in step one. A value of p < 0.05 was considered to be statistically significant. All the statistical analyses were performed using the software program SPSS-version 20 (IBM SPSS Statistics, Armonk, NY, U.S.A.).

Results
Characteristics of family caregivers
One hundred twenty family caregivers were invited to take part in the study, of whom 100 (83.3%) filled in and returned the questionnaire directly to the research assistant. About the same percentages of men (52%) and women (48%) took part in the study. The mean age of the family caregivers was 41 years (range: 14-71), and for the patients that they cared for, it was 49 years (range: 20-80). Most of the family caregivers were married (79%); almost half of them were the spouse (42%); 34% were the children, and 11% were the parents taking care of their child. Of the total population, 8% of the patients were between 20 and 30 years of age. Thirty-nine percent of the respondents had completed senior high school. About three-quarters of the family caregivers (78%) had no previous caring experience for a patient with cancer. More than half of the family caregivers (53%) took care of the patient more than 12 hours a day (Table 1).

Table 1. Respondent demographic

<table>
<thead>
<tr>
<th>Characteristic of family with N=100</th>
<th>(n; %)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>52</td>
</tr>
<tr>
<td>Female</td>
<td>48</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>18</td>
</tr>
<tr>
<td>30-50</td>
<td>57</td>
</tr>
<tr>
<td>51-65</td>
<td>18</td>
</tr>
<tr>
<td>&gt;65</td>
<td>6</td>
</tr>
<tr>
<td>Mean± (SD)</td>
<td>41.1±(13.1)</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>40.5(14-71)</td>
</tr>
</tbody>
</table>
Family caregivers’ involvement in caring for a hospitalized patient with cancer

The mean overall score was 38 ± 16.8. Caring by the family caregivers most often consisted of helping the patient with psychological symptoms (mean 5.5 ± 2.6). Next, family caregivers were involved in addressing social issues (mean 6.3 ± 3.6), autonomy (mean 5.9 ± 3.1), physical (mean 5.0 ± 2.9) and daily activities (mean 7.3 ± 6.9), and spiritual (mean 4.6 ± 2.9) and financial issues (mean 3.6 ± 2.4) of the patients (Table 2).
Table 2. Family caregivers’ involvement in caring for patients with cancer: mean, standard deviation, maximal score, ceiling effect, floor effect and Cronbach’s alpha of subscales FCIC-C\(^a\) (n=100)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Max score</th>
<th>Mean (±SD)</th>
<th>(\alpha)^b</th>
<th>Floor effect (%)</th>
<th>Ceiling effect (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL (six items)</td>
<td>18</td>
<td>7.28 (± .95)</td>
<td>0.82</td>
<td>35</td>
<td>6</td>
</tr>
<tr>
<td>Physical (five items)</td>
<td>15</td>
<td>5.02 (± 2.96)</td>
<td>0.77</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Autonomy (four items)</td>
<td>12</td>
<td>5.89 (± 3.14)</td>
<td>0.80</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Social (four items)</td>
<td>12</td>
<td>6.35 (± 3.63)</td>
<td>0.80</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Psychological (three items)</td>
<td>9</td>
<td>5.49 (± 2.58)</td>
<td>0.82</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>Spiritual (three items)</td>
<td>9</td>
<td>4.60 (± 2.88)</td>
<td>0.83</td>
<td>18</td>
<td>10</td>
</tr>
<tr>
<td>Financial (four items)</td>
<td>12</td>
<td>3.59 (± 2.38)</td>
<td>0.72</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Total score of FCIC-C (29 items)</td>
<td>87</td>
<td>38.20 (± 16.78)</td>
<td>0.74</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

FCIC-C = Family Caregivers Involvement in Caring-Cancer

\(^a\) A higher score of FCIC-C indicates a higher level of involvement in caring for a patient with cancer.

\(^b\) Cronbach’s alpha

Floor effect= the worst possible score; Ceiling effect= the best possible score

Family caregivers’ quality of life

The mean overall family caregivers' QoL score was 67.34 (±19.30). The subscale scores for positive adaptation was 19.53 (±4.50), for burden was 16.42 (±10.08), for disruptiveness was 9.33 (±5.07), for financial concerns was 7.48 (±3.09) and for other subscale scores was 27.22 (±4.72) (Table 3).

Bivariate analysis

We found that a higher age (p=0.03), higher level of education (p=0.006), being the spouse (p=0.04), and having previous caring experience (p=0.001) were significantly correlated with the QoL (CQOLC) of family caregivers. Besides, almost all subscales of the FCIC-C except for the social and autonomy domains were positively correlated with CQOLC. Family caregiver satisfaction, as measured with the FAMCARE (total score) appeared not to be significantly correlated with their QoL (r=-0.047, p=0.643).

Table 3. Quality of life of the family caregivers; mean, standard deviation, maximal score, and Cronbach’s alpha of subscales CQOLC (n=100)^a

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Max score</th>
<th>Mean (±SD)</th>
<th>(\alpha)^d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive adaptation (seven items)</td>
<td>28</td>
<td>19.53 (± 4.50)</td>
<td>0.69</td>
</tr>
<tr>
<td>Burden (10 items)</td>
<td>40</td>
<td>16.42 (± 10.08)</td>
<td>0.77</td>
</tr>
<tr>
<td>Disruptiveness (seven items)</td>
<td>28</td>
<td>9.33 (± 5.07)</td>
<td>0.71</td>
</tr>
<tr>
<td>Financial concern (three items)</td>
<td>12</td>
<td>7.48 (± 3.09)</td>
<td>0.80</td>
</tr>
<tr>
<td>Other^c (eight items)</td>
<td>32</td>
<td>27.22 (± 4.72)</td>
<td>0.70</td>
</tr>
<tr>
<td>Total score of QOL (35 items)</td>
<td>140</td>
<td>67.34 (±19.30)</td>
<td>0.73</td>
</tr>
</tbody>
</table>

CQOLC = Caregivers Quality Of Life index Cancer

\(^a\) A higher score of CQOLC indicates a higher level of QoL.

\(^d\) Cronbach’s alpha

\(^c\) Item without categories.
**Multivariate analysis**

A stepwise linear regression was performed to measure the factors that influenced the QoL of family caregivers (Table 4). The independent variables entered in the analysis were the ADL, physical, psychological, spiritual, and financial domains of the FCIC-C as well as age, education, being the spouse, and having caring experience with the total score on the CQOLC as dependent variable. Being involved in psychological issues of the patient (β =0.374; p= 0.000), a younger age (β=-0.282; p=0.003), not being the spouse (β=-0.228; p=0.015), and having no previous experience in caring for a patient with cancer (β=-0.301; p=0.001) negatively influenced the QoL of the family caregiver and explained 31% of the variation (adjusted R²=0.312; p=0.000). Gender, level of education and time of care did not independently influence the QoL.

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>β</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>age</td>
<td>-0.282</td>
<td>-3.061</td>
<td>0.003*</td>
</tr>
<tr>
<td>Caring experience</td>
<td>-0.301</td>
<td>-3.578</td>
<td>0.001*</td>
</tr>
<tr>
<td>Education level</td>
<td>0.133</td>
<td>1.472</td>
<td>0.144</td>
</tr>
<tr>
<td>Spouse</td>
<td>-0.228</td>
<td>-2.466</td>
<td>0.015**</td>
</tr>
<tr>
<td>FCIC-C</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>0.150</td>
<td>1.573</td>
<td>0.119</td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td>0.374</td>
<td>4.457</td>
<td>0.000*</td>
</tr>
<tr>
<td>Spiritual</td>
<td>0.181</td>
<td>1.846</td>
<td>0.068</td>
</tr>
<tr>
<td>Financial</td>
<td>0.092</td>
<td>1.048</td>
<td>0.297</td>
</tr>
</tbody>
</table>

Stepwise multiple regression analysis of family caregiver’s quality of life (dependent variable) and demographics and subscales of the FCIC-C (independent variables; n=100).

FCIC-C= Family Caregivers Involvement in Caring-Cancer; CQOLC = Caregivers Quality Of Life Index-Cancer

Dependent variable = total score of quality of life (CQOLC); Adjusted R square= 0.312; SE estimate= 16.01
* p<0.01; ** p<0.05

**DISCUSSION**

**Main findings**

In an Indonesian study with 100 family caregivers of hospitalized patients with cancer, we found that being involved in addressing psychological issues, being younger, not being the spouse, and having no previous experience of caring for a hospitalized patient with cancer negatively influenced the QoL of family caregivers.

During hospitalization, patients with cancer experience many symptoms and issues. Even though another study showed that psychological issues were not the most prevalent problem faced by patients, they appeared to be more burdensome for the family caregiver than other issues and symptoms. This finding is consistent with the negative correlation between family caregivers' QoL and patients' depression and emotional well-
being found in a Canadian study with 191 family caregivers of outpatients with advanced cancer,26 and also in a study on family caregivers of patients with HIV in Thailand.27 Our findings are also supported by several studies that showed that psychological issues experienced by a patient also burden the family caregivers because of their strong relationship.28,29 Caregiving is demanding and overwhelming and can be a very stressful experience that affects all aspects of the caregivers' QoL.9,26,30 We also found that younger family caregivers had a lower QoL than the older ones. This finding is in accordance with an American study on family caregivers of cancer survivors,31 and an Italian study on caring for a family member with a stoma.32 Younger family caregivers are more likely to experience more distress than older ones when performing their (new) role as a caregiver of a patient with cancer.33,34 The distress of those who are younger might be related to the fact that younger family caregivers more often combine this caregiver role with a job and being a parent of young children.35,36 Particularly daughters experienced more stress than sons.37 As the percentage of young family caregivers that take care of young patients in our study were very small (less than 5%), the lower QoL in younger family caregivers will not or will hardly be influenced by a higher burden when a young person dies.

In our study, 58% of the family caregivers were non-spousal caregivers, often being the adult child of the patient. Being the non-spousal caregiver appeared negatively correlated to their QoL. Also, Wadhwa et al found that a better QoL of caregivers was associated with not providing care for other dependents.26 In Indonesia, the family is a key element in caring for the ill family member. It is a tradition and considered an obligation to take care of a family member who is ill, at home as well as during hospitalization.4 Most respondents (78%) did not have much experience in caring and were untrained. Also, Palma showed that most family caregivers of patients with cancer are neither prepared nor trained to support the burden of caregiving.32 Providing care for a family member with cancer can be very stressful. A major stress factor for caregivers is the uncertainty about their own knowledge and skills.32 Therefore, it is not a surprise that having no previous caring experience increases the family caregiver burden and affects their QoL.

We were surprised that we found no differences in QoL between men and women, as in other studies, women were more stressed and experienced a lower QoL than men.38 Family values in the Asian culture might be related to this finding.16 Indeed, our finding was consistent with a study of family caregivers for patients with HIV in Thailand.27

**Strengths and limitations**

This is the first study in which predictors for the QoL of family caregivers of hospitalized patients with cancer in Indonesia were studied.
The study also has several limitations. Firstly, this is the first time that the FCIC-C questionnaire has been used. Although the psychometric properties appeared to be good in the studied population, further exploration of the instrument in other populations is necessary. Secondly, the family caregivers were caring for patients with a variety of types of cancer, levels of health status, and symptoms. Although this might have influenced the type of caregiving, all patients were in an advanced stage of their disease. Several studies have shown that in patients with advanced cancer, five symptoms occur very frequently. For that reason, we expect that the type of cancer of the hospitalized patient that was cared for is less important than the advanced stages of the conditions of the patients. We also did not control for type of interventions during hospitalization, like surgery, chemotherapy, or radiotherapy. Thirdly, this study was conducted in just one area of Indonesia, so cultural variations in different areas might have an influence on caring for a patient with cancer and thus on the QoL of the family caregiver. Also for that reason, generalization is not allowed. Nevertheless, this figure can be used to give more information about the QoL of family caregivers in Indonesia and can also be used as some basic data to improve the quality of care for hospitalized patients with cancer.

Implication in practice

Studying family involvement in caring for a patient with cancer at home would be useful to obtain a complete view on this topic. Family caregivers who have to deal with patients having psychological problems and having no previous caring experience need specific attention from a professional caregiver to decrease their burden and enhance their QoL. Timely screening the family caregivers on psychological problems will have a positive effect on their QoL and capability to care for their beloved one. Courses for patients and family caregivers in how to care for their loved ones and how to handle emotional and other symptoms might contribute to a better QoL for family caregivers. It is also very important to help the family caregivers with psychosocial interventions during their obligation in caring for their loved one with cancer during hospitalization. Courses for professionals in healthcare, on how to coach the family in taking care for a patient and on how to recognize that a family member is overburdened, might be useful.

