Exploring how Japanese family physicians understand palliative care and identify patients for primary palliative care

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Doctor of Philosophy

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2020

Declaration

1. I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree.

2. I confirm that this thesis presented for the degree of Doctor of Philosophy, has

   i) been composed entirely by myself

   ii) been solely the result of my own work

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Ai Oishi
May 2020

Abstract

Background:

Primary care clinicians have great potential to play a key role in providing palliative care in the community. However, difficulties in identifying patients for palliative care hinders progress. This problem is particularly relevant in Japan with an elderly population where more complex and increasing amounts of palliative care needs are emerging.

Aims:

This study aimed to explore: 1) how Japanese family physicians understand the concepts of palliative care; 2) their current approaches to the identification of patients for palliative care; and 3) their perceptions and engagement with an international tool for identifying patients for palliative care translated into Japanese: the Supportive and Palliative Care Indicators Tool (SPICT).

Design:

Phase I: The SPICT was translated from English into Japanese following international guidelines including the steps of forward and back translation and expert committee consultations including Japanese family physicians, and other professionals with relevant expertise.

Phase II: Twenty Japanese family physicians with speciality training in family medicine were recruited to use the translated SPICT (SPICT-JP) in their clinical practice. Interviews were conducted before and after they used the SPICT-JP at 4 to 7 months. The first interviews focused on their understanding of palliative care and identification of patients with palliative care needs. The second interviews captured their experiences and impressions of the utility of the SPICT-JP in their clinical practice and its potential application to improve palliative care within Japanese primary care.

Results:

Phase I: The SPICT was translated into Japanese (SPICT-JP). Any words and phrases identified in the translation process as not transferring well to Japanese language or clinical practice were discussed with a collaborator in Japan and supervisors in the UK including the original developers of the SPICT tool and consensus reached.

Phase II: In general, the participating Japanese family physicians considered the principles of palliative care as being broad and relevant for patients with any kind of suffering which could potentially impair their quality of life. However, their application of the term ‘palliative care’ in routine practice was not consistent with this understanding. The term ‘palliative care’ seemed to be narrower, more context-dependent and sensitive to its public association with the imminence of death. The identification of patients with palliative care needs was a complex process incorporating many interconnected factors. The family physicians saw the transition to palliative care as an accumulation of changes, rather than ‘throwing a switch’. The SPICT-JP was perceived as being useful although it did not change the actual practice of the participating family physicians to any great extent. It seemed rather that the SPICT-JP reinforced the participants’ reflections on and in their practice and raised their awareness of the value of more systematic identification of patients with palliative care needs. They also appreciated having objective clinical criteria so that they did not have to rely on instinctive judgements based on personal experiences.

Conclusions:

There was a difference between how Japanese family physicians understand the principles of palliative care and their use of the term ‘palliative care’ in their actual clinical practice. The process of identification of patients with palliative care needs was complex, and a limited prognosis was not the only determinant. The SPICT-JP can potentially contribute to improved identification of patients with palliative care needs in the community by providing a focus and guidance to support for the assessments made by family physicians. More research is needed including with patients and their family carers to understand when and how it is best to identify patients with palliative care needs for holistic palliative care and care planning.

Lay Summary

Recently, there have been many discussions on the importance of the care for people living with a serious illness (professionally called ‘palliative care’) given by family doctors and nurses in patients’ homes. However, there are problems when it comes to choosing which patients should receive such care.

This is a pressing topic in Japan where the population is ageing rapidly, so the need for palliative care is growing. Therefore, my study gathered and examined the views of 20 Japanese family doctors regarding the following three issues: 1) their understanding of what palliative care is; 2) which patients should receive such care; and 3) the use of a tool to help them choose patients suitable for palliative care.

The first step of my research was to find a tool that could assist doctors in identifying patients who may have worsening health or even be at a risk of dying. I decided to use the Supportive and Palliative Care Indicators Tool (SPICT) developed in Scotland. For use in my study, this SPICT was translated from English into Japanese and was renamed as SPICT-JP. Next, I asked the 20 family doctors taking part in my study to use the SPICT-JP in their practice for a few months. I also held interviews with them twice: an interview before and after they used the SPICT-JP.

Regarding issue 1, the 20 Japanese doctors considered that all patients with any kind of suffering (illness, disease, or distress) should be able to receive palliative care, because they saw palliative care as a way to improve patients’ quality of life. On the other hand, the doctors were aware that many people related the term ‘palliative care’ to mean ‘the approach of death’. Therefore, the doctors avoid using the term ‘palliative care’ not to confuse patients and their family. This showed that there was a gap between the doctors’ understanding of palliative care and their use of the term ‘palliative care’.

Regarding issue 2, the doctors saw choosing which patients should receive palliative care as a complicated process with many factors. A low chance of

recovery was not the only factor. The doctors felt that the transfer to palliative care was gradual, rather than quick like ‘throwing a switch’.

Regarding the third issue, the doctors found the tool to be useful, but did not significantly change their practice. The tool improved the doctors’ reflections on their practice; they gained awareness of how valuable it was when choosing patients suitable for palliative care in a timely and more systematic way. The participating doctors also liked having clear guidance rather than relying on their intuition.

Finally, the study found some issues in the current palliative care situation in Japan. For example, there is a need for more public campaigns to tackle the poor image of palliative care. Also, there is little research into understanding patients’ and their family carers’ views on this issue.

To summarise, this study captures rich and deep stories of Japanese doctors’ understanding of palliative care, how patients are chosen, and their views on the SPICT-JP. Moreover, the study showed that the SPICT-JP could improve the selection of patients suitable for palliative care by giving family doctors in Japan the needed guidance to make such important decisions.

Abbreviations

ADL = activity of daily living
AO = Ai Oishi, the author
BSC = best supportive care
COGJ = Cabinet Office, Government of Japan
CPHS = the Centre for Population Health Sciences
GP = general practitioner
GSF = Gold Standard Framework
GSF-PIG = Gold Standard Framework Prognostic Indicator (Proactive Identification) Guidance
HRQOL = health-related quality of life
IHME = Institute of Health Metrics and Evaluation
JAHCM = Japanese Association for Home Care Medicine
JH = Jun Hamano, a collaborator of this research
JPCA = Japan Primary Care Association
JSPM = Japanese Society for Palliative Medicine
MHLW = Ministry of Health, Labour and Welfare of Japan
NECPAL = NECPAL CCOMS-ICO©
NIPSSR = National Institute of Population and Social Security Research
OECD = Organisation for Economic Cooperation and Development
RADPAC = RADbaud indicators for PAlliative Care Needs
SPICT = Supportive and Palliative Care Indicators Tool
SPICT-JP = A Japanese version of the Supportive and Palliative Care Indicators Tool
VoIP = voice over internet protocol
WHO = World Health Organization

Acknowledgements

I would like to thank the opportunity to embark on and complete my PhD at the University of Edinburgh. This owes to the generosity of my supervisors Prof Scott Murray, Dr Kirsty Boyd and Prof Liz Grant to accept me as a PhD student. My advisors in Japan, Dr Jun Hamano and Prof Yoshiyuki Kizawa also provided generous support. I am also grateful for the participants and expert committee members for providing their honest and valuable views. I am very fortunate to be able to work these wonderful people.

There are countless people whom I owe my great experience in the UK: PhD peers I met in Edinburgh, ‘Tomi, Luciana, Emmanuel, Eduardo, Sarah, Tracy, Martine, Jenny and Fabian, Kellen, Libby, Ting, Parisa, Evelyn, Libby and more; PhD holders who supported me from their experience, Dr Jo Hockley, Dr Sally Paul, and Dr Greg Irving; people I met in London, Prof Fliss Murtagh, Dr Jenny Mullen, Asmah, Patrick and Julia, and their cat Kitty. These people helped me in various ways in the early phase of my study.

Being able to work clinically along with my PhD in Japan posed some challenges but was also helpful to keep me sane. I am thankful to the staff at Kamakura Family Clinic for their support and understanding. Also, I truly appreciate the generous support and encouragement from Dr Mayumi Hayashi, towards the end of this journey. Without her, my life must have been entirely collapsed with this PhD study.

Other thanks go to my parents, Yumiko and Masaru Oishi. I hope this work will help heal our bitter experience at the time my father passed away. My mother offered much practical support, which was hugely helpful. Last, but not least, I would like to send my deepest thank you to my beloved husband and children, Goro, Yohei and Asahi. Becoming a wife and a mom during the PhD study was a miraculous experience. Thanks for letting me finish this study while being a part of your life.

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Chapter 1 Introduction

This research grew out of my increasing awareness of the difficulties surrounding the provision of palliative care in primary care settings during my ten years of clinical experience as a family physician in Japan with a special interest in palliative care. One significant difficulty stems from the term ‘palliative care’ which itself has been the subject of continuous debate since the first World Health Organisation (WHO) definition in 1990 (WHO Expert Committee on Cancer Pain Relief and Active Supportive Care & WHO, 1990). Even the current WHO re-definition of palliative care (WHO, 2002) does not translate easily into everyday primary care practice. This difficulty in translation suggests a potential theory-practice gap in the definitions of palliative care. It has never been clear as to when and how doctors can and should identify patients for palliative care.

Theoretically, the identification of such patients is a prerequisite for providing palliative care. Nonetheless, the identification of palliative care needs, let alone a consensus on the starting points of palliative care, is ambiguous. Moreover, despite ongoing debate on the need for tools to identify patients for palliative care, their usefulness in Japanese primary care settings remains uncertain. These challenges could be pertinent to the situation in many countries, but appeared as specific difficulties in my clinical practice in Japan, leading to the motivation for this PhD research and the formation of my research questions.

This opening chapter, therefore, explains how I translated these difficulties into viable research questions. I first discuss the shifting focus of palliative care over the recent decades through a brief history from the beginning of the modern hospice movement in the 1960s. I then consider the role of family physicians in providing palliative care within the contemporary and widening concepts of palliative care. Next, I focus on the identification of patients with palliative care needs which is one important role among the many roles of family physicians. Finally, I conclude with the research aims and questions and an outline of the structure of this thesis, together with a brief discussion of terminology.

1.1 The shifting focus of palliative care

When the first modern hospice was established in London in 1967, it was decided to accept mainly people living with a diagnosis of terminal cancer (Addington-Hall and Hunt, 2012). In the modern hospice movement in the 1960s and 1970s, cancer patients with a limited prognosis of only a few months were the central concern. The pioneers of this new movement sought to challenge the archetypal image of a terrifying and isolated death from cancer, which was the most devastating situation at that time (Clark, 2018). This focus on terminal cancer was essential for the successful development of palliative care education and research at that time (Addington-Hall and Higginson, 2001). Reflecting this notion that palliative care was for people who were no longer eligible for curable treatment and an acceptance that people should be referred to 'palliative care' or a 'hospice' to improve the care for the dying and their quality of life in their final months, the starting points of the provision of palliative care were relatively clear (Meyers *et al.*, 2004). This led to the concept of a 'transition' from active care to palliative care, and this transition could be one of the most traumatic and difficult transitions for patients and families where it encompassed accepting the end of active treatment (Marsella, 2009).

However, there have been several questions raised over the decades on this interpretation of palliative care. First, the question about the cancer focus of palliative care was raised, reflecting changes in disease prevalence and demographics over the last decades (Addington-Hall and Hunt, 2012). The number of people needing palliative care in 2011 was estimated to be 20.1 million (69% of all deaths) worldwide, and 69% of these were estimated to be 60 years old or over, as reported by the Worldwide Hospice Palliative Care Alliance (Connor and Bermedo, 2014). This report stated that the leading cause of deaths for people needing palliative care was cardiovascular diseases (39%), and combining with all disease groups, progressive non-malignant diseases were more prevalent than cancer as a cause of deaths (Connor and Bermedo, 2014). These figures show that palliative care should not be provided exclusively to patients with cancer anymore.

Secondly, the question arose regarding the need for reconsideration of the starting points for palliative care. There have been growing calls for early palliative care (Lynn and Adamson, 2003; Gomes, 2015), which were augmented by pivotal studies showing that early palliative care could improve patients' quality of life and potentially even their prognosis (Temel *et al.*, 2010; Zimmermann *et al.*, 2014).

Preparing earlier for the end of life rather than later could be beneficial for both patients and families. A prospective cohort study from the United States of America (USA) revealed that having end-of-life discussions could reduce aggressive medical treatments at the end of life which could lead to poor psychological well-being for patients and families (Wright *et al.*, 2008). In relation to primary care, Abarshi *et al.* (2009) reported that family physicians' awareness of patients' preferred place of death would improve the likelihood of achieving it. An international systematic review of 'truth-telling', including some Japanese studies, concluded that avoiding honest discussions with patients could have adverse outcomes and that more support and training was needed for healthcare professionals (Hancock, Josephine M Clayton, *et al.*, 2007).

In response to these two questions, the WHO renewed its definition of palliative care in 2002. They defined palliative care as an 'approach' to ensure that people with life-threatening illnesses can live without unnecessary suffering until their deaths (Table 1.1) (WHO, 2002). It was noteworthy that 'prevention of suffering by early identification and impeccable assessment' was included in this WHO re-definition. In addition, this re-definition stated clearly that palliative care was 'applicable early in the course of illnesses' and was designed to 'help patients live as actively as possible until death'. The re-definition showed that palliative care should be provided early in the course of illness and not only to treat already existing symptoms, but also to prevent unnecessary suffering.

Table 1.1 The WHO definition of palliative care (2002)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of *early identification and impeccable assessment* and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to *help patients live as actively as possible until death*;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable *early in the course of illness*, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

**italicised by the author*

This WHO re-definition, which demonstrates the comprehensive nature of palliative care at that time, nearly twenty years ago, has often been referenced and is still in use. However, the underpinning philosophy of this re-definition has seemingly not infiltrated into wider society yet. Images for palliative care are repeatedly reported to be associated with stigma or strong negative connotations with ‘death’, which often hinders people in accessing palliative care (Boldt, Yusuf and Himelstein, 2006; Hanratty *et al.*, 2006;

Fadul *et al.*, 2009; Hui *et al.*, 2012; Zimmermann *et al.*, 2016; Boyd *et al.*, 2019).

In response to a growing body of evidence that palliative care should be more widely provided, a report from the Worldwide Hospice Palliative Care Alliance provided a clearer and more comprehensive concept of palliative care (Connor and Bermedo, 2014). It stated that palliative care should be provided: 1) to people with chronic conditions as well as life-threatening/limiting conditions; 2) without any time or prognostic limits; 3) not only by palliative care specialists but also by all healthcare professionals; and 4) wherever a person’s care takes place.

Putting this concept into practice, the World Health Assembly Resolution 67.19 (2014) and the Astana Declaration (2018) requested that all countries integrate palliative care into their national health strategies. They suggested that palliative care should be provided through primary health care to make it an integral part of universal health coverage. More recently, a Lancet-commissioned paper recommended that the concept of palliative care should be reconsidered emphasising its comprehensiveness (Knaul *et al.*, 2018). Moreover, being able to access palliative care is now considered as a human rights issue (Ahmedzai *et al.*, 2004; Brennan, 2007; Gwyther, Brennan and Harding, 2009; Radbruch *et al.*, 2013; Knaul *et al.*, 2018).

In summary, the concept of palliative care has become broader and now covers various conditions and phases of diseases. This means that palliative care is no longer limited to people with terminal cancer, but is now a central public health issue applicable to all people with life-threatening and chronic diseases (Hall *et al.*, 2011; Knaul *et al.*, 2018). Furthermore, palliative care should now be embedded into universal health coverage and should be discussed as a wider public health issue beyond healthcare systems. This broader interpretation of palliative care has also been well-known in palliative care specialist circles in Japan. However, the extent to which this broader interpretation permeated other healthcare professionals including primary care providers remains unknown. There is a possibility of the existence of a theory-practice gap in the definition of palliative care.

1.2 Identifying patients with palliative care needs in primary care settings

Here, I consider the roles of family physicians in palliative care provision, which is followed by a discussion about the identification of patients with palliative care needs in primary care settings.

1.2.1 Different levels of palliative care

In many high-income countries, palliative care has now become one of the specialities in medicine, which is considered as an indicator of palliative care development in a nation (Lynch, Connor and Clark, 2013). Ironically, the more palliative care has been established as a medical speciality, the stronger the notion becomes that palliative care is a specialised area of medicine which other doctors cannot easily practice (Mahtani *et al.*, 2015). However, since palliative care should be provided through collaborative work involving all health or social care professionals, provision of it should not be monopolised by palliative care specialists.

To elaborate what palliative care specialists and non-specialists could do in providing palliative care, the European Association of Palliative Care (EAPC) proposed the concept of ‘levels of palliative care’ (Radbruch and Payne, 2009) (Table 1.2). The EAPC stated that palliative care should be provided at all levels: from a ‘palliative care approach’, adopted by all healthcare professionals and volunteers, to ‘specialist palliative care’ which is more focused on complex cases (Radbruch and Payne, 2009). A similar concept has been discussed in the articles which described the WHO public health strategies in palliative care (Stjernswärd, 2007; Stjernswärd, Foley and Ferris, 2007), where a community approach was emphasised. These concepts suggest that family physicians should be able to provide ‘general palliative care’ and to take a ‘palliative care approach’ when necessary (Table 1.2).

Table 1.2 Three levels of palliative care (Radbruch and Payne, 2009)

Specialist palliative care:
Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options.

General palliative care:
Professionals who are involved more frequently in palliative care, such as oncologists or geriatric specialists, but do not provide palliative care as the main focus of their work, still may have acquired special education and training in palliative care and may provide additional expertise.

Palliative care approach:
A way to integrate palliative care methods and procedures in settings not specialised in palliative care. Including not only symptom control, but also communication with patient and family as well as other healthcare professionals, decision-making and goal setting in accordance with the principles of palliative care.

1.2.2 Roles of family physicians in palliative care

Family medicine shares similar philosophies with palliative care, including comprehensiveness, patient-centeredness and a holistic approach (Barclay, 2001; Van den Block, 2012). It was reported that family physicians' involvement could potentially improve the quality of home-based palliative care (Dahlhaus *et al.*, 2014). In fact, many family physicians consider palliative care as an essential part of their job and are willing to take their responsibility in providing care for the dying (Field, 1998; Mitchell, 2002; Hanratty *et al.*, 2006).

The continuity of care, a holistic approach and being able to deal with multiple problems - not only limited to medical ones - were identified as major characteristics of palliative care provided by family physicians (Field, 1998; Dahlhaus *et al.*, 2014). According to a study, family physicians considered that becoming engaged with family and community relationships, coordinating care, and symptom management were their roles in providing palliative care (Field, 1998). Not only family physicians themselves, but also other professionals, families and patients regard family physicians as central actors in palliative care in the community (Oishi and Murtagh, 2014). Bereaved families and patients appreciate family physicians’ compassionate, sensitive, and continuing care and support (Grande et al., 2004).

Thus, there are many possible roles which family physicians can play in the delivery of palliative care. However, many of these roles have only been vaguely defined or have not been discussed extensively in policy and research (Shipman *et al.*, 2008). One significant role of family physicians is identification of patients for palliative care which can be a unique role for generalists, in contrast to the role of palliative care specialists in caring for patients already identified as having palliative care needs (Murray *et al.*, 2008, 2015; Schneider, Mitchell and Murray, 2010).

1.2.3 ‘Transitions’ to palliative care

Previously the ‘transition’ to palliative care was a clear cut-off point at which patients were diagnosed as incurable. Over the decades, however, it has been recognised that this transition should happen gradually. While many people proposed models for the transition to palliative care, Boyd and Murray (2010) identified two kinds of transitions (Figure 1.1) and concluded that the better management and facilitation of these transitions could contribute to improved care during the remainder of a person’s life.

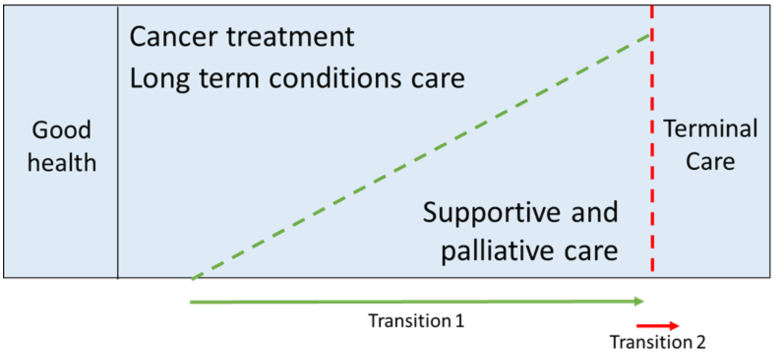

Figure 1.1 Key phases and two transitions at the end of life

(Boyd and Murray 2010, with permission from the authors)

As for challenges around these transitions, Marsella (2009) suggested that a lack of time to prepare for the transition was detrimental for patients and families, while Gardiner *et al.* (2011) placed more emphasis on the importance of early recognition of the point for the transition and suggested potential roles for primary care to contribute to a better transition. It has been argued that the timely identification of patients is a prerequisite for the good management of the transition as it enables planning their care in advance and prevents unnecessary crisis, fear and confusion (Boyd and Murray, 2010; Claessen *et al.*, 2013; Walsh *et al.*, 2015).

1.2.4 Palliative care ‘needs’

Before discussing the identification of patients with palliative care ‘needs’, I will first define healthcare ‘needs’. Bradshaw’s taxonomy of ‘needs’ (1972) categorises needs into four groups: felt; expressed; normative; and comparative. This well-known taxonomy does not reflect palliative care needs satisfactorily because patients are often unaware of their own palliative care needs. Furthermore, setting standards for a quality of life for ‘normative’ and ‘comparative’ needs is problematic as individuals’ values of life differ considerably. Therefore, I decided to adopt ‘capacity to benefit’ as a definition of needs in healthcare (Culyer and Wagstaff, 1993) for this thesis. By using this definition, it is possible to include ‘people who would benefit from palliative care' within 'people with palliative care needs' regardless of their awareness of their own needs. Regarding this, I note here that the following phrases: 'patients (or people) with palliative care needs'; 'patients (or people) needing palliative care'; 'patients (or people) for palliative care'; and 'palliative care patients' will be used interchangeably in this thesis.

1.2.5 Identifying patients for palliative care in primary care settings

It is suggested that family physicians should be able to proactively identify patients with undiscovered palliative care needs (Thomas, Wilson and GSF Team, 2016). However, it remains a significant challenge for family physicians to determine: for which patients; when; and at what level, palliative care should be considered (Farquhar *et al.*, 2002; Shipman *et al.*, 2008). Clinicians in primary care encounter people with diverse healthcare needs. Palliative care needs are only a part of such healthcare needs and arise in various situations within primary care settings. Clinical problems in primary care are generally ill-defined (Royal College of General Practitioners, 2012) and patients themselves are not necessarily aware of having palliative care needs (Beernaert *et al.*, 2014).

Reflecting these substantial difficulties, such identification has relied on the accumulated expertise of experienced doctors, including detecting subtle signs from patients, relatives and other professionals (Claessen *et al.*, 2013). Nonetheless, primary care physicians do report the need for training in the identification of patients with palliative care needs (Selman *et al.*, 2017) and it has been recognised that valid and systematic tools to support such identification would potentially be of benefit (Marie Curie, 2015; Walsh *et al.*, 2015). Having such tools would be particularly useful for healthcare professionals who do not regularly see patients requiring palliative care, or who do not have much experience in providing palliative care. These challenges are pertinent to Japan. Not only we do not know how Japanese family physicians identify patients for palliative care, but the usefulness of supporting tools in Japanese primary care settings is also uncertain.

1.3 Research aims and questions

To summarise, there is a potential theory-practice gap between the definition and practice of palliative care. In addition, despite the apparent importance of the identification of patients for palliative care in primary care settings and of tools to support it, we do not know actual practices of such identification and how useful those tools are. To disentangle these problems, the first step would be to understand family physicians' understanding and experience of these issues particularly in Japan, a step this PhD research will undertake. As with many other countries, in Japan, these problems have not been discussed in academic literature, and so this first step will make a sound basis to address the current difficulties as well as securing further investigations and implications for practices.

Incorporating this first step, the overarching aims of this PhD research are to explore: the Japanese family physicians' understanding of palliative care; their identification of palliative care patients; and their acceptance of a tool for the identification of patients for palliative care. As for the tool, the Supportive and Palliative Care Indicators Tool (SPICT) was chosen for this research as will be discussed in Chapter 2.

These aims are expressed through the following research questions:

> **RQ1: How do the Japanese family physicians understand palliative care?**
>
> **RQ2: How do the Japanese family physicians identify patients with palliative care needs?**
>
> **RQ3: Can the SPICT be translated for and adapted to Japanese primary care settings?**
>
> **RQ4: How would the Japanese version of the SPICT be utilised by family physicians and what are their perceptions of its impact?**

1.4 Outline and structure of this research

This research is conducted in two phases:

Phase I: Translation and cross-cultural adaptation of the SPICT

Phase II: Qualitative interviews with Japanese family physicians

Phase I contains the translation and cultural adaptation of the SPICT. This Phase aims to address the second research question: Can the SPICT be translated for and adapted to Japanese primary care settings? (RQ3) The outputs from this Phase (*i.e.* SPICT-JP and the user-guide) were used in Phase II.

Phase II contains an application of the Japanese version of SPICT (SPICT-JP) together with the user-guide and qualitative interviews with Japanese family physicians. The qualitative interviews explore their understanding of palliative care and identification of patients for palliative care, how the SPICT-JP fits within their current practice, and their perceptions about it.

This PhD thesis consists of nine chapters. While the first three chapters establish the background of this research, Table 1.3 presents how Chapters 4 to 8 address which of Phases I and II and which of the four research questions.

Table 1.3 The structure for this thesis and research

Chapter	Research question	Phase	
4	3	I	Translation and cross-cultural adaptation of the SPICT
5-8	1, 2, 3, 4	II	Qualitative interviews with family physicians

The following is a brief overview of this thesis.

Chapter 1: Introduction provides the readers with an understanding of how I translated my clinical difficulties into the overarching aims and three questions of this research.

Chapter 2: Japan: Contextualising the research setting provides background information about the current status of Japanese healthcare systems with a special focus on primary care and palliative care. It also considers how death and dying are portrayed in modern Japanese society which would influence the interpretation of the results of this research.

Chapter 3: Literature review is a selective literature review addressing three review questions which were formulated from my research questions. While evidence showed family physicians' broad understanding of palliative care and challenges to identification, no qualitative studies involving Japan addressing these issues were found. Among several tools for the identification of patients for palliative care, the SPICT was chosen for use in this research for its conciseness and practicality.

Chapter 4: Translation and cross-cultural adaptation of the SPICT, Phase I of this research, details the process and outputs of the translation and cross-cultural adaptation of the SPICT following the international guideline (Beaton *et al.*, 2002) with some amendments. Along with the actual process undertaken, the comments from the expert committee are also presented. The expert committee members pointed out a lack of awareness among the general public and healthcare professionals as a barrier to palliative care and questioned the effectiveness of the SPICT-JP in the Japanese primary care settings.

Chapter 5: Methodology details how I conducted Phase II of this research in practice with some theoretical perspectives which underpin the research methods I chose. Descriptions of the actual steps undertaken including the recruitment process, data generation and analysis, along with reflexivity and ethical considerations, are offered.

Chapter 6: Understanding of palliative care is the first of three chapters reporting results from the qualitative interviews with Japanese family physicians. This chapter focuses on participants' accounts of their understanding of palliative care. While family physicians understood palliative care as a broader concept, they tended to use the term 'palliative care' only to refer to the care provided at the last phase of patients' lives. They often considered palliative care as a continuum of good family practice.

Chapter 7: Identification of palliative care patients is the second of the three result chapters. This chapter reports on the family physicians' perceptions of the identification of patients needing palliative care. Not only diseases and health status of patients, but many other factors influenced such identification. All factors were interwoven and interrelated with each other, and there were no standard or straightforward ways of identifying such patients.

Chapter 8: Using the SPICT-JP in practice is the final of the result chapters. This chapter reports on Japanese family physicians' accounts of using the SPICT-JP in their practice. The perceived impact of the SPICT-JP in practice seemed to be an improvement in the confidence of those professionals using it, and not changes in their practice. For those who were already confident in identifying patients for palliative care, using SPICT-JP could have little impact. The impact of the SPICT-JP would be more substantial if it weresupplemented with more effective education and information, according to participating family physicians.

Chapter 9: Discussion presents a summary and discussions of the results from Phases I and II (Chapters 4 to 8). It locates these results within the previous literature and knowledge. Implications for clinical practice, policy and research are also presented, followed by my reflections on conducting this research and a conclusion.

Before bringing this introduction chapter to a close, I wish to discuss terminology briefly. Reflecting the evolution of its speciality, the term used for doctors specialising in primary care is not standardised internationally. ‘General practitioner (GP)’ is the term used in the United Kingdom (UK) when referring to doctors trained to provide primary care and this term is often used in other European countries as well as some Commonwealth countries. However, in some such countries, the same term refers to doctors who provide primary care but did not necessarily receive formal training in primary care or family medicine. The term ‘family physician’ was first used in the USA and referred to a doctor trained in primary care. Japan has followed this nomenclature and ‘family physicians’ in Japan are doctors who received formal training in family medicine.

In this thesis, when no background information is available, I will use the generic term ‘family physician’ when referring to doctors specialised in primary care/family medicine. I will also use the term ‘general practitioners (GPs)’ when referring to doctors in the UK as necessary. The roles of primary care doctors vary in different healthcare systems partly reflecting societal expectations of such roles. Employing a single term without consideration would jeopardise subtle but fundamental differences in the understanding of the roles of primary care physicians in different countries.

Chapter 2 Japan: Contextualising the research setting

In this chapter, I will provide background information about Japan, where this research was undertaken. After researching different kinds of healthcare systems worldwide, I came to realise that Japan had a unique and distinct healthcare system which contrasts with those in many Western countries. Therefore, in order to help readers to secure a sound understanding of this research, it was deemed useful to provide background information on Japan’s healthcare system in particular and other relevant issues. In presenting the reader with such information, it was decided to use the healthcare system and related matters in the UK as reference points. This decision was made because my PhD research was conducted at a UK university and more importantly, the UK is a country renowned for its long history of robust primary care (Kringos *et al.*, 2015) and well-developed palliative care (Noble and Winslow, 2015).

In order to do so, in this chapter, I will first offer a brief overview of Japan itself which will provide a contextual basis for its healthcare system. I will then introduce the current status of primary care in Japan with a particular emphasis on its workforce. Following on, I will describe palliative care in Japan with a focus on generalist palliative care and palliative care in the community. Finally, I will discuss some cultural values which may have influenced palliative care in Japan.

2.1 A brief overview of Japan

Japan is an archipelago in the Pacific with four main islands: Honshu (containing the capital city, Tokyo); Hokkaido; Kyushu; and Shikoku, and is located in East Asia having a territory of 364,560 km^2 (Figure 2.1; Table 2.1). The population of Japan is 126 million, giving a mean population density of 340.8/km^2 (Table 2.1). With a high education level and high literacy rates, Japan has succeeded in achieving a high Gross Domestic Product of 39,286 USD per capita (World Bank, 2015) (Table 2.1) and is now the third-largest national economy in the world. Japan is perceived as having achieved good health at a relatively low cost (Organisation for Economic Cooperation and Development [OECD], 2014). Japan enjoys long life expectancy rates, with an average life expectancy of 81.1 years for males and 87.2 years for females (Institute of Health Metrics and Evaluation [IHME], 2018) (Table 2.1), while across the world the rate is 72.0 years for both sexes (WHO, 2018b).

Figure 2.1 Map of East Asia including Japan

The map source: University of Texas Libraries.
(https://legacy.lib.utexas.edu/maps/middle_east_and_asia/asia_east_pol_2004.jpg)

Table 2.1 Demographic data: the UK and Japan

	UK	Japan
Population*	66,488,990 (2018)	126,529,100 (2018)
Land area (km^2)*	241,930 (2018)	364,560 (2018)
Population density (people/km^2 of land)*	275 (2018)	347 (2018)
Life expectancy*	81 years (2017)	84 years (2017)
Population ages 65 and above (% of total population)*	19% (2018)	27% (2018)
Health expenditure (% of a GDP)*	9.76% (2016)	10.93% (2016)
GDP per capita (USD)*	42,491 (2018)	39,286 (2018)
Death rate (deaths /1000 persons)*	9 (2017)	11 (2017)
Birth rate (births /1000 persons)*	11 (2017)	8 (2017)
Major causes of death**	Ischemic heart disease, Alzheimer’s disease, Stroke, COPD	Alzheimer’s disease, Ischemic heart disease, Stroke, Lower respiratory infection

*(World Bank, 2015) **(IHME, 2018)

2.1.1 Japan’s projected demographics

Japan has now entered the so-called fifth stage of its demographic transition, where the death rate exceeds the birth rate (Cohen and Deliens, 2012). While the UK and Japan have similar profiles as high-income countries, population ageing is more prominent in Japan (Table 2.1). It is projected that Japan’s demographics will undergo significant changes in the coming decades: Japan’s population will continue to decrease and to age (National Institute of Population and Social Security Research [NIPSSR], 2017).

In 2018, those aged 65 and over comprised 28.1% of its total population and those aged 75 and over comprised 14.2% (Cabinet Office, Government of Japan [COGJ], 2019). As Figure 2.2 shows, Japan will have more older people while the working-age population continues to shrink. By 2040, the percentage of those aged 65 or over will reach 40% (United Nations, 2019). The number of deaths has been gradually increasing and will reach its highest, over 1.6 million, by 2040, which is about 1.2 times more than the current figure (NIPSSR, 2017). The predicted death rate for 2065 is 17.7 per 1,000 people (COGJ, 2017), while in 2013, it was 10.0 per 1,000 people (MHLW, 2015). Approximately 90% of deaths in 2025 will occur in people aged 65 or over (Ministry of Health, Labour and Welfare [MHLW], 2006), and so the question of who should care for those who are dying has been raised (Central Social Insurance Medical Council, 2011).

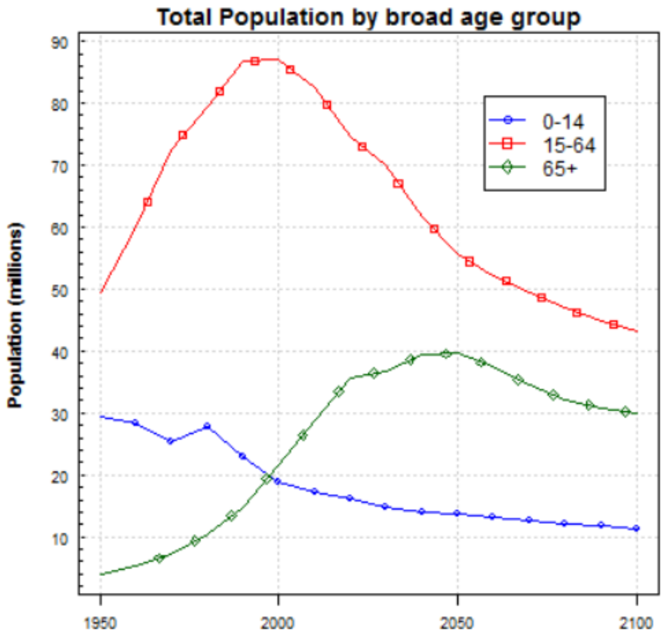

Figure 2.2 Estimated population changes in Japan by broad age group

Generated by World Population Prospects 2019 (United Nations Department of Economic and Social Affairs Population Division, 2017)

The main causes of death in Japan are similar to those in other developed countries (Table 2.1). According to the IHME (2018), in 2007, the top three causes of death in Japan were ischemic heart disease, Alzheimer's disease and stroke. A decade later, however, the number of people who died from Alzheimer's disease increased by 57.7%, positioning it at the top of such categories and so replacing ischemic heart diseases. Similarly, lower respiratory infections increased by 30% during the same decade. This was due to an increase in the number of cases of aspiration pneumonia, a common complication for the frail elderly with long-term conditions, which suggests that more people, particularly those who are older, are living with and dying from long-term illnesses. Providing sufficient support for those who are older, regardless of the imminence of their death, is a concern for Japan's healthcare system (Hirakawa, 2012).

2.1.2 Japan's healthcare system

A universal national health insurance coverage and free access are hallmarks of Japan's healthcare system (Morita and Kizawa, 2013; Kato *et* *al.*, 2019). Japan's National Health Insurance system provides universal healthcare coverage (Matsuda, 2015). The government publishes a national fee schedule every two years, including co-payment rates for treatments - which range from 10% to 30% depending on the patient's age and income - and any reimbursements to healthcare providers. Patients are required to pay the shared cost (co-payments) at the point of care, but those with low incomes are exempted from this cost-sharing. The medical remuneration rate in the schedule works as an incentive for healthcare providers (at least at managerial level) to plan their services. The changes in the remuneration rate act as government levers to nudge healthcare agencies in certain directions (Ikegami and Campbell, 2004). Also, the price regulation through this national fee schedule is the main factor in Japan's achievement in containing healthcare costs (Ikegami and Anderson, 2012).

In addition to this National Health Insurance system, participation in the Long-Term Care Insurance (LTCI) scheme is compulsory in Japan for everyone who is 40 years or older. Long-term care services (*e.g.* day care, care homes, visiting nurses, physiotherapy, respite care *etc.*) for those who are 65 years or over, or those who are 40 years or over and have specific diseases, are covered by the LTCI scheme (Tamiya *et al.*, 2011). Many community-dwelling people with chronic illnesses use some of these services if eligible.

Another characteristic of Japan's healthcare system is its free access. Patients normally self-diagnose themselves before consulting doctors and they opt for doctors whom, they consider, are the most appropriate according to their symptoms and self-diagnoses (Smith, Demers and Garcia-Shelton, 1997). Patients do not have to register with their primary care doctors, and there are no gatekeeping systems (Tatara and Okamoto, 2009; Ministry of Foreign Affairs, 2011a; OECD, 2014; Matsuda, 2015). Although there are some schemes to encourage patients to see primary care doctors first rather than specialists (Tatara and Okamoto, 2009; Matsuda, 2015), they are not strictly required to do so (OECD, 2014). This absence of any gatekeeping systems resulted in doctors based in hospitals providing not only secondary but also primary care. In fact, 32% of the estimated yearly total of outpatient consultations occurred in hospitals rather than in clinics (MHLW, 2007). Healthcare provision in Japan tends to be categorised according to where the care takes place rather than its function, which makes the roles and position of primary care somewhat ambiguous.

In his influential book, Ikai (2010), a sociologist specialising in healthcare policy, compared the healthcare delivery in the UK and in Japan (Figure 2.3). While in the UK, the boundaries between primary and secondary care were clear for both the specialism and the locations for care (*i.e.* clinics and hospitals), neither were so clear in Japan. Patients in Japan can access and leave the healthcare system at any point of its delivery. While there has been no clear functional differentiation between primary, secondary and tertiary care institutions, hospitals and clinics are allowed to provide any services deemed appropriate. This flexibility may have partly contributed to the rapid and efficient development of Japan's healthcare system until now, particularly regarding the improvement of accessibility to and responsiveness of healthcare provision.

Ikai (2010) admitted that historically, hospitals, rather than clinics in the community, have taken the central role in healthcare delivery and medical professional education in Japan. He then highlighted that Japan's healthcare model should adjust accordingly to the changing concept of health. More specifically, he suggested that the 'hospital-dominated century' should cease and accordingly, a change towards a 'community-based comprehensive care' model in every locality should emerge. Furthermore, he argued that this change should and would happen within Japan's historical contexts, rather than replicate any other countries' models.