Conclusions

Our findings identified modifiable factors such as dealing with the psychological issues and lack of experiences of caring that negatively influenced the QoL of family caregivers. These factors are potential targets of intervention strategies. Education and intervention programs focusing on dealing with the psychological problems in cancer care might improve the QoL of both patients and their families.
REFERENCES


Part III

Developing a set of quality indicators of the organization of palliative care for patients with cancer in Indonesia
Chapter 5

Face-validation of quality indicators for the organization of palliative care in hospitals in Indonesia: a contribution to quality improvement

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ABSTRACT

Purpose: Quality indicators (QIs) for the organization of palliative care (PC) can contribute to quality improvement as they assess the key elements for adequate organization of care. They might differ between healthcare organization, cultures and economic resources. The aim of this study was face-validate an Indonesian set of QIs based on a European set, to compare the two sets of QIs and to test the applicability of Indonesian set.

Methods: A modified two-round RAND Delphi process was conducted in Indonesia. Twenty-four health care professionals from different disciplines were invited as panelists to rate clarity and usefulness of 98 QIs. Next, a applicability pilot test took place in five hospitals.

Results: A total of 21 panelists considered 76 QIs (78 %) face-valid and added two new ones. Of the QIs with the highest ratings, eight were evaluated by head nurses and two by reviewing 50 patient records. Each QI was met by at least two hospitals, and only one by all five. Regarding the two QIs on structured clinical record keeping, most medical records contained multidimensional aspects of care.

Conclusions: We found that most QIs for the organization of PC developed for European countries were also considered face-valid for Indonesian hospitals. The top 10 QIs were applicable in Indonesia. This suggests that most of the organizational QIs are universal rather than country specific. The Indonesian set of QIs should be considered as a first step in developing, testing, and implementing a set of QIs for PC in Indonesia. We recommend validation in other Asian regions.
INTRODUCTION

Quality indicators (QIs) for the organization of care are an important tool in providing guidance in complex care.\textsuperscript{3,5,13} They can contribute to quality improvement of palliative care by providing the key elements of an adequate organization.\textsuperscript{3} They allow it to measure, monitor, and evaluate its quality and thus are essential for quality improvement.\textsuperscript{3,5,17}

A QI is "a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality of care provided and can reveal potential problems that might need addressing".\textsuperscript{4} To improve the quality of the organization of palliative care in Europe, a set of structure and process QIs has been developed in Europe, meant to be applicable in different health care systems, settings, and countries, taking geographical, historical, political, and cultural aspects into account.\textsuperscript{26} In this EU co-funded Europall study, experts in palliative care from seven European countries (Belgium, UK, France, Germany, Netherlands, Poland, and Spain) participated in a modified RAND Delphi process.\textsuperscript{26}

Differences between regions all over the world might require a differentiation between generic and more regionally applicable QIs.\textsuperscript{13} Up to now, testing which of this European set of QIs can be used in other continents has not been performed.\textsuperscript{14,18}

Although the WHO definition of palliative care (2002)\textsuperscript{24} has also been recognized in Indonesia, palliative care is still in its infancy. Palliative care in Indonesia is mainly restricted to symptom management during hospitalization.\textsuperscript{25} Care coordination between hospital and primary care centers is not well developed.\textsuperscript{19} As a result, many patients with cancer die in hospitals without having palliative care.

Hardly any evidence-based palliative care guidelines or QIs are available.\textsuperscript{25}

The search for QIs fits into the Indonesian policy that aims to develop and improve the quality of palliative care. Since 2007, the dissemination of specialized palliative care services is on the Indonesian Ministry of Health's agenda.\textsuperscript{15} Yet, as Indonesia has another health care system, culture, and economic situation,\textsuperscript{14} as a first step, the aim of this study was to face-validate the European QIs for the Indonesian context and to test its applicability.

METHODS

A modified two-round RAND Delphi process was used to select those QIs of the European set of process and structure QIs for the organization of palliative care settings that are useful in the Indonesian context. A modified RAND Delphi process is a consensus method to determine the extent of agreement about an issue. It is an accepted method for developing QIs when research evidence is lacking.\textsuperscript{5,11,19} The European set of QIs consists of QIs that can be used in each setting where palliative care is provided and of QIs that
are meant for a specific setting. As palliative care in Indonesia is mainly provided in hospitals, we only used those QIs of the European set that are also meant for hospital settings.

**Panelists**

Twelve experts in palliative care or cancer care were invited to participate as panelists in round 1 of the Delphi process. Experts needed to have at least 5 years of experience in the field of palliative care or cancer care, to be part of a local and regional network (access to or knowledge of different palliative care settings), to have expertise of palliative care in Indonesia, to understand the English language, and to be a professional (physician, nurse, or lecturer/researcher) in palliative care or cancer care. Recruitment of 12 additional experts in round 2 enlarged the multidisciplinarity of the panel.

**European set of QIs**

We used a set of QIs for the organization of palliative care, previously developed in the European Europall project. This set consists of 151 structure and process QIs, divided over 10 domains in a framework for the organization of palliative care. As three of these domains contain QIs that are not meant for hospitals, we only used 98 structure and process QIs divided over seven domains (access to palliative care, infrastructure, assessment tools, personnel in palliative care services, documentation of clinical data, quality and safety issues, and reporting clinical activity of palliative care services).

**Modified RAND Delphi process**

In round 1, a face-to-face meeting of the researcher with each panelist was arranged to explain the purpose of the study. During these meetings, each expert received the questionnaire and a glossary explaining all relevant terms. The experts were asked to rate each process or structure QI for clarity as well as for usefulness on two scales from 1 (not clear or not useful at all) to 9 (very clear or very useful). A QI needed to be rated as being clear if it used wording that makes the meaning clear and easy to understand. A QI needed to be rated useful if it corresponded with a basic quality level and therefore should be met in all palliative care settings in Indonesia and if the QI corresponded with a higher quality level, currently met only in very good palliative care services or if it corresponded with an innovative quality level that was currently exceptional, but could become the optimal quality level in the future. If the phrasing of a draft QI was rated poor (unclear), the panelists were invited to rephrase it. They were also asked to add QIs for relevant topics that were missing. Completed questionnaires were returned by post or e-mail.
To prepare round 2, those QIs that were considered unclear were rephrased with the help of the feedback of the panelists. Both the original phrasings and the adapted phrasings were included in round 2. Additional QIs that the panelists had suggested to add in round 1 were also included in round 2. Those QIs that were already rated as useful and were not accompanied by any remarks in round 1 were not included in round 2 anymore and considered face-valid.

In round 2, the panelists received written feedback about their own previous rating (if applicable), together with the median ratings of all panelists. They were asked to rerate the QIs for usefulness. In order to improve the response rate and reduce delay, the researcher personally collected the questionnaires when it is ready.

Analysis
Concerning the ratings of the original phrasing and rephrased QIs, for each of those, the phrasing with the higher median rating was chosen. QIs considered useful without remarks in round 1 and those considered useful in round 2 together filled the Indonesian face-valid set of QIs.

Analysis was performed based on the modified RAND/UCLA appropriateness method. QIs with a median rating of 7, 8, or 9 by at least 7 of the nine panelists in round 1, and at least 18 of the 21 panelists in round 2, were considered face-valid and useful.

We used the 10 QIs with the highest ratings in the Delphi rounds of the European study and compared those with the top 10 QIs in our Indonesian set. The quality criterion of the top 10 QIs was analyzed using descriptive analysis (frequencies).

Pilot test
We tested the applicability of the top 10 QIs. The 10 QIs with the highest ratings were translated into the Indonesian language (backward-forward procedure). Applicability was operationalized by the number of hospitals that accepted the invitation to participate, the number of completed questionnaires, and the reasons for not taking part or not completing the entire questionnaire. Besides, we checked per QI in which of the participating hospitals it was met.

Head nurses of combined surgical/oncology wards of seven general hospitals were invited to participate, including those five that were obliged by the Indonesian Government to start a palliative care program. Each of these general hospitals is also a teaching hospital for medical and nursing students.

Each QI of the top 10 QIs was reformulated in a question, and of each hospital, a head nurse answered them. With regard to eight QIs, the head nurses indicated whether or not their department met these quality criterions (yes/some/no). The other two QIs concerned structured clinical record keeping, and consisted of 11 sub-questions. To
assess these two QIs, the head nurse was asked to check 10 patient records. Inclusion criteria for these patient records were that the patient had advanced cancer and was already discharged from hospital.

The questionnaire was sent by email, and all respondents were asked to send back the completed questionnaire by email.

**RESULTS**

In round 1, which took place from March to November 2010, 9 of the 12 invited experts (75%) participated. Five of them were physicians and four were nurses (Table 1).

In round 2 (June to September 2011), all 12 invited additional panelists participated together with all nine panellists that rated round 1 (21 panelists; 87%). The panel of round 2 was composed of 13 (62%) physicians, 6 (28%) nurses, and 2 (10%) lecturers. The median age was 47 years (range 32–75 years). Most of them (90%) combined a clinical with an academic position. Twelve panelists (63%) worked in a palliative care unit. The others (10%) only worked at a university.

**Table 1. Characteristics of the panelists**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Round 1 (n=9)</th>
<th>Round 2 (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (45)</td>
<td>6 (29)</td>
</tr>
<tr>
<td>Female</td>
<td>5 (55)</td>
<td>15 (71)</td>
</tr>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;40</td>
<td>0</td>
<td>4 (19)</td>
</tr>
<tr>
<td>41–60</td>
<td>9 (100)</td>
<td>15 (71)</td>
</tr>
<tr>
<td>&gt;60</td>
<td>0</td>
<td>2 (10)</td>
</tr>
<tr>
<td><strong>Median, range</strong></td>
<td>47, 32–75*</td>
<td></td>
</tr>
<tr>
<td><strong>Professional</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haematology oncology specialist</td>
<td>0</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Palliative physician</td>
<td>2 (22)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Anaesthesiologist</td>
<td>1 (11)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Geriatriest</td>
<td>1 (11)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Neurologist</td>
<td>0</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Rehabilitation medical doctor</td>
<td>0</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Medical doctor</td>
<td>1 (11)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Nurse manager</td>
<td>2 (22)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>2 (22)</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Nurse (lecturer)</td>
<td>0</td>
<td>2 (9)</td>
</tr>
</tbody>
</table>

* Round 2

In round 1 of the Delphi process, 51 of the 98 draft QIs were rated useful without suggestions for rephrasing. The remaining 47 QIs were rated invalid, and 17 of them needed rephrasing. Two new QIs were added (Figure 1). Those 49 QIs were rated again in round 2.

In round 2, another 27 QIs were rated useful. Together with those already rated useful in round 1, 78 QIs in total were considered useful (Figure 1 and Table 2).
Face-validation of quality indicators for the organization of palliative care in hospitals

Figure 1. Diagram of the Delphi process

Table 2. Number of indicators rated as face-valid per domain in modified RAND Delphi rounds 1 and 2 in Indonesia

<table>
<thead>
<tr>
<th>Domains</th>
<th>n^a</th>
<th>Face-valid</th>
<th>Invalid</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Access to palliative care</td>
<td>29</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>2. Infrastructure</td>
<td>17</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>3. Assessment tools</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>4. Personnel in palliative care services</td>
<td>20</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>5. Documentation of clinical data</td>
<td>19</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>6. Quality and safety issues</td>
<td>7</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>7. Reporting clinical activity of palliative care services</td>
<td>4</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>98^a +2^b</td>
<td>78</td>
<td>22</td>
</tr>
</tbody>
</table>

^a Number of indicators from a set of draft structure and process Europall Quality Indicators.
^b Suggested by the experts in round 1 of the modified Rand Delphi procedure (new indicators)
Access to palliative care
Twenty-three of 29 QIs were considered useful (median rating 8–9). For example, the panelists agreed that a palliative care team should be available at the patient's home and in the hospital. Furthermore, specialized advice and consultation should be available 24 h a day, 7 days a week, for palliative team members who provide palliative care. A new QI considered important was the availability of a priority bed for patients needing palliative care who are in a crisis when admitted to hospital. Also availability of syringe drivers for a palliative patient 24/7 was not considered useful.