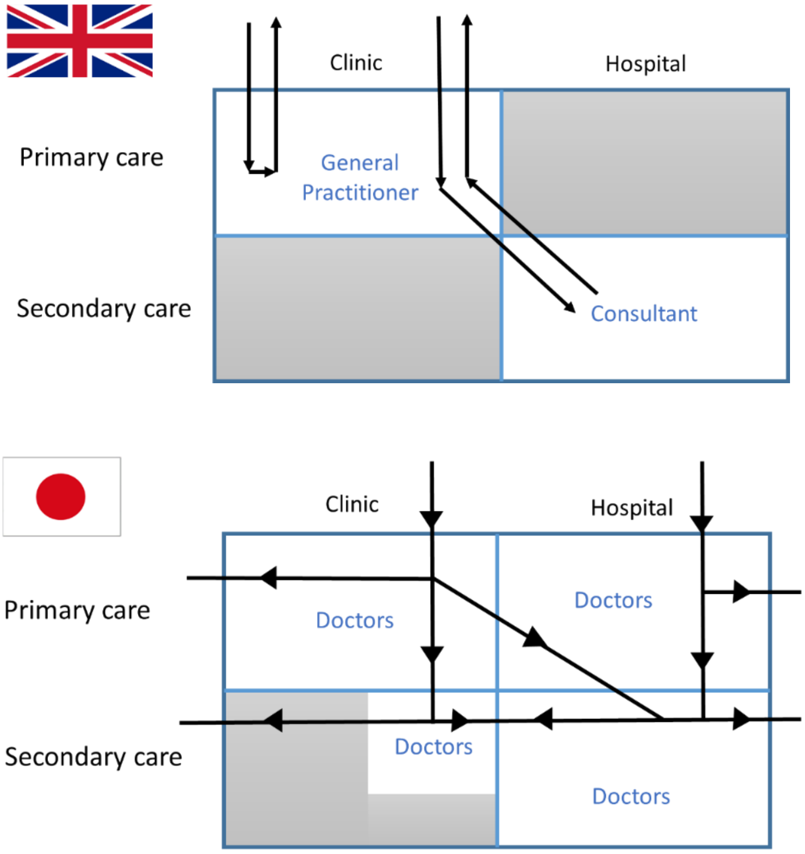

Figure 2.3 Access to healthcare: the UK and Japan (Ikai, 2010)

2.2 Primary care in Japan

Within Japan's healthcare system, there have been no established definitions for primary care (Otaki, 1998). Additionally, under its Medical Care Law, there has been no recognition of family medicine or primary care as being a medical specialism (Koike *et al.*, 2010). Moreover, neither primary care nor specialist care were acknowledged as being distinct disciplines (Matsuda, 2015). Accordingly, there is scant official and statistical information available about primary care in Japan.

Traditionally, primary care in Japan has been provided by 'a cadre of semi-generalist and semi-specialists' who are trained in hospitals without any formal training in primary care (OECD, 2014). While internal medicine doctors have traditionally prevailed as primary care doctors, there are other specialist clinics such as orthopaedic, dermatology, paediatrics, obstetrics and gynaecology and otorhinolaryngology in the community, which are normally solo practice (Matsuda, 2015). These doctors working in such clinics are so-called *‘kaigyo-i’* which literally translates into ‘practice-owner doctors’ and they are supposed to provide some sort of primary care in the community while not being formally trained in primary care.

Regarding medical specialities in Japan, any medical society or association can create specialisms and produce certified specialists based on their own criteria without being regulated by nationwide authorities (OECD, 2014). The absence of national standardisation of specialisms and specialists has been considered to be a longstanding problem (Tatara and Okamoto, 2009). In response to this problem, the government established an independent third-party organisation in 2014, called the Japanese Medical Speciality Board (JMSB), which aimed to launch a new specialism qualification in 2017 (JMSB, 2014; Kaneko and Matsushima, 2017). It was expected that under the JMSB, a new cohort of government-approved, ‘board-certified’ family physicians would be created. However, the JMSB has been criticised for its incapacity for self-regulation (Iwata, Mosby and Sakane, 2017; MHLW, 2018) and its poor organisation of the board certification system (MHLW, 2018; Kaneko *et al.*, 2019).

The Japan Primary Care Association (JPCA), which is a member organisation of the World Organization of Family Doctors (WONCA), has been administering the accreditation scheme for primary care doctors in Japan since the 1990s. In 2005, they launched a family medicine training programme to produce JPCA-certified family physicians, ‘*katei-iryo senmon-i*'. As of April 2020, there are 733 JPCA-certified family physicians (JPCA, 2020) (Table 2.2), compared to only 385 in August 2013 (Toi *et al.*, 2016), suggesting a rapid increase in numbers in the last few years. However, the current number represents only 0.21% of all medical doctors in Japan. Candidates have to complete a minimum three-year formal training on an accredited training programme. After completing this training and submitting portfolios and succeeding in both written and clinical skills exams, they would be certified as family physicians. In April 2020, there were 378 family medicine programmes accredited by the JPCA across Japan (JPCA, 2020). The JPCA curriculum requires training in palliative care for cancer and non-cancer patients and palliative care in the community. Trainees need to submit at least one portfolio about ‘end-of-life care’ to achieve the qualification. However, the amount of palliative care training provided by these programmes depends on the availability of palliative care education in each programme. Although there are no official data or publications about palliative care training in these programmes available, there seems to be a disparity in it.

According to a survey among certified family physicians in 2014 (n=302), 74% of them - or 224 - were in their thirties, with an average age of 37 (Toi *et al.*, 2016). The average length of time as a post-graduate was 12 years, and 94% of those surveyed had been post-graduates for under 18 years. Interestingly, around half of them worked in clinics while the other half were based in hospitals. For those who worked in clinics, only 28% were in solo practice while the others were based in group practices involving more than two full-time doctors. Among all the respondents, 44% of them provided inpatient care, and 69% provided medical homecare. 78% of those who provided medical homecare worked at government-accredited ‘homecare supporting clinics (clinics with a home hospice function)’. 90% of those who provided medical homecare reported that they were taking care of those who were dying in the community.

These figures imply that JPCA-certified family physicians are relatively young and work in hospitals providing inpatient care, which in the UK would be considered as being secondary care settings. In addition, the medical homecare they deliver seems to be intense. All of these data suggested that both JPCA- and future board-certified family physicians in Japan are not -

and would not be - synonymous with GPs in the UK (Kaneko and Matsushima, 2017).

Table 2.2 The Japan Primary Care Association (JPCA) membership (JPCA, 2020)

The Japan Primary Care Association (JPCA): since 2010*

*The three different organisations, the Japanese Medical Society of Primary Care (since 1978), the Japanese Academy of Family Medicine (1986), and the Japanese Society of General Medicine (1993) were merged in 2010 for further development of primary care in Japan (Kato *et al.*, 2019).

Membership[1]	11,890 (February 2019)
JPCA-certified family physicians	733 (April 2020)
JPCA-certified trainers	3,041 (April 2020)

2.3 Palliative care in Japan

Since the first modern hospice was established in Osaka in 1973, palliative care has progressed significantly in Japan. Kizawa *et al.* (2012) categorised specialised palliative care as follows: 1) palliative care units; 2) hospital-based palliative care consultation teams; 3) community palliative care consultation; 4) palliative care outpatient clinics; 5) palliative homecare; and 6) day care services (Table 2.3). The majority of these palliative care services were developed and maintained under the 2007 Cancer Control Act. As the Act’s name indicates, the focus has been on cancer. However, services and programmes developed under this Act have also contributed to improving palliative care knowledge among healthcare professionals at all levels, as well as the general public.

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[1] The combined numbers of the two groups *i.e.* JPCA-certified family physicians and JPCA-certified trainers fall short of the overall membership numbers. This is because all medical doctors, allied healthcare professionals and students are eligible for membership of the JPCA as long as they are interested in primary care and pay the membership fee. The JSPM and the JAHCM (which will be discussed in Section 2.3.2) conduct similar membership criteria.

Table 2.3 Categories of specialist palliative care services in Japan (Kizawa et al., 2012)

1. Palliative care units
2. Hospital-based palliative care consultation teams
3. Community palliative care consultation
4. Palliative care outpatient clinics
5. Palliative homecare
6. Day care services

Palliative Care Units (PCUs), which are typically located within hospital wards, have been considered to be the mainstream of specialised palliative care services along with hospital-based palliative care consultation teams, and these PCUs have increased rapidly in numbers in the last few decades (Morita and Kizawa, 2013) (Figure 2.4). In 2011, it was estimated that about 8.4% of all cancer deaths occurred in PCUs (Morita and Kizawa, 2013).

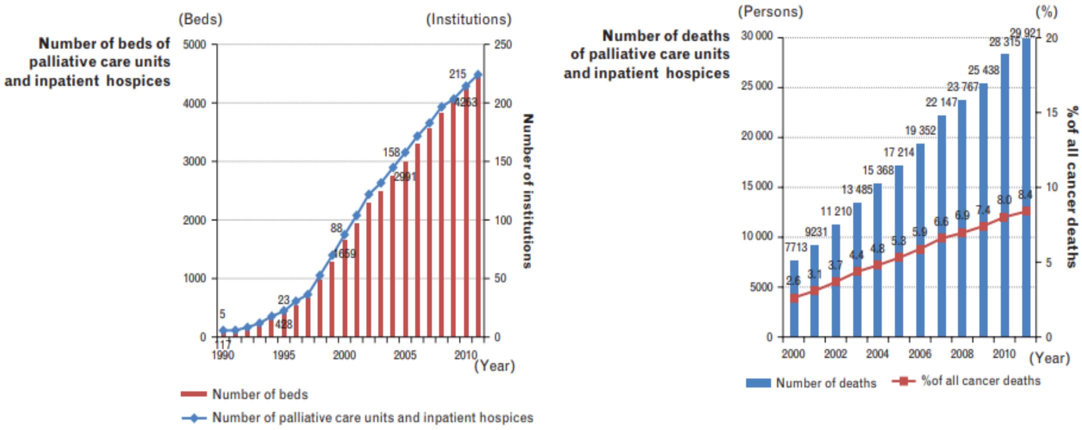

Figure 2.4 Development of palliative care units and inpatient hospices

(Morita and Kizawa, 2013, with permission from the authors)

Meanwhile, most PCUs do not take non-cancer patients because Japan's National Health Insurance system does not cover their admission into the PCUs (Hospice Palliative Care Japan, 2012). In such PCUs, the fee is paid per person per diem, and so almost all PCUs do not provide chemotherapy or other expensive treatments. As a result, patients are required to stop cancer treatments before being admitted into PCUs. This potentially leads to misunderstandings that palliative care is only for people at their terminal stage of cancer.

2.3.1 Palliative homecare in Japan

Japan's medical homecare

Japan has developed its own unique system of medical homecare. To access regular medical homecare, patients have to be registered. Once registered, patients receive on average a regular, fortnightly doctor's visit which typically lasts 20 minutes (Yokobayashi *et al.*, 2013). They can also call doctors for emergency home visits when necessary. Regular home visits ensure continuity of care for patients with long-term conditions.

Furthermore, medical homecare is now becoming a medical specialism in Japan, and there are clinics which specialise in medical homecare. Accreditation is provided by the Japanese Association for Home Care Medicine (JAHCM) which was established in 2019 with the merger of the two existing societies for medical homecare. The Japan Academy of Home Care Physicians, one of the merged societies, launched medical homecare training programmes in 2009 which require extensive knowledge and skills in palliative and geriatric care.

Specialist palliative care in the community

While general medical homecare has been developed in its distinctive way in Japan, palliative homecare is repeatedly referred to as being 'under-developed' by palliative care specialists (Yamagishi *et al.*, 2008; Morita and Kizawa, 2013; Tsuneto, 2013). While inpatient specialist palliative care services have undergone significant growth, the development of palliative homecare has been nebulous. There are in fact no agreed definitions for specialist palliative homecare. This was reflected in its exclusion from the nationwide survey which investigated the availability and utilisation of specialised palliative care services among cancer patients in Japan (Kizawa *et al.* 2012). The only provision we could possibly regard as being specialist palliative homecare provision is the ‘homecare supporting clinics’ (clinics with a home hospice function). These clinics are available around the clock to support patients through their collaboration with local hospitals and visiting nurses (Ohta, 2015). Their function is not limited to palliative care, but they are supposed to take care of patients in the community until their death. The number of these clinics is increasing (13,614 in March 2018) (MHLW, 2020), but their distribution is patchy, and only half of them actually provide palliative care at the end of life (Ohta, 2015). Some palliative specialists work at these clinics (they normally also provide general medical homecare), but their number is unknown. So, in essence, we do not know the volume of palliative homecare provision in Japan.

The national survey identified that 14% of participating institutions provided community palliative care consultation (3. in Table 2.3), reflecting a significant growth compared to the situation a decade ago (Kizawa *et al.*, 2012). However, the number of patients who utilised this service was significantly lower than the number of patients utilising other specialised palliative care services, particularly inpatient ones (1. and 2. in Table 2.3) (Kizawa *et al.*, 2012). From a primary care point of view, this suggests that doctors providing palliative care in the community are left without specialist support.

Here, I will present an example of specialist/generalist palliative homecare in action, drawing on the Yamato Clinic, which provides palliative homecare in the community (Oishi and Hamano, 2015). The Yamato Clinic is located in a rural area in the Ibaraki Prefecture which has a population of around 50,000 people, of whom one fourth are aged 65 years or above. In this clinic, four JPCA-certified family physicians are working full-time along with five practice nurses. Although all of them have had some training in palliative care, they are not qualified as palliative care specialists (which also suggests an ambiguous boundary between specialist and generalist palliative homecare). The clinic has an adjacent home nursing station staffed with ten visiting nurses which collaborates with other healthcare professionals and institutions in the area. In contrast with typical clinics in Japan which are owned by a single hospital-trained doctor, the Yamato Clinic is owned by a medical organisation and is run by four family physicians. Part-time doctors were sent from the nearby Tsukuba University, which connects the clinic to the medical school. This affiliation enables the Clinic to become active outside of clinical practice, such as providing training for healthcare professionals in the area and education for the medical students.

2.3.2 Palliative care workforce

The Japanese Society of Palliative Medicine (JSPM) established in 1996 is the most noticeable association for palliative care, providing speciality training and accreditation (Yamagishi *et al.*, 2008). In April 2019, a total of 1,051 doctors were JPSM-qualified in palliative medicine (Table 2.4). Reflecting the focus of Japan’s healthcare system on hospitals, these specialists tend to stay in such hospitals and do not see community-dwelling patients (Kizawa *et al.*, 2012; Oishi and Hamano, 2015)

Table 2.4 JPSM membership (JSPM, 2019)

The Japanese Society of Palliative Medicine (JSPM) since 1996	
Membership[2]	13,105 (July 2019)
JSPM-certified palliative medicine physicians[3]	244 (April 2019)
JSPM diplomates in palliative medicine	518 (April 2019)
JSPM-certified trainers	253 (April 2019)

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[2] See footnote 1 above

[3] There does not seem to be official English titles for these certifications. So, for greater clarity, I have given equivalent expressions to those used by the JPCA.

Another cohort who provide community palliative care directly is homecare physicians. They are qualified by the JAHCM, and the number of these is just 307 (Table 2.5).

Table 2.5 The Japanese Association for Home Care Medicine (JAHCM) membership

The Japanese Association for Home Care Medicine (JAHCM) since 2019

*Two organisations, the Japanese Academy of Home Care Physicians (since 1999) and the Japanese Society for Homecare Medicine (since 1990) were merged in 2019.

Membership[4]	4,027 (July 2019)
JAHCM-certified Homecare Physicians	307 (July 2019)
JAHCM-certified trainers	142 (July 2019)

There are many more doctors providing medical homecare and community palliative care without any qualifications, but the number of such doctors is uncertain. In addition, doctors who are not necessarily qualified in either palliative care or medical homecare could be providing general palliative care. The Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education (PEACE) project is a nationwide educational programme for all medical doctors in Japan which provides an opportunity to acquire basic knowledge and skills in palliative care (JSPM, 2020). This 2-day interactive course encourages participants to discuss ‘end-of-life care’ in general. In total, 129,738 doctors had attended this programme by September 2019. The PEACE project has been highly valued by participating doctors and has positively promoted palliative care.

2.4 Cultural values influencing palliative care in Japan

When considering primary care providers’ perspectives and roles in palliative care, we need to consider their cultural background which underpins such perspectives and roles. What people portray as being a ‘good death’ is attributed to socio-cultural norms as well as to personal experiences (Hattori,

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[4] See footnote 1 above. The JAHCM does not disclose numbers of their membership. I inquired their office to obtain these numbers.

McCubbin and Ishida, 2006), suggesting that palliative care is also influenced by these socio-cultural norms.

In this section, I will discuss those Japanese cultural values which could influence how people consider palliative care should be in Japan. First, I introduce the current influences of religions in Japan with an emphasis on ancestor worship. I then present the research results and discussions regarding a ‘good death’ in Japan, which includes a consideration of how Japanese people might perceive ‘autonomy’ in decision-making.

2.4.1 Religions in Japan

Religions and cultures influence societal attitudes on death and dying in every country. The most common religions in Japan are Shinto, Buddhism and Christianity. Shinto is an indigenous religion in Japan in which people believe that there is a plurality of ‘gods’, ‘deities’ or ‘divine powers’ located in natural environments such as stones, trees, mountains, the elements and other natural phenomena (Ministry of Foreign Affairs, 2011b). Buddhism arrived in Japan from China via Korea in the middle of the 6th century and has been immensely modified by Shinto since then (Ministry of Foreign Affairs, 2011b). Japanese Buddhism differs from that in all other countries. Confucianism also influences Japanese ethics and philosophies, such as filial piety: being respectful to the elderly and seniority (Paramore, 2016).

According to the Agency for Cultural Affairs (2014), the combined membership of Shintoists and Buddhists exceeds 100% of Japan’s population (Table 2.6). This is because many Japanese consider themselves as being both Shintoist and Buddhist. For most Japanese, Shinto and Buddhism can coexist peacefully in their minds to support their spirituality (Ministry of Foreign Affairs, 2011b). It is common to see *kamidana*, a Shinto altar, and *butsudan*, a Buddhism altar, next to each other in Japanese houses.

Christianity or Christian rituals have also influenced the everyday lives of Japanese people. For example, Christian-style wedding ceremonies are seen as fashionable and have gained in popularity. The Japanese also celebrate Christmas with Christmas cakes and by exchanging Christmas presents with each other. However, Christianity is still considered to be an alien religion by most Japanese (Ministry of Foreign Affairs, 2011b) and ethics and morals in Japan are mainly influenced by Buddhism and Shinto.

Table 2.6 Numbers of followers claimed by religions in Japan (Agency for Cultural Affairs, 2014)

Note: The total Japanese population was 126,529,100 (2018)

Shintoism	91,260,343	(48%)
Buddhism	86,902,013	(45.7%)
Christianity	2,947,765	(1.6%)
Other	9,066,141	(4.8%)
Total	190,176,262	

Ancestor worship and the proximity to death in Japanese culture

Ancestor worship (*sosen-suhai*) shared by Shinto and Japanese Buddhism plays an important part in Japanese culture regarding death and dying. In Japanese, '*jobutsu suru*' and '*hotoke-san*' which literally mean 'to become Buddha' and 'Buddha', respectively, are codes for 'to die' and 'a dead person' in everyday conversations. In Japanese Buddhism, the dead person is believed to have become a Buddha in order to help his or her living descendants (Editorial Committee for Jodoshinshu, 2011). Fostering a relationship with the ancestor is important for the living, and continuing to sustain a bond with the deceased is celebrated (Valentine, 2010). Klass (1996) concludes that ancestor worship is 'an expression of the human community that cannot be separated by death' (Klass, 1996, p.70).

The proximity to the after-world also seems to be closer in Japan than in Western countries. Aoki (1996), the writer of the novel 'Coffinman', which inspired the prize-winning film 'Departure' (Takita, 2008), asserts that the boundary between the deceased and the living is far more ambiguous in the East. The after-world is often described as '*anoyo*', which literally means 'that world', while '*konoyo*', which literally means 'this world', refers to the living world. This metaphor expressing the living and the after-world as 'this' and 'that' also reflects the Japanese perception that the after-world is not so far away.

Several researchers highlighted the positive roles of the family Buddhist altar, *butsudan* (Yamamoto and Okonogi, 1969; Klass, 1996; Deeken, 2004; Valentine, 2010). A study involving interviews with widows in Japan concluded that ancestor worship and the possession of a *butsudan* helped those widows feel that the deceased remained close to them (Yamamoto and Okonogi, 1969). A survey among the 152 *butsudan* purchasers found that the most common reason for praying at altars was to converse with the deceased and that 88% of the respondents had experienced talking to the deceased (Sakaguchi, 2010). The deceased play the role of listeners or consultants for the living through *butsudan*. Yamamoto and Okonogi (1969) characterised *butsudan* as a 'hotline' to the deceased.

In addition, dead bodies have significant meaning in Japanese culture. Several writers have emphasised that Japanese people try hard to find the bodies of the deceased after disasters and that it is significantly important for them to be able to treat the deceased well (Hirayama, 1991; Iizuka, 1998 cited in Sakaguchi, 2010; Tabuchi, 2012). The experience of grief and how one makes sense of death depends on how warmly and with what kindness dead bodies are treated - as if they were still alive.

On the other hand, during a drastic social shift after the Second World War in Japan, there were some changes in people's experiences of ageing, dying and bereavement (Becker, 1999). Japan is now considered to be the most secularised country in the world (Deeken, 2004; Ministry of Foreign Affairs, 2011b). With the weakening of community cohesion, the bereaved or carers do not automatically receive social support from the community (Kashiwagi, 1997). In this context, Katayama, Sakaguchi and Sakaguchi (2006) suggested the potential for online-based support groups to help the bereaved. However, Deeken (2004) questioned whether the maintenance of the bond with the deceased is possible and sufficient to support the bereaved in modern Japanese society. Valentine (2010) states that Japanese people do not follow cultural rites blindly. Instead, they ‘redefine, revise and reject these to produce their own versions of established practice’ (Valentine, 2010, p. 290). This suggests that people tend to adapt social norms to their own way of understanding. Interestingly, this tendency was not observed in Yamamoto and Okonogi’s study conducted in 1969, suggesting that the Japanese people’s attitudes have changed since then.

2.4.2 A ‘good death’ in Japan

Concepts of a ‘good death’ in Japan have been investigated by a group of palliative care researchers in the 2000s. After identifying possible components of a good quality of life for terminal stage cancer patients by qualitative interviews with patients, families, nurses and doctors (Hirai *et al.*, 2006), they conducted a nation-wide survey with citizens (n=2,548) and bereaved family members of cancer patients (n=518) to determine which components were more important than others (Miyashita *et al.*, 2007). These studies identified 18 domains contributing to a ‘good death’ categorised into three groupings according to their importance: consistently important (Table 2.7); mixed important (Table 2.8) and relatively less important (Table 2.9). In addition, they investigated the association between these identified components and the three well-known Japanese populist cultural values for a ‘good death’: ‘dying in one’s sleep’, ‘*pokkuri* (sudden death)’ and ‘*omakase* (entrusting decisions to others, such as medical professionals or families, which will be revisited later)’. As these studies focused on a ‘good death’ in cancer care, a caveat is required regarding interpretation and generalisability of the results. Nonetheless, their findings showed some unique characteristics of a ‘good death in Japan’.

The components identified as consistently important (Table 2.7) showed some similarities to the Western concepts of a ‘good death’ (Steinhauser *et* *al.*, 2000, 2001), which was consistent with a previous study (Long, 2004). This suggests that there are some elements of a 'good death' pertinent to many cultures and ethnicities (Miyashita et al., 2007). On the other hand, some particular characteristics of a 'good death in Japan' – which contrasted with those found in the Western countries – were identified (Hirai *et al.*, 2006; Miyashita *et al.*, 2007). One of the notable findings was that Japanese people thought highly of remaining unaware of and disengaging with death. This may be related to the traditional Japanese preference for not being told of their cancer diagnosis (Konishi and Davis, 1999; Long, 1999; Miyashita *et al.*, 2006). In addition, they did not think 'taking control over the future' as important (Miyashita *et al.*, 2007). They preferred not to be aware of approaching death and rather to live as usual as possible, even in the face of terminal cancer (Miyashita *et al.*, 2007). This contrasts with Westerners' notions of 'taking control over the future' (Voltz *et al.*, 1998; Steinhauser *et al.*, 2000). This, together with the three well-known populist Japanese values: 'dying in one's sleep'; '*pokkuri* (sudden death)'; and '*omakase* (entrusting decisions to others)', indicates Japanese people's submissive and passive attitudes in deciding their future, which could be seen as a fatalistic acceptance of their own circumstances (Hirakawa, 2012).

It is also noticeable that while core domains were consistently considered as important (Table 2.7), the importance of other domains varied significantly from individual to individual (Table 2.8) (Miyashita *et al.*, 2007). This suggests that, although some aspects were shared, there were no uniform notions of a 'good death' among Japanese people. It is crucial for care professionals to explore individual patient's perceptions and values in each set of circumstances and for policymakers to understand this heterogenic nature of a 'good death'. In addition, Akechi *et al.* (2012) investigated differences between younger and older people's concepts of a 'good death'. Although the authors generally found a few differences between the two age groups, older people tended to support the '*omakase*' concept more than younger people, and being able to trust in their doctors still means more for older people than younger ones. This indicates that such passive attitudes in decision-making may be more prominent among older people.

In relation to the '*omakase* (entrusting decisions to others)' notion, the value of 'fighting against cancer', which was highlighted in the qualitative study (Hirai *et al.*, 2006), was categorised in the mixed importance grouping (Table 2.9) (Miyashita *et al.*, 2007). Such 'fighting against cancer' would not probably mean that they wanted to decide their own future through fighting against cancer. Rather, they wanted to fight against cancer for their pride and virtue. Hirai *et al.* (2006) discussed the possible importance for Japanese people to receive all the available treatments.

Table 2.7 Consistently important domains of a 'good death' in cancer care in Japan (Miyashita et al., 2007)

Domain	**Component**
1. Physical and psychological comfort	Being free from psychological distress Being free from pain and physical distress
2. Dying in a favourite place	Being able to stay at one's favourite place
3. Good relationship with medical staff	Trusting physicians Discussing one's treatment with one's physician Having a professional nurse with whom one feels comfortable Having people who listen to me Receiving consistent care from the same physician and nurse Having a physician or nurse with whom one can discuss fears of death
4. Maintaining hope and pleasure	Having some pleasure in daily life Living positively Living in hope
5. Not being a burden to others	Having no financial worries Not being a burden to family members Not making troubles for others
6. Good relationship with family	Spending enough time with one's family Family is prepared for one's death Having family to whom one can express one's feelings Having family by one's side when one is going to die Believing that one's family will do well after one's death Having family support
7. Physical and cognitive control	Being able to eat Being mentally clear Being independent in daily activities
8. Environmental comfort	Living in calm circumstances

	Living like being at home
9. Being respected as an individual	Not being treated as an object or a child Being respected for one's values Being free from trivial routines
10. Life completion	Family has no regrets for one's death Having no regrets Feeling that one's life was completed

Table 2.8 Mixed important domains (Miyashita et al., 2007)

Domain	**Component**
11. Natural death	Dying a natural death Not being connected to medical instruments or tubes
12. Preparation for death	Feeling thankful to people Being prepared for dying Seeing people whom one wants to see Saying good-bye to dear people Being reconciled with people
13. Role accomplishment and contributing to others	Feeling that one's life is worth living Maintaining one's role in family or occupational circumstances Feeling that one can contribute to others
14. Unawareness of death	Living as usual without thinking about death Dying without awareness that one is dying Not being informed of bad news

Table 2.9 Relatively less important domains (Miyashita et al., 2007)

Domain	**Component**
15. Fighting against cancer	Believing that one used all available treatments Fighting against disease until one's last moment Living as long as possible
16. Pride and beauty	Not receiving pity from others Not having a change in one's appearance Not exposing one's physical and mental weakness to family
17. Control over the future	Knowing how long one will live Having planned arrangements for one's grave, funeral and last will Knowing what to expect about one's condition in the future Controlling time of death, like euthanasia
18. Religious and spiritual comfort	Feeling that one is protected by a higher power beyond oneself Having faith

Autonomy in decision-making

It is noticeable that decision-making, which is often discussed as a determinant of a 'good death' in Western culture, was not highlighted in the qualitative study in Japan (Hirai *et al.*, 2006). One study (although conducted nearly 20 years ago) found that 47% of patients surveyed would accept their doctors' recommendations even if they were against their wishes (Asai *et al.*, 1998). This attitude is known as '*omakase*' in Japanese, meaning 'the act of entrusting of a decision or set of decisions on another' (Slingsby, 2004, p.86) or 'leaving the decision to a medical expert' (Miyashita *et al.*, 2007, p.1093). Despite its apparently problematic nature, the '*omakase*' attitude was suggested as being functional in Japanese medicine. Slingby (2004) named the patient participation patterns based on this attitude in decision-making as the *Omakase* Model, claiming that 'active' *omakase* will remain functional alongside the new trend of patient participation in decision-making while 'passive' *omakase* will fade out. Hayashi *et al.*, (2000), in their survey with the general public, highlighted that although the respondents' preference for participation patterns was significantly varied, there has been a gradual transition from a paternalistic patient-doctor relationship to a more liberalistic one.

'*Omakase*' also refers to entrusting families (not just medical professionals). Familial cohesiveness is a common cultural attribute of Japanese and wider Asian culture (Blackhall *et al.*, 1995; Voltz *et al.*, 1998). Concepts such as 'autonomy' or 'decision-making' in healthcare are new to the Japanese culture (Hayashi *et al.*, 2000). Voltz *et al.* (1998) revealed that more Japanese entrusted to their families when making their future decisions than Westerners would. The researchers also highlighted that fewer patients in Japan had negative feelings towards important future decisions about them (Voltz *et al.*, 1998). This may also be attributed to the Japanese acceptance of life's events as being 'fate'. In addition, the researchers discussed that this might be because the traditional Japanese view of an emphasis on interdependent relationships as explored in the '*omakase*' notion may provide a sense of safety for patients (Voltz *et al.*, 1998).

2.5 Conclusions

Based on projected demographic changes, the need for palliative care is significantly increasing in Japan. It is evident that palliative care specialists cannot be responsible for all of the increasing number of people approaching death. Therefore, primary care providers are also expected to play a vital role in providing palliative care, especially in the community.

However, it has been argued that even this arrangement may not be sufficient to meet the more complex and vastly increased volume of palliative care needs arising out of significant socio-demographic shifts in Japan. The lack of primary care in Japan's healthcare system is criticised in the OECD health report which argues that strengthening primary care is critical for Japanese healthcare reform in order to meet the current and future needs and demands (OECD, 2014).

Currently, a small number of qualified family physicians with some palliative care training are working in the community without specialist support – even if they are motivated to provide palliative care and to take care of the dying in the community. In this context, it has become more urgent to find the methods and resources to support such doctors.

Furthermore, the methods should be culturally appropriate. As in many other countries, cultural values influence societal notions of death and dying in Japan. While we have to bear in mind that the values of individuals might be significantly different, it is crucial to understand the broader socio-cultural norms which underpin such individual values. Equally, we need to take into account the distinctive notions of and values around the concepts of a ‘good death’ and ‘decision-making’ in Japan. Only in doing so, can we support such family physicians delivering palliative care in the community in Japan.

Chapter 3 Literature review

Here, I will first discuss the three questions which framed the literature review. This process also informed the choice of the optimum method for the literature review, namely a narrative literature review as this was the most effective approach to a diverse evidence base. Next, I will discuss the review strategy and outcomes, followed by my findings from the literature review aligned with each of the three review questions in turn. Finally, I will present my conclusions.

3.1 Literature review questions

In Chapter 1, I discussed a potential theory-practice gap in the definition of palliative care and the lack of understanding regarding such a gap. I also explored the lack of knowledge in actual clinical practice regarding the identification of patients for palliative care. Furthermore, although there are some tools for identifying patients for palliative care being developed, there is scant evidence regarding the usefulness of such tools in routine practice.

In light of these issues, I formulated three specific literature review questions.

1) **What are family physicians' understandings of palliative care?**

2) **How do family physicians identify (or define) patients for primary palliative care?**

Arising out of these two questions, the third question was formed:

3) **What tools can be used to identify patients for primary palliative care, and which tool is best suited for use in primary care in Japan?**

For this review, I modified the European Association of Palliative Care's definition of 'general palliative care' which I presented and explored in Section 1.2.1 and Table 1.2, to define 'primary palliative care'. I defined 'primary palliative care' as follows: 'palliative care provided by primary care doctors who are treating patients with life-threatening diseases, and who have a good basic knowledge of palliative care'.

3.2 Literature review strategy and outcomes

Given the breadth and qualitative nature of the topic, limited resources and time constraints, it was not feasible to conduct an extensive systematic literature review, so narrowing the scope of the literature review was considered more practical (Green, Johnson and Adams, 2006; Pesut *et al.*, 2014; Gregory and Denniss, 2018). In doing so, I formulated the three specific review questions outlined above, which helped to refine the focus of my literature review. During this process, I decided to deploy a narrative literature review as being the optimal method as it would more fully address the three literature review questions than a systematic review. The answers to the three questions also provided an informed and rigorous rationale and justification for the themes chosen for my PhD research.

3.2.1 Sources of information

Electronic database searches were conducted with Ovid MEDLINE, CINAL, PsychINFO and Ichushi-Web. Ichushi-Web is an online bibliographic database established by the Japan Medical Abstract Society. It contains more than 13 million data items from more than 2,500 biomedical journals and other serial publications in Japan. It has a Japanese thesaurus modelled on Medical Subject Headings terms. It has been reported that adding Ichushi-Web was beneficial in improving the extensiveness of literature retrieval (Kojimahara, Kawai and Morizane, 2015), and it was used for several systematic reviews to identify relevant literature (Irving *et al.*, 2017; Tanimoto, Akuta and Izumi, 2018).

Google Scholar was used to complement the literature retrieval. Using unconventional searches such as Google Scholar has been shown to be beneficial in identifying relevant grey literature (Haddaway *et al.*, 2015). The literature retrieval was also assisted by the use of my personal library from a published systematic review I had conducted which considered the contribution of primary care in palliative care for patients with non-cancer illnesses (Oishi and Murtagh, 2014). In addition, the reference lists of the identified papers were also reviewed.

3.2.2 Search terms

The search terms and keywords I used with Ovid MEDLINE are categorised into Groups I, II and III, as shown in Table 3.1. These three groups of search terms were combined with ‘AND’ as shown in Figure 3.1. For databases other than Ovid MEDLINE, search terms were adapted to fit in with individual databases. For Ichushi-Web, equivalent Japanese words and terms were used. For Google Scholar and my personal library, I only used more simplified sets of keywords as they did not support any thesaurus systems.

Table 3.1 Groups of search terms for Ovid MEDLINE

	OR
Group I = family physicians	general practitioners, family physicians, primary care physicians
Group II = palliative care	palliative care, terminal care, death, attitude to death, terminally ill, advance care planning, end of life*
Group III = understanding or identification	Comprehension, understand*, view*, perception* mass screening, needs assessment, patient selection, referral and consultation, risk assessment, case finding*, identification, identify*, screening, detection, diag*

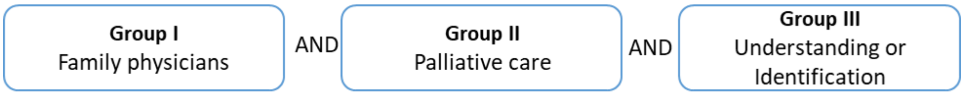


Figure 3.1 Search terms used for Ovid MEDLINE

3.2.3 Selection of literature

While ensuring the identification of as many of the most relevant papers as possible, strict selection criteria for such literature was necessary in light of the limited timeframe and resources. Accordingly, I first focused on English and Japanese papers published between 2000 and 2016. I also decided to include only those papers reporting empirical research with either quantitative, qualitative or mixed-method methodology, and to exclude editorials, letters or general reviews. Whenever any systematic reviews were identified, they were also used to identify further research papers included in them. Table 3.2 shows the inclusion and exclusion criteria for the selection of the literature.

Table 3.2 Inclusion criteria for the literature review

Language	English or Japanese
Publication period	2000 to 2016
Types of studies	Papers reporting empirical research through either quantitative, qualitative or mixed-method methodology Excluding papers reporting on the effectiveness of clinical interventions, not in primary care, letters, editorials and general reviews.
Topics	See the following main text for details

Regarding the research topics, I excluded those papers focusing on assisted dying, euthanasia or sedation at the end of life, as they did not apply to primary care settings in Japan. I also excluded those papers focusing on specific clinical topics such as decision-making about cardiopulmonary resuscitation, opioid prescribing, and hospitalisation at the end of life. Those papers regarding specific types of palliative care such as out-of-hours care were also excluded as they were not the focus of the literature review questions. Furthermore, I excluded papers focusing on two specific groups of patients: paediatrics and ethnic minorities. I acknowledge the possibility of my overlooking some relevant findings by excluding such papers, but these would have been minimal.

3.2.4 Data extraction and synthesis

I drew up a data extraction table which included: authors; publication year; country of origin; methodology; research aims, results and conclusions; and my review notes. Wherever any papers had findings relevant to the focus of my review, *i.e.* family physicians’ views which were significant or possibly influenced the results and conclusions, I included such papers, even though they included views from other people and did not necessarily highlight my review focus. The process of synthesising the data was undertaken in a narrative and iterative manner.

I intentionally excluded a systematic assessment of the quality of the identified studies. This was because the purpose of the literature review was to map out currently available evidence to help formulate my research plan, rather than to answer clinical questions or to identify any specific implications. However, the quality of the studies will be discussed as necessary when reporting the findings from such studies.

3.3 Overview of the identified papers

In this section, I offer an overview of all the twenty identified papers: eighteen empirical studies and two systematic reviews – all of which were published in English. A summary of the included papers is shown in Table 3.3 and 3.4.

The eighteen empirical studies answered the first two literature review questions (Table 3.3). Of these, thirteen papers focused on the first question: family physicians’ understanding of palliative care. The rest of the papers (five) were relevant to the second question: the identification of patients for a palliative care approach, while some aspects of the first question were also included. Four qualitative studies from Belgium, the Netherlands, the UK and the USA explored family physicians’ views on the identification of patients for palliative care (Claessen *et al.*, 2013; Mitchell *et al.*, 2013; Beernaert *et al.*, 2014; Nowels *et al.*, 2016).

Regarding the third question, two systematic reviews on tools for identifying patients with palliative care needs were found (Maas *et al.*, 2013; Walsh *et al.*, 2015) (Table 3.4). The overview of these reviews will be given in Section 3.6 and the tools mentioned in these papers are included in this review.

An overview of the eighteen empirical studies is presented in Table 3.3. Of these papers, seventeen were from Western countries: five from the UK (Farquhar *et al.*, 2002; Hanratty *et al.*, 2002, 2006; Burt *et al.*, 2006; Mitchell *et al.*, 2013); four from the Netherlands (Groot *et al.*, 2005, 2007; Borgsteede *et al.*, 2006; Claessen *et al.*, 2013); three from Australia (O'Connor and Lee-Steere, 2006; Rhee *et al.*, 2008; Phillips, Davidson and Willcock, 2009); two from Belgium (Beernaert *et al.*, 2014, 2015); with one each from Italy (Beccaro *et al.*, 2013), Germany (Dahlhaus *et al.*, 2013) and the United States (Nowels *et al.*, 2016). The eighteenth paper was from Japan (Yamagishi et al., 2012). No papers in Japanese were found even with the Ichushi-Web database search. This was probably due to the low level of research activity in primary care in Japan (Kaneko *et al.*, 2019).

Of the eighteen empirical studies, six were quantitative studies, using surveys as the data collection method. These six quantitative studies involving family physicians had participant numbers ranging from 235 to 1,489, while the remaining twelve qualitative studies had a range from a minimum of two to a maximum of 22 participating family physicians. All of the qualitative studies employed either focus groups or personal interviews as their method.

Although my review focus was on family physicians' perceptions, some studies included other parties such as nurses, patients and other medical professionals as participants in order to highlight their different expectations of family physicians (Hanratty *et al.*, 2002, 2006; Borgsteede *et al.*, 2006; Yamagishi *et al.*, 2012; Beernaert *et al.*, 2014, 2015; Nowels *et al.*, 2016). For example, Belgian researchers conducted focus groups with family physicians and community nurses, and interviews with patients (Beernaert *et al.*, 2014). The triangulation of different perspectives strengthened this study. While acknowledging the range of participants and their valuable insights, I concentrated on family physicians in line with my literature review questions.

Two studies, one each from the Netherlands and the UK, conducted individual interviews with family physicians in their own countries to explore how they identified patients for palliative care (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). The UK study specifically investigated family physicians' views about Palliative Care Registers which were being used to coordinate care of patients identified for palliative care across the UK (Mitchell *et al.*, 2013). The most recent study from the USA conducted telephone interviews with primary care providers which focused on the possible usefulness of patient-centred medical homecare – a team-based health care delivery model for the integration of palliative care into primary care (Nowels *et al.*, 2016).

Some of the twelve qualitative studies had findings which were applicable both to primary palliative care in general and to the Japanese context despite their relatively narrow research focus. These studies included three studies from Australia which focused on residential care (Phillips, Davidson and Willcock, 2009), rural (O'Connor and Lee-Steere, 2006) or urban environments (Rhee *et al.*, 2008), respectively. The remaining studies were two studies on cancer patients (Yamagishi *et al.*, 2012; Dahlhaus *et al.*, 2014); and one study on obstacles to the delivery of primary palliative care (Groot *et al.*, 2007).

Finally, one Australian residential care qualitative study was a brief report with limited numbers of participants and poorly described analysis (Phillips, Davidson and Willcock, 2009). Two studies from the UK had participating doctors from different specialities and included some family physicians (Hanratty *et al.*, 2002, 2006). In addition, there were two papers from Belgium which seemed to be based on the same data set (Beernaert *et al.*, 2014, 2015), although they had different research aims. I carefully extracted only relevant findings from these studies.

Table 3.3 Summary of included empirical studies

Author(s), Year, Country	Study aims	Participants	Data collection methods	Key results
Hanratty *et al.*, 2002, UK	To identify doctors' perceptions of the need for palliative care in heart failure and to identify barriers to change	Two family physicians, two cardiologists, one general physician, two geriatricians, one palliative care physician	Focus groups	Palliative care for patients with heart failure should be developed with the family physician as the central figure. Family physicians tend to consider broader implications for families and carers than other doctors. The identified barriers to palliative care in heart failure were the organisation of healthcare, the unpredictable course of heart failure and the doctors' understanding of roles.
Farquhar *et al.*, 2002, UK	To examine doctors' recognition and acknowledgement of patients' palliative status	Family physicians of 185 patients with a palliative diagnosis	A survey	In 20% of cases, family physicians did not perceive patients as palliative. Family physicians reportedly received no information from hospitals regarding 26% of patients. There was a significant difference in survival between patients perceived as requiring palliative care and those who were not.
Groot *et al.*, 2005, Netherlands	To investigate family physicians' task perceptions and to investigate barriers involved in palliative care	22 family physicians	Focus groups	Family physicians described their palliative care tasks as satisfactory and varied, but burdensome. Opinions differed with respect to whether the coordination of care belonged to the family physicians' tasks. Barriers were categorised into three themes: (1) personal: barriers related to knowledge, skills, and emotions; (2) relational: barriers concerning communication and collaboration; and (3) organisational: barriers related to the organisation of care and compartmentalisation in healthcare.

Hanratty *et al.*, 2006, UK	To report doctors' understandings of palliative care	Ten family physicians, ten cardiologists, six geriatricians, six palliative care physicians, four general physicians	Focus groups	A reasonable grasp of a broader concept of palliative care by the participants was shown while some participants reported some scepticism about the expansion of palliative care outside of cancer. Perceptions of palliative care fell into three areas: it was more than a service; it was about managing dying; it was the concern of nurses rather than doctors. Palliative care was welcomed, although an over-emphasis on the 'quality' of patients' lives and overlooking the 'quantity' of patients' lives were concerned.
O'Connor et al., 2006, Australia	To explore rural family physicians' attitudes towards the philosophy and provision of palliative care	Ten family physicians	Individual interviews	Provision of palliative care was perceived as a fundamental part of being a rural family physician. A key aspect of palliative care was considered to be maintaining patients' and families' quality of life. Family physicians felt more comfortable providing palliative care to patients within longer-term relationships. Emotional issues were identified as a significant source of stress when providing palliative care. Overemphasis on specialist palliative care services and limited funding were identified as barriers. Interprofessional collaboration was considered as beneficial.
Borgsteede *et al.*, 2006, Netherlands	To explore the aspects valued by both patients and family physicians in end-of-life care at home	20 family physicians and 30 of their patients with a limited life expectancy	Individual interviews	Both family physicians and patients valued: the availability of family physicians for home visits and after office-hours; medical competence and cooperation with other professionals; and attention and continuity of care.
Burt *et al.*, 2006, UK	To explore family physicians' current involvement in and attitudes towards the provision of palliative care in primary care	356 family physicians in London	A survey	65% of family physicians were providing palliative care to their patients; 72% agreed that palliative care was a central part of their role; 27% wanted to hand care over to specialists. 66% disagreed that palliative care was mainly nursing work. Four characteristics of family physicians: larger practice size; longer years of family practice experience; receiving palliative care education; and the current provision of palliative care were associated with an agreement that palliative care was central to their role.

Groot *et al.*, 2007, Netherlands	To identify the prevalence of those problems (identified in the 2005 study, above) in providing palliative care and its determinants	320 family physicians	A survey	(This is a follow-up study of Groot *et al.*'s study published in 2005.) The most common obstacles felt by family physicians were: bureaucratic procedures (83.9%); the time necessary to arrange medical homecare equipment (61.1%); and the difficulties associated with the wish or need to obtain extra care (56.3%). More years of family medicine experience and participation in multidisciplinary case discussions were perceived as positive factors countering such obstacles.
Rhee *et al.*, 2008, Australia	To determine the level of participation of Australian urban family physicians in palliative care, and to determine the main barriers facing them in providing this care	500 family physicians in an urban area (near Sydney)	A survey	75% of family physicians were involved in palliative care. Family physicians not providing palliative care were more likely to be younger; have less family practice experience; work fewer hours; be an employee rather than a practice owner; to have been educated overseas. A lack of interest and knowledge, home visits, problems with after-hours care due to family and personal commitments were identified as barriers to their involvement. Family physicians felt least confident about psychosocial problems and technical aspects of palliative care.
Phillips *et al.*, 2009, Australia	To investigate family physicians' perceptions and understandings of a palliative care approach (in residential aged care)	13 family physicians	Focus groups	(This is a brief report.) Family physicians had varied and ambiguous understandings of a palliative care approach. While some participants had positive attitudes towards palliative care, others only reactively responded to the palliative care needs expressed by patients.
Yamagishi *et al.*, 2012, Japan	To investigate: 1) clinical exposure of primary care doctors and community nurses to cancer patients dying at home; 2) availability of symptom control procedures; 3) willingness to	235 primary care doctors and 56 community nursing services	A survey	53% of primary care doctors reported that they saw no cancer patients dying at home in the previous year, and 40% had between one and ten such patients. 35% of primary care doctors reported that oral opioids were unavailable, and 50% reported that subcutaneous opioids or haloperidol were unavailable. 67% of primary care doctors were willing to use palliative care consultation services.

	participate in out-of-hours care and palliative care consultation services; 4) reasons for hospital admission of terminally ill cancer patients			
Dahlhaus *et al.*, 2013, Germany	To explore family physicians' perceptions of their involvement in palliative cancer care and to explore the constraints they face	13 family physicians	Individual interviews	Family physicians described being intensely involved in the final phase of their patients' lives. Family physicians valued continuity of care and emotional support to patients and families when providing home-based end-of-life care to cancer patients. Family physicians were aware of the limitations of their skills and knowledge in symptom management and their ability to provide round-the-clock care. They found it helpful and satisfying to collaborate with respected care providers and to share care with specialist palliative care services for outpatients.
Claessen *et al.*, 2013, Netherlands	To explore how family physicians identify the need for palliative care for patients	20 family physicians	Individual interviews	A combination of several signals, often subtle and not explicit, made family physicians identify the need for palliative care: signals from patients; signals from relatives; and reports from medical specialists. An increasing care dependency and a lack of recovery made them think about starting palliative care. Differences in the identification of palliative care need for cancer patients versus those with other diseases were reported. Family physicians considered that the diagnosis of a life-threatening illness was a crucial point in the disease trajectory. However, this did not automatically mean that a patient needed palliative care at this point.
Mitchell *et al.*, 2013, UK	To explore family physicians' views of what defines a palliative care patient for inclusion on a Palliative Care Resister in the context of identifying clinical service needs	Eight family physicians	Individual interviews	Family physicians found it challenging to define the palliative care patient. The decision was often made by a multidisciplinary team. Patients not identified as 'palliative' were often discussed unofficially when needed. The needs of patients with non-malignant diseases were considered equal to those with cancer, but the challenges of identifying such patients were greater. More emphasis was placed on the intensity of care required than a prognosis when deciding if the patient was 'palliative' or not. Inclusion on a register triggered greater professional input and was considered beneficial to patient care.

Beccaro *et al*., 2013, Italy	To investigate the knowledge, opinions, and activities of Italian family physicians regarding palliative care	1489 family physicians	A telephone survey	66% of family physicians understood that palliative care should be provided by a multi-professional team, and 92% understood that there was no maximum daily morphine dose for pain management. Most participants strongly agreed that family physicians should be available during working hours to break bad news. They also thought that they should collaborate with the multi-professional team in establishing an individual care plan. Most family physicians reported that they discontinued the drugs that were not beneficial to symptom management and sought advice from palliative care physicians when symptom management was ineffective.
Beernaert *et al*., 2014, Belgium	To explore the barriers to and facilitators for the early identification of palliative care needs by family physicians	20 family physicians, 12 community nurses and 18 patients	Focus groups with professionals and interviews with patients	Key barriers and facilitators identified were related to: communication styles; the perceived role of a family physician; and the continuity of care. Family physicians did not systematically assess non-acute care needs, and patients did not mention them to their family physicians. This was embedded within a predominant perception (among patients, nurses, and family physicians) of the family physician as being the person to appeal to in acute and standard follow-up situations rather than for palliative care needs. Family physicians also seemed to pay more frequent attention to the palliative care needs of patients in a terminal phase.
Beernaert *et al*., 2015, Belgium	To explore the views of family physicians, nurses and patients about the tasks of the family physician in palliative care for people with life-limiting illness from diagnosis onwards	20 family physicians, 12 community nurses and 18 patients	Focus groups with professionals and interviews with patients	The tasks attributed to the family physician could be categorised into four roles: (i) an available medical expert, (ii) a communicator, (iii) a collaborator and (iv) a life-long learner committed to improving their palliative care competencies by training. Some perceived tasks varied depending on the different phases of illness, while other tasks were applicable throughout the whole course of illness. This showed the importance of the involvement of the family physicians in a palliative care approach being integrated into the care continuum. The participants mainly shared the same perception of the family physicians' tasks, but there was some disagreement on, for example, the timing of care planning. The participants did not usually refer explicitly to care as palliative care but only used the term for care during the terminal phase.
Nowels *et al*., 2016, USA	To explore primary care providers' willingness and perceived capacity to provide basic palliative care, and to	20 primary care providers (18 physicians, one physician assistant and	Individual interviews	The participants recognised various types of palliative care needs for patients, not only in their terminal stage. They responded reactively to those needs using practice and community resources, believing that meeting those needs at a basic level was within the scope of primary care. They did not see themselves delivering palliative care, as that term implied speciality services. They sometimes felt that they were side-tracked by specialists. They were able to identify opportunities to improve the delivery of a basic palliative approach in primary care.

	explore their concerns and perceived barriers	one nurse practitioner)		

Table 3.4 Summary of included systematic reviews on tools to identify patients with palliative care needs

Author(s), Year	Study aims	Methods	Key results
Maas *et al.*, 2013,	To document those tools for the identification of patients with palliative care needs available in the published literature and to ascertain how family physicians in Europe currently identify patients for palliative care	A systematic literature review and a key informant questionnaire survey	Four tools were identified through the literature review: the Radboud Indicators for palliative care needs (RADPAC); the residential home palliative care tool; the Supportive and Palliative Care Indicators Tool (SPICT); and the early identification tool for palliative care patients. A further three tools were identified through the key informant questionnaire survey: the Gold Standard Framework Prognostic Indicator Guidance (GSF-PIG); the Palliative Necessities CCOMS-ICO© (NECPAL); and a 'Quick Guide'.
Walsh *et al.*, 2015	To identify and assess existing diagnostic tools that can be used for the early identification of palliative care patients	A systematic literature review	Four tools were identified: GSF-PIG; SPICT; NECPAL; and RADPAC.

3.4 Family physicians’ understandings of palliative care

In this and the following two sections, drawing from the studies included in this literature review, I will discuss the findings regarding: family physicians’ understandings of palliative care; their identification of patients for primary palliative care; and available tools to support primary care clinicians to identify patients for primary palliative care. In this section, I will discuss the family physicians’ accounts of their understandings of palliative care to answer the first literature review question: ‘What are family physicians’ understandings of palliative care?’

3.4.1 Definition of ‘palliative care’

In general, family physicians had positive attitudes towards providing palliative care (Groot *et al.*, 2005; Hanratty *et al.*, 2006; O’Connor and Lee-Steere, 2006), while some variations of their awareness and degrees of their involvement were reported (Rhee *et al.*, 2008; Phillips, Davidson and Willcock, 2009).

Family physicians were not clear about the definition of terms such as ‘palliative care approach’ or ‘palliative’ patients (Phillips, Davidson and Willcock, 2009; Mitchell *et al.*, 2013). Furthermore, they were not confident in their understanding of the definitions (Mitchell *et al.*, 2013). Family physicians did not use the term ‘palliative care’ for the support they offered to patients at earlier stages of illnesses (Claessen *et al.*, 2013). In addition, many participating family physicians did not refer to what researchers would regard as ‘palliative care’ (Beernaert *et al.*, 2015; Nowels *et al.*, 2016). They often simply referred to it as either ‘care at the end of life’ or ‘supportive care’ (Nowels *et al.*, 2016).

The usage of the term ‘palliative care’ was avoided due to its negative association with ‘terminal’ stages (Beernaert *et al.*, 2015; Nowels *et al.*, 2016). It was reported that family physicians did not see any advantage in labelling patients as ‘palliative’ particularly in the early stage of illness when the conditions were still curable (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). Furthermore, it was noticeable that Beernaert *et al*. (2014) intentionally omitted using the term 'palliative' in their interviews until their interviewees mentioned it. This avoided putting an emphasis on terminal care in order to identify family physicians' perceptions of the early identification of palliative care needs. Review of all of these papers suggested that family physicians were left without any practical, usable or convincing definition of palliative care.

Nowels *et al.* (2016) reported that participating family physicians thought that a basic palliative care approach was integral to primary care. Participants in other studies expressed similar notions. For example:

> *'For me at least, good palliative care is for me good medical care, it's good history taking, carefully listening, a right diagnosis and proper treatment' (Borgsteede, 2006, p.23).*

Beeranert *et al.* (2015) discussed that, in order to support people with life-limiting conditions effectively, family physicians needed to utilise their abilities as generalists. In other words, 'good' generalist care is a prerequisite for the provision of 'good' palliative care. Some surveys mentioned that older or more experienced family physicians tended to see palliative care as being a central part of their roles and wanted to be more involved in it (Burt *et al.*, 2006; Groot *et al.*, 2007; Rhee *et al.*, 2008).

Prognosis and time

Family physicians often associated palliative care with the last weeks of patients' lives, when patients needed a great deal of physical, psychological or spiritual care (Hanratty *et al.*, 2006; Claessen *et al.*, 2013; Mitchell *et al.*, 2013; Beernaert *et al.*, 2014; Dahlhaus *et al.*, 2014; Nowels *et al.*, 2016). As the amount of care increased towards the end of their patients' lives, family physicians devoted much of their time to home visiting and collaboration with nurses (Claessen *et al.*, 2013; Beernaert *et al.*, 2014). In one study, palliative care was characterised as 'a phase in time, when the goals of medical management change and death is recognised' (Hanratty *et al.*, 2006, p.494).

Another study reported that family physicians would provide palliative care 'when death becomes imminent, when no more treatment is available or when the illness is in an advanced phase' (Beernaert *et al.*, 2015, p.697). Both studies reflected family physicians' notions that patients must have a limited prognosis to be recognised as 'palliative' patients.

On the contrary, some family physicians stated that palliative care should be provided at earlier stages of chronic illnesses (Claessen *et al.*, 2013; Mitchell *et al.*, 2013; Nowels *et al.*, 2016) and that communication about end-of-life decisions should be started before the terminal phase (Beernaert *et al.*, 2015). Borgsteede *et al.* (2006) highlighted that some family physicians provided some form of palliative care much earlier than the point at which patients were diagnosed as being terminally ill. Beernaert *et al.* (2015) categorised family physicians' roles in line with phases of the illness trajectory to prove the importance of family physicians' continuous involvement in the provision of palliative care from an early stage in the course of illnesses. All of these chimed with the WHO definition of palliative care which advocates that palliative care should be provided at earlier stages of illnesses (WHO, 2002).

In conclusion, family physicians had varied understandings of the palliative care spectrum in relation to patients' prognoses or of how imminent the death should be before considering palliative care. Family physicians' varied understandings of the palliative care spectrum seemed to be influenced by phases of diseases and prognoses as well as other different and complex interwoven aspects.

3.4.2 Perceived roles within palliative care

Beyond normal medical care

While solving patients' physical symptoms such as pain was important for family physicians (Borgsteede *et al.*, 2006), palliative care included further aspects of 'care' for them. The participants of one study portrayed palliative care as 'more than a (medical) service' (Hanratty *et al.*, 2006, p. 494), which implied that palliative care should be a holistic care rather than a bio-medical care which focused on physical aspects.

For example, psychological support was often perceived as part of palliative care and the family physicians' role (Hanratty *et al.*, 2006; O'Connor and Lee-Steere, 2006). It was, however, noticeable that some other family physicians thought that psychological support was not necessarily their role but should be provided collaboratively with other professionals (Beernaert *et al.*, 2015).

Communication was often referred to as an important aspect of palliative care. It was also suggested that family physicians should be able to clarify information that patients remained unsure about after communicating with specialists about their diagnosis and conditions (Beernaert *et al.*, 2015). Patients appreciated it when family physicians gave their full attention to communication with them (Borgsteede *et al.*, 2006). However, family physicians themselves did not perceive such attention as a separate or special element of palliative care but rather considered this as normal practice in their care for all kinds of patients (Borgsteede *et al.*, 2006). Not only effective communication but also future care planning was considered an important role for family physicians (Beernaert *et al.*, 2015; Nowels *et al.*, 2016).

Care continuity and coordination

Continuity of care was valued in palliative care provision by family physicians (Groot *et al.*, 2005; Borgsteede *et al.*, 2006; O'Connor and Lee-Steere, 2006; Dahlhaus *et al.*, 2014) and other healthcare professionals, as well as patients and families (Borgsteede *et al.*, 2006; Beernaert *et al.*, 2015). Family physicians were expected to be the first medical contact and available around the clock (Borgsteede *et al.*, 2006; Beernaert *et al.*, 2015), which also placed some pressure on them. Borgsteede *et al.* (2006) highlighted the potential advantages of continuity of care for anticipating problems and preparing for such problems to prevent adverse events and outcomes.

It was also reported that family physicians were more comfortable providing palliative care to those patients with a longer-term relationship, reflecting their awareness of the principle of general practice of ‘caring from birth until death’ (O’Connor and Lee-Steere, 2006). Having a longer-term relationship with patients enabled family physicians to know a patient’s background better, enabling family physicians to respond to signs and signals of evolving palliative care needs sooner and more effectively. It also enabled family physicians to provide family support effectively (Borgsteede *et al.*, 2006; O’Connor and Lee-Steere, 2006), which was also considered an important aspect of palliative care.

Family physicians considered that coordinating care was one of their important roles in providing palliative care (Hanratty *et al.*, 2002; Borgsteede *et al.*, 2006; O’Connor and Lee-Steere, 2006; Beernaert *et al.*, 2015; Nowels *et al.*, 2016). They did not necessarily have to solve all the problems by themselves, but they could ‘offer paths’ to patients through consultation with other professionals (Beernaert *et al.*, 2015, p.697). Furthermore, Groot *et al.* (2005) also mentioned that family physicians should delegate tasks if possible.

Family physicians thought that interprofessional working and a team approach were important in providing palliative care (Borgsteede *et al.*, 2006; O’Connor and Lee-Steere, 2006; Phillips, Davidson and Willcock, 2009; Mitchell *et al.*, 2013). Similar points were also raised in other literature, suggesting that clarification of roles of family physicians was crucial for such effective collaboration (Mitchell *et al.*, 2012; Oishi and Murtagh, 2014). Nurses were identified as an important colleague with whom family physicians worked (Borgsteede *et al.*, 2006; Hanratty *et al.*, 2006; O’Connor and Lee-Steere, 2006), and they were expected to facilitate communication between primary and secondary care (Hanratty *et al.*, 2006).

Knowledge, skills and attitudes for providing palliative care

Family physicians were expected to have sufficient medical knowledge and skills in palliative care and to keep them up-to-date (Borgsteede *et al.*, 2006;

Beernaert *et al.*, 2015). Family physicians themselves thought that continuing palliative care education such as in pain management was important (O'Connor and Lee-Steere, 2006; Phillips, Davidson and Willcock, 2009; Beernaert *et al.*, 2015) while some mixed attitudes towards additional palliative care training were also reported (O'Connor and Lee-Steere, 2006; Rhee *et al.*, 2008). Skills and knowledge in palliative care sometimes depended on the physicians' own experiences, abilities or personal competences, reflecting either a lack of opportunities in formal training or their own competing priorities including their private lives (O'Connor and Lee-Steere, 2006; Rhee *et al.*, 2008; Beernaert *et al.*, 2015).

A survey study conducted in Italy reported that family physicians in general had an appropriate basic knowledge regarding palliative care definitions and opioid prescribing (Beccaro *et al.*, 2013). Other studies in Belgium and Australia also reported that family physicians did not perceive their lack of knowledge as a main barrier to providing palliative care (Groot *et al.*, 2007; Rhee *et al.*, 2008). This contrasted with a report from Japan which noted that many primary care doctors did not have much experience in providing palliative care (Yamagishi *et al.*, 2012). Another study reported that German family physicians found symptom management requiring advanced expertise as challenging (Dahlhaus *et al.*, 2014). Furthermore, it was reported that family physicians were responding rather reactively to palliative care needs of patients (Claessen *et al.*, 2013; Nowels *et al.*, 2016), which was seen as problematic (Claessen *et al.*, 2013).

Views on specialist palliative care services

One family physician reported having tried unsuccessfully to refer patients to a palliative care specialist service, which made them undervalue the specialist service with its narrow focus on cancer patients (Hanratty *et al.*, 2006). The lack of support by specialists towards family physicians was also identified in other studies (Hanratty *et al.*, 2002; O'Connor and Lee-Steere, 2006). In Hanratty *et al.*'s study (2006), some participants even questioned why palliative care should be a separate speciality from 'good medical practice'. These are consistent with a previous study which suggested that the participating family physicians held similar ideas (Field, 1998). However, this contrasted with other studies suggesting that family physicians valued specialist consultations as being a significant source of assistance (O'Connor and Lee-Steere, 2006; Yamagishi *et al.*, 2012; Dahlhaus *et al.*, 2014; Beernaert *et al.*, 2015). Some authors concluded that ensuring adequate access to readily available specialist palliative care consultations would help family physicians to provide palliative care (Rhee *et al.*, 2008; Yamagishi *et al.*, 2012).

When working with palliative care specialists, family physicians sometimes felt frustrated by being excluded from the care plan (Hanratty *et al.*, 2002; Nowels *et al.*, 2016). Family physicians wanted to maintain their leadership role in the patients' care (Beernaert *et al.*, 2015), which reflected their notion of seeing themselves as being a central figure in care provision. 'Handing over' the patients to specialists meant a loss of control for some family physicians (O'Connor and Lee-Steere, 2006). In Hanratty *et al*.'s study (2006), it was seen as being problematic that in many cases, the introduction of palliative care meant focusing purely on the 'quality' of patients' lives, and entirely overlooking the 'quantity' of patients' lives. Interestingly, one study highlighted family physicians' concerns about the much greater emphasis placed on the role and value of specialist palliative care services being a barrier for family physicians who wanted to participate in palliative care (O'Connor and Lee-Steere, 2006).

3.4.3 Perceived barriers to providing palliative care

Organisational factors

Groot *et al.* (2005, 2007) carried out an initial qualitative study including the identification of perceived barriers to providing palliative care by family physicians, followed by a survey which investigated the prevalence of such identified barriers. They concluded that bureaucratic procedures were the most prevalent barrier, echoing findings from another study (Phillips, Davidson and Willcock, 2009). Additionally, funding was identified as another barrier in some other studies (O’Connor and Lee-Steere, 2006; Phillips, Davidson and Willcock, 2009).

The lack of time was often indicated as a barrier to the provision of adequate palliative care and care planning (Groot *et al.*, 2005; Borgsteede *et al.*, 2006; Hanratty *et al.*, 2006; Rhee *et al.*, 2008; Phillips, Davidson and Willcock, 2009). Hanratty *et al.* (2006) linked the participating family physicians’ perception of palliative care being time-consuming with their notion of palliative care belonging to nursing, not medical care. Doctors were ambivalent about their roles and seemed to side-line palliative care and to assign it to nurses (Hanratty *et al.*, 2006).

Emotional distress

Some studies drew attention to the emotional distress for family physicians in delivering palliative care. For example, O’Connor and Lee-Steere (2006) reported that their participating family physicians felt a significant amount of emotional demand made on them in providing palliative care. This was confirmed by other studies which found that family physicians had developed an emotional attachment to patients to some extent (O’Connor and Lee-Steere, 2006; Phillips, Davidson and Willcock, 2009; Beernaert *et al.*, 2015). These findings were particularly prominent in one study focusing on family physicians working in a rural area, and this study also highlighted the family physicians’ perceived difficulty in communicating when disclosing to patients the approach of death (O’Connor and Lee-Steere, 2006).

It was suggested that family physicians felt that providing or learning about palliative care would compromise their private lives (O’Connor and Lee-Steere, 2006; Rhee *et al.*, 2008). Furthermore, Groot *et al.* (2005) mentioned that family physicians often became frustrated with other professionals who failed to take responsibility when coordinating care.

3.5 Identification of patients for primary palliative care

In this section, I will discuss findings from the identified studies to answer the second review question: ‘How do family physicians identify (or define) patients for primary palliative care?’

3.5.1 How do they identify patients’ palliative care needs?

A significant finding from the qualitative studies was that a combination of ‘subtle hints’, rather than diagnoses, prompted family physicians to consider palliative care (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). Family physicians did not follow any fixed rules, and so their identification of patients for palliative care was more based on needs rather than associated with prognosis (Mitchell *et al.*, 2013). The ‘subtle hints’ included changes in patients’ self-care abilities; medical conditions ‘not recuperating’; and social changes such as being withdrawn or depressed (Claessen *et al.*, 2013). Among these, it seemed that increasing care dependency was identified as the most significant signal or ‘subtle hint’ for family physicians (Claessen *et al.*, 2013). Family physicians considered that increasing needs for multidisciplinary support was a trigger for palliative care (Claessen *et al.*, 2013; Mitchell *et al.*, 2013).

Regarding the sources of information to assist the identification of patients for palliative care, family physicians did not rely only on their direct observations of their patients, but they also valued signals from patients’ close relatives, such as ‘I’m finding it a bit too much’ (Claessen *et al.*, 2013, p.4); information from other professionals; and having patients referred back to them from specialists when the patients’ disease was incurable (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). Family physicians considered these signals in their normal routine practice, while some of them used opportunities to see patients in non-healthcare settings, such as in grocery stores in town (Nowels *et al.*, 2016). Mitchell *et al.* (2013) added that family physicians made decisions about introducing palliative care with other healthcare professionals which included letters from hospitals. Part of the reason for this was their perceived difficulty in defining palliative care patients – echoing a previous paper (McIlfatrick, 2007). Family physicians were aware of the various kinds of problems that patients could have: not only directly health-related problems but other problems that potentially impaired patients' lives, such as emotional, social or financial problems together with practical aspects of daily living (Nowels *et al.*, 2016). However, Claessen *et al.* (2013) revealed that the participating family physicians did not raise such psychosocial or spiritual problems as initial signals.

Patients' perceptions about the role of family physicians

Beernaert *et al.* (2014) highlighted that patients' perceptions regarding the role of family physicians influenced the identification of their palliative care needs by family physicians. In their study, patients saw family physicians' role as mainly dealing with acute problems so that they did not necessarily share their palliative care needs with them. Patients also thought that their disease-specific problems should be dealt with by specialist doctors rather than family physicians as patients expected the specialist in their disease to be better at managing these problems (Beernaert *et al.*, 2014). Patients considered that a long-term and trusting relationship would enable them to ask for help from family physicians more readily (Beernaert *et al.*, 2014). In contrast, a reason why patients held back was that they did not want to make demands on 'busy' family physicians (Beernaert *et al.*, 2014). These findings suggest that societal views on the roles of healthcare professionals (including family physicians), healthcare systems and organisations can influence patients' perceptions and attitudes, which can ultimately impact on healthcare professionals' practice.

Patients' conditions: cancer versus non-cancer

It has been repeatedly highlighted that there are particular challenges in identifying palliative care needs among patients with non-malignant, chronic but life-threatening illnesses with less predictable illness trajectories than cancer, such as COPD, heart failure, Parkinson's disease or other neurodegenerative diseases (Shipman *et al.*, 2008; O'leary, 2009; Gott *et al.*, 2011; Harrison *et al.*, 2012; Claessen *et al.*, 2013; Dalgaard *et al.*, 2014). Some family physicians considered that such patients – and older people – would gradually shift to a ‘palliative process’ (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). It was also reported that recognising patients’ palliative care needs was easier when their prognosis was shorter and clearer (Beernaert *et al.*, 2014). In other words, uncertainty about prognosis was one of the barriers for family physicians when identifying patients for palliative care (Beernaert *et al.*, 2014).

This explains why cancer patients were seen as clearer candidates for palliative care than non-cancer patients (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). The nature of cancer diagnoses, which made people (patients, their close relatives and family physicians) aware that such patients had a strong chance of dying in the near future, brought the option of palliative care to the forefront of their mind earlier than with other diseases (Claessen *et al.*, 2013). Meanwhile, Mitchell *et al.* (2013) agreed that non-cancer patients actually had similar needs to those of cancer patients, particularly at their end-stages and also agreed with the appropriateness of inclusion of non-cancer patients for palliative care.

3.5.2 Factors influencing identification processes

Environmental factors

One study specifically investigated family physicians’ views on the Palliative Care Registers in the UK (Mitchell *et al.*, 2013). Family physicians participating in this study favoured having such a register and holding regular meetings for registered patients. The register enabled them to highlight potential patients with palliative care needs, discuss their anticipated care needs and clarify care responsibility with other professionals (Mitchell *et al.*, 2013).

Sufficient time for each consultation and continuity of care seemed to be particularly important for the early identification of patients’ palliative care needs (Beernaert *et al.*, 2014). Seeing patients at home, often allowing more consultation time, was valued by family physicians because it enabled them to understand patients’ backgrounds better and to identify their care needs more efficiently (Beernaert *et al.*, 2014). A lack of continuity of care was suggested as being a barrier to the prompt identification of patients’ palliative care needs by family physicians, with a particular emphasis on cancer patients (Beernaert *et al.*, 2014). It was viewed as problematic that cancer patients lost contact with family physicians during their treatment phases or hospital admissions, only to suddenly reappear with a non-curable disease (Beernaert *et al.*, 2014).

Family physicians’ knowledge and views on palliative care

Not having enough knowledge, skills and experience to identify palliative care needs were perceived as being significant barriers to the early recognition by family physicians (Beernaert *et al.*, 2014). Also, knowing what to do in response to the identified needs seemed to facilitate family physicians’ offer of help (Beernaert *et al.*, 2014). Family physicians were often concerned about depriving their patients’ of hope by discussing their existential or palliative care needs, whilst some family physicians emphasised the importance of addressing these issues (Beernaert *et al.*, 2014). In a survey study by Farquhar *et al.* (2002), family physicians expressed more reluctance than hospital doctors to see patients as being in a palliative stage. This might be because of family physicians’ closer relationships with patients.

Furthermore, some family physicians said that they felt that it was impractical or inappropriate to label patients as being palliative early on in the diagnosis because of potential disadvantages such as missing active treatment for reversible causes of deterioration (Claessen *et al.*, 2013; Mitchell *et al.*, 2013; Beernaert *et al.*, 2014). Family physicians tried to provide the best care regardless of how their patients were categorised (Claessen *et al.*, 2013). This resonated with the findings from other studies in which family physicians saw their roles in palliative care as a continuum of their care for their patients (Field, 1998; Mitchell, 2002; Hanratty *et al.*, 2006)

3.6 Tools for the early identification of people for primary palliative care

This section will address the third literature review question: ‘What tools can be used to identify patients for primary palliative care, and which tool is best suited for use in primary care in Japan?’

In a Beernaert *et al*.'s study (2014), a few family physicians suggested using assessment scales for common palliative care needs so as not to miss them during their regular follow up appointments. This study concluded that the lack of effective tools was one of the reasons why the current practice seemed so far from the palliative care models promoted, which emphasised the value of early initiation of palliative care.

Two systematic reviews regarding such tools (Maas *et al.*, 2013; Walsh *et al.*, 2015) had been published at the time of my literature review indicating that this is a developing field. Maas *et al.* (2013) identified seven tools to identify patients for a palliative care approach in primary care settings. This paper incorporated a traditional, though relatively small, systematic review with a key informant survey. A database search identified four tools and the remaining three tools came from the key informant survey. Maas *et al.* (2013) discussed different situations across European countries. Despite the possible bias of the key informant survey, such as only including the views of key informants known to the authors, the strength of this paper was its provision of valuable information regarding the actual situations across the countries surveyed which practising clinicians had recognised. For example, the paper included a project aiming for more systematic identification and registration of palliative patients in the community in the Netherlands. It also presented some Serbian primary care systems – involving two types of primary care physicians – which influenced the identification of patients for palliative care. The paper also highlighted that the UK was the only country which advocated the use of such tools. In other countries, the identification relied on more subjective criteria, showing a lack of systematic approaches towards the early identification of patients for primary palliative care.

The second of the two systematic reviews was conducted by an Australian research group which deployed a more comprehensive coverage of literature databases (Walsh *et al.*, 2015). This review identified the same four tools as the earlier review (Maas et al., 2013). The second review group was likely aiming to find a tool for use in Australian primary care settings and concluded by recommending the Supportive and Palliative Care Indicators Tool (SPICT).

In the following sections, I will discuss the four tools identified by both reviews, together with the ‘Surprise Question’ – an additional, widely adopted tool.

Tool 1: The Gold Standards Framework Prognostic (Proactive) Indicator Guidance (GSF-PIG)

Among the four tools, the Gold Standards Framework Prognostic Indicator Guidance (GSF-PIG) (The Gold Standards Framework Centre, 2011) was the most cited and well-known tool. This was probably because of its association with UK national primary care policies: the Gold Standards Framework (GSF); and the Quality Outcomes Framework (QOF). In the Maas *et al.*’s key informant survey (2013), multiple respondents suggested that the GSF-PIG could provide a sound platform for the development of similar tools in other countries.

The GSF-PIG guidance paper was originally developed in 2004 to support GPs in the UK to identify patients who were in the last 12 months of their lives for QOF Palliative Care Registers (National Gold Standards Framework Centre, 2019) and included that version of the Surprise Question (See Tool 5). This was the same prognostic time frame as that found in the General Medical Council definition of end of life care (General Medical Council, 2010). The GSF-PIG aimed to lessen the disparity between cancer and non-cancer patients in receiving palliative care. The tool’s name was later changed from the original ‘prognostic indicator guidance’ to ‘proactive identification guidance’ (Thomas, Wilson and GSF Team, 2016). The four-page GSF-PIG guidance paper, including the two A4 page tool itself, is available online.

Despite its wide recognition, the tool's processes of development and evaluation were not well documented, compared to those of other tools. Walsh *et al.* (2015) highlighted that this was the only tool for which no extant or forthcoming validation studies were reported.

Tool 2: Supportive and Palliative Care Indicators Tool (SPICT)
This tool had been developed for the early identification of patients at risk of deteriorating health and of death (Highet *et al.*, 2014). While the original GSF-PIG focused on primary care settings, the SPICT was designed for all care settings at the outset and for use by a range of health and social care professionals. The tool's strength was its comprehensive yet concise coverage of conditions which family physicians would encounter in their practice. The SPICT had only a few indicators requiring investigations or blood tests. Family physicians could answer most of the SPICT criteria without their referring to detailed information in the patients' medical records.

The SPICT was developed as a descriptive clinical tool based on a literature review and expert consensus about indicators of advanced illness found in the most common long-term conditions. The tool consisted of one A4 sheet and was available online, with another A4 guidance sheet to support its use in primary care or in hospitals. The SPICT website allowed users to communicate with the tool's developers, which was a unique feature of the SPICT. In fact, in the first few years following its launch in 2010, the SPICT was revised many times on the basis of recommendations from a growing online community of users. Both the process of the tool's development and the SPICT online forum indicated that the SPICT developers took a pragmatic approach to make the tool more usable and clear for clinicians.

One potential shortcoming of the SPICT, highlighted by an implementation and evaluation study conducted in a hospital setting, was that it did not evaluate quality of life but focused on functional status (Highet *et al.*, 2014). Compared to the NECPAL (discussed below), the earlier versions of SPICT did not capture patients' views nor their psychosocial status.

Tool 3: NECPAL CCOMS-ICO© Tool (NECPAL)

The NECPAL COOMS-ICO© Tool (NECPAL) tool was developed in Catalonia, Spain (Gómez-Batiste *et al.*, 2011). The development was based on the GSF-PIG and the SPICT, adapted to Mediterranean culture and clinical contexts (Gómez-Batiste *et al.*, 2013). Other amendments included patients' expressions of choices and needs and their psychosocial aspects. This tool was embedded in the Catalonian healthcare system through a WHO demonstration project, launched in collaboration with the Catalan Department of Health and the Catalan Institute of Oncology. The NECPAL was developed as part of this project, which gave the tool more recognition.

The first version developed in 2011 was available online and provided information about the NECPAL. The first page contained information about the tool, including what it was – and was not – to be used for. This first page also clearly stated that this was not a prognostic tool but was a tool for both health and social care. Though being the most comprehensive of the four tools, the NECPAL required more precise medical information about patients, while the GSF-PIG and the SPICT relied more on clinical judgements.

Numerous academic papers were discussing the tool, including those reporting on the WHO project (Gómez-Batiste *et al.*, 2013, 2014; Gómez-batiste *et al.*, 2017; Tripodoro *et al.*, 2019). Gomez-Batiste *et al.* (2013) qualitatively analysed the impact of implementing NECPAL and concluded that the tool had a 'positive influence' on the quality of care.

Tool 4: RADbaud indicators for PAlliative Care Needs (RADPAC)

The fourth tool was developed in the Netherlands and was called RADbaud indicators for PAlliative Care Needs (RADPAC). It aimed to help family physicians in the Netherlands to identify patients with congestive heart failure, COPD or cancer for palliative care (Thoonsen *et al.*, 2012). It was developed through a literature review, focus group interviews and a modified Rand Delphi process with family physicians. While the process of its development seemed to be most rigorous, the potential drawback of this tool was that it did not have frailty and dementia as disease categories. In the

Netherlands, specialists were responsible for the majority of medical care for such patients (Alzheimer Europe, 2013), and this is probably why they were excluded from the RADPAC. This reflected the fact that this tool was developed in response to local needs, which, unfortunately, could be a significant drawback for use in other countries. A randomised controlled trial of a series of interventions including education and the use of the RADPAC was conducted, which showed a possible positive impact of implementing such tools (Thoonsen *et al.*, 2011, 2015).

Tool 5: The 'Surprise Question'

In addition to these four tools, there was an additional tool, the Surprise Question: *'Would you be surprised if the patient died within a year?'* The original Surprise Question proposed by an American geriatrician (Lynn, 2005), was later modified to a 12-month prognosis from being a broader judgement about whether the person was sick enough to die in the next weeks, months or years. This tool was considered a useful, simple way to screen for patients with palliative care needs (Moss *et al.*, 2010; Murray and Boyd, 2011; Gómez-Batiste *et al.*, 2013; Pang *et al.*, 2013), although some criticism has been expressed about its potential inappropriateness for patients with an uncertain prognosis including people with non-cancer conditions (Small *et al.*, 2010).

3.7 Conclusions

Family physicians seemed to lack any practical, usable or convincing definition of palliative care. While some family physicians thought that palliative care should be provided from the earlier stages of life-threatening illnesses, others thought that there were few advantages in labelling patients as palliative too early. They acknowledged the importance of their various roles in providing palliative care, although they experienced some emotional pressures and organisational barriers. Furthermore, family physicians identify patients' palliative care needs in various ways. Patients' perceptions about family physicians' roles and patients' medical conditions (cancer and non-cancer) – in addition to environmental factors – all affect how family physicians recognise patients who need palliative care.