Infrastructure
Fourteen of 17 QIs were considered useful. It was agreed that there should be a dedicated room where interdisciplinary team meetings take place. Furthermore, dedicated information about the palliative care service, such as leaflets or brochures were considered a quality criterion. Another QI that appeared important was availability of specialist nursing equipment, such as anti-decubitus mattresses and oxygen delivery. A new QI considered useful was availability of phone facilities for interdisciplinary communication. No consensus was reached on facilities for telephone or videoconference for interdisciplinary communications across settings.

Assessment tools
Consensus was reached on both QIs in this domain, namely, the availability of a validated instrument to assess pain and other symptoms and holistic assessment of the palliative care needs of patients and their family caregivers.

Personnel in palliative care services
Consensus was reached for 12 of 20 QIs. A physician, a nurse, a spiritual or religious caregiver, a physiotherapist, a social worker, and a bereavement counselor were considered important members of the palliative care team. It was also agreed that there should be a daily interdisciplinary meeting to discuss the day-to-day management of each patient as well as a weekly meeting to review patient referrals and care plans. Having standardized induction training for new staff and an annual appraisal were also considered important. No consensus was reached on having a pharmacist as a member of the palliative care team.

Documentation of clinical data
All but one of the 19 QIs were included. It was agreed that there should be a structured clinical record for each patient receiving palliative care, and the record should include a clinical summary, documentation of the physical, psychological, social, spiritual, cultural,
and ethical aspects of care, a multidimensional treatment plan, and follow-up assessment. Other quality criteria considered important were the documentation of pain assessment at 4-h intervals for hospitalized patients. The only invalid QI in this domain was having a computerized medical record, to which all professional caregivers involved in the care of palliative care patient should have access.

**Quality and safety issues**

Consensus was reached for five out of seven quality criteria in this domain. It was agreed that a palliative care service should have a quality improvement program including clinical audits. A patient complaint procedure was considered important. There was also consensus about a register and documentation of adverse events. No consensus was reached on the use of a program about early initiation of palliative care.

**Reporting the clinical activity of palliative care services**

All four QIs in this domain were considered face-valid. An example was having a database for recording clinical activity such as diagnosis, date of diagnosis, date of referral, date of admission to the palliative care, date and place of death, and preferred place of death. It was considered important that the service writes an annual report based on these data.

Table 3 shows the 10 highest rated QIs of Indonesia and of Europe. They shared four QIs, namely, availability of a palliative care team, patient privacy aspects, use of a structured medical record, and certified training in palliative care for team members.

**Pilot applicability test**

Five of seven hospitals participated in this pilot test, of which three were obliged by the Indonesian Government to start a palliative care program. In each of these hospitals, a head nurse completed all questions.

Eight QIs were evaluated by head nurses and 2 through the evaluation of 50 patient records. Regarding the eight QIs that concern the palliative care management, two to five of the five hospitals met them (e.g., on consultation in a room with privacy, having facilities to stay overnight for relatives) (Table 4). All five hospitals mentioned to have a policy to register adverse events and a standard procedure to report them (Table 4).

The two QIs on structured clinical record keeping, consisting of 11 sub-questions, were met in 58–98 % of the medical records (Table 5). The lowest percentages were found for documentation of information on the care of the imminently dying patient (60 %) and for documentation of cultural aspects such as cultural background (Javanese, Sundanese, etc.) (58 %; Table 5).
### Table 3. The ten highest rated quality indicators in Indonesia and Europe *

<table>
<thead>
<tr>
<th>No.</th>
<th>Quality indicator (domain)</th>
<th>Indonesia</th>
<th>Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A palliative care team is available at the in-patient ward (A)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Opioids and other controlled drugs are available for patients receiving palliative care 24 hours a day, 7 days a week (A)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>A palliative care team is available at the out-patient clinic (A)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Anticipatory medication for the dying palliative patient are available for a palliative patient 24 hours a day, 7 days a week (A)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Before discharge, transfer, and admission, information regarding care and treatment is given to the caregivers in the next setting (A)</td>
<td>All volunteers should have training in palliative care (P)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>There are facilities for a relative to stay overnight (I)</td>
<td>A palliative care team is available at home (A)</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Consultations with the patient and/or family and informal caregivers take place in an environment where privacy is guaranteed, e.g. there is a dedicated room (I)</td>
<td>A palliative care team is available in the hospital (A)&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>A physician and a nurse are essential members of a multidisciplinary palliative care team (P)</td>
<td>Consultations with the patient and/or family and informal caregivers take place in an environment where privacy is guaranteed, e.g. there is a dedicated room (I)</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>All team members have accredited training in palliative care that is appropriate to their discipline (P)</td>
<td>Specialist equipment (e.g. antidecubitus mattresses) is available for the nursing care of patients receiving palliative care in each specific setting (I)</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>A structured clinical record is kept for each patient receiving palliative care (D)</td>
<td>A structured clinical record is kept for each patient receiving palliative care (D)</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>The palliative care clinical record contains a clinical summary (D)</td>
<td>A discharge or transfer summary accompanies the patient receiving palliative care when that patient is discharged or transferred (D)</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>There is a register for adverse events (Q)</td>
<td>All team members should have certified training in palliative care that is appropriate to their discipline (P)</td>
<td></td>
</tr>
</tbody>
</table>

(A) Access to palliative care; (D) Documentation of clinical data; (I) Infrastructure; (P) Personnel in palliative care services; (Q) Quality and safety issues

*Quality indicators were ranked on the basis of the highest rating of all the panelists

<sup>b</sup> A palliative care team is available in the hospital (Europe) were divided into in-patients ward and out-patient clinic (Indonesia).
<table>
<thead>
<tr>
<th>QI</th>
<th>Question</th>
<th>Yes</th>
<th>(n/%)</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A palliative care team is available in the hospital</td>
<td>Is there a specialist palliative care team present in your hospital?</td>
<td>4(80)</td>
<td>1(20)</td>
<td>Some (80%) Yes (20%)</td>
</tr>
<tr>
<td>A palliative care team is available at the in-patient ward</td>
<td>If yes, does the ward where patients with advanced cancer stay make use of this specialist palliative care team?</td>
<td>2(40)</td>
<td>2(40)</td>
<td>1(20)</td>
</tr>
<tr>
<td>2. A palliative care team is available at the out-patient clinic</td>
<td>If yes, does the oncology out-patient clinic make use of this specialist palliative care team?</td>
<td>2(40)</td>
<td>1(20)</td>
<td>2(40)</td>
</tr>
<tr>
<td>3. A physician and a nurse are essential members of a multidisciplinary palliative care team</td>
<td>Of which professionals consists the team that delivers palliative care in your hospital? (multi-answer available)</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>4. There is a register for adverse events</td>
<td>Is there in your organization a policy to register adverse events?</td>
<td>5(100)</td>
<td></td>
<td>All participants explain briefly the procedure to register adverse events in their hospitals.</td>
</tr>
<tr>
<td>5. Before discharge, transfer, and admission, information regarding care and treatment is given to the caregivers in the next setting</td>
<td>Is there a standard exchange of information procedure in your hospital regarding care and treatment of the patient for the caregivers in the next setting?</td>
<td>4(80)</td>
<td>1(20)</td>
<td></td>
</tr>
<tr>
<td>QI</td>
<td>Question</td>
<td>(n/%)</td>
<td>Note</td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If yes, which information is given? (multi-answer possible)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Diagnosis and Prognosis</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Summary of medical history</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Summary of treatment undertaken</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Treatment goal including:</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Medical goals</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Nursing goals</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Psychosocial goals</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Spiritual goals</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Care plan</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Medication list</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Spiritual/religious beliefs</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Family situation</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Contact person(s)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Consultations with the patient and/or family and informal caregivers take place in an environment where privacy is guaranteed, e.g. there is a dedicated room</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Is there in your hospital a policy that consultation/meeting with a patient and family takes place in a room with privacy?</td>
<td>4(80)</td>
<td>1(20)</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Does the consultation/meeting with the patient and family usually take place in a private room (without other patients hearing or seeing it)?</td>
<td>3(60)</td>
<td>2(40)</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>All team members have accredited training in palliative care that is appropriate to their discipline</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2-10% nurses had training in palliative care</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Table 5. Percentage of the quality indicators of palliative care management for patients with cancer based on documentation in medical records (n=50) in five hospitals in Indonesia**

<table>
<thead>
<tr>
<th>QI</th>
<th>Quality indicators</th>
<th>Yes n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The palliative care clinical record should contain evidence of documentation of following items: physical symptom e.g. pain, fatigue, sleeping problems, cough etc.</td>
<td>48 (96%)</td>
</tr>
<tr>
<td></td>
<td>psychological aspects e.g. depressed mood, anxiety, etc.</td>
<td>38 (76%)</td>
</tr>
<tr>
<td></td>
<td>social aspects e.g. problems in the relationship with the life companion, difficulties to find someone to talk, name of contact person</td>
<td>39 (78%)</td>
</tr>
<tr>
<td></td>
<td>spiritual and religious aspects e.g. religion, difficulties accepting the disease</td>
<td>49 (98%)</td>
</tr>
<tr>
<td></td>
<td>cultural aspects e.g. cultural background (javanese, sundanese, etc)</td>
<td>29 (58%)</td>
</tr>
<tr>
<td></td>
<td>financial aspects e.g. cover by health insurance</td>
<td>48 (96%)</td>
</tr>
<tr>
<td></td>
<td>autonomy aspects e.g. who make decision of patient's treatment</td>
<td>39 (78%)</td>
</tr>
<tr>
<td></td>
<td>documentation of ethical, legal aspects of care e.g. inform consent for diagnostic procedures</td>
<td>48 (96%)</td>
</tr>
<tr>
<td></td>
<td>documentation of care of imminently dying patient</td>
<td>30 (60%)</td>
</tr>
<tr>
<td></td>
<td>a multi-dimensional treatment plan</td>
<td>36 (72%)</td>
</tr>
<tr>
<td></td>
<td>a follow up assessment</td>
<td>41 (82%)</td>
</tr>
<tr>
<td>2</td>
<td>The medical record contains a clinical summary</td>
<td>48 (96%)</td>
</tr>
</tbody>
</table>

**DISCUSSION**

Based on a European set of QIs, we face-validated and tested the first Indonesian set of structure and process QIs for the organization of palliative care, using a modified two-round RAND Delphi procedure. These QIs cover seven domains. Most QIs of the European set (76 of 98 QIs) were considered useful for assessing the organization of palliative care for hospital setting in Indonesia too, and two new ones were added. Twenty-two QIs were not rated face-valid. Some of them, like having telephone and videoconference facilities or having a computerized medical record that is accessible across settings, probably were rejected as these might be too innovative or expensive for this developing country, even though these might be very useful in Indonesia because of its geography. Also, the indicator about having syringe drivers was rejected, probably because they are expensive. It is not a surprise that no consensus was reached on the use of a program about early initiation of palliative care, as most patients with cancer in Indonesia already have advanced cancer when they first visit the hospital.

In five of the seven invited hospitals, head nurses completed the questionnaire, which consisted of the 10 QIs with the highest rankings. Each QI was met by at least two hospitals and only one by all five. Interestingly, the QI on having facilities to stay overnight for relatives of patients with cancer was only met by two hospitals, although it is a daily practice in Indonesia that the family stays with the patient 24/7. Apparently, mostly the family sleeps on the floor, as only two hospitals provide a fully equipped guest room or a sofa or bed in the room of the patient. All hospitals met the QI on having a policy to register and report adverse events. Also, the QIs on structured medical record...
keeping were mostly met (96–98%). This is not a surprise as all hospitals in Indonesia regularly have internal and external audits as part of national and international accreditation procedures. Nursing documentation is part of this.\(^{10}\) This structured way of medical record keeping is also found in the USA, where patient medical records also are an important resource to evaluate the quality of palliative care.\(^{22,23}\) Transferring and validating QIs between countries using a modified RAND Delphi procedure has been done in previous studies.\(^{14,18}\) For example, Steel and colleagues developed QIs for older adults in the UK by validating an existing USA set of QIs.\(^{18}\) Regarding the organization of general practitioners, Engels et al. also used several existing sets of QIs in an international modified RAND Delphi process with nine countries.\(^{6,7}\) Vasse et al. developed a set of QIs for psychosocial dementia care, also with an international RAND Delphi process.\(^{20}\)

**Strengths and limitations**

In this study, the panelists (physicians, nurses, and lecturers) reached consensus without knowing the other panelists.\(^{11}\) Such anonymity minimizes biasing effects of factors such as personality, seniority, and experience.\(^{9}\) However, the findings of a modified RAND Delphi study do not necessarily offer indisputable facts. The expert consensus that a Delphi study provides is nonetheless stronger than that of other types of consensus such as focus group meetings or conferences.\(^{12,16}\)

We only piloted the top 10 QIs and only in a limited number of hospitals. For that reason, the results of this pilot cannot be generalized for Indonesia as a whole. As three of the five participating hospitals are obliged to have a palliative care program, we expect that in other Indonesian hospitals, without such an obligation, the QIs will less often be met. For that reason, we expect that they will have discriminative power.

**Implications for quality assessment**

The applicability of this set of QIs will become more explicit through wider implementation and utilization in combination with quality-improvement activities.\(^{4,6}\) In the future, this Indonesian set of QIs can also be used for other purposes, such as supporting professional quality-improvement activities, clinical accreditation, and research and enhancing the transparency of the quality of palliative care.

**Conclusion**

We found that most QIs for the organization of palliative care developed for European countries were also considered face-valid and applicable in Indonesia. This might implicate that there is a strong common path in the organization of palliative care even in countries with profound economic and cultural differences. This Indonesian set of QIs
should be considered as a first step in developing, testing, and implementing a set of QIs for palliative care in Indonesia. We recommend validating them also in other Asian countries, in order to develop an Asian set of QIs.
REFERENCES


Appendix 1. Final indicators were rated as useful in a two-round Modified RAND Delphi by all panelists in Indonesia.

<table>
<thead>
<tr>
<th>No.</th>
<th>indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Access to palliative care</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>At day care (for patients who need palliative treatment e.g. transfusion, chemotherapy etc, including respite care), a palliative care team is available at the request of the treating professional</td>
</tr>
<tr>
<td>2</td>
<td>A palliative care team is available at home</td>
</tr>
<tr>
<td>3</td>
<td>A palliative care team is available at Hospital</td>
</tr>
<tr>
<td>4</td>
<td>A palliative care team is available at Out-patient clinic</td>
</tr>
<tr>
<td>5</td>
<td>All patients and their families have access to palliative care facilities throughout the entire duration of their disease</td>
</tr>
<tr>
<td>6</td>
<td>All patients and their families have access to palliative care facilities with acceptable extra financial consequences for the patient</td>
</tr>
<tr>
<td>7</td>
<td>Patients receiving palliative care have access to diagnostic investigations (e.g. X-rays, blood samples) as need it regardless of their setting (not for dying patients)</td>
</tr>
<tr>
<td>8</td>
<td>Specialized palliative care is available for the patient by phone</td>
</tr>
<tr>
<td>9</td>
<td>Admission for a palliative patient in a crisis, is arranged within 24 hours</td>
</tr>
<tr>
<td>10</td>
<td>An urgent discharge to patients home for a palliative patient in a crisis, is arranged within 24 hours</td>
</tr>
<tr>
<td>11</td>
<td>Transfer to another setting of care for a palliative patient in a crisis, is arranged within 24 hours</td>
</tr>
<tr>
<td>12</td>
<td>There is an in-patient bed dedicated for a palliative patient in crisis as priority</td>
</tr>
<tr>
<td>13</td>
<td>A member of a palliative care team is available 24 hours a day, 7 days a week for palliative care consultation by phone</td>
</tr>
<tr>
<td>14</td>
<td>A member of a palliative care team is available 24 hours a day, 7 days a week to provide bedside care in a crisis</td>
</tr>
<tr>
<td>15</td>
<td>Opioids and other controlled drugs are available for a palliative patient 24 hours a day, 7 days a week</td>
</tr>
<tr>
<td>16</td>
<td>Anticipatory medication for the dying patient is available for a palliative patient 24 hours a day, 7 days a week</td>
</tr>
<tr>
<td>17</td>
<td>Syringe drivers are available for a palliative patient 24 hours a day, 7 days a week (if applicable)</td>
</tr>
<tr>
<td>18</td>
<td>There is a procedure for exchange of clinical information across caregivers, disciplines and settings</td>
</tr>
<tr>
<td>19</td>
<td>Before discharge/transfer/admission there is information transfer to the caregivers in the next setting regarding care and treatment</td>
</tr>
<tr>
<td>20</td>
<td>The responsible ‘case manager’ pays special attention to continuity of care within and across settings</td>
</tr>
<tr>
<td>21</td>
<td>Member of palliative team is routinely called to monitor/follow up the patient's condition when discharged home or transferred to another setting</td>
</tr>
<tr>
<td>22</td>
<td>The discharge/transfer letter of palliative care patients contains a multidimensional diagnosis, prognosis and treatment plan</td>
</tr>
<tr>
<td>23</td>
<td>The out-of-hours service has handover forms (written or -electronic) with clinical information of all palliative care patients in the terminal phase at home</td>
</tr>
<tr>
<td><strong>Infrastructure</strong></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Specialist equipment (e.g. anti decubitus mattresses) is available for the nursing care of palliative care patients in each specific setting</td>
</tr>
<tr>
<td>25</td>
<td>There is a dedicated room where interdisciplinarty team meetings within one setting take place</td>
</tr>
<tr>
<td>26</td>
<td>There is dedicated facilities for multidisciplinary communications across settings: A dedicated room for meetings</td>
</tr>
<tr>
<td>No.</td>
<td>Indicators</td>
</tr>
<tr>
<td>-----</td>
<td>------------</td>
</tr>
<tr>
<td>27</td>
<td>There are facilities for interdisciplinary communications across settings take place by phone (if applicable)</td>
</tr>
<tr>
<td>28</td>
<td>There is an up to date directory of local caregivers and organizations that can have a role in palliative care</td>
</tr>
<tr>
<td>29</td>
<td>There is dedicated information about the palliative care service: Leaflets or brochures</td>
</tr>
<tr>
<td>30</td>
<td>There is a website with dedicated information about the palliative care service</td>
</tr>
<tr>
<td>31</td>
<td>Patient information is available in relevant national and/or foreign languages (should be someone to translate in English for foreign patients)</td>
</tr>
<tr>
<td>32</td>
<td>Appropriately trained translators is available if professional caregivers and patient or family members do not speak the same language</td>
</tr>
<tr>
<td>33</td>
<td>There is a computerized medical record, to which all professional caregivers involved in the care of palliative care patients should have access: within one setting</td>
</tr>
<tr>
<td>34</td>
<td>Consultations with the patient and/or family / informal caregivers are done in an environment where privacy is guaranteed (e.g. there is a dedicated room)</td>
</tr>
<tr>
<td>35</td>
<td>Dying patients are able to have a single bedroom if they want to</td>
</tr>
<tr>
<td>36</td>
<td>There is the facilities for a relative to stay overnight</td>
</tr>
<tr>
<td>37</td>
<td>Family members and friends are able to visit the dying patient without restrictions of visiting hours</td>
</tr>
</tbody>
</table>

**Assessment tools**

<table>
<thead>
<tr>
<th>No.</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>38</td>
<td>There is a holistic assessment of palliative care needs of patients and their family caregivers</td>
</tr>
<tr>
<td>39</td>
<td>There is an assessment of pain and other symptoms using a validated instrument</td>
</tr>
</tbody>
</table>

**Personnel in palliative care services**

<table>
<thead>
<tr>
<th>No.</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>40</td>
<td>A physician and a nurse are essential members to have in a multidisciplinary palliative care team</td>
</tr>
<tr>
<td>41</td>
<td>A spiritual/religious caregiver is essential member to have in a multidisciplinary palliative care team</td>
</tr>
<tr>
<td>42</td>
<td>A Social worker and a bereavement counselor are essential members to have in a multidisciplinary palliative care team</td>
</tr>
<tr>
<td>43</td>
<td>A Physiotherapist is essential member to have in a multidisciplinary palliative care team</td>
</tr>
<tr>
<td>44</td>
<td>New staff receives a standardized induction training</td>
</tr>
<tr>
<td>45</td>
<td>All team members have accredited training in palliative care that appropriate to their discipline</td>
</tr>
<tr>
<td>46</td>
<td>All volunteer should have training in palliative care</td>
</tr>
<tr>
<td>47</td>
<td>All staff should have an annual appraisal</td>
</tr>
<tr>
<td>48</td>
<td>Satisfaction with working in the team is assessed (e.g. with the Team Climate Inventory)</td>
</tr>
<tr>
<td>49</td>
<td>Palliative care services works in conjunction with the referring professional/team</td>
</tr>
<tr>
<td>50</td>
<td>There is a daily inter- and multidisciplinary meeting to discuss day-to-day management of each palliative care patient</td>
</tr>
<tr>
<td>51</td>
<td>There is a regular inter-and multidisciplinary meeting to discuss palliative care patients: weekly meetings to review patients referrals and care plans</td>
</tr>
<tr>
<td>52</td>
<td>All relevant team members is informed about patients who have died</td>
</tr>
</tbody>
</table>

**Documentation of clinical data**

<table>
<thead>
<tr>
<th>No.</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>53</td>
<td>For patients receiving palliative care a structured clinical record is used</td>
</tr>
<tr>
<td>54</td>
<td>The palliative care clinical record contains a clinical summary</td>
</tr>
<tr>
<td>55</td>
<td>The palliative care clinical record contains documentation of physical aspects of care</td>
</tr>
<tr>
<td>56</td>
<td>The palliative care clinical record contains documentation of psychological and psychiatric aspects of care</td>
</tr>
<tr>
<td>57</td>
<td>The palliative care clinical record contains documentation of social aspects of care</td>
</tr>
<tr>
<td>58</td>
<td>The palliative care clinical record contains documentation of spiritual, religious, existential aspects of care</td>
</tr>
<tr>
<td>59</td>
<td>The palliative care clinical record contains documentation of cultural aspects of care</td>
</tr>
<tr>
<td>60</td>
<td>The palliative care clinical record contains documentation of care of imminently dying patient</td>
</tr>
<tr>
<td>61</td>
<td>The palliative care clinical record contains documentation of ethical, legal aspects of care</td>
</tr>
</tbody>
</table>
### Chapter 5

<table>
<thead>
<tr>
<th>No.</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>62</td>
<td>The palliative care clinical record contains a multidimensional treatment plan</td>
</tr>
<tr>
<td>63</td>
<td>The palliative care clinical record contains a follow up assessment</td>
</tr>
<tr>
<td>64</td>
<td>Within 48 hours of admission there is documentation of the initial assessment of: prognosis, functional status, pain and other symptoms, psychosocial symptoms and the patient’s capacity to make decisions</td>
</tr>
<tr>
<td>65</td>
<td>There is documentation that patients reporting pain or other symptoms at the time of admission, had their pain or other symptoms relieved or reduced to a level of their satisfaction within 48 hours of admission</td>
</tr>
<tr>
<td>66</td>
<td>A discharge/ transfer summary is available in the medical record within 48 hours after discharge/ transfer</td>
</tr>
<tr>
<td>67</td>
<td>There is documentation of pain assessment at 4 hour intervals</td>
</tr>
<tr>
<td>68</td>
<td>The discussion of patient’s preferences is reviewed on a regular basis (in parallel with disease progression) or on request of the patient</td>
</tr>
<tr>
<td>69</td>
<td>There is documentation that the responsible physician has visited the patient within 24 hours after patient transfer</td>
</tr>
<tr>
<td>70</td>
<td>There is documentation that the new palliative care team has visited the patient within 24 hours after patient transfer from one setting to another setting (for example: from in-patients to out-patients)</td>
</tr>
</tbody>
</table>

#### Quality and safety issues

<table>
<thead>
<tr>
<th>No.</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>71</td>
<td>There is documentation whether targets set for quality improvement have been met</td>
</tr>
<tr>
<td>72</td>
<td>Clinical audit is a part of the quality improvement program</td>
</tr>
<tr>
<td>73</td>
<td>There is a register for adverse events</td>
</tr>
<tr>
<td>74</td>
<td>There is a documented procedure to analyze and follow up adverse events</td>
</tr>
<tr>
<td>75</td>
<td>There is a patient complaints procedure</td>
</tr>
</tbody>
</table>

#### Reporting clinical activity of palliative care services

<table>
<thead>
<tr>
<th>No.</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>76</td>
<td>The palliative care service uses a database for recording clinical activity</td>
</tr>
<tr>
<td>77</td>
<td>The following is part of the database: diagnosis, date of diagnosis, date of referral, date of admission to the palliative service, date of death, place of death and prefer place of death</td>
</tr>
</tbody>
</table>
| 78  | From the database the service is able to derive:  
  a. Time from diagnosis to referral to palliative care  
  b. Time from referral to initiation of palliative care  
  c. Time from initiation of palliative care to death  
  d. Frequency of unplanned consultations with the out-of-hours service for palliative care patients who are at home  
  e. Frequency of unplanned hospital admissions of palliative care patients  
  f. Percentage of non-oncology patients receiving palliative care |
Chapter 6

General discussion
Considering that palliative care is patient-centered, concerns physical, psychological, social and spiritual issues, and is preferably delivered by a multi-professional team working in partnership with patients and their families, I started my PhD trajectory by assessing the problems and unmet needs of patients with advanced cancer in Indonesia (chapter 2). I also aimed to discover whether patients' problems were addressed, and if so by whom, during hospitalization (chapter 3). Since, in Indonesia, family caregivers accompany the patient 24/7, I also assessed how family caregivers are involved in caring for hospitalized patients with cancer and which factors influence their quality of life (chapter 4). In order to improve the quality of the organization of palliative care in hospitals in Indonesia, I also conducted a two-round RAND Delphi process to face-validate quality indicators for the organization of palliative care in hospitals (chapter 5).