It was promising that several tools for the early identification of patients needing palliative care were available. These tools should enable clinicians to review patients’ palliative care needs systemically and provide appropriate care accordingly. However, there were several concerns identified regarding these tools, including insufficient studies to prove their effectiveness on patients’ outcomes or their quality of care. It was nevertheless understandable why there was only a little research on the effectiveness of such tools. While the current healthcare research field emphasises patient-reported outcomes, it is challenging to define the expected ‘outcomes’ or even the potential beneficiaries of implementing such tools. For example, Thoonsen *et al.* (2015) used out-of-hours contacts as their primary outcome, and contacts with the patient’s own family physician, place of death and hospitalisations in the last months of their life as secondary outcomes. However, there was a possibility of these outcomes not reflecting the potential impact of implementing the tool adequately. Considering that we did not know much about the effectiveness of the tools for identifying patients for palliative care in primary care, I decided that it would be meaningful and important to explore the views of family physicians on such a tool and its impact on these users before determining the possible outcomes of implementing a tool. Implementing a tool should involve cultural and system changes in practice. Despite the apparent need for such tools in Japan, it was essential to consider what changes would or should accompany the implementation of any tool so that we could prepare for them. Furthermore, it was crucial to assess the value of introducing a new identification tool based on the predicted changes in clinical practice.

Based on this literature review, I chose the SPICT for translation and cross-cultural adaptation for my PhD research. In view of the limited timeframe and resources, I chose not to develop a new tool in Japanese. Instead, I compared all the tools discussed to decide which one was most appropriate for translation and cross-cultural adaptation. The NECPAL’s strength, the precision and a level of detail of the information, could discourage family physicians in Japan from using the tool as it would take considerable time to complete. The RADPAC lacked general indicators and did not include dementia and frail patients as target disease groups. This was an important consideration given that such groups comprised a significant part of Japanese family physicians’ workload. The GSF-PIG was widely recognised and covered a wide range of conditions together with well-written guidance, but it lacked academic publications regarding its development processes.

The SPICT had easily understandable items, and its website encouraged and supported developments in different countries. These factors were considered when selecting the SPICT for my PhD research. In addition, in considering the ultimate purpose of my research, the selection of a tool was not the sole factor. Rather, how I would investigate the tool’s use and how the participating family physicians would use the tool were of more critical importance.

Chapter 4 A Japanese translation of the SPICT – a tool to identify patients needing palliative care

This chapter describes Phase I of this research: the translation and cross-cultural adaptation of the SPICT. This Japanese version of the SPICT was used in Phase II, which will be discussed in Chapters 5, 6, 7 and 8. Phase I of the research addressed a part of the third research question: *Can the SPICT be translated for and adapted to Japanese primary care settings? (RQ3)* Phase I focused on the translation of the SPICT into a Japanese version which could be easily and fluently understood by Japanese family physicians. Thus, the objectives of Phase I were:

1. To develop a Japanese translation of the SPICT (called SPICT-JP hereafter)

2. To collect views on the SPICT-JP from experts to inform the design of Phase II and the analysis of interview data within Phase II

This chapter begins with an overview of the translation and cross-cultural adaptation of health-related tools. This is followed by a discussion of how I actually translated the SPICT for this research. This discussion contains a description of the translation process and the findings which were obtained through the process of translation. These findings were collated and summarised to inform Phase II of the research.

4.1 Overview of the translation and cross-cultural adaptation of health-related tools

This section, through a review of current literature, provides an overview of the translation and cross-cultural adaptation of instruments in healthcare in relation to the objectives stated above. Although the SPICT was not a health status measure *per se*, much of the literature around the translation and cross-cultural adaptation in healthcare focuses on health status or health-related quality of life (HRQOL) measures. I review this literature and then discuss how I adapted the SPICT for my research.

Achieving the equivalence

Given the globalisation of healthcare, there is a growing need to consider and adapt health-related tools developed in one setting to another (Sousa and Rojjanasrirat, 2011). To use an established health status measure in a new country, it has to be adapted culturally as well as linguistically (Beaton *et al.*, 2002; WHO, 2007).

Guillemin, Bombardier and Beaton (1993) categorised situations that needed the translation or cross-cultural adaptation of the HRQOL measures into five (Table 4.1). In this categorisation, the translation of the SPICT into Japanese falls into category 5 (shown in bold in Table 4.1) which suggested that I needed to both translate and culturally adapt the SPICT for the use in a Japanese setting.

Table 4.1 Categorisation for situations needing the translation and cross-cultural adaptation of the HRQOL (Guillemin, Bombardier and Beaton, 1993)

	Culture	*Language*	*Country*	*Translation required*	*Adaptation required*
1	Same	Similar	Same	-	-
2	Other	Similar	Same	-	✓
3	Other	Similar	Other	-	✓
4	Other	Other	Same	✓	✓
5	**Other**	**Other**	**Other**	✓	✓

The need for the cultural adaptation of the SPICT was obvious from my experience of comparing the healthcare systems in Japan and the UK. Patients' self-referral to hospital specialists was accepted in Japan while in the UK patients first saw their local GPs. Due to this, the characteristics of patients seen by Japanese family physicians and Scottish GPs might differ. It was also anticipated that direct translations of some words and phrases in the original SPICT, such as ‘low body mass index’, ‘care plan’ and ‘treatment withdrawal’, could be understood differently in Japan.

Herdman, Fox-Rushby and Badia (1998) developed a model of equivalence for cross-cultural research from a universalist perspective and categorised equivalence into five groups with one summary group, as shown in Table 4.2.

Table 4.2 Framework of equivalence by Herdman, Fox-Rushby and Badia (1998) (adapted a summary made by Epstein et al. 2015)

	Explanations	**Examples of achieving equivalence (in target culture/language)**
Conceptual equivalence	Domains have the same relevance, meaning and importance regarding the explored concept in both cultures.	Domains have the same relevance.
Item equivalence	Items are as relevant and acceptable in both cultures.	Items are considered as appropriate (not offensive or taboo).
Semantic equivalence	The meaning of the items is the same in both cultures.	Appropriate use of words or phrases
Operational equivalence	The questionnaire can be used in the same way by its target population in both cultures.	The same method of administration can be used.
Measurement equivalence	No significant difference in psychometric properties (construct validity, reliability, responsiveness, and so forth) of the two versions.	Formal validation study for reliability and validity
Functional equivalence	A summary of all the above types of equivalence	

This model was developed to examine the equivalence of translated HRQOL measures for cross-cultural research. I decided to use this model as my reference point in deciding and discussing the equivalence that I should consider in this research because this was the most comprehensive among similar models.

Herdman, Fox-Rushby and Badia (1998) argued that conceptual, item and operational equivalence in this model could be ensured by a literature review, expert consultation and anthropological or sociological investigation such as participant observation of the cultural environment. According to Herdman, Fox-Rushby and Badia (1998), item equivalence involves investigating the psychometric properties of items, whereas semantic equivalence is concerned with linguistic issues and is achieved by appropriately understanding original questionnaires and careful translations ‘to express the original message as accurately, clearly and naturally’(p.328). This semantic measurement equivalence is achieved by various kinds of psychometric tests to verify the questionnaires’ reliability and validity as a tool. They concluded that as a result of achieving these five equivalences, the functional equivalence of the translated versions is ensured, and that functional equivalence was defined as ‘the extent to which an instrument does what it is supposed to do equally well in two or more cultures’ (Herdman, Fox-Rushby and Badia, 1998, p.331).

In considering sufficient equivalence for the translated SPICT, I revisited the purpose of my research. The majority of the discussion on translating instruments in health were for HRQOL measurements in cross-cultural research, but the current study was not aiming at comparing the results of the original SPICT and the SPICT-JP tested within two different cultures (*i.e.* the UK and Japan), though there might be such needs in the future. The purpose of translating the SPICT was to examine if the contents of the SPICT were adaptable, usable and useful in primary care settings in Japan. In addition, careful consideration of ‘equivalence’ referring to Herdman, Fox-Rushby and Badia’s framework (1998) (Table 4.2) informed the process of translation and the decision regarding which equivalence I should obtain. Following this, I concentrated on obtaining conceptual, item, semantic and operational equivalence but not measurement equivalence which requires examining the psychometric properties of instruments.

In fact, it was argued that cross-cultural adaptation and validation of the questionnaires are two different processes (Epstein, Santo and Guillemin, 2015). While appropriately adapted measurements should have the same psychometric properties as the original version in theory, culturally adapted measurements should be validated for their own validity within the target culture. A systematic review with health assessment scales translated into Turkish, Arab and Surinamese pointed out that many studies failed to perform psychometric analysis of the translated scales (Uysal-Bozkir, Parlevliet and De Rooij, 2013). However, the concept of validity and reliability is for measurements 'assigning numbers to observations to quantify phenomena' (Kimberlin and Winterstein, 2008, p.2276). As the SPICT is not a measurement with any kinds of scales or scores, this concept could not be applied.

Herdman, Fox-Rushby and Badia (1998) also highlighted a need for some degree of qualitative work and the examination of available local literature to understand target culture in order to obtain the overall equivalence. I aimed to investigate family physicians' understanding of palliative care and the identification of palliative care patients in Phase II of this research (described in Chapters 5 to 8), which would later enable the revision of the SPICT-JP. In the light of the nature of the SPICT and the overall objectives and structure of this research, I concluded that the accurate translation of the SPICT into Japanese without any psychometric analysis would be sufficient and appropriate for Phase I of my PhD research.

The translation of English-written HRQOL instruments into Japanese

Numerous HRQOL instruments originally produced in English have been translated into Japanese to date. Most papers reporting the process focus on their validation rather than translation and cross-cultural adaptation while some papers reported particular challenges they faced in the translation (Fukuhara *et al.*, 1998; Green *et al.*, 2001). It was reported a great difficulty in translation of cognitive functioning, social interaction and questions and response choices regarding patients' satisfaction (Green *et al.*, 2001).

Fukuhara *et al.* (1998) detailed how they resolved challenges of translating unfamiliar or awkward expressions in the original questionnaire into Japanese. However, the challenges described by them were regarding expressions of concepts rather than concepts themselves. In other words, they had more challenges in the translation process (*i.e.* semantic equivalence) than in the conceptual or item equivalences. These findings informed the design of the translation process in Phase I of this research.

The Guideline

In deciding the method for the translation and cross-cultural adaptation of the SPICT, I referred to several international literature reviews and guidelines (Guillemin, Bombardier and Beaton, 1993; Beaton *et al.*, 2000, 2002; WHO, 2007; Acquadro *et al.*, 2008; Sousa and Rojjanasrirat, 2011). These guidelines were for HRQOL measures and have been applied to other kinds of tools in healthcare. Among them, the guideline by Beaton *et al.* (2002) seemed to be the most practical and frequently cited. This guideline was developed based on a literature review conducted by Guillemin, Bombardier and Beaton (1993). Although both the guideline and the literature review were for HRQOL measures, their recommendations have been widely used for other types of health-related tools. Additionally, the guideline by Beaton *et al.* (2002) did not include psychometric analysis as part of the recommendation process, which met the needs of Phase I of my research. Therefore, I decided to adapt Beaton *et al.*'s guideline which I refer to as 'the Guideline' hereafter.

In the Guideline, the cross-cultural adaptation process comprised six stages: I) forward translation, II) synthesis, III) back translation, IV) expert committee review, V) pretesting and VI) submission and appraisal of all written reports (Figure 4.1). Among these, stages I to V were for the actual methods of translation. I made some amendments to each stage to adapt the Guideline for my research, which will be shown in the next section.

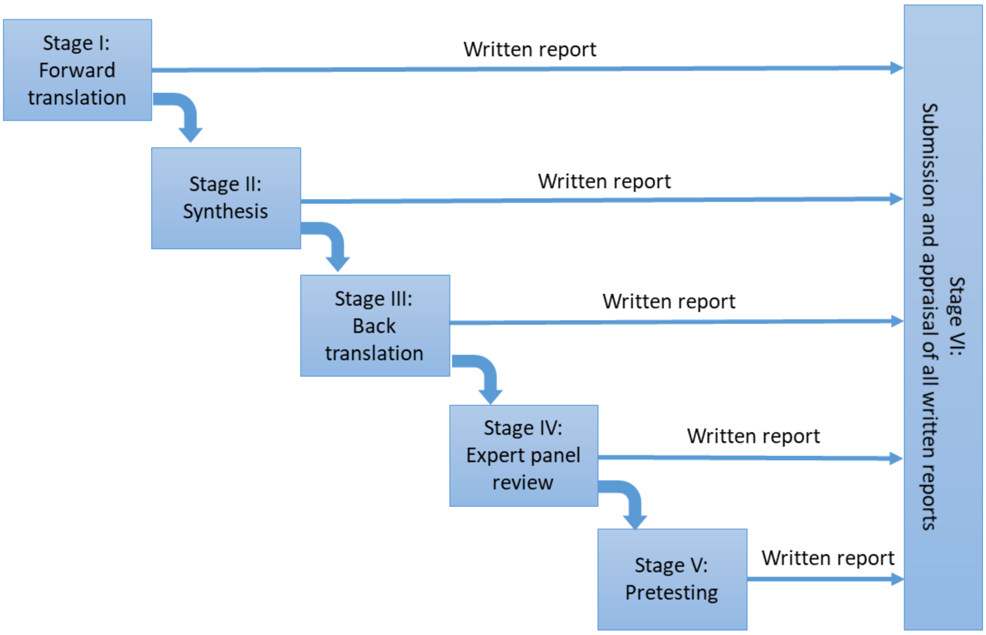


Figure 4.1 Stages of cross-cultural adaptation in the Guideline (Beaton et al., 2002)

4.2 Translation process

The nature of the SPICT, the purpose of developing the SPICT-JP and the available resources for this research – together with an understanding of the established guidelines – all informed the planning of the process of translation and adaptation. In this section, I will describe the amendments made to each stage followed by the details of actual translation steps. Table 4.3 is a summary of the amendments made to the Guideline.

Table 4.3 Amendments made to the Guideline (Beaton et al., 2002)

Stages in the Guideline	Recommendations in the Guideline	Amendments made
Stage I: Translation	Two translators, preferably one who is knowledgeable in the field, and another lay person.	Two translators who are both knowledgeable in the field.
Stage II: Synthesis	A third unbiased person to mediate discussions is added to produce a synthesis of two translations.	Inputs from the developer of the original version replacing a third unbiased person.
Stage III: Back translation	Two back-translators who are native to a source language.	One Japanese back translator confirmed by an English native speaker. The back translation was double checked by another translator and a native English speaker.
Stage IV: Expert committee review	A methodologist, health professional, language professional as well as translators are recommended.	No language professionals or methodologists were utilised.
Stage V: Pretesting	The field test with 30-40 persons.	Omitted because Phase II of this research served as pre-testing.

4.2.1 Stage I: Forward translation

The purpose of Stages I to III was to produce a translation for the expert committee review in Stage IV. The outline of Stages I to III is shown in Figure 4.2.

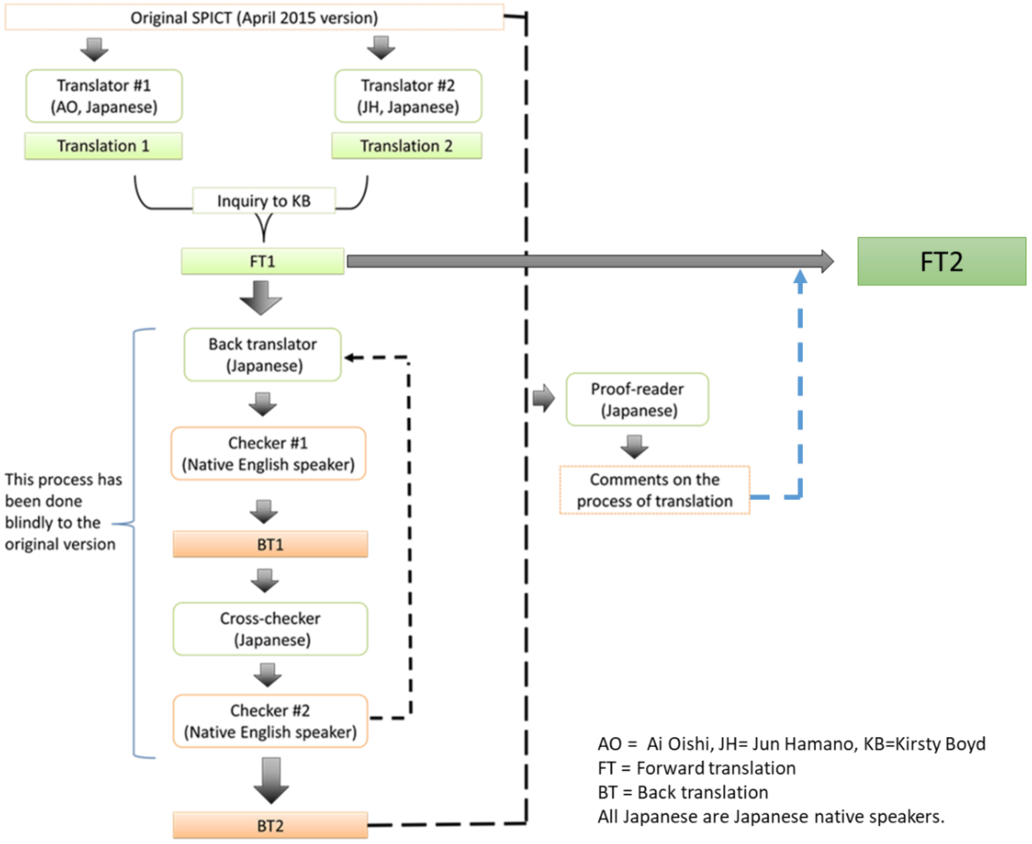


Figure 4.2 Process of translation (Stages I to III)

AO=Ai Oishi, JH=Jun Hamano, KB=Kirsty Boyd
All Japanese are Japanese native speakers

Amendments to the Guideline

In Stage I, it was recommended that two independent native translators with the target language as their mother tongue translate the original instrument into the target language, *i.e.* into their mother tongue (Beaton *et al.*, 2002). This is because translations into the mother tongue reflect any nuances more accurately (Hendricson *et al.*, 1989; Beaton *et al.*, 2002).

According to the Guideline, Translator #1 should be knowledgeable about the clinical background of the measure, and Translator #2 should not have any knowledge of the subject and academic aims of the research. The purpose of having Translator #2 meeting this specification is to ensure that the translation reflects the language used by the general population (Beaton *et al.*, 2002; Sousa and Rojjanasrirat, 2011). However, unlike self-administered

HRQOL measures, the SPICT was originally developed for the use of healthcare professionals, and because of this, medical terms predominate the SPICT. Therefore, I decided to have two translators who were familiar with the culture in which the SPICT will be used, namely, the Japanese primary care settings. These two translators should know the clinical context within the Japanese community settings as well as medical terms and also should be able to understand the purpose of this research fully.

Actual process

I started the translation process after obtaining permission from the developer of the original version. It was decided that a Japanese family physician who was interested in palliative care and myself would be suitable as Stage I translators. It was felt appropriate that having two translators instead of the one recommended by the Guideline would still prove useful in avoiding potential biases and to secure accuracy. Therefore, Translator #1 was myself (AO), and a family physician who had been interested in and advised on my research, Dr Jun Hamano (JH) was invited to be Translator #2.

AO and JH independently translated the latest version of the original English SPICT (April 2015 version) into Japanese in April 2015. We both had clinical experience in palliative care in the community, and we both also understood how words and phrases would be understood by family physicians in Japan. In translating the SPICT into Japanese, problematic and unclear expressions were recorded for Stage II.

4.2.2 Stage II: Synthesis of translations

Amendments to the Guideline

The Guideline suggested having a third person to facilitate and mediate the discussion, but it was neither possible nor practical for the research to get another person. The two translators (*i.e.* AO and JH) had worked together on several projects, which made honest discussions possible without mediation.

Actual process

After translating the SPICT independently, translators #1 and #2 met and discussed the two translations in May 2015 to synthesise the two translations into one. We noted down any unclear expressions in the original version, most of which were linguistic issues, *i.e.* lack of direct translations or seeking for fluent expressions to make the translation easily understood. Any disagreements and unclear points were recorded, and we consulted the developer of the original version of SPICT for clearer explanations. Comments from the developer were shared between the two translators and were used to determine word choices in Japanese. With the additional information, the translators could make the translation more fluent and accurate. The completed synthesised version (FT1) was kept for the back translation.

During the process of synthesis, only one specific question was raised regarding the sentence: ‘Patients ask for supportive and palliative care, or treatment withdrawal’. This question was possibly related to the cultural differences between Japan and the UK. According to translator #2 (JH), in Japan, some patients make such requests, but most do not with family members doing so on their behalf, which could be a sign of a deterioration in health. However, translator #1 (AO) was unconvinced by this view. Meanwhile, consultation with the developer indicated that it was normal in the UK for patients to express their needs directly to doctors. It was decided to leave this sentence in the translation for the time being for discussion at the later phase during which expert committee members would raise a question if they felt that it was an issue.

4.2.3 Stage III: Back translation

Amendments to the Guideline

The purpose of back translation is to confirm the accuracy of the translation. While it could not guarantee to produce a satisfactory translation, the process often illuminates unclear expressions in the forward translations (Beaton *et al.*, 2002). Although the Guideline recommended having two independent back translators who are native English speakers, it proved difficult to find two native English speakers who had both competence in Japanese and knowledge of medical terms. To compensate for the lack of two back translators, multiple checkers (described in detail in the next section) were deployed. This measure was sufficient as the content of the SPICT was more straightforward than the HRQOL measures for which the Guideline was developed. In addition, it was anticipated that the input from the expert committee review would be more crucial than the strict procedure of back translation in finalising the translation.

Actual process

Due to the limited time frame and the difficulty in appointing appropriate translators, a professional translation agency was used for Stage III. The synthesised version (FT1) was back-translated by a Japanese professional translator (=back translator) and subsequently checked by a native English speaker (=checker #1) for the appropriateness of English expressions used. The translation (BT1 in English) was checked by a second Japanese professional translator (=cross checker) referring to the original version for semantic equivalence, followed by a further review by a second native English speaker (=checker #2). This process produced the final version of the back translation (BT2). An independent professional proof-reader with English competency compared FT1 and BT2 and provided a report. Figure 4.2 on p. 83 shows the process of translation (Stages I to III).

The proof-reader approved that FT1 conveyed the same meaning in the original version, while suggesting some amendments regarding some expressions in FT1. AO and JH reviewed the comments from the proof-reader to develop FT1 into FT2. The FT2 was kept for use in the later part of the research.

Throughout Stages I to III, there were no significant issues raised. This might have reflected the fact that the contents of the SPICT focused on the physical aspects of patients’ conditions which would raise fewer issues than social or cultural aspects.

4.2.4 Stage IV: Expert committee review

Amendments to the Guideline

Stage IV was the expert committee review which aimed to secure quality control and to ensure the cultural and linguistic appropriateness of the translation. An important goal of Stage IV was to achieve equivalence between the original and the translated version. Regarding the ‘equivalence’, the Guideline adopted slightly different categories of equivalence from those of Herdman, Fox-Rushby and Badia (1998), which comprised the semantic, idiomatic, experimental and conceptual equivalence (Guillemin, Bombardier and Beaton, 1993) (Table 4.4). This model covered the first three categories of Herdman, Fox-Rushby and Badia (1998)’s model for equivalence (*i.e.* conceptual, item and semantic equivalence), but not the last three categories (*i.e.* operational, measurement and functional equivalence). It was decided to use the model adopted by the Guideline, which was considered more appropriate, practical and useful for this stage, especially as the last three equivalences by Herdman, Fox-Rushby and Badia (1998) were unnecessary for the translation of the SPICT in this phase.

Table 4.4 Categories of equivalence adopted in the Guideline (Guillemin, Bombardier and Beaton, 1993)

	The equivalence is challenged when…
Sematic equivalence	Words do not mean the same thing, or a given item has multiple meanings. There are grammatical difficulties in the translation.
Idiomatic equivalence	Colloquialisms or idioms are difficult to translate. Formulation of an equivalent expression may be needed.
Experimental equivalence	A given task in an item may simply not be experienced in the target culture even if it is translatable. This would be problematic in items seeking to capture and experience of daily life. The experience of daily life often varies in different countries and cultures. *e.g.* 'Do you have difficulty eating with a fork?' may need to be replaced with another utensil.
Conceptual equivalence	Words hold different conceptual meaning between source and target cultures.

In the Guideline, it was recommended to deploy at least one of each from methodologists, health professionals, linguists as well as all translators and the translation synthesis recorder for the expert committee. However, the content of the SPICT focused on physical functions and medical conditions of patients and was designed for use by clinicians, as opposed to the general public. Therefore, obtaining feedback from healthcare professionals was deemed to be more valuable than deploying methodologists or linguists.

Actual process

Figure 4.3 shows an overview of how the expert committee review proceeded through three rounds of consultation from August 2015 to September 2016 with eight selected experts.

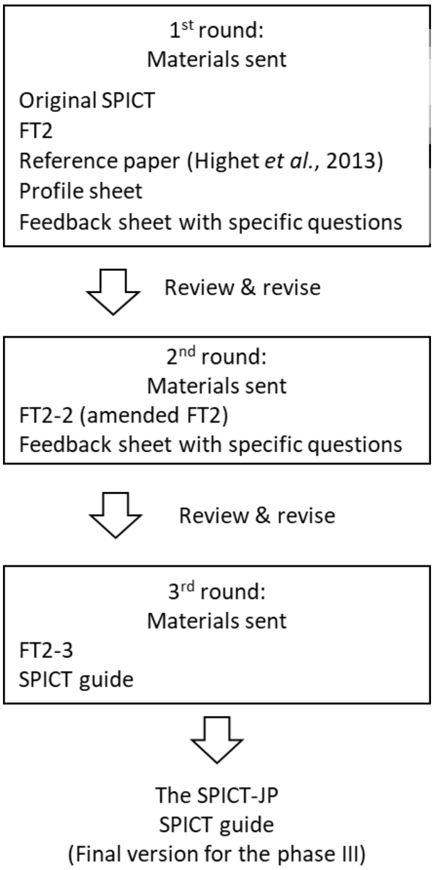


Figure 4.3 Overview of the expert committee review

The expert committee was formed from August to October 2015. Physicians were invited to be members if they met at least one of the following criteria: 1) family physician with or without a special interest in palliative care, 2) palliative care specialist, and 3) homecare specialist. It was ensured that panel members came from at least one of each from these three categories. A letter of invitation was sent to candidates, and all of them agreed to join the panel (See Table 4.5 for brief profiles of the members). All were given the original version of the SPICT, the SPICT-JP (FT2) and a feedback sheet containing some specific questions (Table 4.6). The members were also given an article describing the development of the SPICT (Highet *et al.*, 2014) and the link to the SPICT website (http://www.spict.org.uk/). Additionally, Amazon gift cards worth 1,000 JPY (equivalent to £5 in July 2015) were given to the members as a token of appreciation.

Table 4.5 Brief profiles of expert committee members

No	Affiliation	Background
1	University	Family physician with special interests in medical education and palliative care
2	Metropolitan cancer centre	Palliative care specialist, originally trained in internal medicine
3	Community hospital (160 beds)	Palliative care doctor, originally trained in family medicine
4	Home care department at a hospital (>800 beds)	Home care doctor, originally trained in family medicine
5	Palliative care department at a hospital (>800 beds)	Palliative care specialist and home care doctor, originally trained in internal medicine
6	Home care clinic	Home care specialist, originally trained in internal medicine
7	Family medicine clinic	Family physician
8	Family medicine clinic	Family physician with special interests in infectious diseases

Table 4.6 Specific questions sent at the 1st round of the expert committee review

1. Capacity: would it be acceptable to translate capacity into ‘意思決定能力 *ishi-kettei-nouryoku* (a capacity for making a decision)’?
2. Coordinate: Given the word ‘コーディネート *ko-dine-to*’ is now widely accepted in Japan, it might be better to translate the term into ‘コーディネート *ko-dine-to*’ rather than ‘調整 *cho-sei*’(the direct translation). What do you think?

After collecting feedback sheets from all the members, I summarised their comments and amended the forward translation based on their opinions. Another researcher (JH) reviewed original comments from the expert committee members, the summary, and the amended translation and commented on them all. Based on these comments, I finalised the second version of the FT2 (FT2-2) which was subsequently confirmed by JH. We also summarised those points which we considered necessary to clarify in the second rounds (Table 4.7).

Table 4.7 Specific questions sent at the 2nd round of the expert committee review

1. Do you think it is better to have a specific cut-off for the ‘low BMI’?
2. A comment was raised questioning the translation of ‘functional ability’. We were unable to find any other translation. Do you have any alternatives for this? Or do you think the current translation is OK?
3. An opinion was raised that allied health professionals might not understand the word ‘frail’. The usage of this word is based on the statement from the Japan Geriatrics Society. Do you have any comments on this?
4. In respiratory diseases, do you think it is better to say that ‘they are not suitable for ventilation anymore’? The original sentence, ‘ventilation is contraindicated’ means ‘ventilation is contraindicated because it does not improve either their prognosis or quality of life’.
5. Care planning: an opinion was raised that the term ‘care planning’ could be confused with the term ‘care plan’ used in the long-term care insurance scheme. Therefore, it was changed to ‘ケア計画 *kea-keikaku*’. What do you think?
6. Regarding performance status, weight loss, the degree of independence of daily living and the first item in the neurological disease (‘Progressive deterioration in physical and/or cognitive function despite optimal therapy’), some said there were patients who were relatively stable even though they met these criteria. What do you think?

For the second round, FT2-2 was sent to the members again, together with those questions raised by the first round (Table 4.7) and the first draft of the SPICT user-guide which will be discussed in Section 4.3. The replies from the expert committee members were once more collated, and the same procedures as the first round were taken to create the third version of the FT2 (FT2-3). FT2-3 and the revised SPICT user-guide were completed in September 2016. FT2-3 and the revised user-guide were re-sent to the expert committee members. There were no more additional views and comments from the expert committee members regarding the FT2-3 and so it was confirmed as the final version. All processes of the translation were kept in electronic files.

4.2.5 Stage V: Pretesting

The Guideline suggested that at Stage V of the process, the translated HRQOL measures should be pilot tested with 30-40 participants followed by interviews with them. The interviews were to ensure that the adapted version possessed the equivalence in an applied setting (Beaton *et al.*, 2002). This process was omitted because Phase II of this research could be deemed as a pilot testing of the SPICT-JP with Japanese family physicians. Regarding the participant numbers, these appear to be arbitrary. For example, another guideline for the cross-cultural adaptation recommends 5-8 participants at this stage when conducting a cognitive debriefing (Antunes *et al.*, 2015). The decision for the number of participants in this research will be discussed in Chapter 5.

4.3 The SPICT user-guide

One of the recommendations from the expert committee was to provide a guide or support to help users understand the SPICT-JP better. The members mentioned that some additional information would be helpful because providing potential users with only the tool might confuse them. Following their recommendation, it was decided to develop such a user-guide to enhance its usability.

4.3.1 Developing a SPICT-JP user-guide

In the search for the most appropriate guide, it was first considered to develop educational materials such as PowerPoint presentations containing comprehensive information. In particular, it was thought to be highly valuable to provide information in person rather than by distributing written materials. However, it was impossible to provide face-to-face education in this research because of its limited timeframe and resources. Meanwhile, comprehensively written materials could compromise the succinctness of the SPICT-JP.

After careful consideration, the decision was made to develop a concise and simple user-guide for the SPICT-JP (one A4 sheet) which would not compromise the conciseness of the SPICT-JP. Furthermore, it was assumed that the views to be collected from family physicians in the latter part of the research would be useful in judging the need for a more extensive and comprehensive user-guide. As there was little information available in academic literature about the development of 'guides' for instruments used in healthcare, I devised the following steps for developing such a user-guide (Figure 4.4).

Figure 4.4 Process for developing a user-guide for the SPICT-JP

Drafting the first version

Before drafting the first version of the user-guide, I referred to available guides for the original SPICT, the GSF-PIG, the NECPAL (guides for the RADPAC were unavailable) and analysed their contents. In addition to this, comments from the expert committee on the SPICT-JP also informed the content of the user-guide. I also referred to the Japanese article on how to start end-of-life related conversations (Kizawa, 2015) as I felt it was important for the user-guide to indicate what should happen after identifying patients for palliative care when using the SPICT-JP. In drafting the user-guide, JH and I ensured that the user-guide would be both practically and culturally appropriate for the Japanese primary care settings.

The developer of the original SPICT examined the first draft, and then AO and the developer discussed it face-to-face in October 2015. In this discussion, we explored the cultural and contextual differences between the UK and Japan. There were no disputes on the contents themselves although sometimes considerable thought was given to word choice.

Expert committee review

After completing the first version of the SPICT-JP user-guide, I circulated it to the expert committee members together with FT2-2 (Figure 4.3 and Figure 4.4). Along with the comments on the SPICT-JP itself, I collected the panel members' views on the user-guide (Table 4.8). These suggestions were reflected in the second version of the user-guide. The second version was reviewed by the expert committee again, and no modifications were recommended by the committee.

Table 4.8 Opinions from the expert committee on the first version of the SPICT-JP user-guide

The user-guide could contain some advice and information regarding patients who are unable to make decisions by themselves.
The user-guide could contain some family dimensions, *e.g.* the process and outcomes of the discussion with the families. I think it is particularly important in Japan. *e.g.* Does the family (or the loved one) understand the patient's wishes?

The final version of the user-guide contains the following (See also Appendix 2):

- The purpose of the SPICT-JP
- What is not the purpose of the SPICT-JP (*e.g.* prognostication)
- In what situations we can use the SPICT-JP (*e.g.* screening, multidisciplinary meetings, joint meetings with specialists)
- What we need to do after the identification of patients using examples of how to start end-of-life conversations with such patients

4.4 Discussion of the process

In this section, I will discuss the outcomes of the translation process. Overall, the translation was completed without significant problems. There were several contentious expressions and words which we were able to resolve after discussions between researchers and consultation with the developer.

The first part of this section describes how the resolutions were found in the translation of difficult words and expressions to maintain the equivalence. The second part presents views from the expert committee, which often went beyond the mere translation. These views were not necessarily reflected in the translation but were included here as valuable insights. The third and last part of the section discusses the methods of translation.

4.4.1 Obtaining the equivalence

There were several words and phrases highlighted as being challenging to translate during the translation process. Most of the points, particularly those raised in Stage II, were related to semantic equivalence and resolved by discussion among researchers including the original developer. We also sought opinions from the expert committee (Table 4.6 and Table 4.7) whenever we felt it was necessary. In Stage II and the first and second rounds of the expert committee review, most changes made were to make the texts in the SPICT-JP more readable and fluent, while avoiding potential misunderstanding. These changes were made mostly by rephrasing potentially misleading expressions or sometimes by replacing words in the texts with more appropriate ones. Regarding semi-colons and instances of ‘and/or’ used in the original SPICT which were found to be confusing, we decided to omit them to make the texts as clear as possible because there were no equivalent expressions in Japanese.

Table 4.9 Words and phrases discussed in the translation process

Stages	Expressions (italicised) needed to be discussed	Relevant equivalence (Guillemin et al. 1993)
II	No longer able to communicate using *verbal language*;	Semantic (vocabulary)
II	Depend on others for most *care needs* due to ...	Semantic (vocabulary)
II	Patient *asks for* supportive and palliative care, or ...	Idiomatic, experiential, conceptual
II	Persistent, *troublesome* symptoms:	Semantic (vocabulary), conceptual
IV	*Supportive* and palliative care needs	Semantic (vocabulary), conceptual
IV	*: or ;*	Semantic (grammatical)
IV	Ventilation is *contraindicated*	Conceptual
IV	Agree current and future care goals, and a *care plan* with the person and their family.	Conceptual
II&IV	Too frail for *oncology treatment* ...	Semantic, idiomatic, conceptual
II&IV	Too *frail* for oncology treatment ...	Semantic (vocabulary)
II&IV	*optimal treatment* of underlying condition(s)	Conceptual

Among these expressions, only a few were related to conceptual equivalence. An example was an item on ventilation in respiratory diseases. The real meaning of ‘ventilation is contraindicated’ in the original SPICT was ‘ventilation is contraindicated because it would not improve patients’ prognosis or quality of life’. Nevertheless, this short sentence was not properly understood by some of the expert committee members in the first round. The confusion might be related to the cultural differences between the UK and Japan, as long-term ventilation was much more common in Japan than in the UK. Japanese doctors found it difficult to imagine situations in which ventilation was contraindicated without any background information given. I replaced the sentence with ‘ventilation is contraindicated because it would not improve patients’ prognosis or quality of life’ and asked the expert committee members for their views on this in the second round (See Table 4.7). Their responses to this replacement were favourable.

Adjustment to Japanese healthcare of expressions in the SPICT

Some translations were suggested as not fitting in with Japanese healthcare. These were categorised as coming under a conceptual equivalence. After the discussion between AO and JH, the translations were paraphrased to align with Japanese healthcare while retaining their original meaning. One example was the phrase ‘care planning’. In the Japanese long-term care insurance scheme, the term ‘care plan’ specifically meant the long-term care service plan. So, we replaced the word with ‘plan’.

Another example was ‘supportive and palliative care’. Some members said that ‘supportive care’ was not a recognised term in Japan and one doctor suggested to omit the word ‘supportive’. After careful consideration, we decided to keep the word ‘supportive’. We felt it was still recognisable particularly for those working in palliative care, and it would be better to keep the original phrases whenever possible.

4.4.2 Expert committee review

The expert committee review identified several points for improvement while welcoming the SPICT-JP as a tool. Despite clarifying that the purpose of the expert committee was to secure an accurate translation of the original SPICT, the members provided valuable insights not only on language issues but also on its contents and how the SPICT-JP could be operationalised in Japan. Some of the members even mentioned general issues on palliative care in Japan in relation to the identification of patients needing palliative care. Unfortunately, it was impossible to present all of the points they mentioned in the final version of the SPICT-JP due to the specific role of the expert committee review. However, I summarised their comments and our reflections here to navigate the later phase of this PhD research. Meanwhile, many of the points suggested by the members did not directly inform the design of Phase II of the research, but instead, they complemented findings from the interviews in Phase II which will be presented in Chapters 6, 7 and 8.

Format of the SPICT-JP

Firstly, there were some comments regarding instructions in the SPICT-JP. It was unclear for some members when patients were considered as ‘positive’. For example:

> *It’s not easy to understand how to use this tool. If the patient meets two or more general indicators or one or more clinical indicators, then should we review the patient? It would be better to have an explanation on how to use it at the beginning. (Expert committee member No.2)*

The original SPICT has general indicators and clinical indicators for specific advanced conditions (Appendix 1 and 2). It was not clearly written if both or either of these indicators need to be met for patients to be considered as ‘identified’ by the SPICT. However, we felt that it was not appropriate to add new texts which did not exist in the original SPICT at this stage. We decided to leave this and wait for findings from qualitative investigations.

Unclear criteria within the tool

In Stage IV, expert committee members identified some unclear criteria within the tool, such as ‘low BMI’ or ‘severe’ diseases. Developers intentionally left these criteria vague so that users could act intuitively when making their decisions in accordance with patients’ situations. However, some members thought that a ‘tool’ should have a clear cut-off and not allow users to act intuitively. While their opinions were worth considering, inventing and adding cut-offs at this phase seemed to be beyond the remit of translation. I recorded their opinions but set them aside at this point, expecting that I would obtain further views from family physicians who would be using the SPICT-JP in their practice in Phase II of the research.

Who should use the SPICT-JP?

Some members raised the issue of the position of the SPICT-JP within the Japanese healthcare system. One member believed that the original SPICT was for GPs in the UK. He claimed that the lack of family physicians and the less-established primary care in Japan might impede the implementation of the SPICT-JP. For example:

> *In the UK, GPs, who are looking at patients holistically, would undertake the role of evaluating their patients regarding indications for supportive and palliative care needs and provide them accordingly. However, in Japan, many such patients are seen by hospital specialists in the first instance, and these specialists are only looking at organs within their speciality. It is probably difficult for them to use this tool in hospital. It is difficult for me to imagine in what situations this tool would be used in Japan. (Expert committee member No.6)*

This point extended to the question regarding in which situations the SPICT-JP would be used in Japan. One member thought that patients who needed to be evaluated for palliative care needs were seen by hospital doctors rather than family physicians in Japan. Similarly, another member argued that doctors or hospital specialists – other than family physicians – might be best placed to use the SPICT-JP on the basis that hospital doctors rather than family physicians would more often see people needing palliative care. Conversely, another comment from the panel member indicated that family physicians were better placed to use the tool because they were generally better at introducing discussions about end-of-life care.