In this current chapter, the main findings of these studies are presented and discussed in the light of relevant and recent literature. Also the methodology of the research project will be discussed. Finally, recommendations for practice and for policy makers, as well as for future research, will be offered.

Problems of patients with cancer and their unmet needs

In order to provide patient-centered palliative care, having insight into patients' symptoms and needs is a prerequisite. It was assumed that patients with advanced cancer, in a country with a relatively low economic status, will have more problems and unmet needs than in an economically stronger country. It was also assumed that a different health care system and culture will influence patients' problems and unmet needs. For those reasons, the problems and needs of patients with advanced cancer in Indonesia were compared with a similar group of patients in the Netherlands, using an equal questionnaire (chapter 2).

We found that the prevalence of most physical problems, except fatigue, was similar in the Dutch and in the Indonesian study group. Apparently, economic and cultural differences hardly influence physical problems, as these are widely determined by the disease. Cultural differences, such as strong family bonds in Indonesia and a more individualistic culture in the Netherlands, might override economic differences.

In Indonesia, fewer respondents reported to be fatigued than in the Dutch study's population. This might be explained by the fact that cancer-related fatigue is not merely a physical symptom but also a subjective and multidimensional symptom with physical, emotional and mental components.\textsuperscript{1,3} Besides, a different culture-related perception of the meaning of fatigue might also have influenced these figures.

Psychological problems appeared more often in the Dutch study population (50 to 90\%) than in Indonesia (20 to 50\%). People living in Java, for example, have Javanese values such as temen (being earnest), nrima (being sincere), sabar (being patient) and rila
(being compassionate). These values are important for Javanese people, in daily life and also when facing a disease,\(^4\) and might have positively influenced the psychological condition of the patients. Furthermore, in Indonesia it is considered obligatory to take care of an ill loved one, including during hospitalization. Almost always a family member accompanies the hospitalized patient 24 hours a day.\(^5\) Being accompanied by the family might also have positively influenced the psychological status of the Indonesian respondents. Yet, reluctance to discuss their psychological and social concerns with healthcare providers may also have contributed to these figures.\(^6\)-\(^9\)

Problems related to issues of autonomy were less prevalent in Indonesia than in the Netherlands. Probably autonomy is not an issue in Indonesia, as being dependent on the family during illness is in line with Indonesian culture. Autonomy, in relation to patient-centered care, has been identified as a key element of palliative care provision internationally.\(^10\) Therefore, understanding patient autonomy is very important in providing patient-centered palliative care. Yet, in Indonesia autonomy seems to be not an individual's but a family's concern.\(^5\),\(^6\) For example, when a female patient with cancer has to make a decision regarding her treatment, she might say "Please ask my husband, he will make the decision for me" or "I have to ask my children about it." Yet, although often the patient will refer to her family in decision-making, with regard to patient-centeredness, this family involvement is a decision that the patient makes, and not the health professional.

It was found that spiritual problems were less often mentioned in Indonesia than in the Netherlands. This is not a surprise as spirituality is strongly influenced by culture.\(^11\)-\(^13\) As was mentioned in chapter 1, culture, religion and beliefs influence palliative care implementation in Indonesia. The majority of Indonesians are Muslim and religion plays an important role in their daily lives. This might ease acceptance of their disease and limited life expectancy. Besides, almost every hospital in Indonesia has spiritual caregivers to support patients in accordance with their religion, which might have contributed to relieving or preventing spiritual problems.

In Indonesia, financial problems were most prevalent (72 to 79%). About 30% of the respondents were government employees, which implies that they have a health insurance and most other respondents probably did not. Besides, about 15% of the Indonesian population is poor,\(^14\) yet still has to pay for their hospital stay, transportation, food, and medication.\(^5\) Recently, the health care system has changed, which will make it easier for poor people to get adequate health care.\(^15\),\(^16\)

Considering the concept of patient-centered care, as described in chapter 1, this study not only assessed patients' problems but also patients' needs. Regarding almost all problems, respondents in Indonesia needed more professional attention. For that reason it is crucial that health care providers in Indonesia pay more attention not only to
physical but also to non-physical problems of patients with cancer, in order to improve the quality of life of those patients with cancer.

The role of professionals and family caregivers in addressing problems of hospitalized patients with cancer

This study assessed what kind of symptoms and issues of Indonesian patients with cancer are addressed during hospitalization and who addressed their problems (chapter 3).

Of the 150 invited hospitalized patients, 119 (79%) filled in the questionnaire. Almost all respondents (93–98%) replied that their physical symptoms, their restrictions regarding activities of daily living (ADL) and their psychological issues were addressed.

We found that the family was strongly involved in addressing patients' symptoms and issues during hospitalization. Very often, only the family and not the professionals, was involved in addressing financial, autonomy, psychological, and social issues. The patients, as well as their families, feel more comfortable when they are near each other. They also feel comfortable sharing their psychosocial concerns with their own family. However, reluctance of patients to discuss their psychosocial concerns with their healthcare providers may also have contributed to these figures.

Indonesian family bonds are strong and contribute to the fact that families are cohesive groups that protect each other and demand loyalty throughout life. Particularly in Java, the importance of the family is reflected in the proverb: mangan ora mangan waton kumpul (even if there is no food to eat, being together is the most important thing).

We found that as well the family, the nurse and the doctor usually address physical symptoms. Regarding physical symptoms, usually the patient reports the symptoms to the family caregiver and then the family caregiver directly goes to the nursing station to report these problems. The nurse will also address the patient's problems based on instructions by the doctor, or the doctor will directly react to symptoms he assessed himself.

Patients also reported that, as well the family, the nurse and the doctor addressed their spiritual issues. This is not a surprise as spirituality is not restricted to religion only, but also concerns values and beliefs such as culture, life itself and relationships with family and friends. The doctor visiting the patient or 'being there' for the patient might also have contributed to spiritual well-being.

Patients reported that the doctors focused mainly on physical symptoms, while nurses also took care of other disease-related symptoms and issues, which is congruent with the nursing paradigm and the concept of caring in Indonesia. A study of doctor-patient communication in Indonesia showed that there was inadequate communication between the doctor and the patient. This appeared to be due to no or insufficient training of the
doctor, lack of time due to high patient load, which is inherent in the organization of health care in the hospital, and the doctors' belief that patients were not prepared for a more participatory style.\textsuperscript{23} Besides, participation of patients in active communication is often low.\textsuperscript{9}

A quarter of the patients reported that nurses addressed their financial issues. As nurses do not have the resources to give financial support, this reporting probably refers to the fact that the nurse tells the patient how to apply for reduced hospital payment via the Jamkesmas program, which is a health care program for people with low incomes who need hospitalization.\textsuperscript{15} Nonetheless, most patients stated that the family took care of financial issues. This finding is logical, as they need to pay the hospital fees, and solve other financial issues by helping the patients get funding from the Jamkesmas program.

Patient-centered palliative care also involves teamwork (chapter 1). Yet, we did not study whether there was partnership between professionals and family in caring for a hospitalized patient or whether they work independently of each other; each group not knowing what the other does.

\textbf{Family involvement in caring for hospitalized patients with cancer: does it influence their quality of life?}

As mentioned before, in Indonesia the family almost always accompanies the patient 24/7 during hospitalization. Care giving is demanding and overwhelming and can be a very stressful experience that affects all aspects of the caregivers' quality of life (QoL).\textsuperscript{24-26} As the WHO definition of palliative care mentions, not only patients need to be cared for, but so do their family caregivers;\textsuperscript{27} we identified what kind of involvement the family caregivers provide and how this involvement in caring for a hospitalized patient with cancer influences their quality of life (chapter 4).

Exactly 100 family caregivers of hospitalized patients with cancer completed the questionnaire. We found that being involved in addressing psychological issues, being younger, not being the spouse, and having no previous experience of caring for a hospitalized patient with cancer negatively influenced the QoL of family caregivers.

Several studies support these findings and show that psychological issues experienced by a patient also burden the family caregivers, because of their strong relationship.\textsuperscript{28,29} For example, family caregivers also experience physical and psychological problems as a result of their involvement in caring.\textsuperscript{30} And they also experience some challenges, extra pressure to adapt and extra work, creating frustration and uncertainty during the period of care giving.\textsuperscript{31}

We also found that younger family caregivers had a lower QoL than the older ones. Younger family caregivers are more likely to experience distress than older ones when performing their (new) role as a caregiver of a relative with cancer.\textsuperscript{32,33} The distress of
Chapter 6

those who are younger might be related to combining this caregiver role with a job and being the parent of young children.\(^{34,35}\)

We found that 58% of the family caregivers were non-spousal caregivers, often being the adult child of the patient. Being the non-spousal caregiver appeared negatively correlated to their QoL. Also Wadhwa et al. (2013) found that a better QoL of family caregivers was associated with not providing care to other dependents.\(^{25}\)

We found that most respondents (78\%) did not have previous experience in caring. This confirms findings of another study: a major stress factor for caregivers is uncertainty about their own knowledge and skills.\(^{36}\) Apparently, family caregivers without previous caring experience, as well as those who have to deal with patients that have psychological problems, need specific attention from a professional caregiver to decrease their burden and enhance their QoL.

The findings of this study provide new insights into the involvement of family caregivers in caring for hospitalized patients with cancer. Timely screening of family caregivers' problems will have a positive effect on their QoL and capability to care for their loved one.\(^{37}\) Training family caregivers in how to care for the patient, and how to handle emotional and other symptoms, might contribute to a better QoL of them.\(^{38}\) Besides, they might need psychosocial interventions themselves.

Assessing the quality of the organization of palliative care in Indonesian hospitals: face-validation of quality indicators

In Indonesia, more than 60\% of the patients seek healthcare service when they are already in an advanced stage of the disease.\(^{39}\) As a result, many hospitalized patients with cancer need palliative care. Professionals who provide palliative care should work as a team and involve both the patient and their family. Quality indicators (QIs) for the organization of palliative care can help them to evaluate and improve the quality of the palliative care. Even though there is a regulation on palliative care in Indonesia (Kep MenKes. No 812/Menkes/SK/VII/2007 tentang Kebijakan perawatan paliatif),\(^{40}\) there were no QIs that measure the organization of palliative care in hospitals for patients with cancer (chapter 5).

We performed a modified two-round Rand Delphi process to face-validate a European set of structure and process QIs for the organization of palliative care for the Indonesian context.

The set of structure and process QIs we developed covers 7 domains. Three out four QIs developed for European countries (76 of 98 QIs) were considered face-valid and applicable in Indonesia too. This suggests that there is a common path in the organization of palliative care, even in countries with profound economic and cultural
differences. Two new QIs were added and 22 QIs of the original European set were not rated face-valid and excluded.