> *It would be better to promote and cascade this (SPICT-JP) to organ-specific specialists and co-medicals [allied health professionals] working in their specialities. It would make appropriate supportive and palliative care accessible to many more people. (Expert committee member No.4)*

> *Family physicians, in general, tend to have advanced care planning (ACP) in their mind when seeing patients. And most frail elderly patients would meet these criteria, I would question the value of using this tool (It would be easy to suggest we should consider ACP with all frail elderly patients without using this tool). On the other hand, it might be useful as a tool for junior doctors or family medicine trainees to remind them of ACP, or to flag up to them the situations when ACP should be considered. It might be more valuable for organ-specific specialists to*

> *use the tool as they tend to concentrate on organ-specific treatments [and do not take a holistic approach] compared to family physicians. (Expert committee member No.8)*

Lack of awareness of palliative care and end-of-life issues

There were some comments regarding awareness of palliative care among the general public and healthcare professionals. One member stated:

> *In addition, the concept of palliative care is not common in Japan as yet. The problem is that not only opioids but other resources for palliative care are limited for non-cancer patients. (Expert committee member No.6)*

He also suggested that the ‘not-telling the truth’ culture would interfere with providing palliative care as well as identifying patients needing palliative care in relation to one specific item (quoted below) in the SPICT-JP.

> *In order to respond to the item ‘patient asks for supportive and palliative care, or treatment withdrawal’, patients should have been informed of their medical conditions and prognosis. But in Japan, there are many cases in which only families are informed. I mean, we need to evaluate if the patients are well informed to make it possible for them to make their own decisions. (Expert committee member No.6)*

Interestingly, the very same doctor wrote the following comment, which in a sense showed that he was unable to connect end-of-life discussions with palliative care.

> *Combining these general indicators, bedbound people – due to cerebral infarction, for example – would be indicated as needing supportive and palliative care as well, but many of these people would be stable for more than ten years. I cannot imagine what palliative care is like for these people, including dementia. (Expert committee member No.6)*

The confusion about palliative care for non-cancer patients, together with the low level of public awareness of palliative care, will be revisited and discussed further in later chapters.

Concerning general public awareness, one member suggested that only a few patients were ready to accept palliative care when they needed it. He explained that to relieve their anxiety of being abandoned, a careful review of care and treatment was of significant importance.

> *It would be possible to identify people with 'indications' for supportive and palliative care by using SPICT-JP. However, the issue is to what extent patients feel their 'needs' for supportive and palliative care. This is the case, particularly for non-cancer patients. Even if these patients themselves don't wish for so-called resuscitation or artificial ventilation, their families request for artificial nutrition or specialist treatment for acute exacerbation which sometimes makes the gradual transition to supportive and palliative care difficult. (Expert committee member No.4)*

> *It is very important to review carefully and sensitively the current treatments and care plans rather than promoting the advance are planning to prevent them from feeling abandoned [by medical professionals] or any misunderstandings by patients regarding the lack of necessary treatments just because they are too old. And, it would make it easier for patients and families to agree on appropriate treatment and care. (Expert committee member No.4)*

Similarly, another member indicated that not many Japanese doctors were good at reviewing, discussing and communicating patients' care plans. He suggested that there would be many patients who suffered from being treated without having their wishes heard or respected.

> *Many Japanese doctors are not good at carrying out the five reviews [i.e. the five bullet points in the care planning box in the SPICT-JP], reviewing the treatment and drugs, referring patients to palliative care or the introduction of palliative care, and advance care planning (It's not only the doctors' problem, but it has a lot to do with society). Is it only me to feel these reviews are still valuable? It's valuable if we could recognise that many more people would benefit from being reviewed. This would help those patients who are only receiving treatment and thus suffering. (Expert committee member No.5)*

'Effectiveness' of the SPICT-JP

Another issue raised by the expert committee members was the 'effectiveness' of the tool. Several members commented that it would be useful if the information is made available regarding the 'effectiveness' of the tool or potential benefits of using the tool in their practice.

> *It would be much better if any data about the effectiveness of the SPICT were made available. It would motivate us to use it. (Expert committee member No.8)*

These opinions were related to the absence of the ultimate and explicit purpose of the SPICT-JP and of the contexts for SPICT-JP usage within the Japanese primary care setting.

> *It's not clear what one would like to do with this tool and what would be the benefits of using this tool. Is this a checklist, not a prognostic tool? Has anyone achieved a better quality of care by using the SPICT? It would be easy to understand if it provides a score, and that score indicates some specific action. It's not clear what one would like to achieve and how this would be useful. Providing information on the effectiveness and the possible usage of the tool would make it more attractive. (Expert committee member No.7)*

> *In our hospital, we advocate 'palliative care for all'. I mean we separate specialist and basic palliative care to some extent. But is the SPICT for specialist palliative care (for the severely ill)? (Expert committee member No.5)*

These problems might be solved by providing more information on the potential usefulness of the SPICT-JP in the Japanese primary care setting. On the other hand, there is little evidence for its 'effectiveness'. Furthermore, the best way to use the SPICT-JP in Japanese healthcare settings remains unknown, which this research aims to address. Therefore, it was impossible to provide detailed information about the effectiveness or ultimate goals of using the SPICT-JP in Japanese contexts. Additionally, it could be claimed that it was not the tool but the users (Japanese clinicians) who should define how the tool would be used.

Given all these considerations, it was decided to develop a concise user-guide for the SPICT-JP as described in Section 4.3. The user-guide was not to ensure the adaptation of the SPICT-JP within Japanese healthcare, but rather it describes how the SPICT-JP may be used and what should be done after the identification of patients needing supportive and palliative care.

4.4.3 The translation procedure

As discussed in the previous section, there are many guidelines available for translation and cross-cultural adaptation of health-related questionnaires. While the SPICT is not exactly considered to be a questionnaire, I decided to follow one of such guidelines. This section examines and discusses possible problems relating to applying methods from different kinds of questionnaires.

Value of back translation and expert committee review

With some amendments, I adopted the well-established and well-cited guidelines for translation and cross-cultural adaptation of health-related instruments for this research. Overall, forward and back translation were not significantly informative. Some issues were identified in the process, but it seemed that in many cases we would have to wait until Stage IV to obtain views from the expert committee. In fact, comments from the panel were significantly informative and valuable compared to Stages I to III.

Just before commencing the translation (after all the planning was completed), a review of guidelines for cross-cultural adaptation of questionnaires was published (Epstein, Santo and Guillemin, 2015). The authors argued that there was no agreement in published guidelines or evidence to support the recommendations in such guidelines. Importantly, while they discussed the role of an expert committee as crucial, they questioned the value of a back-translation. The authors of the review published a study to examine the value of a back translation and of having an expert committee. The study showed that an expert committee contributed substantially towards a better translation and cross-cultural adaptation, but not back translation (Epstein *et al.*, 2015). Their findings and several other papers suggested that back translation might have a limited role compared to an expert committee review and pilot testing.

To maximise the role of an expert committee review, it was recommended to have multidisciplinary input. However, I only recruited expert committee members from doctors who were working in related fields as the target group in mind. However, having other professionals other than doctors or doctors with other specialities or professionals could have produced further and different insights and perspectives. This could be considered as a limitation for this translation. Further consultation with different professionals should be considered for further improvement of the SPICT-JP in the future.

4.5 Conclusions

Translation and cross-cultural adaptation of the original SPICT was conducted using the Guideline – with some amendments. While some contentious and difficult expressions were identified and resolved, the expert committee review provided valuable insights over and above the improvement of the translation itself. Finally, the Japanese version of the SPICT (SPICT-JP) and its user-guide for use by family physicians were produced.

Some of the comments from the expert committee members were related to the current situations and problems of palliative care in Japan rather than the tool itself. Their comments suggested that palliative care was seen as a measure of care for people who are imminently dying with some severe symptoms or life-threatening diseases. It was difficult for the members to imagine providing palliative care actively to those who were medically stable. People with long-term illnesses were considered as candidates for advance care planning rather than for palliative care. While some members suggested that family physicians were better than other doctors at starting end-of-life conversations with patients, other members considered these conversations as difficult for all doctors in general. They also remarked that some patients often felt abandoned by specialists who suggested palliative care. One member commented that there was a possibility that in Japan, many patients were not informed of their diagnosis or prognosis, which was unusual in Western countries. This may be due to the cultural differences between the UK and Japan regarding autonomy in decision making which was discussed in Section 2.4.2 in Chapter 2 and will be revisited in the final chapter.

These comments provided some insights in refining and answering the questions of this research. Besides, the comments highlighted possible challenges in implementing the SPICT-JP into Japanese primary care contexts, which were to be discussed in the later phase of the research.

Chapter 5 Research design for qualitative interviews

This chapter outlines the research design for Phase II of this PhD research: a qualitative investigation through interviews with family physicians in Japan. The chapter begins with an introduction to the theoretical perspectives used in this research, which provide the foundation for my research. Based on this foundation, the actual three stages taken in conducting the research will be discussed: the recruitment of participants; data generation; and data analysis. Finally, a discussion on reflexivity and ethical considerations is presented. In reporting the research design and findings, I referred to the Consolidated criteria for reporting qualitative research (COREQ) checklist (Tong, Sainsbury and Craig, 2007), which is included in Appendix 9.

5.1 Theoretical perspectives

The method of scientific investigation should be underpinned by researchers' assumptions about society (Bowling, 2009). In this section, I introduce epistemological and ontological discussions relating to healthcare research within which this research fits. I then discuss my personal worldview formed by my experiences. Finally, I consider the methodological stance which I took in this research in relation to these philosophical perspectives.

5.1.1 Positivism and interpretivism

It is impossible to avoid mentioning 'positivism' when discussing theoretical positions underpinning this research. Although, as Bryman (2012) pointed out, there seemed to be some confusion in the definitions of positivism, here I use the most widely used definition of 'positivism': the epistemological position which advocates investigations in natural sciences (Snape and Spencer, 2003; Bowling, 2009). In this definition of 'positivism', only observable phenomena are counted as knowledge (Snape and Spencer, 2003), and the world which positivism addresses is different from the everyday world we experience (Crotty, 1998). According to Crotty (1998), 'science imposes a very tight grid on the world it (positivism) observes' (p.28). Since medicine has long been considered as being part of natural sciences, the majority of research in medicine has taken positivist approaches.

A movement of evidence-based medicine which started in the early 1990s has also influenced a dominant positivist culture in healthcare research. The original intention of evidence-based medicine did not oppose using individual clinical expertise and intuition (Sackett *et al.*, 1996). Nevertheless, evidence-based medicine has often been linked to an image of medical practice rigorously following 'evidence' generated from a positivist stance and normally produced by quantitative research without paying much attention to the contexts of individual patients (Yokota, Kojima and Yamauchi, 2005). While the evidence-based medicine has contributed to reduced mortality in some conditions, Greenhalgh *et al.* (2014) argued that the maladaptation of evidence-based medicine marginalising patients' personal contexts often resulted in management driven rather than patient-centred care. This is a particular problem in primary care and palliative care which place patients' contexts as a central value. In fact, in the real world, our lived experiences are not the mere result of objective facts but are formed by interweaving objective facts and different values, interpretations and emotions generated by humans. Objective data could only explain some small part of our experience.

Interpretivism is the term for an epistemological stance which is opposed to positivism (Bryman, 2012). This term emerged from a need for different logics for investigations in social sciences to understand social actions and to provide causal explanations for them (Bryman, 2012; Chowdhury, 2014). It is argued that 'truth and knowledge are subjective, as well as culturally and historically situated, based on people's experiences and their understanding of them' (Ryan, 2018, p.17). This epistemological stance has some links to the ontological position called constructivism, in which 'meanings are constructed by human beings as they engage with the world they are interpreting' (Crotty, 1998, p.43).

In my view, both interpretivism and constructivism have an affinity with primary care and palliative care. In family medicine, ‘interpretation’ is considered to be an important part of its expert practice. Reeve, a researcher in primary care, coined the term ‘interpretive medicine’ to assert how the interpretation of background information such as patients’ values and contexts was critical in providing high-quality family medicine (Reeve, 2010). The practice of considering people’s interpretation for clinical judgement and care is also pertinent to palliative care. Similarly, palliative care deals with complex problems with much emphasis on patients’ values and preferences.

In a dominant positivist culture of healthcare research and practice, in order to secure the ‘real’ evidence-based medicine, it would be useful to include qualitative research, which takes interpretivism and constructivism based approaches acknowledging patients’ contexts such as their values, backgrounds and clinical settings (Greenhalgh *et al.*, 2014). An increasing number of qualitative and mixed-method research studies in primary care also suggests that such research is attracting considerable attention in the primary care field (Kaneko *et al.*, 2018).

My worldview

My professional experience of practising medicine for more than ten years in Japan has strongly influenced my worldview along with my personal experiences. While having been immersed in a very positivist culture since I entered medical school, I have witnessed many situations in my clinical practice which could not be explained by a positivist stance. For example, people’s decisions, particularly at the end of life, often depended on their emotions or situational contexts rather than on objective facts. Also, we, as healthcare professionals, work in ever-changing environments in which truth is not continuously maintained. It was soon after entering the medical world that I started to sense an inadequacy of ‘evidence’ when providing the best possible support for patients. After numerous instances of simply employing the ‘evidence’ produced by randomised controlled trials in consultation with patients, I have gradually learned that there must be something equally or even more valid and important in addition to that ‘evidence’ in medical practice. My appreciation of an interpretivist way of constructing a worldview lay beyond the realm of conventional medical practice. I came to value nuances in everyday conversations and embodiments (tone of voice, posture and gaze) and to believe that numerical data could never fully explain everything.

I now acknowledge that, as a family physician, I have a dual responsibility to understand and share accurate and valid medical knowledge supported by the natural sciences and also to listen to and value patients’ voices which may create meaningful narratives. I believe that engaging with and acknowledging these two rather different sets of facts can enable us to provide the best possible patient care.

I also believe that bringing an interpretivist approach into research has particular importance in Japanese primary care. Although qualitative and mixed-method research has been drawing attention for their potential to inform clinical practice, the number of such research studies is still limited in Japan (Kaneko *et al.*, 2018). Given that there has been much evidence already created by positivist approaches, as a researcher, I decided to take an interpretivist approach to enhance the benefits for patients. In addition, by acquiring qualitative research skills, I would be able to support the development of such research in primary care in Japan.

5.1.2 Theoretical approach of this research

The research questions inevitably presupposed my personal worldview outlined above. The identification of patients occurs in contexts containing constantly changing features which include services available, clinical and societal settings (cultural, religious and societal backgrounds) and the physical and emotional states of patients. I assumed that there would be no universal truth or ‘absolute standards’ for identifying patients for palliative care. I was interested in how these features could influence clinicians’ attitudes towards identification of patients for palliative care, rather than their making value-free decisions based on objective medical information.

Therefore, I planned to explore how family physicians viewed palliative care before exploring their approaches when identifying patients for palliative care. In addition, this research was exploratory, reflecting the limited evidence available in this field. Furthermore, it was the first time that the SPICT-JP had been introduced in Japan. These elements required the research questions to be addressed in a different way from a positivist approach. I concluded that an interpretivist and constructivist approach would be the best methodology to achieve this.

Methodological stance

This research aimed to provide an account of Japanese family physicians' approach to identifying patients for palliative care from the family physicians' perspective. Given this aim and the theoretical perspectives explored, a qualitative research study based on interviews seemed to be the best approach. Furthermore, the aim of this research was not to develop a theory of a process (grounded theory), a thick description of events or phenomena (ethnography), or an interpretive understanding of experience (phenomenology). Rather, it aimed to provide descriptions of events or experiences from an interpretive perspective. After appraising several methods of qualitative research, a thematic analysis of the qualitative interviews was chosen for this research. Thematic analysis has been widely used in health research including the palliative care field and has been shown to be flexible when handling complex data (Pope and Mays, 2006).

5.2 Participant profile and recruitment

5.2.1 Selection of participants

Why select JPCA-certified family physicians as potential participants?

In order to answer my research questions, I decided to recruit Japan Primary Care Association (JPCA)-certified family physicians and trainees at the JPCA-accredited family medicine training programmes as participants in this research. Given the nature of the formal training programme they had completed, these physicians should have been sensitive to the multi-faceted characteristics of palliative care and able to offer valuable insights on the SPICT-JP. In addition, unlike those doctors traditionally providing primary care without having had the formal training in primary care, those who had completed this programme tended to have deeper insights into primary care and palliative care in the community. Considering that this research was the first of its kind in the context of Japan, it seemed pertinent to recruit such pioneers in primary care for this research. A further reason for selecting this cohort of doctors as research participants was that it would enable a comparison of the results from this research with those from other countries. The training programme they completed to be JPCA-certified was essentially equivalent to family medicine training in other countries.

Sampling method

This research was the first opportunity for the SPICT-JP to be tested in clinical settings in Japan. Research participants should be prepared to use this new tool in their practices and to provide their candid views regarding any improvements necessary. The participants should have had a deeper understanding of and insights into palliative care in primary care because this would potentially enrich the data. It was also preferable that the participants represented a mixture of urban and rural settings.

Random sampling from a list of JPCA-certified family physicians, or sending invitations to all of them, was considered initially, but these sampling methods were rejected. The reason for this was that these sampling methods were considered to be too challenging to secure the right quality, characteristics and numbers of potential participants. In the expectation of obtaining deeper insights, I decided to take a purposive sampling approach in the selection of potential participants from the JPCA-certified family physicians. Furthermore, I considered that it was important for this research to establish face-to-face relationships and to obtain some background information when recruiting, which precluded a random sampling method.

Sample size

For qualitative research, it is difficult to decide a sample size in advance (Mason, 2002c). My initial target sample size was set at 20 JPCA-certified family physicians. This decision was based on: 1) my previous experience of interviewing primary care physicians and family medicine trainees in Japan; 2) a recommendation that the individual interviews in a single study should usually be under 50 (Ritchie, Lewis and Elam, 2003) and a report that 12 interviews were enough to reach data saturation (Guest, Bunce and Johnson, 2006); 3) similar palliative care research using interviews with family doctors which found that this number seemed to yield data saturation (Boyd *et al.*, 2010); and 4) the available time-frame and budget for this research. The final decision was reached in discussions with my supervisors.

5.2.2 Recruitment sites

I purposively chose four organisations running JPCA-accredited family medicine training programmes in four different regions across Japan in order to recruit research participants. From a practical standpoint, the four recruitment sites were within reach of Yokohama where I was based during the recruitment period. I ensured that the recruitment sites had an urban and rural mixture. I selected four recruitment sites which had a relatively long history of family medicine or community-oriented healthcare, or were research-active. The reason for this was that doctors working within such settings might have a deeper understanding about the roles of primary care in palliative care. Therefore, it was expected that they could provide invaluable insights to this research. I ensured that I had some understanding of the backgrounds of each recruitment site so that I could more fully understand the participants' accounts. My personal network which I established before embarking on my PhD study helped me to identify these recruitment sites and a key person at each site.

1. Family Medicine Centre X

The first recruitment site was Family Medicine Centre X, located in an urban area. This organisation promotes family medicine through education, research, and the development of clinics. It had ten training clinics and several other member clinics. It has a practice-based research network to enhance collaboration between the community clinics for research. An organiser of the trainee meetings agreed to my recruiting potential research participants at the meetings.

2. Family Clinic Y

The Family Clinic Y runs one of the oldest family medicine programmes in Japan. It was established as a branch clinic of a large-scale medical centre which consisted of several medical institutions and provided primary to tertiary care in the region. The Family Clinic Y offered primary care to patients in outpatient and home settings. It had five JPCA-certified family physicians besides several family medicine trainees. A medical director of the Family Clinic Y agreed to support the recruitment.

3. Hospital Z

The Hospital Z is a community hospital in a mountainous district established to improve access to healthcare for local people after the Second World War. In the absence of sufficient healthcare facilities, the hospital had been functioning as a health centre for local residents by providing both primary and secondary care. It always had focused on preventive medicine and had also always been accessible to the local people before the concept of ‘family medicine’ arrived in Japan. Although the Hospital Z had provided primary care since its establishment, their family medicine programme was relatively new. A programme director at that time agreed to my recruiting for this research.

4. University W

University W has a department of community medicine and education with four training clinics and seven JPCA-certified family physicians. It is one of the few Japanese medical school departments which focus on primary care and its education. All four training clinics provided out-patient and medical homecare and were located in rural areas. An associate professor at

University W agreed to recruit participants from University W and helped my recruitment process for this research.

5.2.3 Recruitment process

After being granted ethics approval by both the University of Edinburgh and the JPCA Ethics Committees, I contacted a key person at each of the four recruitment sites. An invitation package, *i.e.* an invitation letter and an information sheet (Appendix 4), was sent to potential research participants prior to my planned visit to each site when possible. In addition, I planned to give a presentation at one of their regular meetings. It was deemed important for potential research participants to meet with me as the researcher before deciding to participate in this research which would require them to communicate regularly with the researcher. I visited these recruitment sites in August and September 2016. After I explained the research and a Q&A session, eight doctors from Family Medicine Centre X, seven from Family Clinic Y, four from Hospital Z, and one from University W agreed to participate in the research.

This recruitment process strategy enabled me to communicate with potential research participants through either in-person or email contact. Through this process, I found that the participants had different motivations for engaging with this research which will be explored in Chapter 9.

5.3 Data generation

The overview of the data generation process is presented in Figure 5.1. Firstly, I had one-to-one first interviews with the participants before they used the SPICT-JP. Then I asked them to use the SPICT-JP in their practice for several months. Before they used the SPICT-JP, I offered some education to provide an understanding of the SPICT-JP and the research. While they were using the SPICT-JP in their practice, I made a series of quick contacts with the participants to encourage their continuous involvement. After this period of using the SPICT-JP in their practice, I conducted second interviews with the participants. The details of each stage will be described in Sections 5.3.2; 5.3.3; and 5.3.4.

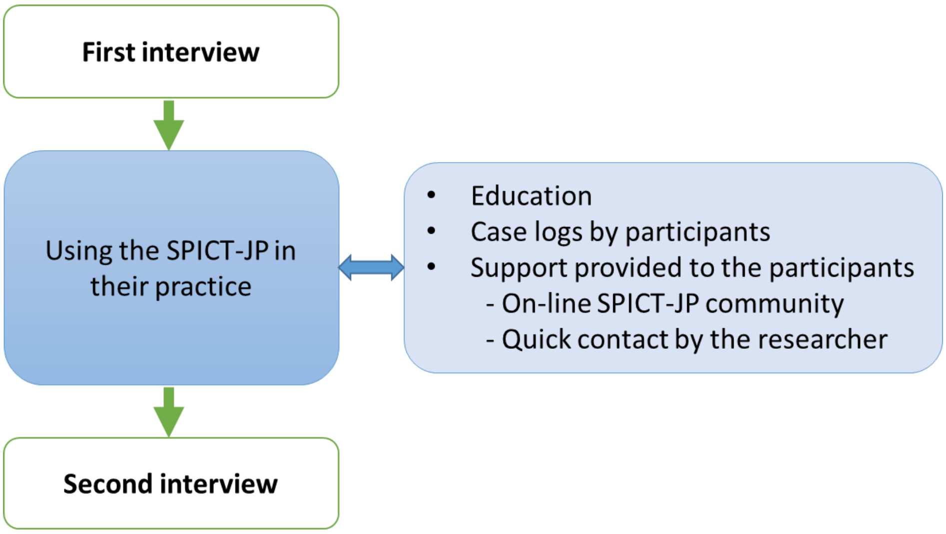


Figure 5.1 Overview of the data generation process

5.3.1 Planning for the interviews

Choosing qualitative interviews as a data generation method

I chose qualitative interviewing as a data generation method for this research. This decision was made because I considered that each participant's knowledge, interpretations and experiences would be valuable in understanding the issues reflected in my research questions and qualitative interviews would be the best method to capture them. Furthermore, the decision was based on my epistemological assumption that the optimal data would be generated by talking with people interactively (Mason, 2002b). In particular, the research aimed to investigate the participants' understanding and perceptions of palliative care in their practice, a topic which could be best explored through interactive questioning. Furthermore, I presumed that 'practitioners' might find it difficult to verbalise their understanding of palliative care. I assumed that discussing what the participants were actually doing would help explore how they understood palliative care. In fact, Kayama (2007) suggested that the best way to understand practitioners' practice in the real world would be to ask them directly what they have done in specific cases.

I offered the participants the choice between a face-to-face interview or a Voice-over-Internet Protocol (VoIP, such as Skype) interview. VoIP or telephone interviews are increasingly used in healthcare research with remote participants, as these are less demanding of their time (Hanna, 2012; Sullivan, 2012; Brecher, 2013; Oates, 2015). A rich qualitative dataset can be collected in this way, especially when the interviewer understands the nature of the interviews well, as was the case in this research.

Preparing for the interviews

Mason (2002b) argued that all qualitative interviews would or should be more or less ‘semi-structured’ by nature. Semi-structured interviews allow a researcher to use the limited time available best while focusing on issues needing to be explored (Savin-baden and Major, 2013).

I had previously conducted a mini project to investigate Japanese family physicians’ understanding of palliative care for non-cancer patients (Oishi, 2011). I also contributed to the analysis of transcribed interview data from two studies from 2012 to 2014. Before and while working on these projects, I had attended several courses on qualitative research. These experiences, in addition to qualitative research training at the University of Edinburgh, helped me to construct a research design and devise an interview schedule for this research.

A schedule for the first interviews was drafted based on my research questions and referring to previous research (Claessen *et al.*, 2013; Beernaert *et al.*, 2014). The first interviews focused on the participants’ understanding of palliative care and their views on the identification of patients for palliative care. I also prepared several other supplementary questions regarding the content of palliative care.

I was aware that subtle differences in wording and phrases could influence how the participants interpreted and eventually answered my questions. After careful consideration, I decided not to use the phrase ‘primary palliative care’ or ‘palliative care approach’ in the interview, but instead to use ‘palliative care’. It seemed reasonable to use the more common phrase ‘palliative care’ in order to gain more insights by looking at how participants might interpret the phrase, and whether there were any ‘primary palliative care’ or ‘palliative care approach’ concepts in their understanding of the phrase ‘palliative care’.

The draft of the interview schedule was tested in two pilot interviews in December 2015 and January 2016, and was amended to improve the order of questions and wording after each pilot interview. These pilot interviews were also for my practice to ensure that I could properly conduct them. These interviews were audio-recorded and reviewed to improve my interview skills, which I found helpful. Compared to the first interviews which were somewhat exploratory, the second set of interviews was more focused on systematically addressing the utility of the SPICT-JP. The interview schedule for the second interviews was prepared and tested in November 2016. The structure of the interviews was designed to remain as flexible as possible so that I could change the order of questions in response to participants’ reactions. The data generated was also used iteratively to refine the focus of the subsequent interviews of each set. The interview schedule is shown in Appendix 7 in English, which was translated into Japanese and used in Japanese.

5.3.2 The first interviews

I sent each participant by email a package of materials to be used in the interviews: the SPICT-JP; its user-guide; and case log sheets. The printed copies were posted to them on their request. I also provided them with a 2,000 Japanese yen Amazon electronic gift card (equivalent to £10 in July 2015) as is normal practice. The first interviews were conducted between September and December 2016. Only two participants chose in-person interviews while the rest preferred Skype. The interviews with these two participants were conducted at their workplace. All Skype interviews were conducted with video while only audio was recorded. All the interviews (in-person and Skype) were conducted only between a participant and me. At the beginning of the first interviews, I collected information for the participants' profile including their experiences in family medicine and palliative care, and their clinical settings. I also had a brief talk with each participant to become better acquainted with each of them, which functioned as an ice breaker.

The first interviews lasted for between 40 and 70 minutes. In addition to audio-recording of the interviews, I made field notes during and after the interviews to record what I found significant.

The key questions in the first interviews were:

- How do the participants understand palliative care?
- How do the participants identify patients for palliative care?

5.3.3 Research activities between the two interviews

Education

I provided the participants with a brief one-to-one lecture about the SPICT-JP based on its user-guide (developed in Phase I of this research, as detailed in Section 4.3), in addition to an explanation of the subsequent research stages. The user-guide suggested situations in which using the SPICT-JP would possibly prove helpful. However, although I reviewed the situations in the user-guide with the participants, I intentionally left them to choose which situations and with which patients they would use the SPICT-JP. This decision was made with the intention of observing the most natural manner for the participants to use the SPICT-JP in their clinical practice. I expected that through the observation of how they would use the SPICT-JP, we could infer the possible usefulness of the tool and the effective environments in which the SPICT-JP could best improve clinical practice.

Using the SPICT-JP in practice

It was planned that the participants would use the SPICT-JP for at least three months between the first and second interviews. The length of time was decided by taking into account the frequency of the doctors' home visits in Japanese primary care settings. I assumed that many of the participants would be using the SPICT-JP with those homecare patients who tended to be frailer, compared to outpatients. It has been reported that on average registered medical homecare patients received fortnightly visits (Yokobayashi *et al.*, 2014). This suggested that during the three-month period, on average, the participants would see one patient six times. From my own clinical experience, four homecare visits were generally sufficient to gather enough information about the patient to assess their need for palliative care. Outpatients were usually seen less frequently so that the number of visits to acquire this information would take more than three months. However, too long an intervention period (*i.e.* over three months) could discourage the participants from continuing the research. Therefore, three months seemed to be optimal in terms of both appropriateness and feasibility. In reality, however, it proved difficult for most participants to use the SPICT-JP with six patients within three months (the reason for which will be presented in Chapter 8). The actual intervals between the first and the second interviews ranged from four to eight months.

Case logs

As mentioned in the previous section, it was for the participants to decide when and with which patients they would use the SPICT-JP. During the period they were using the SPICT-JP in their practice, the participants were asked to keep case logs (Appendix 6) with at least six patients with whom they used the SPICT-JP. The participants' reflection on their use of the SPICT-JP was recorded on the case log sheets. I suggested that the participants record informative or impressive cases which generated their thoughts and reflections, but the decision on which patients they chose was left to the participants.

Case logs were intended to preserve the participants' memory so that a better quality of information could be secured during the interviews. The case log sheets were used to facilitate discussions and to enhance the quality of data. The case log did not include any identifiable information about patients and was not treated as data for analysis.

On-line SPICT-JP community

The on-line SPICT-JP community was added to the already existing SPICT website, and it was password-protected and could be visited by the participants and researchers only. It was created as a space where all the research participants and the researcher, myself, could share any queries or views on the research or on the SPICT-JP. It was also possible to download research materials from the online community. While many Japanese colleagues use mailing lists for communication between researchers and participating physicians (or research collaborators), it was an experiment to see if this add-on community created within the SPICT main website would work for the same purpose.

Throughout the research, no comments were posted on the on-line SPICT-JP community. One possible reason for non-usage was that the participants were too busy. It might have been easier for them if this on-line community had been linked to any social networking platforms which they normally used. I used personal emails or Facebook messages, sometimes followed by Skype chats, to communicate with the research participants. This form of communication worked effectively to encourage their participation and retention in this research.

Quick contacts

During the period when the participants were testing the SPICT-JP, I contacted them about every three to six weeks depending on their preference. My initial plan was to contact them fortnightly, however, it was not only unfeasible but also seemed to put unnecessary pressure on the participants. The contacts were made through the participants' preference, *i.e.* email, Skype or messaging via social network services. Most participants chose emails. I sent them a list of questions asking them to return their answers. The questions were designed to encourage their engagement and reflection (Table 5.1). I also ensured that all the participants were able to contact me personally by email, Skype, phone or any method they preferred when necessary.

Table 5.1 Quick contact questions

How are you getting on?
With how many patients have you used the SPICT-JP this week?
How did you use it?
What are the results?
What were the difficulties and facilitators?
Any differences from the last time?
Any thoughts?

Towards the end of the research period, I had Skype conversations with some participants who were experiencing difficulty in starting to use the SPICT-JP, which was not planned beforehand. It seemed that even though these participants wanted to use the SPICT-JP, they failed to do so because they were too busy or had other work pressures. We briefly discussed what would be helpful for them to start using the SPICT-JP.

5.3.4 The second interviews

After each participant had used the SPICT-JP with at least six patients, I had the second, one-to-one semi-structured interviews with participants except for one who missed the second interview due to sick leave. These second interviews took place between February and June 2017. The interviews ranged from 30 to 70 minutes. The first part of the interview was focused on their experience of the use of the SPICT-JP. The second part covered their views on the identification of patients for palliative care, together with relating factors such as cultural or organisational influences and personal or professional experiences. Before each interview began, I reminded them that they should not mention any identifiable patient information.

The key questions in the second interviews were:

- How did the participants use the SPICT-JP in their practice?
- How did they feel about using the SPICT-JP and why?
- What insights do they have for the further development of the SPICT-JP?

5.4 Data analysis

5.4.1 Data management

All audio-recordings were transcribed by a professional transcriber. All files of audio-recordings and transcribed interviews were kept in a password-protected computer. Field notes made by the researcher during the interviews and about the quick contacts were used to support the analysis process and to enhance the understanding of the qualitative accounts generated in the interviews.

5.4.2 Using NVivo

Coding and analysis of qualitative data can be a complex, time-consuming process. Computer-Assisted Qualitative Data Analysis Software (CAQDAS) is used increasingly (Mason, 2002a; Silverman, 2013). I decided to use the NVivo software (version 11 and subsequently version 12) for my data management and analysis hoping for the efficient organisation of the data and analysis. In addition, because NVivo was one of the most-used CAQDAS in health research, it was anticipated that the process of analysis could be more easily shared with other researchers when necessary. Another reason for choosing NVivo for this research was that I wished to gain expertise and knowledge in its use. Although qualitative research has attracted more attention in health research than before, not many researchers in Japan have used CAQDAS. One of my intentions as a primary care researcher from Japan was to gain skills which could be shared with other novice researchers in Japan.

5.4.3 Thematic analysis

Braun and Clarke (2006) divided the process of thematic analysis into six phases as illustrated in Table 5.2. Here, I present the process of my analysis following these phases. However, undertaking the analysis proved to be iterative, complex and not straightforward.

Table 5.2 Phases of thematic analysis (Braun and Clarke, 2006)

Phase 1.	Familiarising yourself with your data
Phase 2.	Generating initial codes
Phase 3.	Searching for themes
Phase 4.	Reviewing themes
Phase 5.	Defining and naming themes
Phase 6.	Producing the report

It was particularly challenging when dealing with two sets of interviews: the first interviews conducted before participants used the SPICT-JP in their practice; and the second interviews containing their views on the utilisation of the SPICT-JP. The first interviews were intended to function as a baseline, and I hoped to compare participants' perspectives between the first and the second interviews. In reality, although each set of interviews had a different predetermined focus, the participants' comments moved between topics in the first and second interview schedules. This was because the predetermined focus of the first and second interviews were interrelated and could not be easily separated. Bearing this in mind, I decided to analyse the two sets of the interviews altogether, paying equal attention to all the interviews in order to answer my research questions.

Another challenge was the issue of analysing data collected in Japanese with the results being reported in English. Given that I am a native Japanese speaker, the challenge for me was more in the reporting of the results in English. This challenge will be revisited later in Chapter 9.

Phase 1: Familiarising myself with the data

Firstly, I double-checked the interview transcripts while listening to the original audio recordings. In addition to familiarising myself with the data, I did this to ensure that I did not miss any nuances which could affect the interpretation of the data and to correct any errors in the transcriptions. While checking the transcripts, I underlined anything I found important and took notes. These notes were either in English or in Japanese. Each time I checked an interview, I took time to reflect and made an analytical memo. I compared the memo with the field note that I had taken during the interview to ensure that I did not miss any significant findings. All the checked transcripts were then entered into the NVivo software along with the memos. I also created two MS Word files to summarise the first and second sets of interviews respectively and to identify overarching themes. Making analytical memos and summaries allowed me to have some ideas on the emerging themes before I started coding using NVivo.

According to Braun and Clarke (2006), familiarisation with the data should be treated as a separate and proceeding phase to other steps of the analysis, which highlighted the importance of ensuring that this familiarisation was completed before starting actual coding or any kind of processing of the data. In fact, this familiarisation helped me considerably in developing a better idea of what the set of data conveyed as a whole. Familiarising myself with the data was also a continuous process along with all the other phases. I often revisited this ‘Phase 1’ during the analysis process.

Phase 2: Generating the initial codes

Bearing in mind my philosophical standpoint and the ultimate purposes of analysing the data, I tried several ways to code the transcripts. It took me some time to identify an effective, comprehensive and feasible way to code the data. Firstly, I coded for as many potential meanings as possible. Reading the transcripts, listening to the audio recordings and referring to the analytical memos repeatedly helped me make sense of the data. At this stage, I could see some links between the codes and narratives I had constructed in order to explain those links, and these were kept in the notes.

Some codes were created inductively, while others were deductive. Where the questions were prepared, such as ‘Was the guide useful?’, ‘What would be your first action to initiate palliative care?’ and ‘What is your definition of palliative care?’, the interview segments were coded for structure (Saldaña, 2015). I also coded these segments for their meaning. I had some ideas in my mind for these prepared questions, and so the codes tended to be deductive and theory-driven. In contrast, where questions were asked in response to participants’ specific accounts, the codes tended to be inductive and data-driven. This mixed nature of the initial codes challenged the organisation of them, but the NVivo software was useful in organising these codes. Some initial codes were in English while others were in Japanese. I chose the language which could express the concepts of the codes better. I intentionally decided not to try to use one language only in the early phases of coding. I felt that restricting the use of language interrupted the natural interpretation of the interviews.

By December 2017, I had 186 codes for the first set of interviews. I proceeded to code the second set of interviews after reviewing the initial codes for the first interviews. This decision was made with the intention of identifying the underlining themes as early as possible, and due to the time gap between the two sets of interviews. This strategy worked well at the beginning but impeded the analysis process later because I discovered that many themes emerging from the second interviews were the same as those from the first. This led me to the decision to integrate the two sets of interviews. By February 2019, I had 324 codes in total.

Phase 3: Searching for themes

Phase 3 was to find connections between the created codes, which would lead to the identification of the themes. This phase of the analysis was particularly challenging. The challenges mainly stemmed from the dilemma I faced in deciding how to treat the first and second sets of interviews. I tried several ways of categorising the codes before reaching the final set of categories to ensure that each category was represented in at least one theme. A part of this process was undertaken along with writing passages for each of the themes. Writing helped me to clarify each theme and highlight some conflicts between the codes and categories.

At this phase, I tried to use English as much as possible for the theme titles. The initial categories of the codes are shown in Table 5.3. Finally, the codes were organised in such a way as to answer the research questions. The themes in each category were examined for their content and inter-theme relationships.

Table 5.3 Initial categories of codes

Understanding of palliative care
Content of palliative care
Triggers and indications for palliative care
Ways to identify patients for palliative care
Factors influencing the identification of patients for palliative care
Communication
Family medicine and palliative care
Cancer vs non-cancer
SPICT-JP
Additional comments

Phase 4: Reviewing themes

Phase 4 was for reviewing themes (final set of categories) to identify and resolve any conflicts between themes. Clear and solid definitions of themes would be achieved by examining the themes, their contained codes and any relationships between the themes as well as between the themes and the whole data set. Braun and Clarke (2006) argued that ‘Data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes' (p.91). However, it was sometimes challenging to find 'clear distinctions between themes' because all the identified themes were inter-related to some extent. At this phase, I also examined any particularly striking or memorable accounts from the participants.

Phase 5: Defining and naming themes

This phase was actually undertaken along with the next phase: producing the report. At first, I tried to write the definition of each theme on the NVivo software, but it seemed more effective to do this in the form of writing a report. In doing so, I was able to visualise any relationships with other themes. I defined and named the themes while writing the corresponding sections of this thesis.

This decision resulted in several advantages and drawbacks. The greatest advantage was that I was probably able to save some time and to see the relationships between the themes and other parts of the thesis more clearly. This decision also allowed me to create some distance from the raw data, which was in Japanese, and so I was able to think analytically in English. The drawback was that I had to repeatedly rewrite the corresponding sections every time I found better definitions. However, these countless re-writings helped to refine the analysis.

Phase 6: Producing the report

As I mentioned in the previous section, I produced the report along with analysing the data. I selected compelling quotes from the data which vividly illustrated the themes in the report. Writing the report led to a deeper understanding of the data, and sometimes drew my attention to relationships between apparently irrelevant themes. When this occurred, I returned to the earlier phases (sometimes even to Phase 1) and confirmed that the themes represented the participants' accounts accurately, and I re-organised the themes when they did not.

Participant feedback

The COREQ guideline recommends the participant checking and feedback as it ‘adds validity to the researcher’s interpretations by ensuring that the participants’ own meanings and perspectives are represented and not curtailed by the researchers’ own agenda and knowledge’ (Tong, Sainsbury and Craig, 2007, p. 356). Unfortunately, it was impossible to formally obtain feedback from the participants on the research findings during this PhD study period due to the limited timeframe. However, the constant communication with the participants during the data generation (and some analysis) period made the chance of their perspectives being curtailed slim. In addition, I often reflected the content of the first interview during the second interviews and confirmed that my interpretations were correct with the participants. I also presented the findings from the interviews at conferences where the participants attended for their feedback (Appendix 10).