Some QIs, like 'having telephone and video-conference facilities', 'having a computerized medical record that is accessible across settings' and 'the use of a syringe driver' were rejected. Probably they are too innovative or expensive for Indonesia, even though these techniques might be very useful in Indonesia because of its geography.

Finally, no consensus was reached on the use of a program about early initiation of palliative care, which is obvious as most patients with cancer in Indonesia already have advanced cancer when they first visit the hospital.16

Next, an applicability pilot test for the 10 QIs with the highest rankings was performed in five hospitals. The results of the pilot test can be used to evaluate whether these QIs are applicable in Indonesian hospitals. For example, the QI on having facilities to stay overnight for relatives of patients with cancer was only met by two hospitals, although it is daily practice in Indonesia that the family mostly stays with the patient 24/7.5

Apparently, most of the family members sleep on the floor, as only two hospitals provide a fully equipped guest room, or a sofa or bed in the room of the patient. All hospitals met the QI on having a policy to register and report adverse events. Also the QIs on 'structured medical record keeping' were mostly met (96-98%). Recently, almost all hospitals in Indonesia regularly have internal and external audits as part of national and international accreditation procedures. Nursing documentation is part of this.41 The applicability of this set of QIs will become more explicit through wider implementation and utilization in combination with quality improvement activities.42,43

This set of Indonesian QIs has only a few QIs that are related to the quality of care for family caregivers. Since family in Indonesia is highly involved in caring for hospitalized patients with cancer, we expect that explicit QIs on family care giving in Indonesian hospitals are required. Just asking to mention missing QIs, as has been done during the Delphi procedure, probably is not enough to retrieve QIs on all relevant aspects of the organization of palliative care. Thus, this set of QIs should be considered a first step in developing, testing and implementing a set of QIs for palliative care in Indonesia.

**Methodological considerations**

We used a variety of research methods to answer the research questions of this thesis. I will reflect on the strengths and limitations of these methods.

A cross-sectional design (chapters 2, 3 and 4) was an appropriate method to receive a first insight in several aspects concerning advanced cancer care in Indonesia. When I started my research project in 2009, the literature on palliative care in Indonesia was scarce. To get more insights into the quality of palliative care in my country, I decided to assess problems and needs in patients with advanced cancer with a cross-sectional study,
To answer these research questions, I made use of an instrument that was developed in the Netherlands about 10 years ago, the Problems and Needs in Palliative Care short version (PNPC-sv).\textsuperscript{44} By translating and adapting this existing Dutch instrument, I probably missed problems and needs that were not in the Dutch instrument, but might have been relevant in the Indonesia. Yet, this tool covers the same domains as mentioned in the regulation of palliative care in Indonesia.\textsuperscript{40}

Although it is well-known that in Indonesia the family feels responsible and obliged to take care of the patient, including during hospitalization, there was no study about the kind of involvement in caring by the family caregivers during accompanying the hospitalized patient and how this involvement in caring influences their own QoL. For this reason, again based on the domains and problems of the PNPC-sv questionnaire,\textsuperscript{44} we developed the Family Involvement in Caring for Cancer patients (FCIC-C) questionnaire to identify family caregivers' involvement in caring for patients with cancer (chapter 4).

These cross-sectional studies, (chapters 2, 3 and 4) give a first impression on problems and needs of patients with advanced cancer in Indonesian hospitals, on how family caregivers are involved in caring for their hospitalized relative with cancer, and on how this involvement in caring influences the quality of life of the family caregivers. The information gathered within the studies described in chapters 2, 3 and 4 resulted in new research questions that can be studied in future projects, in which the effect of appropriate interventions can be tested with the help of prospective cohort or controlled studies.

We used a two-round modified Rand Delphi process to face-validate the first Indonesian set of structure and process QIs for the organization of palliative care in hospitals (chapter 5). When research evidence is lacking, such a consensus method to determine the extent of agreement about an issue is an accepted approach.\textsuperscript{45} Further exploration of missing country-specific QIs, validation and pilot-testing is needed.\textsuperscript{43}

We invited experts from five Indonesian hospitals (Jakarta, Surabaya, Yogyakarta, Makassar and Denpasar) that are obliged by the Ministry of Health to provide palliative care.\textsuperscript{40} In this study, the panelists (physicians, nurses, and lecturers) reached consensus without knowing the other panelists.

We only pilot tested the top 10 QIs, and only in a limited number of hospitals. For those reasons, the results of this pilot cannot be generalized for Indonesia as a whole. As three of the five participating hospitals are obliged to have a palliative care program, we expect that in other Indonesian hospitals, without such an obligation, the QIs will less often be met. For that reason, we expect that they will have discriminative power.
Developing QIs and pilot testing them is not a guarantee that they will be implemented widely in Indonesian hospitals. A thorough implementation plan, including involvement of the relevant stakeholders, is necessary to facilitate this important next step.

**Recommendations for practice and policy makers**

This thesis adds that in caring for hospitalized patient with cancer, it is important to assess not only patient problems but also their needs, in order to implement patient-centered palliative care. Patients with cancer in Indonesia possibly are reluctant to express their feelings spontaneously, and to report their problems and needs to the professionals. For that reason, healthcare providers need to assess problems and needs of each individual patient, proactively, and in a systematic way. I found that hospitalized patients with cancer in Indonesia require more professional attention to address their problems and needs. For that reason, it is important for healthcare professionals to apply multidimensional patient-centered palliative care. We recommend to use a screening questionnaire for this, like the PNPC-sv. This questionnaire, to make an inventory of problems and needs in patients with cancer, contains the WHO dimensions of palliative care and some additional domains.

Pain was quite prevalent in patients with cancer in Indonesia. For that reason, I recommend the ministry of Health of Indonesia, as well as the other Indonesian policy makers to facilitate a better pain control program all over the archipelago. Also financial problems were common in my Indonesian study population. For that reason I completely support the implementation of the recently launched *Badan Penyelenggara Jaminan Sosial (BPJS) Kesehatan* program. This is a health insurance program for all citizens.

As palliative care is provided by several kind of professionals, as well as by family members, we advice specific training for all health care professionals involved in palliative care. This training should include how to adequately communicate within the team, with the patients and with their family, as well as training for healthcare providers to be competent to implement palliative care in hospitals. Preferably, such training combines separate modules per discipline with interdisciplinary modules, in which at least doctors as nurses are trained together.

Family caregivers appeared highly involved in addressing patients' problems in Indonesia. Their quality of life was negatively influenced by psychological problems of the patients and the fact that they do not receive training in caring for their loved ones. We recommended to design and provide training for family caregivers in caring for patient with cancer. For example, as almost always a family member accompanies the hospitalized patients 24/7, each nurse should teach the family member how to perform those caring aspects that will still be important when the patient is discharged from hospital. Besides, development of a hotline service for patients and their families, family
consultation and family meetings can also be good manners to provide a partnership between patient, family caregiver and the professional in palliative care. The QIs for the organization of palliative care in Indonesian hospitals that we developed can be used to evaluate whether the regulation of the Indonesian government regarding palliative care is implemented in Indonesian hospitals, and whether it contributes to improved quality of palliative care. Based on the set of QIs for the organization of palliative care, standard operating procedures (SOPs) for palliative care in hospitals in Indonesia can be developed. Additionally, they can be used for other purposes, such as supporting quality improvement activities and clinical accreditation. As the top ten QIs has already been pilot tested, we recommended to use this subset already as a basic standard to implement palliative care in hospitals in Indonesia. To reach this aim, I will involve the Indonesian Palliative Society,47 of which my Indonesian supervisor, professor Sunaryadi, is a consultant. Via this organization, I am also able to disseminate my tool, my results and my recommendations to representative of the Ministry of Health, as my QI set can be used to evaluate the implementation of palliative care.

Recently, during the invitation conference 'Palliative care 2020; towards integration of palliative care in an age-friendly European Union', 10 recommendations have been launched by the consortia of two international research projects, Age Platform Europe, the European Union Geriatric Medicine Society (EUGMS), the European Association of Palliative Care (EAPC), Early detection and timely intervention in dementia (Interdem) and the European Forum for Primary Care (EFPC).48 I recommend the Indonesian Ministry of Health and the organization of Indonesian Palliative Society in Indonesia, to also adopt these recommendations:

1. Recognise that the delivery of and access to high quality palliative care is a **public health priority** which requires a **public health approach**.

2. Develop or redraft **national and international health care policies**, such as policies on healthy ageing, long-term care and dementia, to include palliative care as an essential component.

3. Develop or redraft **palliative care-specific policies** to include referral criteria that allow patients and their families timely access to palliative care consistent with their **level of need**, regardless of diagnosis, age, prognosis, estimated life expectancy or care setting.

4. Develop or redraft policies to include mechanisms to ensure **access to specialist multidisciplinary palliative care services or teams** in all health care settings.
5. Promote a **paradigm shift in health and social care** towards basic palliative care skills for all health care professionals, to empower them to deliver **patient-centred family-focused care** for all people with a life-limiting illness, **based on personalised or tailored care plans**, with attention to all needs of the patient and his or her family.

6. Support **inter-professional and multi-disciplinary collaboration** as a cornerstone of high-quality **care and education** in palliative care.

7. Invest in **curriculum development and education** in palliative care across all disciplines of health and social care at undergraduate and post-graduate level, and **establish palliative care as a specialty**.

8. Promote public awareness through **community level approaches**: education of the **public** and training of **family carers and volunteers**.

9. Increase **funding opportunities** for national and international **research** in palliative care.

10. Establish continuous mechanisms to **monitor and improve the quality of and access** to palliative care.

**Recommendations for future research**

In this thesis, quantitative studies were performed. We found that although the number of problems and issues is not higher in a similar group of Dutch patients, hospitalized cancer patients in Indonesia need more attention for their problems and issues from the health care professionals. For that reason, I recommend a qualitative study to explore in what way patients want to receive more attention from the professional, taking account of their cultural values, for example regarding the role of the family in the care process. We also found that autonomy was less often considered a problem in the Indonesian patient group than in the Dutch. Yet, we do not know whether the concept autonomy has the same meaning in Indonesia as it has in the Netherlands. This needs further exploration, particularly in relation to palliative care.

We also found that family caregivers are highly involved in caring for their hospitalized relative with cancer. This is not a surprise, as most patients are accompanied 24/7 by one or more family caregivers. We do not know what the positive and negative impact of this involvement is on the care process and outcome. This needs to be studied in the future.
We also found that particularly dealing with psychological issues of the patient, as well as having no previous experience in caring negatively influenced the quality of life of the family caregiver. For that reason, I recommend to explore the effects of skills and knowledge training for family caregivers, in which they also learn how to deal with psychological issues.

An Indonesian PhD student, being a nurse and lecturer, will start this year to further explore family caregiver related research questions.

We performed our studies in Java, Makassar and Bali, as these regions have been obliged by the Ministry of Health of Indonesia to implement palliative care. These are all urban areas. I therefore recommend studies that include rural areas of Indonesia, and, like I did, include patients with different religions and cultures of this archipelagic country. As I limited my studies on cancer patients in hospitals, I also suggest performing studies on palliative care outside the hospital, for non-cancer conditions such as HIV/AIDS, stroke, congestive heart failure, renal failure and COPD in Indonesia.

The development of a set of quality indicators which I did as part of my PhD studies is a first step in developing QIs for the organization of palliative care in Indonesia. The presented Indonesian set was merely based on a European one. Although the professionals that took part in the RAND Delphi process were explicitly invited to mention missing aspects for the organization of palliative care in Indonesian hospitals, they only mentioned a few. As for example palliative care in Indonesia is still in its infancy, and the family has an important role in caring for the palliative patient, there certainly will be more aspects that were not covered in the European set and not mentioned by the panelists. For that reason, I recommend a qualitative study to find important missing quality indicators for the organization of palliative care in Indonesia. Thus, development of missing QIs for continuity of care, community care, and care for and by family caregivers as well as QIs for training and education is necessary. Further validation of the set of QIs, and a structured nation-wide implementation process is also necessary. To contribute to the implementation of palliative care in all Indonesian hospitals, I recommend making an overview of barriers and facilitators experienced by health care professionals, as well in hospitals that already have a palliative care service, as in hospitals that don't have it yet.

**General conclusion**

Evidently, 'problems' are not synonymous with unmet needs, therefore not only problems but also needs for care should be assessed. Caring for patients with cancer should be based on their personal needs. This is in line with a patient-centered care approach, and fits the Indonesian nursing paradigm and the concept of holistic care.
Patients with cancer in Indonesia suffer multiple symptoms and unmet needs. To evaluate problems and needs, we used European, validated instruments and adapted them for the Indonesian context. The comparison between an Asian and a European country showed strong common pathways, as well as interesting differences. Different values, cultures and health care systems might influence patients' problems and needs. This should be considered when developing and applying patient-centered palliative care.

In contrast to Western countries, family caregivers appeared highly involved in addressing patients' problems. The patients' QoL influences their own QoL and vice versa. Even more than in Western countries, in Indonesia supportive cancer care should focus on as well patients as their family caregivers.

In Indonesia, the concept 'patient-centered approach' probably needs to be changed into a ‘family-centered approach'. This needs further exploration, in combination with research questions around autonomy.

As Indonesia has inhabitants with all kind of religions and cultures, such a patient- or family-centered approach needs to be studied in all relevant populations within the country.

The strong family bonds in Indonesia are not yet represented in the Indonesian set of QIs. This needs further exploration.

This study adds that in a country like Indonesia, an archipelago with all kinds of religions, cultures and beliefs, patient-centered palliative care should consider all of these aspects.
Chapter 6

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Summary
In this thesis, four aspects of care for patients with advanced cancer care in Indonesia have been studied:
Firstly, we identified problems and needs of patients with advanced cancer in Indonesian hospitals, and compared them to a comparable group of patients in the Netherlands. Secondly, we assessed whether the problems of hospitalized patients with cancer in Indonesia were addressed and by whom. Thirdly, we identified the kind of family caregivers' involvement in caring for patients with cancer during hospitalization and the factors that influence their quality of life. Finally, we face-validated quality indicators for the organization of palliative care in hospitals in Indonesia.

In chapter 1, I provided the background of this thesis, with epidemiologic data, definitions of palliative care, the concept of patient-centeredness, and I ended with the researched questions.

In chapter 2, the data of 180 (72%) patients with advanced cancer collected in 5 Indonesian hospitals were compared with the data of 94 patients with advanced cancer in the Netherlands. We found that the prevalence of most physical problems, including pain, was similar in the two groups. In Indonesia, financial problems were the most common: 70 to 80% vs. 30 to 42% in the Netherlands. In Indonesia, 25 to 50% of the patients reported psychological and autonomy problems versus 55 to 86% in the Netherlands. The Indonesian group had much more unmet needs for each problem (> 54%) than the Dutch group (< 35%). Apparently, economic and cultural differences hardly influence physical problems. Nonetheless, fewer Indonesian patients reported psychological and autonomy problems than Dutch patients. This difference contradicts our hypothesis. However, we found more unmet needs for professional attention in Indonesia than in the Netherlands, which is compatible with our hypothesis. These simple comparative data provide interesting insights into problems and unmet needs and give rise to our new hypothesis about cultural influences. This hypothesis should be studied in more depth.

The study described in chapter 3 is based on the results of a cross-sectional survey regarding symptoms and issues of patients with cancer performed in three general hospitals in Indonesia (in Yogyakarta, Denpasar, and Makassar). Of 119 patients (79%) who completed the questionnaire, 85% of them stated that their symptoms and issues were addressed. According to these patients, financial (56%), autonomy (36%), and psychosocial (34%) issues were most often addressed by the family alone. Physical symptoms (52%) and spiritual issues (33%) were addressed mainly by a combination of family, nurses, and physicians. Hospitalized patients with cancer in Indonesia felt that
most of their symptoms and issues had been addressed, and the family was highly involved. The strong family ties in the Indonesian culture may have contributed to this family role. More research is needed to clarify how this influences patient outcome, quality of care, and quality of life of both the patients and their families, along with the degree of partnership between families and professionals. This information might help answer the question what advantages and disadvantages the family role in caring for a hospitalized patient with cancer generates for the patient, the family, and professional caregivers.

In **chapter 4**, we describe the kind of family caregivers' involvement in caring for patients with cancer during hospitalization and the factors that influence their quality of life. In this study, 100 of 120 invited caregivers (83%) completed the questionnaire. About the same percentages of men (52%) and women (48%) took part in the study. The mean age of the family caregivers was 41 years (range: 14-71) and for the patients they cared for it was 49 years (range 20-80). Almost half of the family caregivers were the spouse (42%); 34% were the children and 11% were the parents taking care of their child. Of the total population, 8% of the patients were between 20 and 30 years of age. About three-quarters of the family caregivers (78%) had no previous caring experience for a patient with cancer. More than half of the family caregivers (53%) took care of the patient more than 12 hours a day. Being involved in psychological issues in caring ($\beta=0.374; p=0.000$), younger age ($\beta=-0.282; p=0.003$), no previous caring experience ($\beta=-0.301; p=0.001$), and not being the spouse ($\beta=-0.228; p=0.015$) negatively influenced the QoL and explained 31% of the variation (adj$R^2=0.312; F=12.24$; $p=0.000$). Gender, education level, and time spent on caring did not influence the QoL of family caregivers. Our findings identified modifiable factors such as dealing with psychological issues and lack of experience in caring which negatively influenced the QoL of family caregivers. These factors are potential targets for intervention strategies. Education and intervention programs focusing on dealing with psychological problems in cancer care might improve the QoL of both patients and their families.

The study described in **chapter 5** aimed to face-validate an Indonesian set of QIs based on a European set, to compare the two sets of QIs and to test the applicability of Indonesian set. A modified two-round RAND Delphi process was conducted in Indonesia. Twenty-four health care professionals from different disciplines were invited as panelists to rate clarity and usefulness of 98 QIs and to add missing indicators. Next, an applicability pilot test took place in five hospitals. A total of 21 panelists considered 76 QIs (78%) face-valid and added two new ones. Of the QIs with the highest ratings, eight need to be evaluated by head nurses, and two by reviewing patient records. Each
Summary

QI was met by at least two hospitals, and only one by all five. Regarding the two QIs on structured clinical record keeping, most medical records contained multidimensional aspects of care.

We found that most QIs for the organization of PC developed for European countries were also considered face-valid for Indonesian hospitals. The top 10 QIs were applicable in Indonesia. This suggests that most of the organizational QIs are universal rather than country specific. The Indonesian set of QIs should be considered a first step in developing, testing, and implementing a set of QIs for PC in Indonesia. We recommend validation in other Asian regions.

In chapter 6, the final chapter of this thesis, the most important findings and conclusions from the studies in chapter 2 through 5 are discussed. The results are described within a relevant theoretical background and relevant literature. Besides, methodological issues are discussed and recommendations for future research, for practice and for policy are provided.

This thesis adds that in a country like Indonesia, an archipelago with all kind of religions, cultures and beliefs, patient-centered palliative care should consider all these aspects. Shared decision making with the family should be considered in the application of patient-centered palliative care in Indonesia.
Samenvatting
Samenvatting

In dit proefschrift zijn vier aspecten met betrekking tot de zorg voor patiënten met ongeneeslijke kanker in Indonesië onderzocht.

Als eerste hebben we de wensen en behoeften van patiënten met ongeneeslijke kanker in Indonesische ziekenhuizen geïdentificeerd en vergeleken met een vergelijkbare groep patiënten in Nederland. Ten tweede zijn we nagegaan of aan de behoeften van patiënten met kanker tijdens hun ziekenhuisopname in Indonesië aandacht werd besteed en door wie. Ten derde hebben we de betrokkenheid van mantelzorgers aan de zorg van hun naasten met kanker tijdens hun ziekenhuisopname onderzocht, alsmede de factoren die van invloed waren op de kwaliteit van leven van die mantelzorgers. Ten slotte hebben we een set van kwaliteitsindicatoren voor de organisatie van Palliatieve zorg in Indonesische ziekenhuizen gevalideerd.

In hoofdstuk 1 heb ik de achtergrond van dit proefschrift beschreven, met epidemiologische data, de definitie van Palliatieve zorg, het concept patient-centeredness (patiëntgerichtheid). Ik eindig dit hoofdstuk met de onderzoeksvragen.

In Hoofdstuk 2, zijn de data van 180 (72%) patiënten met ongeneeslijke kanker verzameld in vijf Indonesische ziekenhuizen, en vergeleken met 94 soortgelijke patiënten in Nederland.

We zagen dat de prevalentie van de meeste fysieke problemen, zoals pijn, vergelijkbaar waren in de twee groepen. In Indonesië waren financiële problemen het meest voorkomend: 70 tot 80% versus 30 tot 42% in Nederland. In Indonesië rapporteerde 25 tot 50% van de patiënten psychologische- en autonomieproblemen versus 55 tot 85% in Nederland. De Indonesische groep had veel vaker dat aan bestaande behoeften te weinig aandacht door de professional was besteed (>54%) dan de Nederlands groep (<35%).

Onze resultaten tonen aan dat blijkbaar economische en culturele verschillende de fysieke problemen nauwelijks beïnvloeden. We vonden ook dat Indonesische patiënten minder vaak psychologische- of autonomieproblemen ervaren dan Nederlandse patiënten, wat overeenkomt met onze hypothese.

Dit onderzoek geeft een interessante kijk op de wensen en behoeften van patiënten in Indonesië en roept een nieuwe hypothese op over de invloed van cultuur op problemen en behoeften bij patiënten met kanker. Deze hypothese dient in meer detail bestudeerd te worden.

Hoofdstuk 3 beschrijft de resultaten van een cross-sectionele vragenlijststudie aangaande symptomen en problemen van patiënten met kanker, uitgevoerd in drie algemene ziekenhuizen in Indonesië (in Yogyakarta, Denpasar, and Makassar). Van de 119 opgenomen patiënten (79%) die de vragenlijst invulden, gaf 85% aan dat hun
wensen en behoeften waren vervuld. Volgens deze patiënten werden financiële (56%), autonomie- (36%) en psychologische (34%) problemen meestal door alleen de familie opgepakt. Fysieke symptomen (52%) en spirituele problemen (33%) werden door zowel de familie, de verpleegkundige als artsen opgepakt. De patiënten gaven aan dat de meeste van hun symptomen en problemen werden behandeld en dat de familie daar meestal nauw bij betrokken was. De sterke familieband, passend bij de Indonesische cultuur, heeft hoogstwaarschijnlijk bijgedragen aan deze betrokkenheid van de familie. Meer onderzoek is nodig om te verklaren hoe dit patiëntgerelateerde uitkomsten, kwaliteit van zorg en de kwaliteit van leven van zowel de patiënt als hun naasten beïnvloedt, alsmede hoe dit de relatie tussen zorgverlener en familie beïnvloedt. Deze informatie kan bijdragen aan het beantwoorden van de vraag welke voor- en nadelen de rol van de familie die zorgt voor een gehospitaliseerde patiënt met kanker heeft voor de patiënt, familie en zorgprofessional.

In hoofdstuk 4 beschrijven we het type van betrokkenheid van naasten die zorgen voor patiënten met kanker ten tijde van hun ziekenhuisopname, alsmede welke factoren hun kwaliteit van leven beïnvloeden. In deze studie hebben 100 van de 120 uitgenodigde mantelzorgers (83%) de vragenlijst beantwoord. Hiervan was ongeveer een vergelijkbaar percentage man (52%) als vrouw (48%). De gemiddelde leeftijd van de mantelzorgers was 41 jaar (variërend van 14-71) en voor de patiënten voor wie zij zorgden was dit 49 jaar (met een spreiding van 20-80 jaar). Ongeveer de helft van de mantelzorgers was de echtgenoot (42%); 34% waren kinderen en 11% waren ouders die hun kind verzorgden. Van de totale populatie was 8% van de patiënten tussen de 20 en 30 jaar oud. Ongeveer driekwart van de mantelzorgers (78%) had geen eerdere ervaringen in het verzorgen van een patiënt met kanker. Meer dan de helft van de mantelzorgers (53%) verzorgde de patiënt meer dan 12 uur per dag. Betrokkenheid in psychologische aspecten van de zorg ($\beta=0.374$; $p=0.000$), jonge leeftijd ($\beta=-0.282$; $p=0.003$), geen eerdere zorgervaring ($\beta=-0.301$; $p=0.001$) en niet de echtgenoot zijn ($\beta=-0.228$; $p=0.015$) hadden een negatieve invloed op de kwaliteit van leven en verklaarde 31% van de variatie (adj$R^2=0.312$; F=12.24; $p=0.000$). Geslacht, opleidingsniveau en de tijd gespendeerd aan de zorg had geen invloed op de kwaliteit van leven van de mantelzorgers.