5.4.4 Data saturation

According to Fusch and Ness (2015), ‘data saturation is reached when there is enough information to replicate the study when the ability to obtain additional new information has been attained, and when further coding is no longer feasible’ (p.1408). Francis *et al.* (2010) suggested the principle of 10+3 for data saturation which means ‘purposive diversity sampling for a minimum of 10 interviews, [and] three further consecutive interviews with no new themes and presentation of data sequentially’ (p.1241).

It was difficult to decide when the data generated in this research was saturated as the process of analysis itself was iterative. However, by the time I had conducted around five interviews, I had already found some repetitiveness among the emerging themes, which suggested that data saturation was occurring. Furthermore, after coding about the first ten sets of the first and second interview transcripts, no more new categories of codes (*i.e.* themes) were created apart from some new codes to represent some subtle differences in nuances. I postulate that this was when saturation had been reached based on the definition and the principle above. The data saturation in this research occurred earlier than expected, which was probably due to the homogeneity of the participants (Guest, Bunce and Johnson, 2006).

5.5 Ethical considerations

Ethics in palliative care research has been discussed repeatedly (Casarett and Karlawish, 2000; Addington-Hall, 2002; Duke and Bennett, 2010; Abernethy *et al.*, 2014; Casarett, 2015), with a particular focus on the sensitivity of the end of life and on how to guarantee the safety of patients who were considered as being ‘vulnerable’ (Koffman, Stone and Murtagh, 2015). Palliative care has often been considered as a sensitive topic, not only in the research field but also in wider society, and that notion has posed some ethical challenges in palliative care research. This could probably stem from biased views on death and dying which have been challenged by recent emerging evidence highlighting the merits and benefits of participating in palliative care research (Aoun *et al.*, 2010; Bloomer *et al.*, 2018).

While acknowledging these discussions regarding ethics in palliative care research, my research did not include patients as research participants. The research involved discussing patients in the interviews, but without any identifiable information to protect their anonymity. Notwithstanding, a researcher should pay careful attention to make sure they undertake ethically appropriate research. In the following sections, I will identify the potential ethical challenges I expected to encounter in this research along with the process of obtaining ethics approvals, and discuss them.

5.5.1 Obtaining ethics approval from two countries

Obtaining ethics approval is an opportunity to improve research design (Silverman, 2013a), and provides valuable learning for novice researchers, such as myself. However, it proved to be a major challenge and significant extra hurdle in undertaking my research study. In particular, being a UK-based student but carrying out my research in Japan meant I had to obtain ethics committee approvals from both Japan and the University of Edinburgh.

It is well-recognised that what is required for ethics approval is different in each country (Silverman, 2013a).

At the start, the ethics application was submitted to the Centre for Population Health Sciences (CPHS) Ethics Committee at the University of Edinburgh in November 2015. After detailed correspondence, they granted final approval in April 2016 (Appendix 3). In the case of Japan, even finding a Japanese ethics committee to consider my application was problematic as I did not have any official affiliations with Japanese institutes. This was solved by protracted negotiations with the JPCA office, assisted by formal and informal support from my colleagues in Japan. I first applied to the JPCA Ethics Committee at the same time that I sought approval from the CPHS Ethics Committee with the intention of accelerating the process. However, after the initial contact with a CPHS Ethics Committee member, I decided to complete the process with the CPHS first. This was discussed with the Chair of the JPCA Ethics Committee, and I re-submitted the application to the JPCA Ethics Committee in May 2016. I was granted the JPCA approval at the beginning of August 2016 (Appendix 3). This decision ensured that the correct and final versions of all the documents were translated into Japanese after obtaining the CPHS approval.

The whole process of obtaining ethics approvals from the two countries took much longer than expected as it required continual negotiations to bridge the gulf between the different research and medical cultures in the UK and Japan. For example, while the CPHS ethics committee required me to prepare an ‘exact’ translation of the documents, that was inappropriate for the JPCA committee which wanted a more concise and shorter protocol. I had to pay very careful attention to translating the study documents without any change in the primary meaning while ensuring that my translation remained culturally valid and comprehensible to both sides.

5.5.2 Informed consent

Securing informed consent, an apparently straightforward ‘procedure’, is in fact a complex process requiring careful consideration and communication with all potential research participants (Mason, 2002b; Lewis, 2003). Potential research participants for this study were informed about the research in an invitation letter sent before I visited them at their practices. I gave them a short presentation about the research at one of their regular meetings and provided them with written information about the research including its purpose, eligibility criteria, what participation would involve and the possible benefits and disadvantages of participation. Furthermore, the information sheet (Appendix 4) emphasised that participation was voluntary and how their confidentiality and anonymity would be protected.

Potential research participants were often willing to sign the informed consent form during my presentation, but I advised them to do that after careful consideration. I wanted them to review the information sheet and the informed consent form (Appendix 5) in more detail so they could make an informed decision about participation in the research. I confirmed their intention to participate in the research in follow-up emails at least 24 hours later. Because there were no opportunities for any one-to-one or group meetings with research participants between the presentation and the data collection (*i.e.* the first interviews with the participants), I ensured that the potential participants could contact me by emails, telephone, Skype, or any other social network services, should they have any further questions. I also re-confirmed their consent to participation at the beginning of the first interviews and explained that they could withdraw from participating at any stage of the research without providing reasons. The signed consent forms were kept in a safe.

I paid close attention to the process of obtaining the research participants’ informed consent and acknowledged the increasing requirement to obtain written consent from all participants (Bryman, 2012). Nevertheless, I appreciate that obtaining and keeping documentation securely was not the main focus or aim of informed consent. In particular, qualitative research is less predictable regarding what may happen during data generation, and so it is impossible to cover all risks and benefits in advance (Mason, 2002b). Therefore, it seemed to be important to be flexible and maintain open and honest communication with participants based on a sound understanding and application of the principles of ethical research conduct, rather than merely following the informed consent process itself.

5.5.3 Confidentiality and anonymity

To protect the confidentiality and the anonymity of the research participants and any patients who were discussed in the interviews, I anonymised all the participants’ names and any identifiable names of individuals or organisations appearing in the interviews. The recruitment sites could be identified from the description given in Section 5.2.2. However, I decided to include this site information because not to do so would have affected interpretation of the results and implications arising from them to make the discussions transparent and reliable.

Another point for consideration was my use of a professional transcriber for the recorded interviews. During the interview, I did not mention the interviewees’ names so that the transcriber could not identify them. I also asked the interviewees not to mention any identifiable information during the interviews. However, there was still the small possibility that the transcriber could identify the participants by recognising their voices. Therefore, I chose a transcriber who had been working closely with a university, and who had an extensive experience and knowledge of ethical research conduct. Furthermore, I ensured that the transcriber followed the confidentiality guidelines detailed in the study protocol covered by the ethics approval.

5.5.4 Potential harm to participants and patients

The research participants were family physicians who took care of terminally ill patients in their professional role. Because the subjects of this research were healthcare professionals, I considered that any risk to patients would be minimal. The only possible exception would be that any patients identified as needing palliative care by the SPICT-JP might then have difficult conversations about their end of life care with their family physicians (*i.e.* research participants). However, the decisions to initiate such conversations were left to the participants, which meant that the research did not oblige the participants to initiate end-of-life care discussions. Furthermore, having a conversation about their end of life care should not be considered as being harmful. It is more important to ensure that such conversations are initiated in an appropriate manner. I provided some information about how to initiate discussions about patients' end-of-life care in the SPICT-JP user-guide to prevent inappropriate communication.

Acknowledging the last stages of life of patients in longer-term relationships with the participating family physicians could be a cause of sadness for the participants. Because of this, the participants might find it difficult to discuss some cases in the interviews. Therefore, I remained alert to these possibilities and paid close attention to their comments and reactions at all stages throughout the research.

5.6 Reflexivity

From the outset of the planning of this research, I was aware of the importance of my being reflexive about my position in this research. I was in the unique position of conducting a PhD research study into primary palliative care at a UK university in the dual role of being a PhD student as well as being a Japanese family physician. It offered me both insider and outsider perspectives, which makes my research rather unique, but at the same time, had implications for the overall design of this research. In addition, I was aware that the research would never be completely free from being influenced by its context and the researchers' values because these were already inherent factors of the research, particularly qualitative one. It is vital to maintain awareness and open attitudes to the research context to make a research rigorous. Here, I present reflections on the motivations for this research and on the relationship with the research participants, which would later influence decisions regarding the process of the research.

5.6.1 My motivation for this research

My personal motivation for this study went back to more than 20 years ago, when my father died from chronic liver disease. At that time, no one knew that he was going to die or that he needed palliative care. This experience left me with the seed which later grew into my becoming a family physician with a special interest in palliative care. As a doctor practising in primary care, I have observed many patients who were not recognised as being at the end of their lives, and so they could not access palliative care. This observation made me contemplate how we could identify patients' palliative care needs better regardless of their diagnosis in a timely manner to provide the best possible care for them and their families.

When I first saw the SPICT some years before embarking on my PhD study, I thought that it was a useful tool from a clinical point of view. I presented the SPICT to Japanese healthcare professionals, including family physicians, through my contribution to several Japanese articles and books. However, as I continued reviewing literature on this tool, I became aware that there was insufficient evidence to prove the tool's validity. Furthermore, I became unsure whether the tool would fit within Japanese clinical settings. Therefore, the primary aim of this research was to explore the best possible way to support family physicians in Japan to identify patients' palliative care needs in a timely manner.

As mentioned earlier, another motivation rose from my awareness of the need to develop research activity in primary care in Japan. By undertaking this research in a UK University, I expected to gain unique and valuable experience and knowledge which I could share with my colleagues to enhance primary care and primary care research in Japan, ultimately leading to better health and wellbeing for Japanese citizens.

5.6.2 My relationship with research participants

My relationship with research participants had many implications, particularly ethical considerations. Reflecting on this relationship and acknowledging any possible consequences were critical in undertaking ethical and rigorous research.

I was one of the 456 Japan Primary Care Association (JPCA)-certified family physicians at the time when I embarked on this research. I was certified in 2009, the year the certification started. This means that potential research participants might regard me as being somewhat ‘senior’ since I had a longer experience as a qualified family physician. In the Japanese cultural context where juniors are expected to respect seniors, there could be a possible deference towards me as a senior by more junior research participants, resulting in hesitance to state their honest views and opinions. In addition to this, the fact that I had published some articles and textbook chapters on palliative care in Japan could present me as a ‘palliative care specialist’, and research participants might think that I had the ‘right’ answers to palliative care issues.

Meanwhile, I have gained a sound understanding of the clinical context of palliative care and primary care in Japan by practising as a clinician for more than ten years, which provided me with an insider’s perspectives. I could be regarded as a ‘colleague’ being on the research participants’ side as opposed to someone from outside of their clinical world or of Japan. This contrasted with the fact that I completed the Masters in Palliative Care in the UK and was a PhD student at a UK university, both of which gave me the status of being an outsider. While these contexts positioned me positively to undertake this research with both insider and outsider perspectives, they could raise some issues in the planning and conduct of the research. For example, as explored earlier, the research participants could feel pressure to participate in the research or uneasiness about revealing their practice of palliative care. To avoid such possible negative dynamics, I took neutral and open attitudes to the research participants as much as possible. The reflection on the impact of the insider and outsider perspectives will be discussed again in Chapter 9.

5.7 Chapter Summary

This chapter has described the methodological considerations that underpinned the research design of Phase II of this research: a qualitative investigation with family physicians. Firstly, I discussed the theoretical perspectives which formed the basis of the conduct for this research. These were followed by details of the actual stages of data generation and analysis. Subsequently, ethical considerations which contained some challenges and how I overcame them were described. Finally, I reflected on my motivations for this research and my relationships with potential participants which had some implications for planning and conducting this research. In the following three chapters, I will present the results of this study.

Chapter 6 Results: An understanding of palliative care

This is the first of three chapters reporting the findings of the qualitative interviews with family physicians in Japan. After a short section describing the characteristics of participants and a prologue to the analysis of results, the findings concerning the participants' understanding of palliative care are presented. The findings are organised to show the participants' understanding of: 1) principles of palliative care; 2) practices of palliative care; and 3) the term 'palliative care'.

Participants' characteristics

The participants' characteristics are shown in Table 6.1. The length of clinical experience of the participating family physicians ranged from 3 to 12 years, reflecting the short history of family medicine in Japan. Almost half of them practised in rural hospitals, with the rest practising in urban areas. Most of them had palliative care training ranging from 2 weeks to 3 months. Seven of the participants practised at a hospital, resulting in their mainly seeing inpatients.

Table 6.1 Summary of the participants' profile and interview dates

ID	Fist interview	Second interview	No. of months between the first and second interview	Year of qualification in family medicine	Years of experience in medicine	Practice setting	Location	Palliative care training	No. of palliative care patients per month
01	15/09/2016	09&16/02/2017	5	2016	7	Clinic	Rural	1-month block rotation	5
02	08/11/2016	3&18/04/2017	5	2014	9	Clinic	Rural	2-week block rotation + 1-month pain clinic	3 to 4
03	05/09/2016	15/03/2017	6	2014	7	Clinic	Rural	2-week block rotation + 1-month	10-15
04	19/10/2016	01/06/2017	8	2017	4	Clinic	Rural	1-month block rotation both in palliative care and homecare	5 to 8
05	16/09/2016	17/03/2017	6	2013	10	Hospital/Clinic	Rural	2.5-month block rotation	5 to 10
06	18/10/2016	12/04&17/05/2017	6	2019	2	Hospital/Clinic	Rural	No formal training	-
07	14/09/2016	13/04/2017	7	2009	12	Clinic	Urban	3-month block rotation	3 to 4
08	21/10/2016	08/02/2017	4	2013	7	Clinic	Urban	No formal training	15
09	11/10/2016	14/02/2017	4	2012	9	Clinic	Urban	3-month block rotation	5 to 6*
10	14/10/2016	01/03/2017	5	2011	11	Clinic	Urban	3-month block rotation & 2 years in a home care clinic	3
11	07/10/2016	08/03/2017	5	2016	15	Clinic	Urban	3-month block rotation & as a consultant in psychosomatic medicine	5 to 10
12	09/10/2016	-	-	2012	11	Clinic	Urban	2-week training at a homecare clinic	4 to 9
13	12/10/2016	03/03/2017	5	2012	10	Clinic	Urban	3-month block rotation	3 to 4
14	08/10/2016	08/03/2017	5	2013	12	Clinic	Urban	3-month block rotation	5
15	12/10/2016	01/02/2017	4	2018	3	Hospital	Rural	No formal training	2 to 3
16	17/11/2016	18/04/2017	5	2014	8	Hospital	Urban	No formal training	4 to 5
17	10/11/2016	28/03/2017	4	2013	8	Hospital*	Rural	Block rotation	5
18	29/10/2016	02/04/2017	6	2019	4	Hospital	Rural	No formal training	1 to 2
19	16/11/2016	16/06/2017	7	2018	3	Hospital	Rural	No formal training	2 to 3
20	05/12/2016	29/03/2017	4	2013	9	Clinic	Rural	3-month block rotation	40

*NB: not seeing inpatients

Prologue to the analysis results

The following sections of this chapter present the results to partly answer the first research question: *How do the Japanese family physicians understand palliative care and identify patients with palliative care needs in their practice? (RQ1)* While acknowledging that discerning participating family physicians' understanding of palliative care was a fundamental part of this research, it was challenging to do so. Most participants were aware that there were many, different kinds of palliative care. During the interviews, some participants asked me to clarify what I meant by ‘palliative care’.

> *Well… let’s say… what, what sort of thing do you mean by palliative care? (ID08, first interview)*

During the interviews and at the beginning of the analysis, it was quite confusing for me if what the participants said was to be taken at face value. It took me some time to finally discover the true meaning behind their expressed understanding of palliative care principles and practice.

It seemed that the participating family physicians used the term ‘palliative care’ in a context-dependent way (this issue will be revisited in Section 6.3). They sometimes defined ‘palliative care’ as specialist palliative care, while at other times they defined it as general palliative care. A turning point in my analysis was discovering that how they used the term did not necessarily reflect how they understood ‘palliative care’.

In the following sections of this chapter, I first present the participants’ understanding of principles and practice of palliative care (Sections 6.1 and 6.2) which were revealed only after disentangling their use of the term ‘palliative care’. Their use of the term ‘palliative care’ is shown in Section 6.3 to support the next two sections and other findings.

6.1 Principles of palliative care

6.1.1 The purpose of palliative care: to reduce patients' suffering

The most common response to the question on their definition of palliative care was 'reducing patients' suffering'. All the participants mentioned at some point in the interviews that the purpose of palliative care was to reduce suffering but not to cure the underlying diseases. Such suffering was not limited to physical symptoms but included spiritual, psychological and social suffering (See also Section 6.2.1).

The purpose of reducing suffering was to improve patients' quality of life. They did not necessarily use the term 'quality of life', but they used the word *seikatsu* (meaning day-to-day living) which reflected their emphasis on practical aspects of everyday life. They included any support to maintain patients' daily life as well as possible as being part of palliative care. Some participants said that the ultimate purpose of palliative care was to make patients 'happy'.

> *While aiming at a zero level of pain or distress, symptoms which cause patients to suffer, we won't be necessarily able to achieve a complete zero, but we should aim at patients being able to live without onerous suffering. I feel we're successful in providing palliative care when I see a grandad who can come to our clinic smiling while he has some symptoms. (ID03, first interview)*

As ID03 reported in the above quote, the participants tried to minimise patients' suffering so that patients could live the life they aspired to. This notion that palliative care was to relieve patients' suffering of any kind was the fundamental basis of all the themes in the results.

6.1.2 Palliative care for all conditions from early stages

The participants understood the principles of palliative care as being 'comprehensive whole person care' which should be started early in the illness trajectory and should be for all diseases. The participants not only expressed a wide range of problems that palliative care could deal with, but also they identified time points in the course of the illness and the kinds of conditions which palliative care should cover. Early palliative care, especially for cancer patients, had attracted much interest in Japan. In the interviews, I specifically asked the participants for their views on this ‘early palliative care’. Most participants could recall a campaign for early palliative care, indicating the seeming effectiveness of such promotions. Some participants said that they were seeing more patients referred from their oncologists while receiving chemotherapy than before. Until recently, such patients tended to stay in hospital care, and family physicians had scant opportunity to see them.

> *We now share lots of patient care with hospital doctors. Unexpectedly, there are hospital doctors who refer patients to us who are in an advanced stage of cancer but still receiving chemo, and will probably be receiving homecare in the future. They foresee such a future. We now have such doctors. (ID09, first interview)*

However, the participants did not necessarily consider ‘early palliative care’ as a new concept because they had thought that they were already providing some sort of ‘early palliative care’ in their everyday practice, which was not limited to cancer patients. Nonetheless, what they had been providing was not known to them as palliative care, and there was little support or guidelines to operationalise the ‘early palliative care’ they were providing. ID13 indicated by the following quote that what they meant by ‘early palliative care’ was already embedded in his practice.

> *What I imagine palliative care to be doesn’t start at an early stage. I understand what they are trying to say. … I think, as a reaction to the development of palliative care, palliative care has become something rather special. And so, we have become less aware of pain management until the patients reach the point of needing palliative care. In reaction to this, I think that they have to promote ‘early palliative care’, but in our day-to-day practice, essentially, we provide normal palliative treatment or pain management, don’t we? (ID13, first interview)*

ID20 added that, for him, early palliative care was part of his practice for all patients he had taken care of.

> *In my opinion, palliative care starts when you're born. So, for me, it [i.e. early palliative care] is taken for granted. (ID20, first interview)*

Regarding the target conditions for palliative care, the participants acknowledged the preponderance of cancer patients for palliative care, while often they clearly mentioned that non-cancer patients should be able to receive palliative care.

> *Firstly, I immediately imagine palliative care for patients with a diagnosis of cancer. Particularly those with a referral letter indicating they were currently receiving best supportive care which is exactly like palliative care. And then, [I imagine palliative care for] patients without cancer but who have chronic illnesses who don't have any effective treatment available or can't eat or have a limited prognosis. (ID05, first interview)*

The contrast between cancer and non-cancer care repeatedly appeared across the interviews suggesting that this made a significant impression on them. At the same time, the participants consistently argued that patients with non-cancer conditions should be considered as being candidates for palliative care in many ways. The impact of patients' diagnoses on the identification of candidates for palliative care will be discussed later in Section 7.1.1 in Chapter 7.

6.1.3 Overlapping philosophy of palliative care with family medicine

To many participants, the principles of palliative care from their perspectives overlapped with those of family medicine. In the following quote, ID19 explained how these two specialities: family medicine and palliative care, overlapped in her practice.

> *What we family physicians do is to stabilise health problems which disrupt patients' day-to-day living, or to provide continuing care, or to draw up priorities, or similar things.*

> *Palliative care weighs rather heavily in such a practice. So, for example, reducing pain or suffering, or lessening the disruptions to their day-to-day living, or palliating pain a little bit when they're receiving treatment. These [palliative care] activities are more synchronised or overlapping with what family physicians do to a great extent, in contrast with thinking about fixing problems of some specific organs. (ID19, first interview)*

This perception of palliative care principles overlapping those of family medicine was linked with their providing palliative care subconsciously in their normal practice. Some participants used the phrase '*jikkan ga aru* (or *jikkan ga nai*)' to mean 'feeling (or not feeling) that we are providing palliative care'. They showed how consciously (or subconsciously) they provided palliative care in their practice by this phrase.

> *I do not necessarily consider that this patient is needing more palliative care, but I do believe that the disease is progressing or we need this or that kind of treatment or action for the patient. (ID20, first interview)*

Some participants said that they felt more that they were providing palliative care to cancer patients who are at their terminal stage than to other patients with chronic diseases. Patients with advanced cancer seemed to be considered as 'typical' candidates for palliative care, and so the participants could easily be conscious that they were providing 'palliative care' to such patients, on top of their normal family practice.

> *I feel more that I am providing palliative care when the patients are close to death, but what I actually do is the same as for patients with chronic pain. So even though what I am doing is the same [for both groups of patients], I believe that I decide to call it palliative care when the prognosis is limited. (ID06, first interview)*

As described in the above quote, one of the ways for the participants to demarcate palliative care from their own speciality, family medicine, was to take palliative care as being for the dying. This relates to their notion of proximity to dying requiring such support as to be called palliative care (See also Section 7.4.1).

> *Hmm, to me, the term ‘palliative care’ comes up when I think of ‘terminal [patients]’. I know the textbook definitions of palliative care, which should be started from the early stages of illness, and I have no objections to that, but I only become aware of palliative care when patients are approaching death or are in their terminal stage. (ID19, first interview)*

Subconsciously providing palliative care meant that the principles of palliative care were already embedded in their care for those patients. For them, providing good holistic care and anticipatory care planning with their patients were all part of their expert family practice rather than palliative care. This particularly held true in the case of care for patients with long-term illnesses. The participants mentioned that they might subconsciously provide palliative-like care to such patients. In addition, because palliative care was so embedded in their normal family practice, it was difficult for them to draw a clear line between palliative care and normal family practice.

> *I would see the pain of people with frailty [as being suitable for palliative care]. I have an image of [palliative care as being] how we support people with pain who cannot manage things they used to be able to. And how we as a team can support such people. […] In that sense, people with chronic illnesses [could be candidates for palliative care] when they have knee pain for example, which makes me wonder to what extent [we should call palliative care] (ID04, first interview)*

6.2 Practice of palliative care

6.2.1 Management of suffering

The goal of palliative care, which was to reduce patients’ suffering and therefore to improve their quality of life, inevitably led us to discuss the management of patients’ suffering in the interviews. While the participants pointed out that multiple aspects of suffering should be dealt with, they emphasised that physical symptom management was still a central concern. Among various physical symptoms, pain predominated, followed by breathlessness.

> *The priority is, I’d like to get rid of pain and breathlessness if patients have them. (ID06, second interview)*

The participants thought that they were better at symptom management than oncology doctors or other doctors who were not familiar with palliative care. This seemed to be one of the reasons why they felt they were responsible for symptom management of patients.

> *Sometimes, we have more experience than specialist doctors in removing pain or distress. And, we could talk with patients about adjusting their treatment or drugs within the context of the overall conditions. I say these sorts of things to my patients from an early stage, little by little. (ID12, first interview)*

The existence of physical symptoms could thus be a trigger for initiating palliative care. The participants not only recognised currently existing symptoms, but also anticipated future symptoms or suffering.

> *When we expect that patients have a chronic condition or any chronic disease which will potentially worsen their physical condition and also when we expect that this will hinder patients' daily living or cause them suffering. (ID15, first interview)*

The participants clearly stated that palliative care should deal with 'total pain' which includes not only physical but also psycho-social or spiritual pain. Meanwhile, they thought that patients with physical pain which was difficult to treat were also candidates for palliative care regardless of their having a life-threatening illness. For these participants, physical pain was a strong indicator for palliative care, and so they considered patients with unbearable pain for such palliative care. In addition, they argued that pain could worsen patients' quality of life even without life-threatening illnesses so that those patients needed palliative care to improve their quality of life.

> *We see many people with spinal canal stenosis and with chronic pain. They might have had an operation for it but are still suffering from pain. They're often told their paralysis has been fixed and so it's fine by doctors but they are still suffering from pain. Their function or diseases might have got better, but they still have pain. That pain impairs their ADL [ability of daily living] or SOL [sanctity of life]. […] They may be older or not, but there are so many people with such pain. We mainly*

> *aim to relieve their suffering to support reconstructing their day-to-day life, rather than curing diseases. So, that may also be based on palliative care type of thinking. (ID09, first interview)*

While the management of physical symptoms was an obvious task in palliative care, the participants also thought that it was only a part of palliative care. To my questions concerning what they actually do for patients needing palliative care, the participants' answers were not limited to symptom management. They mentioned that providing (or contacting someone who can provide) social or psychological support as being part of palliative care. Psychological, spiritual and financial problems were supposed to be dealt with in palliative care.

> *I always have a 'total pain' point of view [when seeing patients]. I always look for signs suggesting bio-, psycho-, social and spiritual sort of pain…. (ID17, first interview)*

Another participant reported how he would provide psychological support, which included a life review and encouragement for families to communicate more with patients.

> *How I'd provide psychological support may differ between patients and families. I would like more to have informal chats with patients about various things rather than offering them support. Of course, we ask patients about their suffering, but I'd like to help them review their lives. I also would like to encourage their family to chat more with them. They could use this as an opportunity to make their bond stronger and have a better relationship. (ID06, first interview)*

In providing such care and dealing with multi-dimensional problems, the participants said that they often collaborated with other professionals such as nurses, clinical psychologists, social workers, or even clerical staff.

> *⋯ and they [patients] tend to be mentally swaying, so I listen to them with a clinical psychologist. Or they often have financial problems as a result of having chemotherapy, and then I consult with a caseworker [social worker] to see if they*

> *can continue the therapy and where they can stay…(ID19, first interview)*

> *If it's about money, the medical clerk would be involved. If it's more about direct care, myself, nurses and a care manager in our clinic [would be involved]. If professionals outside of our clinic were involved, our nurses would contact them if they are visiting nurses. If not, a care manager would help me contact other professionals, so that I could integrate all the information from them. (ID07, first interview)*

> *Yes. Nurses, including home visiting nurses and rehab staff. And it's not that common but I did have dieticians to work with for their advice about how and what to eat. I remember they gave families some advice on preparing food for patients. And volunteers. (ID20, first interview)*

For the participants, interprofessional collaboration was essential for palliative care provision to solve patients' non-physical problems. Feeling that interprofessional collaboration was helpful could even be a signal that patients need palliative care. This point will be discussed further in Section 7.5.2 in Chapter 7.

It was noteworthy that a few participants considered that the prevention of symptoms or other unfavourable patients' circumstances would be part of palliative care.

> *Preparing vaccinations or a range of things to prevent medical crises, doing what we can do beforehand, could also be considered as being part of palliative care. (ID18, first interview)*

Prevention was included in the WHO definition of palliative care, yet insufficient integration of prevention and palliative care has been pointed out (Schneider and Walter, 2007). It was notable that the above participant mentioned prevention as part of palliative care in such a natural manner during the interview. He was one of the youngest, and his views may have reflected changing views on palliative care in Japan.

6.2.2 Communication

The participants considered communication to be important in palliative care provision. Although communication in palliative care has many dynamics, the focus of this section is on communication with patients.

Understanding patients' perceptions and hopes

According to the participants, an understanding of how patients perceive their situations and what they hope for would form a basis for communication in providing palliative care. They often indicated asking patients for their understanding and hopes as the first step to take when initiating palliative care.

Explaining patients' medical conditions in a way they could understand was important for the participants. This included explaining what would be expected to happen in the near future. Helping patients understand their condition better was considered as an important part of their roles, as it was not necessarily undertaken by hospital doctors. Patients who had different doctors at hospitals who were treating their diseases often did not receive adequate information about their conditions. Cancer patients were typical examples of such situations. The participating family physicians somehow seemed to try to fill the communication gaps between patients and hospital doctors. As ID12 reported in the quote below, the patients' lack of understanding of their condition was considered as problematic because it could cause possible unnecessary anxiety.

> *I always feel they [patients] can't ask questions to specialist doctors. So they are not satisfied, or they seem to have anxiety about pain or something they sense because they have so many unknown things (ID12, first interview)*

Not only cancer patients, but also patients whose illness trajectories were gradually deteriorating needed additional information for different reasons. As their debility accumulated so gradually, it was often difficult for patients, families, and even medical professionals to recognise such deterioration (The accumulation of debility will be discussed again in Section 7.4.2).

> *We also support families to accept that patients wouldn't get better than they are now and are gradually and naturally dying. (ID14, first interview)*

One participant, when discussing palliative care for people with dementia, explained that families of people with dementia often missed being told their diagnosis properly and could confuse the patients' conditions at the end of life with being old. The participating family physicians saw patients' or families' misunderstandings of their conditions as a problem which they should respond to.

> *So, what we do [as palliative care] would include family support. We support families to accept the fact that the patients would not get well again and they will deteriorate as their conditions get worse, although they look like they are simply getting old, and eventually will die. (ID14, first interview)*

Understanding patients' perceptions sometimes extended to embracing their values in life. The interview with the participant ID11 showed why understanding patients' values was important for her.

> *ID11: The first thing to do is the setting of a shared goal, and asking what patients think as being important.*
>
> *Interviewer: Shared between who and what? Or who and who?*
>
> *ID11: Shared between patients and doctors. Families are included when patients have cognitive impairment.*
>
> *Interviewer: And you said what patients think as being important? About what?*
>
> *ID11: How they want to live, how they want to die, or something like advance care planning or what they expect from medical care.*
>
> *Interviewer: I see, what do you mean by advance care planning?*

> *ID12: For example, where they would like to die, to what extent they would like to have as medical treatment or, something like how to prolong their life.*
>
> *(first interview)*

Future care planning

The participants suggested that discussions about future care planning were a critical part of palliative care. Understanding patients' perceptions of their conditions would form a basis for future care planning. Some participants used phrases such as 'advance directives' and 'advance care planning' to refer to what they were trying to do. Others did not use such specific, recognised phrases but mentioned directly or indirectly the importance of future care planning.

> *What I'd do first would be, asking a patient, roughly, about how they thought of their prognosis, or what they would like to do. It's like ACP [advance care planning], but I'd also like to talk about how they'd like to die and how they wouldn't. With the patient and their families. I feel I need to ask them earlier than later. (ID19, first interview)*

Listening to patients' perceptions of their condition was often mentioned when discussing care for cancer patients. However, the participants listed care planning as being part of palliative care for non-cancer patients too. The following quote describes an example of the care for a patient with end-stage Alzheimer's disease.

> *[Palliative care includes] continuously and repeatedly discussing the place of care for the person, how we will take care of their end of life, or the direction of care such as to what extent we should provide medical treatment for them. Those people are also under palliative care, I assume. (ID07, first interview)*

The participants mainly focused on treatment escalation plans, place of care and death. The central part of future care planning was medical problems. However, the participants were aware that these decisions should be in accordance with patients' value.

Make positive the experience around death

Some participants thought that they should cultivate an ethos of caring which embraces death as an opportunity to strengthen the family bonds and change their negative perceptions towards death.

> *I myself don't have conclusions yet, and I cannot say what [palliative care is], but, I'd like to help patients to make it an opportunity to review their lives, if they are conscious. And it'd be great if families could also take death as a plus not a minus and as another step towards a next stage. That would be palliative care. (ID06, first interview)*

This suggested that the participants considered palliative care was not only to relieve patients' suffering, but also to provide family support and to change the negative connotations attached to death and dying.

6.2.3 Coordinating care

Some participants reported that they felt responsible for coordinating care for the patients, and they considered doing so as being part of palliative care in the community. In accordance with the purpose of palliative care, they coordinated care to reduce patients' suffering and maximise their *seikatsu*, meaning day-to-day living.

> *What we normally do is to take care of such patients until the last moments of their lives through combining resources in the community as a coordinator, while managing their total pain. (ID07, first interview)*

The process of coordinating care was summarised by ID17 as follows:

> *Patients themselves, families, or healthcare providers or those involved including informal supporters, all share the process towards the completion of their lives, and problems on the way, and goals at that stage, and each of us undertake our roles. (ID17, first interview)*

The care they were coordinating included not only medical but also social care. They used the phrase *'seikatsu-kankyo wo totonoeru'* meaning 'organising living environment' which often included preparing assistive living aids and involving professional carers. As shown in the following interview quotes, the participants often talked about the social aspects of care.

> *Interviewer: What are you doing (when providing palliative care)?*
>
> *ID01: Mainly, pain management, breathlessness management, social adjustment, care for families.*
>
> *Interviewer: What do you mean by social adjustment?*
>
> *ID01: Organising social care, environment setting. And organising family support and…*
>
> *(first interview)*

Establishing methods of communication and involving professionals were also considered as being important. The participants often started palliative care by sharing information about the patients with care professionals and signposting such information to their families. In this sense, coordinating care for patients included communication with other care professionals, in addition to patients and families.

6.3 The term ‘palliative care’

As mentioned earlier in this chapter, family physicians used the term ‘palliative care’ in many ways. This section explores how they used the term in the interviews. Describing their use of the term also highlights the process of how I disentangled their understanding of palliative care.

6.3.1 Theory versus practice

In Section 6.1, I showed how family physicians understood theoretical principles of palliative care, which included: the purpose of palliative care being to reduce patients’ suffering; being delivered from early in the illness trajectory; and for all conditions. However, it was also observed in the interviews that they acknowledged that other people and themselves held different perceptions of palliative care. Furthermore, their usage of the term ‘palliative care’ in the interviews was not necessarily consistent with their understanding of palliative care principles. Rather, they meant palliative care in the narrower sense, namely, palliative care at the end of life. The participants tended to refer to ‘palliative care’ in this sense, particularly when we were not discussing their definition of palliative care but discussing their everyday practice. One participant articulated how it was unnatural for her to think about and verbalise ‘palliative care’ for younger patients with chronic non-cancer illnesses, even though palliative care principles applied to them.

> *Yes, except for cases of cancer or other such vivid ones. Even if patients have COPD or heart failure, when I’m seeing patients in their 40s and 50s, the word ‘palliative care’ wouldn’t come to mind, though I’d talk to them what I mentioned about [i.e. prevention of exacerbation]. But what I’m doing might be the same [with those for palliative care patients], actually. (ID18, first interview)*

This relates to the previous point of their providing palliative care subconsciously in their normal practice, particularly to non-cancer patients (see Section 6.1.3). Although the participants understood the breadth of palliative care principles, and it seemed these were already embedded in their practice, they considered patients with advanced cancer or at their terminal phase as typical candidates for a narrower form of ‘palliative care’ and used the term accordingly. Another participant articulated the difference between her understanding of the definition of palliative care and the use of the term ‘palliative care’ in her practice:

> *The image, the image of when we say, ‘let’s do palliative care’, is symptom management at the terminal stage. The image is that. But when you’re told you have cancer, that’s also painful and difficult. They would have pain during the treatment [for cancer] too. I’d like to say, ‘let’s get over those difficulties together with support from us all’. That can be included, or should be included [in palliative care]. So, in everyday practice, we use it [palliative care] for that image [of it being for terminal patients], but when asked what an appropriate definition of palliative care would be, the latter would be included. (ID16, first interview)*

Another participant suggested that there were broad and narrow definitions of palliative care, which corresponded to the above-mentioned difference between principles and perception of palliative care. She reported how she stratified the breadth of palliative care as follows:

> *What I mean by depending on the definition [of palliative care] is if it's for cancer patients in its narrow sense, then we're doing that too. I think all homecare patients are sort of aiming at symptom palliation, so, how shall I explain… for homecare patients, we put more emphasis on their quality of life than on aggressive treatment. So, in that sense, homecare patients are nearly equal to palliative care. (ID11, first interview)*

Considering these accounts from the participants, it seemed that the participants had two different concepts of palliative care in their mind, and used either of the concepts whichever suited better to describe what they wanted to say. These two concepts of palliative care featured in the interviews are summarised in Table 6.2. These two concepts of palliative care featured throughout the interviews regardless of whether the participants deliberately differentiated between these two concepts or not. Furthermore, these two concepts were not necessarily clear cut, and were sometimes presented within a spectrum.

Table 6.2 Comparison of participants' concepts of palliative care

	Understanding of palliative care principles	**Everyday use of the term 'palliative care'**
Scope	Broader	Narrower
Types of problems	Any type	Physical symptoms
Types of diseases	Any diseases causing suffering (including non-life-threatening ones)	Predominantly cancer
Time	From early stage in illness trajectory (patients can have a longer prognosis)	At a terminal phase (patients must have a short prognosis)

6.3.2 Context-dependent use of the term 'palliative care'

While the participants had a strong and clear understanding of broad principles of palliative care, they decided how and when to use the term 'palliative care' depending on how the term was understood by people with whom they were communicating. In general, it seemed that they tended to use the term 'palliative care' to refer to the care for dying patients which was consistent with the general understanding of palliative care (*i.e.* everyday use of the term 'palliative care' in the right column in Table 6.2). In this section, I will show how the participants used the term 'palliative care' in everyday communication along with the reasons why they sometimes restricted the use of the term 'palliative care' to mean care for dying patients.

Keeping in step with others

Some participants said that they used the term 'palliative care' when they wanted to 'keep in step with' or communicate with other health and social care professionals about any risk of deterioration of patients. When the participants wanted to make it clear that patients needed extra attention for their care, they referred to them as patients who needed palliative care. By calling these patients ‘palliative care patients’ such patients were signposted to the multidisciplinary care team for better collaboration.

It was significantly important for the participants to share patient care plans with other healthcare professionals. ID13 explained the importance of agreement on a care plan with healthcare professionals by giving an example below, which illustrated how misunderstanding might arise.

> *When I saw patients for palliative care in group homes, as staff there were not used to seeing such patients, they tried feeding the patients to make them better. But that would cause more trouble. Sometimes, visiting nurses say we should give patients fluid as they cannot eat. It’s important to agree with these points as well as to provide consistent care. […] They’d think I’m not taking care of patients appropriately, when things don’t go well. (ID13, first interview)*

Using the term ‘palliative care’ made it easy for the participants to make explicit what they think of as appropriate care for the patient, particularly when the patients were in their terminal stage. Although they thought that palliative care was already embedded in their normal practice, this viewpoint was not necessarily shared with other healthcare professionals. There were occasions when the participants needed to declare that patients needed ‘palliative care’ when patients needed so-called end-of-life care.

> *We’d use the term [palliative care] when their prognosis is evident to some extent. Sharing such things [i.e. this patient needs palliative care] would make it easier to imagine what the term palliative care means among us and to discuss how to support patients with their families. (ID04, first interview)*

ID04 explained when he used the term ‘palliative care’ in relation to the estimated prognosis, and how this made it possible for him and his colleagues to discuss patients’ care proactively.

> *ID04: Well, when it becomes so-called palliative care and when we use ‘palliative care’ as a shared term in our clinic, we think about how we tackle ‘pain’ together. That’s when the use*

> *of the term 'palliative' becomes more frequent than before as a shared term.*
>
> *Interviewer: Could you tell me who are 'we'?*
>
> *ID04: Healthcare professionals at a meeting. And, I think the term palliative care is easier for families to imagine [what would happen]. When we all think together about how we can support patients, I'd intentionally use the term palliative care if it's helpful [for families].*
>
> *(first interview)*

He also used the phrase 'so-called palliative care' to refer to the narrower palliative care (*i.e*. everyday use of the term 'palliative care') which was again an indicator that what people thought of palliative care was not necessarily consistent with what the participants thought of palliative care.