Dit onderzoek heeft beïnvloedbare factoren geïdentificeerd, zoals de omgang met psychologische problemen van de patiënt en het gebrek aan zorgervaring, welke factoren een negatieve invloed hadden op de kwaliteit van leven van de mantelzorgers. Deze factoren kunnen van belang zijn voor interventiestrategieën. Scholing en interventies gericht op de omgang met psychologische problemen rondom de zorg voor een patiënt met kanker kunnen de kwaliteit van leven van zowel de patiënt als hun naasten verbeteren.
De studie beschreven in **hoofdstuk 5** had als doel om een Europese set van kwaliteitsindicatoren te valideren voor de organisatie van Palliatieve zorg in Indonesische ziekenhuizen, deze set te vergelijken met de Europese, en de toepasbaarheid in Indonesië vast te stellen. Een gemodificeerde RAND Delphi procedure, bestaande uit twee rondes, werd uitgevoerd in Indonesië. Vierentwintig zorgverleners van verschillende disciplines waren uitgenodigd als panellid om de duidelijkheid en bruikbaarheid van 98 kwaliteitsindicatoren te scoren, en missende indicatoren toe te voegen. Vervolgens werd de bruikbaarheid getest in een piloot in vijf ziekenhuizen. Een totaal van 21 panelleden, vonden 76 kwaliteitsindicatoren (78%) valide en voegden twee nieuwe toe. Van de tien kwaliteitsindicatoren met de hoogste score zijn er acht bedoeld om ingevuld te worden door de hoofdverpleegkundige, en voor twee indicatoren dienen patiëntendossiers beoordeeld te worden op inhoudsaspecten. Met betrekking tot elke gemeten indicator bleek dat minstens twee ziekenhuizen aan het criterium voldeden. Slechts met betrekking tot één indicator voldeden alle vijf de ziekenhuizen aan het criterium. Aangaande de twee kwaliteitsindicatoren over het medisch dossier, bleek dat de meeste onderzochte medische dossiers een beschrijving van multidimensionele aspecten van zorg te bevatten.

We vonden dat de meeste kwaliteitsindicatoren met betrekking tot de organisatie van de Palliatieve zorg, ontwikkeld voor Europese landen ook in Indonesië relevant werd gevonden. De 10 indicatoren met de hoogste rating bleken in een piloot test toepasbaar te zijn. Dit suggereert dat de meeste organisatorische kwaliteitsindicatoren universeel zijn, en niet specifiek per land of cultuur. De Indonesische set indicatoren moet beschouwd worden als een eerste stap in het ontwikkelen, testen en implementeren van een set van kwaliteitsindicatoren voor de organisatie van Palliatieve zorg in Indonesië. We raden aan deze set ook te valideren in andere Aziatische regio’s.

In **hoofdstuk 6**, het laatste hoofdstuk van dit proefschrift, worden de belangrijkste bevindingen en conclusies uit hoofdstuk 2 tot en met 5 bediscussieerd. De resultaten worden beschreven vanuit een theoretisch kader en vergeleken met relevante literatuur. Vervolgens worden de gehanteerde methodes van onderzoek bediscussieerd en wordt afgesloten met aanbevelingen voor verder onderzoek, de dagelijkse praktijk en beleid.

Dit proefschrift heeft bijgedragen aan het inzicht dat bij het organiseren van en inhoud geven aan Palliatieve zorg in Indonesië, een archipel met verschillende religies, culturen en opvattingen, rekening moet worden gehouden met al deze aspecten. Bij gezamenlijke besluitvorming (*shared decision making*) in Indonesië dient niet alleen de patiënt maar ook de familie een rol te spelen.
Intisari
Intisari

Pada tesis ini dibahas empat aspek perawatan pasien kanker di Indonesia:

Pada bab 1, saya menyajikan latar belakang tesis ini, data epidemiologi kanker baik global maupun nasional, definisi perawatan paliatif, konsep perawatan paliatif berdasarkan ‘patient-centeredness’, dan diakhiri dengan pertanyaan penelitian.


Studi yang dijelaskan pada bab 3 berdasarkan hasil survei cross-sectional (potong – lintang) yang dilakukan di 3 rumah sakit umum di Indonesia (di Yogyakarta, Denpasar, dan Makassar). Dari 119 pasien (79%) yang mengisi kuesioner, 85% dari mereka menyatakan bahwa hampir semua gejala dan masalah-masalah yang mereka alami telah teratasi. Menurut pasien, masalah keuangan (56%), otonomi (36%), dan psikososial (34%) adalah masalah yang paling sering ditangani hanya oleh keluarga saja. Gejala fisik (52%) dan spiritual (33%) merupakan masalah yang seringkali diatasi oleh kombinasi
antara keluarga, perawat, dan dokter. Pasien kanker yang sedang dirawat inap merasa bahwa sebagian besar masalah yang mereka alami telah ditangani, dan keluarga yang paling terlibat dalam penanganan masalah mereka. Ikatan keluarga yang kuat dalam budaya Indonesia mungkin telah berkontribusi terhadap peran dan keterlibatan keluarga ini. Penelitian lebih lanjut diperlukan untuk mengklarifikasi bagaimana hal ini mempengaruhi keberhasilan perawatan bagi pasien, kualitas perawatan, dan kualitas hidup pasien dan keluarga mereka, serta tingkat kemitraan antara keluarga dan tenaga kesehatan. Informasi ini mungkin membantu menjawab pertanyaan apa kelebihan dan kekurangan peran keluarga dalam merawat pasien di rumah sakit dengan kanker menghasilkan bagi pasien, keluarga, dan petugas kesehatan profesional.

Pada bab 4, kami memaparkan tentang keterlibatan keluarga dalam merawat pasien dengan kanker selama rawat inap dan faktor-faktor yang mempengaruhi kualitas hidup mereka. Terdapat 100 (83%) anggota keluarga yang menyelesaikan pengisian kuesioner dan mengembalikan kuesioner pada peneliti. Partisipan yang terlibat dalam penelitian ini adalah laki-laki (52%) dan perempuan (48%). Usia rata-rata partisipan keluarga adalah 41 tahun (antara usia 14-71 tahun) dan usia rata-rata pasien adalah 49 tahun (20-80 tahun). Hampir setengah dari pengasuh keluarga adalah pasangan (42%); 34% adalah anak dari pasien dan 11% adalah orang tua pasien. Dari total populasi, 8% dari pengasuh keluarga merawat pasien dengan usia antara 20 dan 30 tahun. Sekitar tiga-perempat dari pengasuh keluarga (78%) tidak memiliki pengalaman merawat pasien sebelumnya. Lebih dari setengah dari perawat keluarga (53%) merawat pasien lebih dari 12 jam sehari. Keterlibatan dalam mengatasi masalah psikologis pasien ($\beta=0.374$, $p=0.000$), usia yang lebih muda ($\beta=-0.282$, $p=0.003$), tidak mempunyai pengalaman merawat pasien sebelumnya ($\beta=-0.301$, $p=0.001$), dan bukan pasangan ($\beta=-0.228$, $p=0.015$) memberikan pengaruh negatif pada kualitas hidup pengasuh keluarga dan menjelaskan 31% dari variasi (adj$R^2=0.312$; $F=12.24$, $p=0.000$). Jenis kelamin, tingkat pendidikan, dan waktu yang dihabiskan untuk merawat pasien tidak mempengaruhi kualitas hidup mereka. Temuan kami mengidentifikasi faktor-faktor yang dapat dimodifikasi seperti menangani masalah-masalah psikologis dan kurangnya pengalaman dalam merawat yang berpengaruh negatif pada kualitas hidup pengasuh keluarga. Faktor-faktor ini merupakan kemungkinan target yang dapat dimodifikasi untuk strategi intervensi dalam perawatan pasien kanker. Program edukasi dan intervensi yang berfokus pada penanganan masalah psikologis dalam perawatan pasien kanker mungkin dapat meningkatkan kualitas hidup dari pasien dan keluarga mereka.


Pada bab 6, bab terakhir dari tesis ini, kami membahas tentang hasil penelitian yang paling penting dan kesimpulan penelitian yang terdapat pada bab 2 sampai 5. Hasil penelitian dikaitkan dengan landasan teori dan literatur yang relevan. Bab ini juga memaparkan tentang metodologi penelitian yang digunakan, rekomendasi untuk penelitian lanjut dan rekomendasi untuk praktek dan pembuat kebijakan. Tesis ini menambahkan bahwa di negara seperti Indonesia, negara kepulauan dengan berbagai budaya, agama dan keyakinan, perawatan paliatif berpusat pada pasien harus memperhatikan semua aspek tersebut. Pasien dalam pengambilan keputusan terkait pengobatan seringkali melibatkan keluarga, hal ini harus dipertimbangkan dalam penerapan perawatan paliatif berpusat pada pasien di Indonesia.
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Acknowledgement

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This thesis is part of my journey as a clinician, researcher, lecturer and a friend. In this thesis there are hopes and prayers that what I do will help to promote changes, to help those who are suffering from cancer. I can say that writing this thesis was the most challenging road that I ever walked. Yet, I never felt alone, because I was surrounded by various extraordinary people. In that perspective, I would like to thank the following persons for their invaluable contribution.

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Curriculum vitae

Christantie Effendy was born on March 27th, 1967 in Purwokerto, Central Java, Indonesia. She finished her bachelor degree in Nursing in 1992. Shortly after her graduation, she started working as a clinical nurse at Sint Carolus, Catholic hospital in Jakarta. In 1994, she became a government employee and started working as a clinical nurse as well as a clinical instructor for Nursing students at Dr Sardjito general hospital, in Yogyakarta. By then, she has been interested in cancer care, colostomy care, and wound care.

In 1994, she was involved in caring for the victims of the Merapi Mountain eruption. In 1995, she learned about wound care management in the Alfred Hospital, Melbourne, Victoria, Australia, sponsored by Wound Foundation Australia (WFA). In 1997, she became a head nurse in the surgical ward in the same hospital, and during her position as a head nurse, she had written many books for nursing students, such as 'Burn wound management', 'Nursing care for patients with dengue hemorrhagic fever', and 'Perioperative care'.

In 1999, besides being a head nurse, she started working as a part time lecturer in the School of Nursing, Medical Faculty Universitas Gadjah Mada. In 2002, she moved to the School of Nursing as a full time lecturer. In 2005 she was involved in caring for about 200 patients, the victims of Bantul earthquake, Yogyakarta. In 2007 she received funding from Linneaus Palme to be a guest lecturer at the Boras University, Sweden. In 2008, she finished her Master degree in Clinical Epidemiology at the Universitas Gadjah Mada, Yogyakarta. She was a Manager of International Collaboration and Research Affairs and an editor-in-chief of Jurnal Ilmu Keperawatan (Nursing Science Journal) of the School of Nursing, Medical Faculty, Universitas Gadjah Mada, Yogyakarta.
She became more focused on cancer patients' care when she joined the Indonesian Ostomy Association (InOA), which is an organization under auspices of the Indonesian Cancer Foundation (ICF). She was actively conducting "bedside teaching" about how to treat the stoma and use a colostomy bag correctly for cancer patients with a colostomy, and she taught families how to be prepared for the treatment of cancer patients at home. She has been active in providing information on cancer patient care due to a variety of opportunities she had at seminars for volunteers.

She has been active in social organizations such as Rotary Club Yogyakarta Malioboro, Rotary International. In 2005, she was elected as a President of Rotary Club Yogyakarta Malioboro.

In 2009, she received a postgraduate scholarship from the Directorate General of Higher Education, the Ministry of National Education Republic Indonesia for her PhD study. The results of her PhD project are described in this thesis. In 2010, she and her colleagues developed a Palliative team in the School of Nursing. A yearly Seminar in Palliative care and research in palliative care and cancer care are the priority of the team. Currently she is a member of IAHPC and the Indonesian Palliative Society.

After obtaining her PhD she will be back as a full-time lecturer and further develop her skills as a 'senior researcher'. Besides, she will be involved in disseminating and developing palliative care particularly in Yogyakarta. She is married to AY. Harijanto Setiawan and lives in Yogyakarta, Indonesia.