Negative connotation of 'palliative care'

Some negative perceptions of palliative care held by the general public led the participants to reserve the term 'palliative care' until the very last phase of patients' lives to avoid any misunderstandings of their conditions by the patients and their families as well as avoiding unnecessary confusion or worries. According to the participants, the general public often linked palliative care to the care for cancer patients imminently close to death. Similar to the comment made by ID16 in Section 6.3.1, ID01 mentioned that both healthcare professionals and the general public might have negative perceptions of palliative care.

> *[…] if healthcare professionals think palliative care comes to the fore when they cannot do anything more for patients, then they would talk like that to their patients, and patients might feel abandoned. […] Or, patients themselves have a stronger understanding that palliative care is for the very end of the end. (ID01, second interview)*

In the following conversation, ID09 articulated how it was difficult for her to bring up 'palliative care' in front of patients. She attributed this difficulty to both the public image of palliative care and to confusion among professionals.

> *ID09: There's also a public image [of palliative care]. There's an image of 'the end' when being told you're for palliative care.*
>
> *Interviewer: Does that make it difficult to have a discussion?*
>
> *ID09: Yes, that's one thing. After all, there are people who still say they thought that morphine would be the drug used at the very last stage. There is various information from the media, which can be bad and good. I pretty much feel that we, doctors, and medical circles, are also confused as well as the general public.*
>
> *(first interview)*

It was thought that such a negative connotation could hinder and delay timely discussion about the future. Some participants also thought that the broader understanding of palliative care should be promoted so that discussing end-of-life issues with patients could become easier. ID04 explained as follows:

> *A slogan or a strapline such as 'palliative care for all' would be appealing, I think. If the general public could understand the concept of broader palliative care as a shared common language to discuss how they would like to spend their remaining years or what they want at the end of their lives, then it'd be easier for us to discuss what they want for their future. The word 'palliative care' is still not an easy word to share with patients… (ID04, second interview)*

Influences of the healthcare structure and specialist palliative care

Japan's healthcare structure and the kinds of specialist palliative care services available also affected the perceptions of palliative care and how the participants used the term 'palliative care'. Where specialist palliative care was located in the current Japanese healthcare structure affected one participant's perception of palliative care.

> *In my mind, [what would be] palliative care-like is complex. I think all of such patients [whose priorities are not on having a diagnosis or fixing diseases] are fundamentally suitable for*

> *palliative care, but in the healthcare system structure with its separate departments, such as internal medicine, or some-ology, in that sense, I think palliative care is for cancer patients with difficult pain or who finished [active] treatment or who have huge needs other than cancer treatment are also palliative care-like. (ID17, first interview)*

As suggested in the quote above, the fact that palliative care departments, namely, specialist palliative care services, only provided care for terminal cancer patients strengthened the notion of palliative care as a last resort. The influence was more obvious in the interviews with those participants who were working closely with palliative care specialists who specifically treated patients with cancer – this was the case for all other palliative care specialists in Japan.

> *When being simply asked about palliative care, I think of cancer patients. One of the reasons for this is that only patients with a cancer diagnosis can be admitted to the palliative care unit in our hospital. (ID16, first interview)*

Another participant admitted to the awkwardness and confusion she felt about the discrepancy between what she thought of as palliative care and the fact that the palliative care units only dealt with cancer patients. She was working for a clinic affiliated to a hospital with a palliative care unit.

> *Palliative care units are currently limited to cancer in Japan. […] and it's only for patients who have a limited prognosis and won't receive any more chemotherapy and who need to have their suffering removed. If that's the definition of palliative care, then that's not quite right. (ID09, first interview)*

After the interview, she added that she had to pay the most careful attention when using the term 'palliative care'. She could not use the term 'palliative care' to mean the broad concept in front of patients, as this would contradict what the palliative care unit in her local area offers and this could eventually confuse patients.

As mentioned in Section 6.1.3, the participants' understanding of palliative care principles overlapped with the philosophy of family medicine, reflecting their view that palliative care was part of family medicine and for everyone. On the contrary, what specialist palliative care, namely, palliative care units could offer focused narrowly on cancer patients at a terminal stage. In other words, the participants' understandings of palliative care principles were not reflected in the specialist palliative care service in the current healthcare system in Japan. When they used the term 'palliative care', they also bore this in mind, and this affected their usage of the term 'palliative care'.

Impact of verbalising their thoughts

Some of the participants mentioned in the interviews that it was the first time they had verbalised their understandings of palliative care. They seemed to be discovering how they thought about palliative care by verbalising it. Some even mentioned in the second interviews that it was useful for them to have had an opportunity to discuss what palliative care meant for them in their first interviews. Given that we had intervals of several months between the two sets of interviews, discussing the definition of palliative care had some impact on them.

ID10 reported that discussing his understanding of palliative care in the first interview helped him form a clear concept of palliative care, particularly for non-cancer patients. This eventually helped him to explain the concept to his patients, families and other healthcare professionals in his practice.

> *Well, yes, I got an opportunity to verbalise what I thought in the previous interview. I've become conscious of what I think [about palliative care] in my practice after the first interview, [that's not because I used the SPICT-JP,] but because I had the interview, I could put together my feelings or thoughts on palliative care for non-cancer patients. (ID10, second interview)*

No sense in making one definition

Some of the participants even said that it would make no sense to bring all the different kinds of palliative care altogether and discuss which one was correct. They argued that its form and name were fluid and should be adjusted according to the patients' conditions. In fact, there were deviant comments in all the themes. For example, while the majority of the participants reported that physical symptoms were important, some said that physical symptoms were just one part of palliative care. While some participants consciously distinguished between broader and narrower palliative care, some were self-contradictory. They used the phrase palliative care at some point to mean the narrower one (*i.e.* everyday use of the term 'palliative care') and then later they used the same phrase when referring to the broader one (*i.e.* understanding of palliative care principles). I finally achieved some sort of uniform understanding by categorising them under principles, practice and the use of the term. I assumed that the contradictions among the participants' accounts on palliative care were due to the two different concepts of palliative care held in their minds. In addition, as previously mentioned, these two concepts were at the two ends of one continuum which did not necessarily have clear lines between them. It was therefore suspected that in their mind, the participants had various and tangled ideas about palliative care. Even for those who could consciously differentiate between the two different concepts of palliative care, it was the first time they had verbalised the difference.

> *Is it a specialist palliative care, or general....? I think it's called general palliative care, but the palliative care provided by us or family physicians, or a palliative care approach taken by everyone to some extent to be palliative care. They are all different so I don't think it's hugely meaningful to have one phrase 'palliative care'. (ID17, first interview)*

In summary, their understanding of palliative care seemed to be a continuum with one end at broad palliative care and the other end at the narrow one. The broad palliative care includes early palliative care and palliative care for non-cancer patients. The narrow one is for patients imminently close to death with terminal stage cancer. Family physicians seemed to operate in this continuum freely and flexibly according to the context and to use vocabulary that was most helpful for the patient.

6.4 Chapter Summary

This chapter described how family physicians understood the concept of palliative care and their practice of it. It was difficult for the participants to provide a uniform, standard definition of palliative care. For these doctors, palliative care seemed to be better ‘defined’ by a philosophy rather than a scope of practice when they had to describe it. This philosophy overlapped with the principles of family medicine as well as the global definition of palliative care. It seemed that the participants understood and agreed with the textbook definition of palliative care.

In practising palliative care, while considering symptom management as being central, they also thought that other problems should be embraced. They considered that communication; coordinating care; and good interprofessional collaboration were all critical for delivering palliative care.

While their overall understanding of palliative care was broad and consistent with the concept of palliative care being discussed internationally, they used the term palliative care in a rather narrower sense in their clinical practice with their patients and colleagues. Their usage of the term ‘palliative care’ was context-dependent and sensitive to its public association with the imminence of death.

These findings posed a significant challenge to the next question which was about the timely identification of patients for palliative care. The findings shown in this chapter suggest that there could be no clear transition to palliative care. The participants could have great difficulty in drawing lines between people who needed palliative care and those who did not.

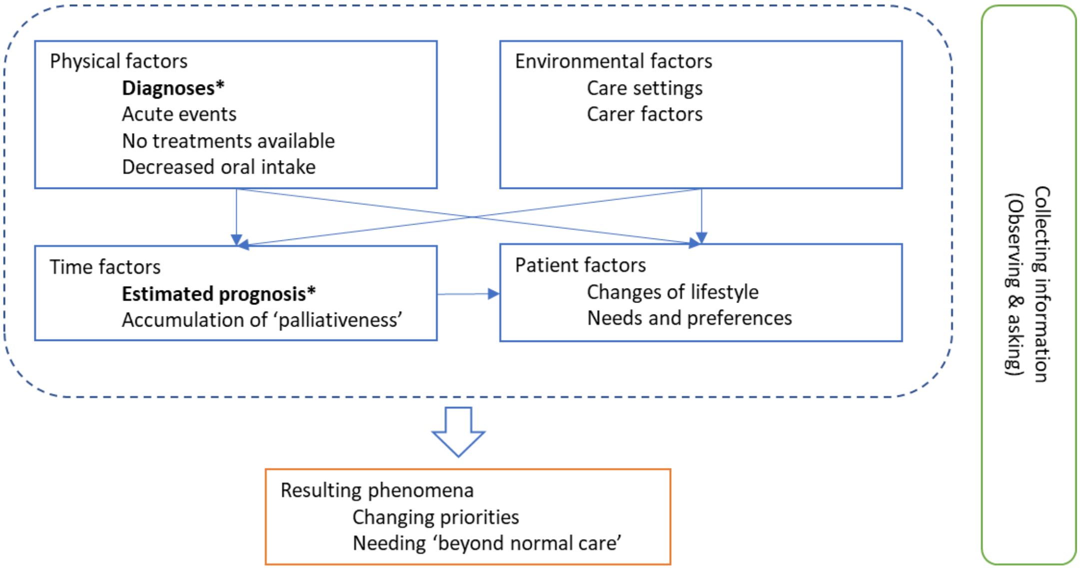
Chapter 7 Results: Identification of palliative care patients

This is the second of three chapters reporting the findings from the two sets of interviews with family physicians. In this chapter, I present the participants' accounts of their identification of palliative care patients, including conditions or events which made them think of palliative care. These are derived from the analysis of interview data to answer the second research question: *How do the Japanese family physicians identify patients with palliative care needs in their practice? (RQ2)*

The ultimate purpose of palliative care explained in the previous chapter – to reduce patients' suffering in order to improve their quality of life formed the basis for all the results presented in this chapter. For the participating family physicians, identifying patients for palliative care meant finding patients who needed to have their suffering reduced.

When planning this research, it was already theorised that there were no defined sets of criteria which could identify patients for palliative care in primary care. Furthermore, as discussed in Chapter 6, the participants did not have clear definitions of palliative care but had two concepts of palliative care in their minds. In fact, the analysis proved that many factors influenced each other and how they identified patients for palliative care.

The findings related to identification were categorised under six themes. The first two were direct triggers related to **physical** (Section 7.1) and **patient factors** (Section 7.2) which included changes of lifestyle and patients' and families' needs and preferences. In addition, the participants explored **environmental** (Section 7.3) and **time factors** (Section 7.4) in recognising patients' palliative care needs. As **resulting phenomena** (Section 7.5), the participants observed patients' needing beyond normal routine care and changing priorities. The participants used various methods for **collecting information** (Section 7.6) relating to the identification. The relationship between these factors is shown in Figure 7.1.



* These are linked to the narrower concept of palliative care = everyday use of the term 'palliative care' in Table 6.2

Figure 7.1 Factors involved in identifying patients for palliative care

7.1 Physical factors

Among all the factors which the participants considered when identifying patients' palliative care needs, physical factors were the most prominent. The physical factors included diagnosis, particularly cancer or non-cancer illnesses; acute events suggesting the patients' deterioration; no medical treatment being available; and the patients' oral intake decreasing.

7.1.1 Diagnosis: Cancer versus non-cancer

Patients' diseases and associated conditions could trigger the identification of their need for palliative care, although not all the participants thought that a specific diagnosis was essential for it. A diagnosis of cancer and degenerative neurological diseases regardless of their stages suggested palliative care for some participants. Among all conditions, a diagnosis of cancer was particularly crucial. Most participants thought that all cancer patients should be considered for palliative care regardless of its stage while a diagnosis of advanced cancer seemed to focus their attention.

Furthermore, they considered the diagnosis of advanced cancer as an ‘easy’ indicator to recognise the need for palliative care. The quote below showed how easy it was for them to recognise and share the patients’ ‘palliative’ status with families and other professionals when the patient had cancer. This comment also included some elements related to ‘no medical treatment available’ which will be discussed later in Sections 7.1.3 in this chapter.

> *If patients have got cancer and it’s written as BSC [best supportive care] in a referral letter, then I think he might be so [i.e. needing palliative care], and it’s easy to share that with families and staff… (ID08, first interview)*

While a cancer diagnosis – particularly one with no indications for curative treatment – was suggested, some long-term chronic diseases such as COPD, heart failure and neurodegenerative diseases were also often mentioned as candidate diseases for palliative care. Unlike cancer patients, patients with such diagnoses were considered for palliative care only when they had obvious signs of deterioration. Many participants found it difficult to provide ‘good’ palliative care to non-cancer patients compared to those with cancer, and particularly in deciding when to raise the issue. Some of the participants worried about not having adequate skills or experience to do so. ID04 compared cancer and non-cancer patients to explain the difficulties she felt about care for non-cancer patients.

> *I’d say drawing a line to say it [i.e. recovery] is impossible or really difficult [for non-cancer patients]. We health professionals can be greatly puzzled, and families can’t sufficiently understand. I always find it difficult. For cancer patients and their families, they’d think about a possibility of death, more or less, regardless of whether they’d be prepared to accept it or not. We can also foresee an expected prognosis [and explain it] according to families’ understanding. For cancer, it feels easier to provide so-called palliative care or a care which includes everyone on board to support patients. (ID04, first interview)*

As shown in the quote above, the perceived difficulty of palliative care for non-cancer patients was mainly located in an uncertainty of their illness trajectories and patients not being able to see themselves as having life-threatening illnesses. Another doctor remembered that he had been told repeatedly by his mentor that palliative care for non-cancer patients was very different from and more difficult than cancer patients, mainly due to their unpredictable trajectories. This suggested that what has been discussed internationally about palliative care for non-cancer patients had been shared with these Japanese family physicians. At least, it was evident in the interviews that the participants acknowledged different features of care for cancer and non-cancer patients, which led them to find palliative care for non-cancer patients difficult.

The quote below from ID02, while illustrating how patients would obviously be for palliative care when an incurable cancer is found, revealed his confusion about palliative care for non-cancer patients despite having heard about it in the lectures. He was uncertain, particularly regarding when to start palliative care for patients with non-cancer illnesses.

> *An easy one [to consider for palliative care] would be a cancer or tumour, and when we expect that the patients' conditions will get worse. And when they have pain or suffering, and their lives have clearly deteriorated because of their symptoms. That'd be when I think of palliative care. I've heard about palliative care for non-cancer patients in lectures, but the timing is difficult. I'm not sure when we should start. I've now realised, by being asked that question, that palliative care for non-cancer patients doesn't have much presence in practice. (ID02, first interview)*

Furthermore, there seemed to be some variations even among non-cancer patients. ID15 explained in the quote below how he understood the challenges in recognising palliative care needs of patients with chronic organ failure. He suggested that patients with organ failure without cancer are more difficult to be recognised as needing palliative care than obviously frail patients.

> *Cancer patients are easy to be recognised as needing palliative care. And, in short, so-called frail, or, well, people who are poor at first glance or people who are in such a range,*

> *are also easy to be recognised. But so-called organ failure, people who have damaged organs…people with such diseases are not easy, I think. (ID15, second interview)*

It was noticeable, however, that a few participants actively insisted that diagnoses were not important in starting palliative care. They thought that palliative care should be purely based on patients' needs or their physical conditions which could negatively impact on their lifestyles. They said that medical diagnoses were even unnecessary for these people to receive support to reduce their suffering.

> *Yes, a diagnosis isn't even needed for palliative care. It doesn't necessarily need a diagnosis and it's more like nursing, or may be close to humanitarianism, or I don't know. But of course we need to make a diagnosis, but the first thing I want to do is to reduce pain or suffering. That would be the first thing, not finding the cause of pain. (ID13, first interview)*

These notions were more related to the broader concept of palliative care rather than the narrower one in Table 6.2, and the participants' perceptions that patients with difficult pain should be considered for palliative care regardless of their diagnoses, which was discussed in Section 6.2.1 in Chapter 6.

7.1.2 Acute events

Being admitted to hospital or having an acute problem such as infection or acute exacerbation of chronic conditions would give the participants an impression of patients' baseline conditions getting worse and possibly reaching a terminal stage. That eventually made them think of palliative care.

> *When patients had big events, they may have had pneumonia or fever, for example. When they dropped down the step from their expected trajectory, and we had to completely change our perspective. That's when I think such patients were now entering their terminal stage [and therefore needing palliative care]. (ID10, first interview)*

Also, it was deemed relatively easy for some of the participating family physicians to start a discussion about future care planning when patients were admitted. This could give them a clear reason why they did so, which prevented patients from worrying unnecessarily. ID18, who mainly saw inpatients, articulated this point in the following quote:

> *ID18: […] it's more common for us to see patients when they were admitted because they had got worse. Just as when we discuss an advance care planning, it's essentially better to discuss when they are well with plenty of time, but I say that it could be a good opportunity to think about this kind of stuff [created by the emergency].*
>
> *Interviewer: I see, then being admitted could be a good opportunity in a way?*
>
> *ID18: Yes. I often tell patients that this might be an unpleasant talk for you, but it's a good opportunity. We can rarely discuss this [i.e. future care planning] without such an hospital admission.*
>
> *Interviewer: That's right. It might make it easier to discuss?*
>
> *ID18: I'd say let's get organised at this opportunity.*
>
> *(first interview)*

7.1.3 No medical treatment available

One of the most evident situations suggesting palliative care for participants was when no effective medical treatment was available for patients. Again, this was more obvious for cancer patients because there was a clear line when none of the cancer treatments was effective.

> *The commonest situation would be, the time when the diagnosis was made for untreatable and out-of-control cancer. When the cancer is spread all over, and no chemotherapy would be indicated. That's the clearest. (ID11, first interview)*

However, the concept was not only for cancer patients. The participants also talked about other illnesses such as heart failure having no more effective treatments possible.

> *When we cannot prescribe any treatments. We don't have any drugs for them, we cannot offer them any operations either, and we only can see them deteriorating. Their deterioration is accelerating. Such situations [would be considered for palliative care]. (ID06, first interview)*

This point of view extended to those situations where the efficacy of standardised treatment in hospitals was in question. For example, although possible treatments existed, patients were too frail, and thus it was supposed that such treatments would be in vain. Similarly, progressing cognitive impairment makes it difficult for patients to stay in hospitals to receive further treatment safely. These situations made the participants think of stopping the escalation of treatment which eventually led them to consider palliative care for the patients.

> *Other patients with dementia would have more relocation damage [by being admitted to hospitals than benefits]. There are cases which, we think, even from our medical point of view, it would be more harmful than beneficial to receive further treatment. In other cases, patients or their families decide not to receive further burdensome treatment according to their own wishes and values. (ID07, first interview)*

> *Patients wouldn't like to receive treatment if required to stay in a hospital. They just want what's available at home. From this point of view, not going into a hospital would be one point [of considering palliative care] (ID13, first interview).*

Reasons for avoiding aggressive treatment were predominantly related to physical or cognitive impairment. However, patients' or carers' preferences or values could be reasons for not receiving aggressive treatment in some cases. This will be discussed in detail in Section 7.2.2.

In some cases, referral letters from other doctors reported that the patients had no medical treatment available. Cancer patients who were considered to be no longer eligible for further cancer treatments were often offered an option to 'switch' to palliative care by their oncologists. These patients were referred to family physicians with a letter indicating the need for 'best supportive care (BSC)' (See also the quote from ID08 in Section 7.1.1).

> *Patients with a referral letter saying they are palliative, though not necessarily directly, are obvious. Patients who are not easy to recognise as palliative would be those to whom we're providing normal care, not palliative care, and who are deteriorating gradually. We do not necessarily have a concept of palliative care for these patients. (ID07, first interview)*

As indicated in the quote above, these patients were perceived as obvious candidates for palliative care by family physicians, which contrasted with patients with long-term illnesses who are gradually deteriorating. So, it seemed easier for both the participating family physicians and the patients to agree with the suggestion of introducing palliative care.

7.1.4 Decreased oral intake

Many participants suggested at some point in their interviews that their patients' loss of capacity to eat was a sign of their deterioration and that eventually they would need palliative care. Decreased oral intake was considered as a sign of physical debility and seemed to be strongly linked to the participants' perception of a poor prognosis for patients, particularly patients with chronic conditions such as dementia, but without malignant diseases.

> *[When asked who would be for palliative care] it would be a patient with little oral intake and who was not able to communicate. End-stage dementia [with these conditions] is recognised in my mind as being equal to terminal, so I consider that this patient would be terminal and so needing palliative care. (ID10, first interview)*

One participant mentioned the Japanese tendency to worry about decreased oral intake:

> *I think carers say a lot about 'eating' in Japan. They say things like the patient starting not to eat at all as being their concerns behind the patients' back. (ID02, first interview)*

In this case, decreased oral intake was treated as the families' concern rather than a sign of deterioration while he also noted it as a possible sign of physical deterioration.

7.2 Patient factors

Apart from physical factors, it seemed that the participating family physicians took patient factors into account when considering the indications for palliative care. Patient factors were categorised into two aspects: changes in their lifestyle; and patients' needs and preferences.

7.2.1 Changes in lifestyle

The participants thought of palliative care when patients had to compromise their preferred lifestyles because of suffering, including physical symptoms, caused by illnesses. This resonates with the discussion in Section 6.1.1 which was about the purpose of palliative care: to reduce patients' suffering.

> *When they cannot keep up with their daily lives, we need not only pain management or drugs, but also environment adjustments or other various means as well. When I sensed at some point that this patient's life is at risk because of such suffering symptoms, that would be a starting point [for palliative care]. (ID09, first interview)*

In the interviews, a reference to any deterioration in 'activity of daily living (ADL)' often appeared as an indication for palliative care. ADLs include bathing, personal hygiene and grooming, dressing, toilet hygiene, functional mobility and self-feeding functions, and the term is often used in clinical practice in Japan. What ADLs consider is practicalities for daily living, which links to not only physical, but also psychological, cognitive and social factors (Huang *et al.*, 2010). These are considered as important for quality of life, especially for older people (Cipher and Clifford, 2004; Wada *et al.*, 2004). Deteriorating ADLs were mentioned as triggers for all patients, but were particularly important for older people with chronic conditions.

> *ID06: I mean, you change the gear completely only when the situations change drastically. It's more like putting a little pin one by one, and increasing the number of those pins.*
>
> *Interviewer: I'd like to know what would be those trivial 'pins'.*

> *ID06: Yes, but, for older people, it's about increasing frailty, decreasing capability of decision making, or similar. It's not like the person is in trouble because the disease is progressing. Well, sometimes it is. But in most cases, when their frailty is increasing, or mental capability is worsening because cognitive impairment is progressing.*
>
> *(first interview)*

The participants also mentioned changes in patients' lifestyles which could be signs of deteriorating ADLs. For example, some of them mentioned that they thought of palliative care when the patients could not come to their clinic anymore. This, not being able to come and see doctors, could be caused by many factors including a decline in their functional ability or changes in their living environment. For the participating family physicians, the phenomenon that patients could not come triggered palliative care regardless of the reasons for it. Any kind of reasons was treated as being equally important indicators of patients' possible deteriorating quality of life. In other words, the participants potentially looked for an overall picture of patients' lives by discussing their ADLs. ID09, who also thought that palliative care was embedded in her everyday practice, discussed as follows to show how identifying 'obstacles in daily living' was important.

> *At the end of the day, it's been discussed when we should start calling it as palliative care, and I agree with that [discussion]. I think palliative care is needed in everyday practice. […] But as I suggested a few minutes ago, it's more about the obstacles in their daily living and their quality of life caused by some sort of pain or suffering, rather than medical conditions needing treatment (ID09, first interview)*

In this sense, participants detected patients' deteriorating quality of life through looking at changes in patients' ADLs, which often appeared as lifestyle changes. This notion is linked to the participants' broader concepts of palliative care *i.e.* 'understanding of palliative care principles' in Table 6.2, and also related to the points about the importance of the management of suffering in palliative care (Section 6.2.1) and that diagnosis is less important for considering palliative care (Section 7.1.1).

7.2.2 Patients' needs or preferences

Patients' perceived needs and preferences for care and their lifestyle also affected family physicians' recognition of their palliative care needs. As briefly mentioned in Section 7.1.3, patients and families could request not to receive further aggressive treatments as their chosen way to maintain patients' quality of life based on their values and preferences.

> *[Palliative care is considered] when patients cannot envisage themselves recovering from their diseases, in their perception. (ID06, first interview)*

> *For example, patients with renal failure decide not to receive dialysis because they see it as a life-prolonging treatment. (ID07, first interview)*

> *It's understandable when families want no more admissions. Some people have lived enough, and that makes sense to us too. […] we could easily assume they would not want to be admitted [to hospital]. They may be frail or it might be difficult for them to find meaning in prolonging their lives by being admitted. (ID13, second interview)*

Patients not wanting further aggressive treatments or hospital admissions prompted the participants to consider palliative care. It was particularly so when such decisions were also agreeable from a medical point of view. However, the stronger the patients' desire not to have further aggressive treatment was, the more this convinced the family physicians. This made it easy for the participants to acknowledge that the patients were for palliative care.

For example, ID02 talked about one of his patients who actively decided not to receive any treatments for his cancer after his diagnosis. The patient tried to prepare fully for his end of life, which included writing a letter to his wife and planning to sell his house. The patients' medical conditions were not investigated in detail based on the patients' decision, but ID02 was convinced that not receiving aggressive treatment and focusing on palliative care was the best choice for this particular patient. In addition, ID02 said that this patient was the first one to come to mind when he was looking for any palliative care patients on his patient list.

> *I suggested to him [i.e. the patient] that they [i.e. specialists] have to know the type of his cancer to suggest any kinds of treatment or palliative chemotherapy. Then he said he wouldn't like to be bothered by further scopes. He said he would like to die elegantly, so it's enough for him to get his troublesome symptoms out. (ID02, first interview)*

> *Yeah, this patient came to mind immediately. He's got a clear mind, or, I could truly think and plan with him. Probably because of his long illness experience, I had an impression that he's had good ideation of his illnesses, and had an image for his end of life. (ID02, first interview)*

Interestingly, no participants mentioned that they would actively suggest to patients and families the option of no more treatments even though they might think more treatments could be harmful. They often described suggesting such an option on their part as 'difficult', a word used in Japanese as a euphemism for 'impossible'.

> *Patients cannot receive treatments to remove their suffering. It looks obvious to me that the chemo hurts the body more [than it does good], but they are young, so I could understand their wish to continue it. Therefore, I cannot say easily to them let's focus on treatment to remove their suffering - because it [i.e. the aggressive treatment to cure the cancer] hurts them. That makes me ponder and stressed. (ID09, first interview)*

The participants were aware that such hesitation could hinder timely transition of care, namely from aggressive, potentially harmful, treatment to palliative care. Not discussing any suggestion of 'giving up' the aggressive treatment was felt as being a 'difficult situation' for some participants.

> *If no one [on the patient's side] can say 'it's enough' then it's difficult. (ID13, first interview)*

> *Yes, I think that patients' or families' decisions are important. If they could say, 'It's ok to stay at home [, we wouldn't like to go to hospital anymore]', then it's easier to recognise [them as needing palliative care], yes. (ID13, first interview)*

In relation to this, other participants suggested that palliative care should start only when patients perceived their needs for palliative care as being increasing. It was because some patients did not want to get involved with many professionals, which was common in palliative care, as it could be a burden for them.

> *Indeed, it's better to start [palliative care] early, but understanding patients' needs is rather important. When we start palliative care, multiple professionals intervene with patients, but some patients would not like that. Particularly male patients who are like 'leave me alone' or 'none of your business' would reject if we all go and take care of them at once. (ID14, first interview)*

One participant suggested that patients who would like to start preparing for their end of life were candidates for palliative care. He said that it was more natural to start discussing their end of life according to patients' preferences or needs, but not according to medical professionals' needs. He called this 'patient-centred initiation of palliative care'.

> *It's more natural if we can start palliative care when the patient feels like it, for example, when they happen to be in hospital or when they happen to fall or when they experience the death of their friend. It's more about the timing than physical factors or prognoses… (ID17, first interview)*

It seemed that for the participating family physicians, protecting patients' hopes or preferences outweighed providing apparently 'appropriate' medical treatment supported by the evidence. Patients' needs or preferences, reflecting their life values, could exist independently from their physical conditions, while patients' preferences were often influenced by and formed based on their experiences of illnesses as suggested in the previous quotes from ID02. In addition, how the participants would have identified patients for palliative care depended on what they would have done afterwards. If they thought that they would not have changed their practice because, for example, the patients were too afraid of discussing something related to the end of life, officially identifying them as palliative care patients would not have been meaningful or helpful enough for them to introduce palliative care.

7.3 Environmental factors

Patients' surrounding environments did affect the participants' judgements on how much patients would benefit from palliative care, which included the participants' practice settings and patients' available social support.

7.3.1 Settings

The setting of each participant's practice seemed to influence their identification of patients for palliative care. As mentioned in Chapter 2, around half of Japanese family physicians are based in hospitals. The severity of patients' medical conditions differs in the settings, and so the participants' perception of identifying palliative care patients could differ accordingly. In the following quote, ID15 reported that he found it more difficult to identify patients' palliative care needs in an outpatient setting than in an inpatient one.

> *Being admitted to hospitals could be a good opportunity, so it could be a trigger, but at an outpatient clinic, we see patients there because they are stable, so I assume there are not many triggers there. (ID15, first interview)*

Furthermore, some of the participants were working in urban settings while others were in rural areas, where patients' characteristics and available resources also differed. ID14 explained how patients' behaviour was different in an urban area of Tokyo than where he used to work in a more rural area. Patients could go and see different doctors much more easily in Tokyo.

> *The patients trusted hospital doctors so much [in Tokyo]. They probably have some problems, but when I try to help them, then they would say it's all right because they would ask hospital doctors. In Tokyo, both we and hospital doctors see the same patients. In Saitama [i.e. a more rural area], I had to be responsible for all of the care for one person, but here in Tokyo, patients and families can decide to go and see specialists by themselves. So, I would say it's more difficult to provide comprehensive care in a way. (ID14, first interview)*

This made it difficult for him to take the initiative to start discussing palliative care or future care planning with patients and families, which would eventually affect how he identified patients' palliative care needs.

For some participants, the identification of patients for palliative care was akin to determining the extent of patients' need for care in general. This is consistent with their accounts that everyone needs a degree of palliative care. The decision on stratification was made based on the participants' understanding of the characteristics of their population. For these participants, palliative care equated to needing more attention and support. This point will be further discussed in Section 7.5.2.

In addition, the participants often referred to homecare patients when discussing palliative care patients. In Japan, patients are registered as being homecare when they cannot come to a clinic for whatever reasons and so need regular home visits. This overlaps with the participants' recognition of needing palliative care. In homecare settings, the participants tend to place more emphasis on their patients' quality of life than curing diseases. ID03 reported that patients needing palliative care would be almost the same as patients needing homecare, particularly for those with chronic organ failure.

> *Personally, the situations in which I think homecare might be needed and those in which I think palliative care might be needed are very much the same [for patients with chronic organ failure]. (ID03, first interview)*

7.3.2 Carer factors

Social factors alone would not be indicators for palliative care, but the participants set the bar low when the patients had poor social support, represented as 'family support' in a Japanese context. The lack of family carers or family carers' capacity to manage difficult situations was perceived as a possible reason for patients needing palliative care.

> *When I see insufficient capacity in carers, then I may be thinking I have to take action or do it quickly. (ID02, first interview)*

After the quote above, ID02 explained that he looked at how patients could manage their daily lives, including necessities for everyday living such as food, clothing and housing when deciding the amount of care patients needed. When patients were starting to fail to manage their daily lives, he thought that he needed to offer extra support, including what they call palliative care. Patients would have been in such situations more easily if there was not enough family support. Some participants thought that carers helped patients manage their daily lives while patients coped with their diseases. In addition, from ID02's account, we can assume that other social factors could have potentially influenced how family physicians perceived patients' need for palliative care. Another participant expanded on this point in the following quote:

> *One thing I can say is that, patients living alone or having their own money or not, will be listed as problems to be considered when planning their care. I think it's our role as family physicians to consider patients' backgrounds or family relationships. (ID08, first interview)*

7.4 Time factors

The time factors comprise two aspects: the estimated prognosis and an accumulation of changes. Issues related to the estimated prognosis were often discussed in the interviews, indicating that it was an important topic for them. It was also evident that the participants were conscious of gradual and chronological changes in patients' conditions, which could be considered as an accumulation of changes towards their debility.

7.4.1 Estimated prognosis

Although not all the participants mentioned prognosis explicitly, how close the patients were to death was often mentioned as an indication for palliative care, which was related to their narrower concept of palliative care. Moreover, given the frequency of them mentioning this, prognosis seemed to be an essential aspect for them. Some common terms expressed in the interviews relating to this point included that death is 'approaching' or ‘expected’. One participant articulated this point by arguing that patients who had a shorter prognosis tended to have more palliative care needs.

> *In the end, patients needing palliative care have some sort of suffering. That suffering could be physical, mental or social. And I think the amount of suffering they have, to some extent, correlates with the prognosis. So I’m thinking of prognosis [as being important] (ID15, first interview).*

The shorter the time left to live that the patient has, the more readily the participants thought of palliative care. Most did not specify the explicit time frame for palliative care in conversations, but they commonly mentioned ‘months’ when asked to specify. The following quote shows a typical prognosis suggested from the hospital specialists when the patients were referred to as being palliative status or for best supportive care.

> *Interviewer: You said they usually had only a month or so, is that right?*
>
> *ID14: More or less so. It’s common that patients think they would have six months left while when I confirm with the referring doctors, they say two months or less.*
>
> *(first interview)*

ID20 was mainly seeing homecare patients, all of whom were somewhat frail at the time of their first consultation. To him, patients who were for palliative care had an even worse prognosis. This was probably due to his population being sicker than other participants’ patients.

> *Interviewer: How long a prognosis would patients have who mainly receive palliative care?*
>
> *ID20: Weeks, I think.*
>
> *(first interview)*

Another participant said in the interview that although what he did for the patients would be the same, it was easier for him to call patients with a short prognosis palliative care patients, which is similar to the cancer versus non-cancer viewpoint (See also Section 7.1.1). The two concepts of palliative care in Table 6.2 can be applied to these notions. Namely, while the participants understood the principle of palliative care as being broad and inclusive (*i.e.* understanding of palliative care principles on Table 6.2), the narrower concept of palliative care (*i.e.* everyday use of the term ‘palliative care’ on Table 6.2) was more natural to operationalise in their practice.

> *ID18: I am not over-specifying a prognosis. But, for patients with an obviously longer prognosis, like [how] a surprise question [identifies patients], I would not have an image of palliative care for these patients who, I think, have a very long prognosis.*
>
> *Interviewer: But you said what you’re doing would be the same, didn’t you?*
>
> *ID18: Yes, I think so. Now I think so while I am talking with you.*
>
> *(first interview)*

The participating family physicians’ perception of prognosis was different according to patients’ diagnoses. They thought that it was easier to estimate a prognosis for cancer patients, and so these patients could more easily be recognised as palliative care patients – which has been explored in Section 7.1.1. On the other hand, some other participants reported that a prognosis was not that important although they could not ignore it, which was similar to those accounts which insisted that a diagnosis was not necessary when deciding if patients needed palliative care. In either case, what these participants had in mind was that the focus should be on patients’ suffering rather than their background medical conditions such as diagnoses or estimated prognoses. These notions seemed to be based on their understanding of palliative care principles. ID07 articulated how fluidly he treated a prognosis when deciding who needed palliative care.

> *Yes, I would think patients needed palliative care if they had a short prognosis, and their diseases were progressing, their symptoms were getting worse, and they needed various kinds of care. … But, how long I would think a short prognosis was would depend on the situation. I wouldn't think that straightforwardly, like 'this patient hasn't got six months so he needs palliative care'. It's not like that. (ID07, first interview)*

Progressive disease

When the participants saw that patients' underlying diseases or conditions were 'progressing', they also took this as a sign for palliative care. Like a prognosis, they were vague as to what extent and did not specify how severe a disease the patients should have to be considered for palliative care. However, active progression of the disease, which potentially means a short prognosis, seemed to trigger palliative care. Also, when diseases are progressing, this could cause unpleasant symptoms which could interfere with patients' daily lives and trigger identification by the participants. For example, ID20 first said that progressing diseases made him think of palliative care. However, by exploring what was meant by 'progressing diseases', he admitted that he also looked at changes in patients' symptoms, lifestyles, and ADLs, which could be the real reasons why he thought patients needed palliative care.

> *Interviewer: How would you decide how quickly they are [progressing their diseases]?*
>
> *ID20: It would be changes in symptoms or things like that. Transitions of conditions, maybe. If their condition has changed over days, weeks or months.*
>
> *Interviewer: What do you mean by transitions of conditions?*
>
> *ID20: For example, their pain is getting worse or they've got a new pain or numbness, or such things. Or they are losing their appetite. Those sort of new things or new events happening. Those events are [normally] about symptoms but also include they cannot go out anymore, which they used to without problems. Such changes in ADLs are included.*
>
> *(first interview)*

7.4.2 Accumulation of ‘palliativeness’

The participants used words such as ‘proportion’, ‘ratio’, and ‘weight’ to describe how patients gradually become more ‘palliative’. For the participants, their patients gradually increased the proportion of palliative care needs within their overall care needs rather than suddenly becoming ‘palliative’ patients at a particular point.

> *It’s simply about the proportion that is changing. (ID07, first interview)*
>
> *It’s not like suddenly switching on. (ID03, first interview)*
>
> *So, palliative care is always there. It’s just about how prominent it is. (ID20, first interview)*

One participant, ID07, said that several kinds of trivial events or facts could prompt him to consider the need for palliative care. These were so trivial that he could not identify them in the interview, and none of them alone was strong enough to indicate the patients need palliative care. The accumulation of these events made him decide that the patient needed palliative care. As in the quote in Section 7.2.1, he metaphorically described those trivial events as ‘pins’.

> *It’s more like putting a little pin one by one and increasing the number of those pins. (ID07, first interview)*

Because of this gradual accumulation of ‘palliativeness’ or burden of suffering, there were no clear starting lines for palliative care for the participants. The participating family physicians calmly observed how the patients accumulated ‘palliativeness’ with these trivial events and decided when to start dealing with them proactively.

This gradual deterioration in their conditions without obvious indications was more evident for patients with non-malignant chronic conditions than those with cancer. As shown in the following quote, their deterioration crept in almost unnoticeably.

> *We don’t know [when is the time for palliative care] for non-cancer patients. But when patients go down a gentle slope to the point where they are expected to have a fatal outcome when they miss the step off from that slope. That’s when I think the patients are for palliative care. (ID07, first interview)*

Therefore, it was difficult for the participants to pinpoint the moment when their patients needed palliative care. It was rather a gradual occurrence, and sometimes they could only perceive the resulting phenomena (shown in the next section). The accumulation of all these complex factors in this chapter could lead to patients becoming palliative care patients.

7.5 Resulting phenomena

All of the conditions or situations discussed above could result in patients changing their priorities from medical care to comfort care, or as needing attention beyond normal care. These would be directly perceived by family physicians as an opportunity for introducing palliative care. From the participants’ point of view, it seemed that identifying patients for palliative care was almost equal to identifying signs of changing priorities of patients’ care or needs beyond normal care.

7.5.1 Changing priorities

As a result of an accumulation of the indications for palliative care, family physicians, and patients and families when they could, raised the priority of reducing patients’ suffering resulting from aggressive treatment which could potentially add further suffering for the patients. This would be the end result of the accumulation of their ‘palliativeness’ shown in Section 7.4.2. One participant described this point as follows:

> *The occasion when we must prioritise easing their suffering in the first place, rather than trying to fix something through a painful experience [i.e. aggressive treatment] would be the time I think that we need palliative care for the patient. (ID13, first interview)*

Another participant thought that patients, for whom the priority of having a diagnosis and following medical treatments was low, would be for palliative care.

> *Patients with a low priority of having a diagnosis and receiving treatment looked like to me palliative. (ID17, first interview)*

Other participants were explicit that it was time for palliative care when the quality of life or happiness of the patients outweighed their desire for recovery from the disease.

> *In the end, it might be when, the happiness of this person, although 'happiness' of this person might be overstated, so perhaps, the most important thing for this person would not be so-called recovery. When we recognise recovery is not the most important issue any more would be a cue [to switch palliative care], wouldn't it? (ID13, first interview)*

Although various factors which could potentially change the priorities of care, no medical treatment available (Section 7.1.3) and patients' and families' preferences (Section 7.2.2) were often reported. The quote below summarises these points.

> *When there're no operations or treatments available, and patients do not want them either and there are no indications. That's when we put more priorities on symptom alleviation and quality of life, and that's when I think the transition to palliative care occurs. (ID08, first interview)*

7.5.2 Needing 'beyond normal care'

Many participants suggested that situations or patients needing much more attention from the primary care team and other services triggered palliative care. Some said that they felt uneasy when they saw such patients, while others said that they felt patients were very resource-intensive. These were the signs of patients needing palliative care. These patients often needed close follow-ups and frequent reviews, or interprofessional collaboration to resolve complicated problems (See also Section 6.2.1). When asked with whom he used the SPICT-JP, ID02 answered as follows, suggesting that he thought resource-intensive patients were potentially in need of palliative care:

> *Those I'm spending more cost and energy on, compared to the others. The cost can be communication, time, or anything in medical care. They have more needs in medical care, and I have to prepare more time and capacity for them by organising the appointment time specifically… (ID02, second interview)*

A necessary resource could be the frequent follow-ups by the doctors:

> *[Palliative care would be needed] when I think the regular follow-up is not enough. … For example, when I started to think this patient needs visits between regular visits which are biweekly, that's a trigger for palliative care. (ID14, first interview)*

One participant mentioned that feeling that he would need help from other professionals would be a sign that the patients need palliative care.

> *ID18: It's like interprofessional work I mentioned just now, but patients go in a direction in which they don't need me. Or I should say, I cannot do anything by myself. When I think this patient doesn't need palliative care yet, then I would be able to manage by myself….I wouldn't talk to social workers, or think of homecare or home visiting nurses. But, when I think this patient is in a phase of palliative care or I have to coordinate the care for the end [of life], I will start talking with many colleagues. So that may be the big point for change.*
>
> *Interviewer: I see. So you collaborate with other professionals to provide something beyond what you could do as a medical doctor, and you call it 'whole person care'?*
>
> *ID18: Yeah, not only diseases, but there're times when you don't have to worry about the living conditions of patients who are coming to your clinic with a certain diagnosis. Well, you don't have to worry about that in the majority of cases. But, when the patients' ADL or disease are getting worse, or patients are getting older, or have more cognitive problems. Then I feel the patients are on a cusp of palliative care.*
>
> *(first interview)*

While these participants were relatively clear about what kind of resources the patient potentially needed, some participants often omitted to provide clear reasons for this feeling in the interviews. It sounded like their ‘gut feeling’ telling them that the patients needed more care or they just perceived the situations in that way. For example, the immediate answer of ID10 to the question about his way of recognising patients for palliative care was:

> *When I am left with a bitter taste in my mouth after seeing a patient. (ID10, second interview)*

It can be assumed that for whatever reasons, for the participants, recognising patients needing more resources was seen as a sign of the need for palliative care. It was only after a detailed analysis that all of the factors above could be listed as the reasons for them needing more resources. So, identifying people who needed a greater degree of support, regardless of the reasons for it, could be a way of identifying people who would benefit from palliative care.

7.6 Collecting information

While I proactively asked the participants during the interviews how they collected patient information which possibly triggered palliative care, some participants did not provide any clear answers to the question, showing that they subconsciously or intuitively recognised signs for palliative care. However, some participants answered that they actively asked the patients about their ADLs and how they were getting on, and this seemed to be the primary source of information for participating family physicians. ID16 explained how they asked patients about their available social support.

> *We ask all the patients about their families when they are admitted, and if they have someone to support them and where they are, how often they contact them. We ask that of all the patients, regardless of whether they need palliative care. (ID16, first interview)*

In addition to this, some participants deliberately observed patients’ physical conditions, such as how they entered the consultation room.

> *Well, we listen to patients. But the first thing may be their appearance. (ID16, first interview)*
>
> *Of course, we sometimes directly ask families and patients. Normally, we see how they open the door and enter the consulting room. If he or she uses a stick and stumbles, then I think of them as frail. (ID04, first interview)*

The two main methods of collecting information were to directly or indirectly ask patients about their ability to do what they wanted to do and through direct observation of their physical conditions. However, given that many participants could not answer clearly about these methods, there was a possibility that other methods were subconsciously used. It was suggested that there were no standard or straightforward ways of doing so.

7.7 Chapter summary

Considering patients’ medical conditions including diagnosis and estimated prognosis seemed to be particularly important for the participating family physicians, although they were not the only factors to be considered. They also thought that patients’ preferences, lifestyle changes and deteriorating ADLs were equally important. The family physicians saw a transition to palliative care as an accumulation of changes, rather than ‘throwing a switch’. Environmental and time factors also influenced their identification.

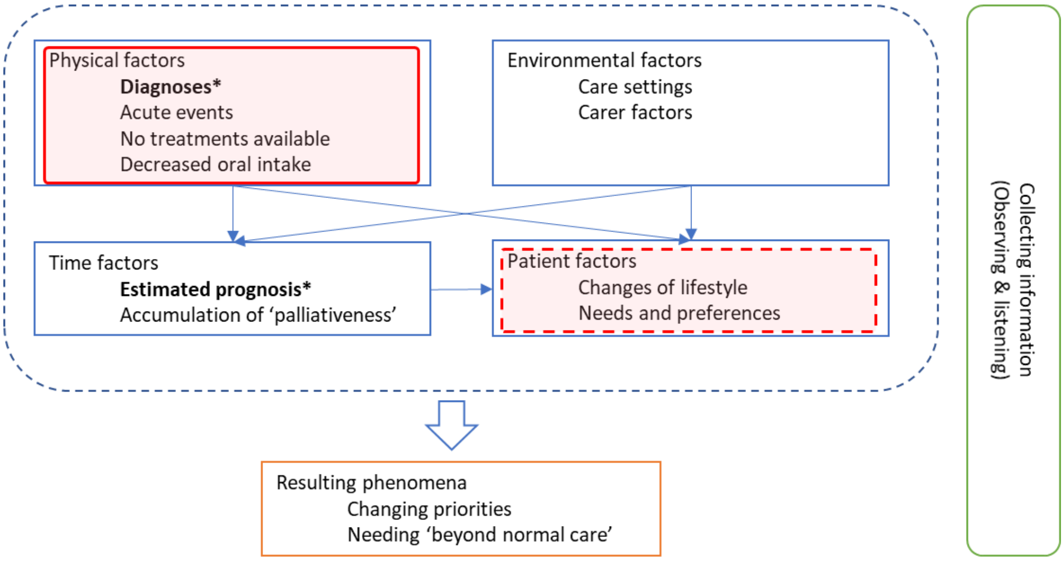
For the participating family physicians, those patients with changing priorities within their medical care, and needing beyond normal care, could be candidates for palliative care. These patients could be recognised as such without any specific reasons or diagnoses. The family physicians sometimes seemed to use their ‘gut feeling’ or overall impressions in recognising this.

Regarding the methods for collecting information, the participating family physicians collected patient information by listening to and observing patients. The participants were often quite vague in how they answered more direct questions about specific methods of looking for patients for palliative care. They did not report using systematic approaches but rather a variable and flexible range of factual and intuitive approaches.

Chapter 8 Results: Using the SPICT-JP in practice

This is the third of the three chapters reporting the findings from the interviews with the participating family physicians. This chapter explores these family physicians’ perceptions of the usefulness of the SPICT-JP in their practice with their patients to address the fourth research question: *How would the Japanese version of the SPICT be utilised by family physicians and what are their perceptions of its impact?* (RQ4)

In this chapter, I report how the SPICT-JP could fit into their complicated approach to identifying people for palliative care as described in the previous chapters. It was apparent that among the themes identified in Chapter 7, the SPICT-JP mainly deals with disease or patient factors in the identification of palliative care patients (See Figure 8.1). As medical professionals by their nature, it was easy to assume that they would prefer to have something specific to use to ease the complexity of identification. However, it was also suspected that such a checklist like tool, the SPICT-JP, might not sit well within the skills of their complicated practice. The SPICT-JP does not include broader social influences of environmental factors, time factors, or the interaction of such factors. Exploring how this type of tool might be blended into the family physicians’ practice and could be useful in developing strategies to support family physicians in their crucial role to provide palliative care was the objective for this part of my research. Participants’ views on the use of the SPICT-JP in their practice were categorised under seven themes, as shown in Table 8.1. The second set of interviews provided the primary source of the analysis.



* These are linked to the narrower concept of palliative care = everyday use of the term 'palliative care' in Table 6.2

Figure 8.1 Identification of patients' palliative care needs

The red rectangles indicate the areas the SPICT-JP deals with.

Table 8.1 Themes for Chapter 8

	Themes
Before using the tool	1) Pre-selection of patients
When using the tool	2) Review, act and reflect
After using the tool	3) Raising awareness
About the SPICT-JP	4) Meaning of having the SPICT-JP 5) Appropriateness of the SPICT-JP
Potentialities	6) Potential roles 7) Potential risks and challenges

8.1 Pre-selection of patients

As described in Section 5.3.3, I left the participants to decide how they would use the SPICT-JP in their practice. All participants except for one (whose use of the SPICT-JP will be discussed later) selected patients for the SPICT-JP based on their clinical judgements.

8.1.1 Diagnoses of the patients

Unsurprisingly, most participants selected patients for the SPICT-JP based on their understanding of patients' physical conditions which include their diseases and diagnoses. Some participants referred to disease categories within the SPICT-JP as reasons why they selected particular patients for evaluation.

> *At the end of the day, I think I used it [i.e. the SPICT-JP] with the patients who had some chronic conditions that come under categories listed here, such as cancer, dementia or 'frail'. Looking back, there were patients with simple pneumonia, ischemic colitis or pyelonephritis or others…. but I subconsciously picked up patients who fit into these categories. (ID05, second interview)*

They also said that being able to refer to the disease categories within the SPICT-JP was useful because it raised their and their colleagues' awareness of the need for palliative care for non-cancer patients. As reported in Chapter 7, while patients with advanced cancer were deemed to be archetypal for palliative care, the participating family physicians found it challenging to identify palliative care needs in non-cancer patients. Having a tangible list of various conditions confirmed the participants' notions of the need for palliative care for people with non-cancer conditions.

It was also suggested that for the participants, the diagnosis remained important information. This was related to their earlier accounts of the importance of diagnoses when identifying patients for palliative care (See also Section 7.1.1), and somewhat contradicted the notion that palliative care should be offered based on patients' needs and not just on diagnoses and prognosis (*i.e.* their understanding of palliative care principles, listed on Table 6.2). It was probably impossible and inappropriate for medical professionals to completely ignore patients' diseases and diagnoses.

Interestingly, one participant did not use the SPICT-JP with non-cancer patients at all, despite having insisted in his first interview that non-cancer patients should be considered for palliative care. During the interview, he became aware that many other patients could have been identified by the SPICT-JP than just those with cancer (whom he had picked up). However, he said that his practice would not change as he thought that he had been providing good and appropriate care to them, including elements of palliative care.

> *I now realised that there was a patient who would have been suitable for palliative care. He has COPD. I noticed this while talking with you [in the interview]. […] I hadn't seen him as a candidate for palliative care. He had an acute exacerbation once. Even after it settled, he still had breathlessness for no reason. I dealt with that and prescribed medicine for sputum drainage. I explained what COPD patients could expect such as natural prognosis, risks, and how important family support is, but that family could also possibly feel the strain. I then told them I would always support them. This is definitely what we do in palliative care, but I did not recognise this person as a candidate for palliative care. (ID01, second interview)*

This might have been due to him subconsciously taking a 'palliative care approach' for non-cancer patients. This participant's account was outstanding in this regard. Nonetheless, it was also suggested by other interviews that palliative care for non-cancer patients might have been delivered more often than the participating family physicians perceived; it seemed it was delivered without being called 'palliative care'. This also might be the reason why 'palliative care for non-cancer patients' does not have much presence in family practice.

8.1.2 Uncertainty about clinical decisions

A few participants said they had used the SPICT-JP with patients whom they were not sure if there was an indication for palliative care. An example was those patients who looked better than what their recorded medical conditions suggested. The participating family physicians used the SPICT-JP with such patients to clarify this issue.

> *Yes, I used it [SPICT-JP] with someone who made me uneasy or uncertain, or, patients who gave me a different impression. Different from the impression that the diagnosis gave me. They could be better or worse [than the impression from the diagnosis]. (ID16, second interview)*

> *It was worrying, so I used it [SPICT-JP] and confirmed that he needed palliative care. (ID14, second interview)*

The participants recognised their feelings of uneasiness as a sign for considering palliative care (See Section 7.5.2). In most cases, the participants more or less knew that the patient would need special attention. Using the SPICT-JP with such patients had a confirming effect for the participating family physicians. Some participants explained how it had cleared their uneasiness.

> *After all, she met only a few criteria in this [i.e. SPICT-JP], so it supported that my impression was not wrong. (ID16, second interview)*

> *All in all, when we reviewed him against this [i.e. SPICT-JP], we ticked many indications for palliative care, so we could confirm with nurses that we should look at this patient in that way [i.e. needing palliative care]. And we reviewed those patients together. That was good. (ID08, second interview)*

8.1.3 Screening

Only one participant used the SPICT-JP as a screening tool with all medical homecare patients at his clinic. He was the medical director of the clinic and decided to screen all medical homecare patients as it would allow him to check the practice of other doctors who were mainly trainees. He intended to identify patients who had been overlooked by using the SPICT-JP in this public health way. Despite this screening, he could not identify any patients because most patients needing palliative care had already been identified, resulting in him not being impressed with the tool.

> *I didn’t feel it [i.e. SPICT-JP] was incredibly useful […] Many patients were already considered for advance directives or some sort of discussion. They [i.e. family medicine trainees] may or may not have already discussed that, but at least it [i.e.*

> *advance directive or some sort of discussion] had already been on their problem list. These patients were identified by the SPICT as well. So, there were no cases like ‘Oh we have to change the direction of care!’ (ID07, second interview)*

This participant added that the results might have been different if he used the SPICT-JP at outpatient clinics. He thought that there might be unidentified patients who needed a palliative care approach in an outpatient setting. The comments from this participant indicated that settings and environments would affect how the SPICT-JP should be used. This point will be further discussed in Sections 8.1.5 and 8.7.3.

8.1.4 Using the SPICT-JP to confirm clinical identification

Some participants pre-selected patients who obviously needed palliative care for the SPICT-JP. For these patients, the participants usually had already taken some action and using the SPICT-JP did not add any new actions except for confirming their judgement. This caused confusion for those participants about how they could better utilise the SPICT-JP in their practice. ID03 showed her confusion about how she should have selected patients for the SPICT-JP.

> *I ended up using the SPICT-JP with patients I had picked up because I thought these patients would be identified [by the SPICT-JP], rather than reviewing all my patients. But, while doing so, I became unsure if that’s the right thing. (ID03, second interview)*

> *I didn’t use it [i.e. SPICT-JP] with people whom I thought would be negative. Meaning that I had already filtered my patients. But I think the real purpose of the SPICT was to use it against on people of whom we doctors were uncertain [about their need for palliative care]. So I wasn’t sure if this was the right way of using it. (ID03, second interview)*

Another participant showed similar confusions and confessed that she selected patients who would be identified:

> *For example, if I'd use it with all my patients as a screening tool, then there might be patients who would be unexpectedly identified, and that'd be its merit. But, if we had already known that the patients would be identified, then we would be like, oh yes, we had known it already…. In that sense, if I would have used it [i.e. SPICT-JP] with all my 30 inpatients without any pre-selection, then that might have been different…. I selected patients who would be identified. (ID16, second interview)*

For these participants, the SPICT-JP confirmed their clinical judgement about which patients needed palliative care. Confirming their instinct was sometimes welcomed by the participants while at other times it was not.

8.1.5 Places of care

I have already discussed how the settings affected the participants' identification of patients with palliative care needs (See Section 7.3.1). Similarly, the places of care influenced the pre-selection of patients for the SPICT-JP. Most participants were working at clinics and took care of home-dwelling people at outpatient clinics or through medical homecare services. Medical homecare patients tended to be frail and required more care than outpatients, which reasonably led the participants to use the SPICT-JP with such patients. The participants thought that this cohort of patients was more likely to benefit from a palliative care approach due to their frailty. In addition, in Japan, family physicians generally have more time for each patient during medical homecare services, and so adding the SPICT-JP was easier during medical homecare services than at outpatient clinics. ID08 suggested a further reason: interprofessional collaboration would be more likely required in medical homecare.

> *Interviewer: So, you used it [i.e. SPICT-JP] with homecare patients, didn't you?*
>
> *ID08: Yes.*

> *Interviewer: Was that because it was easy in a homecare setting?*
>
> *ID08: Because it was easy in a homecare setting, and I remember we talked about it being used with other healthcare professionals at the beginning, and I thought it would be easier during homecare to discuss it with nurses.*
>
> *(second interview)*

Places of care have influences and impact on the actual usage of the SPICT-JP, not only the pre-selection of the patients. This will be further discussed in Section 8.7.3.

8.2 Review, act and reflect

Using the SPICT-JP offered the participating family physicians some time to pause and think. It allowed them to review patient care, undertake actions when needed, and reflect on their practice. This chain reaction eventually raised their awareness of the timely identification of palliative care patients (See also Section 8.3). The most prominent benefit of using the SPICT-JP for the participants was gaining an opportunity to review patient care.

> *The overall impression was, as I've written [on a log sheet], it gave, and will give, me an opportunity to review my patients' care or medical treatment. (ID13, second interview)*

Spending some time solely to think about the patients and their care was perceived as being valuable by many participants. As illustrated in the following quote, the participating family physicians felt that they did not have enough time to make decisions with their patients during consultations. Using such a tool 'forced' them to review patient care.

> *Using the SPICT-JP might have allowed me to think. There were times when I thought the result was expected, and times when I thought this was it. Shall I say I reviewed the patient [when using the SPICT-JP]? At outpatient clinics, I make decisions about the patient care only during the consultation, but this time, I used the SPICT-JP after I saw patients, which allowed me to think about patients again and I wondered what*

> *I'd do next and what I'd missed out, and that was good. (ID02, second interview)*

After reviewing patients with the SPICT-JP, the participating family physicians decided whether to take the next step or not. The participants often initiated conversations about future care plan with patients after using the SPICT-JP. As previously discussed, the participants tended to use the SPICT-JP with patients who they thought might need palliative care or who might need a discussion regarding future care planning, which means that the participants had some readiness to begin such conversations. The SPICT-JP nudged them gently to proceed.

Interestingly, the use of the SPICT-JP (whether the patients were indicated as needing palliative care or not) did not affect the doctors' decision on whether they would open up conversations for future care planning. There were more cases with negative results in the sense that the participants had some sort of discussions about future care planning. It seemed that using the SPICT-JP triggered the actions they already had in mind.

> *… He didn't meet the criteria, but it gave me an opportunity to initiate a talk about future care. (ID04, second interview)*

> *Using the SPICT-JP itself [but not the result of the SPICT-JP] switched me on to 'shall I start an end-of-life discussion'. (ID17, second interview)*

Some participants articulated that being able to review patient care mattered more than the guidance given by the SPICT-JP.

> *In the end, he wasn't [SPICT-JP positive], but looking at items [in the SPICT-JP], even though he didn't meet, made me notice I hadn't seen this or that, such as bedsores. So, using the SPICT-JP made me notice and reflect. (ID04, second interview)*

For participants who reported that the SPICT-JP did not change their actions, it was somewhat disappointing that the SPICT-JP did not radically change their practice. It left them with an impression that the SPICT-JP was not that useful. As in the quote from ID07 in 8.1.3, these participants already had some plans for those patients as guided as needing future care planning by the SPICT-JP. In addition, there were some cases where the participants purposefully decided *not* to initiate end-of-life discussions, as shown in the following quote:

> *If we start talking directly about the end-of-life stage based on the content of the SPICT-JP to patients, for example, to patients with anxiety problems, then, they would become very unsettled… (ID15, second interview)*

This participant presented a case of a patient who was too afraid of talking about bad news, so he postponed discussing such issues with this patient at that time. Overall, the participants seemed to evaluate the patients' readiness for a discussion about future care planning, which mattered more than the SPICT-JP guidance. This seemed to reflect the participants' intention to provide more person-centred care, which is also culturally sensitive, than just to follow routine clinical guidance.

It was noteworthy that the participants sometimes reported that negative results equally, if not more, informed patient care, particularly for patients without cancer. The following quote shows how the participant realised that the patient was not in the terminal stage by using the SPICT-JP.

> *Yes, this gentleman would be identified [as palliative care] if I take incontinence into account, but as he has had both stoma and a urostomy, so if I don't take it into account, then he would be 'negative'. So, although he has a stoma, he is not at the terminal stage of cancer. On paper, it's written as terminal*[5]*, and once it's written as such, we all think this patient as terminal. I myself didn't think I was affected, but it was so. But, I realised except for his incontinence, this patient doesn't meet any criteria. We need to do anything we could for him. […] So, this gentleman overcame his cancer, so now he doesn't have it. He doesn't have cancer now. He did have a significant operation which made him frail, but if we could give him good*

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[5] She probably meant that the patient was coded as 'terminal cancer patients' in the healthcare reimbursement scheme. In Japan, healthcare facilities can receive extra reimbursement by coding patients as 'terminal cancer patients'.

> *support, like encouraging him to eat well, then he could live well normally. I realised that. (ID10, second interview)*

This suggests that the participant used the lack of SPICT-JP indicators as a sign that the patient still had an opportunity for recovery or a more active intervention to improve their well-being. This probably reflected the participants needing some sort of ‘confirmation’ because of their uncertainty of the patients’ illness trajectory.

8.2.1 Patients with long-term relationships and conditions

Gaining an opportunity to review patient care and to act accordingly was welcomed for all kinds of patients, but the participants found it especially useful for patients with whom there had been a long-term relationship and who had chronic conditions. They reported that the long-term conditions, without significant events but with gradual deterioration, had made it difficult for them to review the patients’ care plan and to open up a conversation about it, particularly a plan for when the patients deteriorate. Using a tool like the SPICT-JP allows such users to acknowledge patients’ deteriorating conditions. It offered the participants opportunities to think about and discuss future care plans with these patients, as shown in the following quote:

> *I’ve seen this patient for three years, and we had lost the momentum for such a conversation. …The SPICT-JP gave us an opportunity to pause and review. (ID04, second interview)*

Another participant mentioned more specifically that those patients with non-cancer chronic diseases would benefit most by being evaluated by the SPICT-JP.

> *The most useful situation would be when there are no clear answers. I think I could use it [i.e. the SPICT-JP] ideally with non-cancer patients such as the first case [on a case log] with pulmonary disease. So non-cancer patients without dementia but with COPD, for example, who are essentially progressing towards a terminal phase. It’s useful for those kinds of patients as we unexpectedly miss doing such a thing [i.e. discussing their future care] with such patients. (ID09, second interview)*

8.2.2 Reflecting on their practice

The participants commented that using the SPICT-JP promoted their reflection on their practice. The reflection helped the participants to understand what the problems with the patients were and how quickly they should respond to those problems. The following quote explains how this participant found the SPICT-JP useful to reflect on his practice.

> *Changes made by using it [i.e. SPICT-JP] were, it gave me an opportunity to reflect on myself. I realised once again that metacognition is important. What I mean by metacognition is that I realised that I could categorise the stresses I felt towards patients. They could be social or medical. And also [evaluating] swiftness on my part needed for the patients. (ID02, second interview)*

Some participants said that they gained new insights into their practice, including noticing their tendency to put more emphasis on psychosocial aspects than on medical aspects or vice versa. Other participants felt reassured that their practice had not tremendously deviated from the aims of the SPICT-JP, as shown in the following quote:

> *The useful aspect was because many of the patients were identified, though I only did my palliative care training for three months, [I realised] there was not a massive gap between my [understanding of] palliative care needs and this sort of international criteria. (ID14, second interview)*

The participants seemed to gain such insights by having a dedicated time to reflect on their practice with the SPICT-JP. This allowed them to step back and observe their practice from a distance with a reference point.

8.3 Raising awareness

Some participants commented that as a result of using the SPICT-JP in their practice, their awareness was raised regarding the value of timely identification of palliative care patients. This seemed to be brought about as a result of reviewing patients’ care and reflecting on their practice.

> *[Although there might not be obvious changes in my practice, but] there are certainly good things arising out of using it. In the end, it raised my motivation to think about patients and their future plans, and that's good. (ID04, second interview)*

In addition, a few participants changed their perception of identifying patients for palliative care. The following participant seemed to have had a narrower perception of palliative care in mind at the beginning of the research, but using the SPICT-JP and seeing the outcome made her think that she should plan patient care more proactively.

> *It was different from what I had expected at the beginning. [At the beginning] I thought I should pick up people who had symptoms to be resolved, but having seen many frail older people picked up, I thought I should talk with them more about what they would like to do or how they would like to live… (ID03, second interview)*

Even more, some participants stated that the existence of such a tool like the SPICT-JP – or this research itself – impacted positively on their awareness.

> *My perspectives on palliative care haven't changed a lot, but seeing the development of the SPICT-JP itself, or hearing about this research made me realise once again the importance of assessing people who might need palliative care, or discussing such patients among care professionals. Such attitudes haven't changed, but have been reinforced. (ID07, second interview)*

As shown in the quote above, the participants regarded the existence of this research as a sign of increasing interest in this topic internationally, which also fostered their motivation for early recognition of patients needing palliative care.

8.3.1 Awareness of palliative care needs for non-cancer patients

As briefly discussed in Section 8.2.1, the participants found the SPICT-JP useful for patients with non-cancer illnesses. An awareness of palliative care for non-cancer patients seems to have been strengthened by using the SPICT-JP. Having the non-cancer diagnoses listed on the SPICT-JP sheet seemed to be particularly important (see also Section 8.1.1). The existence of a tool, which includes patients with non-cancer problems as candidates for palliative care, seemed to enhance users' awareness of palliative care for non-cancer patients.

> *While using the SPICT-JP, because it has a section for them [i.e. non-cancer illnesses], I became more conscious about checking any problems caused by non-cancer illnesses. […] These problems can be candidates for palliative care, and I became aware of this. […] I mean, there are somethings which I haven't thought of as being palliative care, yes, there are. (ID04, second interview)*

ID05, who worked in a hospital, discussed that raising awareness by having such a tool was particularly important for hospitalists:

> *This [palliative care] perspective could be easily overlooked, particularly for patients without cancer. For example, people with dementia and frailty, patients with neurological disorders, those with heart and vascular conditions, or those with severe heart failure or respiratory failure. For all of these, our attention goes to ad-hoc treatments. So, these objective criteria [of the SPICT-JP] being available and our building awareness based on these, such as we have to think of palliative care for these patients, would be very valuable in hospitals. (ID05, second interview)*

8.3.2 Ripple effect

It was noteworthy that one participating family physician reported that a patient's wife became interested in discussing her own wishes for the end of her life when witnessing 'advance care planning' discussion with her husband.

> *When I was talking about end-of-life discussion with my patient while using the SPICT-JP, his wife was impressed with this, and she said she'd heard something very important. She started to think that's also important for her. I myself wasn't taking care of her, but she decided to talk about her DNR with her doctor. (ID17, second interview)*

Although this was observed by only one participating doctor, it was an important finding considering the purpose of the SPICT-JP. From the interview with this participant, it was revealed that ID20 was exceptionally good at bringing up end-of-life issues. He also had a positive attitude towards so-called end-of-life discussions. It may not have been his using the tool, but his positive attitude that led to her reaction of wanting to discuss her end-of-life issues with her own doctor. In either case, it indicates that having an open conversation about end-of-life issues with patients could normalise discussing end-of-life issues for those close to the patients.

8.4 Meaning of having the SPICT-JP

In the interviews, the participants expressed various views on the value and appropriateness of having the SPICT-JP in their practice. Some participants in this study welcomed the benefit of having a set of criteria in order to evaluate the patients' conditions systemically. They liked having a tangible 'checklist' in their hand, which could potentially prevent their overlooking something critical about patients. It seemed to relieve the participants' uneasiness when dealing with uncertain situations. In their clinical practice, they often looked for signs of patients' deterioration without clues, sometimes ending up relying on their 'gut feeling' (See also Section 7.5.2).

> *If asked were there any useful points [about the use of the SPICT-JP], the answer would be it prevents our missing something when we were busy or distracted. It would be ideal not to miss anything without using this, but we're human beings, and we can make mistakes. (ID18, second interview)*

They also liked the relatively objective criteria in the SPICT-JP. ID05 who is working in a hospital emphasised this point:

> *Having these objective items would be very valuable in hospitals as they raise awareness for palliative care, not only the treatment which we tend to focus on. (ID05, second interview)*

Moreover, some participants found items in the SPICT-JP helpful and instructive. They interpreted such items in the SPICT-JP as being critical points which they should constantly be referring to in order to understand patients' conditions better.

> *… looking at the clinical indicators below [in the SPICT-JP] made me realise that this patient had chronic kidney failure. So it was good, I think. (ID04, second interview)*

Some of them said that they ‘learnt’ from the SPICT-JP criteria that they should be checking these points for patients:

> *After all, I learnt that these criteria would be the things we should be looking at carefully. Particularly for those patients with something like frailty, I’ve now got a picture of the criteria which we should be checking. (ID11, second interview)*

Sometimes, it sounded like the participants perceived the SPICT-JP as a gold standard recommended by an authorised body. Furthermore, ID17 mentioned that he understood that the items in the SPICT-JP were listed as ‘prognostic factors’, which was not necessarily consistent with the aim of the SPICT development.

> *And looking at such items made me understand that these could be prognostic factors. (ID17, second interview)*

When the patients were identified as candidates for palliative care by the SPICT-JP, it was affirmative for the participants that their instincts had been correct. Thus, it reinforced what they thought they should do for their patients. While most participants already had a rough idea to whom they should provide palliative care and what they should do for them, it was often difficult to take an actual step forward, and they paused at this stage. Bringing a tool like the SPICT-JP into the practice was seemingly helpful as it gave them a nudge to proceed to the path they planned. ID02 used the word ‘verbalise’ to refer to this point:

> *Well, it was good that I could verbalise the patients’ getting unwell, or that something was wrong [by using the SPICT-JP]. (ID02, second interview)*

For these participants, this feature of using the SPICT-JP was highly regarded as it could make them feel confident and comfortable. On the other hand, this feature was not so attractive to some other participants because they had already been doing what the SPICT-JP suggested, namely, selecting patients who would need palliative care, and taking some actions accordingly.

> *'What we did was confirmed by the SPICT-JP. Yes, we're right!' – this wasn't that useful to me. Of course, there might be some people who would like to have their judgement confirmed by a tool like this, but I want some changes [by using such a tool]. (ID07, second interview)*

As shown in the above quote, ID07 wanted a system to change his practice and did not find the SPICT-JP as being so useful because it did not change his practice. In addition, some participants thought that family physicians should be good at identifying patients for palliative care and at initiating conversations about the future and end of life when needed. They considered that dealing with such issues was an important part of family medicine, and so it was already integrated within their practice. Singling out this function of family medicine by such a tool as the SPICT-JP was not significantly helpful for some participants.

> *If you are thinking about the indication for palliative care, then you'd better just provide palliative care [without further pondering about it or evaluating such a need with the SPICT-JP]. (ID07, second interview)*

Another participant (who was very confused with how to interpret the recommendations on the SPICT-JP, see Section 8.7.4) did not find the SPICT-JP so useful as she could already communicate with other professionals about patients' conditions listed on the SPICT-JP.

> *[The indicators in the SPICT-JP] were already shared with medical professionals. It's not a prognostic tool, so it's difficult to decide how we change our actions. […] I didn't know how and why I could share this information with other people. […] We already communicate with nurses and social workers on a daily basis about such patients, and we have weekly meetings. I didn't know if our own - and their - actions and approaches would change if I brought this before them. (ID16, second interview)*

It could be interpreted that she might not have needed the SPICT-JP because she was already making time to think about the future of her patients and working in a good environment with sufficient communication with other healthcare professionals. She was working in a hospital with a focus on community and palliative care. All of this could make it easier for her to recognise patients' palliative care needs than other participants who were working in the community without much direct interaction with other healthcare professionals. In such an environment, it might be more difficult to find a role for a tool like the SPICT-JP.

8.5 Appropriateness of the SPICT-JP

The participants also gave their accounts of the appropriateness of the SPICT-JP as a tool. These cover its practicality, the appropriateness of each criterion and formatting.

8.5.1 'Easy enough' – practicality

Generally speaking, the participants regarded the SPICT-JP as being easy and concise enough to use in their practice. Only one participant said that it took her too long to complete the evaluation with the SPICT-JP for each patient.

> *I wondered how long…. It didn't take too long…. 20 minutes, but I go back and forth while seeing this [i.e. the SPICT-JP] and then got back to the patients' notes and summarise. So about 20 to 30 minutes? […] It may be difficult to use this with a large number of patients. […] Yes, it's a bit tricky if you don't have access to patients' notes. I might want to go off duty. (ID17, second interview)*

Most of the participants said that it had taken a much shorter time.

> *It was not difficult [to use the SPICT-JP]. At the beginning [I found it difficult], but once you get underway, it's not difficult. Honestly, even if I had to check all the patients [with the SPICT-JP], I would be able to do so without any stress. I think the nurses could use this, too. (ID02, second interview)*

As indicated in this quote, not only did the participants welcome the tool's conciseness for its own sake, but they found it helpful because nurses or other healthcare professionals could also use it.

8.5.2 Lack of psychosocial aspects

As discussed already, the participating family physicians understood that palliative care did not only deal with physical problems (See also Section 6.2.1). They regarded the social environments and psychological status of patients as being as important as physical factors. The participants often highlighted that psychosocial aspects were not included in the SPICT-JP, and instead, it rather concentrated on medical or physical aspects.

> *I used it [i.e. SPICT-JP] with patients whom I found difficult, for example, those with complicated family relationships, or social problems, but these patients resulted in not being identified. I'm not sure if that's good or not, but at least such patients may not have life-threatening medical problems although I find them difficult to manage. I probably find them difficult for other reasons. (ID02, second interview)*

As shown in this quote, ID02 did not necessarily regard the absence of psychosocial aspects in the SPICT-JP as a deficit. Similar views were shown by many of the other participants too. Some participants disagreed with such factors being included in a tool like the SPICT-JP, arguing that it would make the tool too complicated.

> *It could present identified patients as being more seriously ill if we have additional criteria or factors to check such as being unable to get changed or unable to walk or needing a full package of care, but using such criteria or factors would be too complicated. It's probably better to stay in a light check mode. It'd be better to remain as a screener. I think that'll be better. (ID02, second interview)*

8.5.3 Stringency of criteria

There were different opinions on the stringency of indicators in the SPICT-JP. On the whole, the participants thought that more patients should have been identified by the SPICT-JP. ID01 insisted that all cancer patients should be regarded as candidates for palliative care. For him, the SPICT-JP indicators only identified patients who were too close to death for timely initiation of palliative care.

> *For example, with cancer, there are only two criteria. One is daily-living physical functional decline due to metastatic aggressive cancer, and the other is the inability to receive chemotherapy or anti-cancer treatment for symptom alleviation. For me, they were already palliative [care patients] as soon as they were diagnosed with cancer. (ID02, second interview)*

Another participant, ID04, found it difficult to indicate which situations the SPICT-JP could be used, because it did not identify patients who he thought should be identified, and those who were identified were too sick – and some sort of palliative care had already been put in place for them. The latter part of the following quote is related to the quotes from ID07 in Sections 8.1.3 and 8.4, showing this view that the SPICT-JP did not change his practice or action in care.

> *My overall impression, is, well, I used it at my outpatient clinic with patients who were frail and who I think will deteriorate, and they were not necessarily identified by the SPICT-JP, which wasn't what I'd expected. On the contrary, I used it with a so-called terminal cancer patient out of curiosity, and then they were not suitable, either. I mean, he was already in palliative care mode and various interventions were about to start. Discussions such as advance care planning had been already done. So the SPICT-JP didn't trigger any new discussions. (ID04, second interview)*

Not surprisingly, the participants' views on the stringency of the SPICT-JP criteria depended on their perception of palliative care (*e.g.* narrower or broader concepts of palliative care in Table 6.2). Often, the SPICT-JP criteria were too stringent to start future care planning discussions, which was considered as being included in the principles of palliative care. The participants thought that these discussions should be initiated before patients showed clear signs of their deterioration.

Among all categories of patients' conditions, frailty appeared in the interviews more frequently than other conditions, indicating that the participants often saw patients with frailty and so their comments varied regarding how stringent the SPICT-JP criteria should be. Following the quote above, ID04 went on to detail his concerns that the SPICT-JP would not be able to identify patients with frailty.

> *When I looked at it [i.e. SPICT-JP], it seemed to try to identify patients with dementia, probably those with severe dementia. But it concerns me that it probably cannot identify patients with manifest disuse [syndrome] or frailty. (ID04, second interview)*

On the contrary, other participants argued that the SPICT-JP would identify too many patients with frailty probably because they saw so many patients with such frailty.

> *There would be many patients who would meet this [i.e. frailty] category. If you 'catch' older people who are around, many of them would meet the category [more than people who are in other disease categories]. There would be so many people meeting this category. (ID03, second interview)*

It can be assumed that, for the participating family physicians, identifying patients who need palliative care may be similar to stratifying patients in their patient panel, which is related to the points in Sections 7.3.1 and 7.5.2. Some participants indicated that they consciously or subconsciously tried to relate the number of met items in the SPICT-JP to the severity of their patients' condition.

8.5.4 Formatting & User-Guide

There were some comments on the formatting of the SPICT-JP sheet. One participant could not understand how to use the SPICT-JP even with the user-guide. He was obviously confused and kept asking how he should score each section. In particular, he could not understand whether he should check both the general indicators and the clinical indicators.

> *Yes, items in the cancer category, […] and other categories [in general indicators]. […] Should I have checked all [categories] for each patient? […] Then this patient would have frailty as well. I only looked at the cancer category. Should I check all? (ID06, second interview)*

In addition to his confusion, ID07 stated that the format of the SPICT-JP could not support users to use it intuitively.

> *It isn't explained well enough how each section [in the SPICT-JP] is related. I mean, they don't explain about looking for general indicators AND or OR clinical indicators. (ID07, second interview)*

It seemed that the information on how to interpret each section provided in this research was not clear enough and made some participants confused.

Regarding the attached user-guide, including those who did not use it, most of the participants agreed that having a user-guide was useful. In particular, they found it useful to have a clear description of the purpose of the SPICT-JP: the aim is not to provide an accurate prognostication, but to provide an opportunity to start thinking about future care plans.

> *It was emphasised that it was not a tool for prognostication, which I bore in mind when I was using it. Also, examples of when to use it were also good. I was thinking of using it with homecare patients, so it made me think that I could use it when patients' conditions changed, or when the place of their care changed. By looking at it [i.e. user-guide], I actually decided to use it with a patient who was recently discharged from hospital. I also found helpful some examples of starting conversations [in the user-guide]. (ID09, second interview)*

As shown in the above quote, it seemed that providing a clear description about the purpose of the SPICT-JP was important, either within the SPICT-JP itself or in additional material such as a use-guide. On the other hand, while most participants had looked at the user-guide, some participants were still confused with the ultimate purpose of the SPICT-JP and how they could best use it in their practice. Their confusion regarding the ultimate purpose of the SPICT-JP will be discussed later (See Section 8.7.3).

8.6 Potential roles of the SPICT-JP

In the interviews, the participants also mentioned the potential roles that the SPICT-JP could play in education, communication and quality control. The participants did not necessarily use the SPICT-JP for these purposes during the study period, but they identified the potential of the SPICT-JP in these areas.

8.6.1 Education

The participants thought that the SPICT-JP would function as an educational tool, commenting that not themselves but other more inexperienced doctors would benefit from using the SPICT-JP. More precisely, potential beneficiaries would be family medicine trainees and doctors trained in other fields without formal training in palliative care. Some participants said that they would like to – or did – share the SPICT-JP with junior doctors for educational purposes, while they did not think that they would use it themselves.

> *I wouldn't use it [i.e. SPICT-JP] myself, but I introduced it to junior or younger doctors several times. That is, there are people who are unsure about how to identify such patients and they could use the SPICT-JP to write their portfolio*[6]*. I would like to introduce the SPICT-JP to doctors who do not have a developed palliative care mind-set. (ID17, second interview)*

This participant repeatedly said that he would not use the SPICT-JP, whilst trying to identify why he still thought that the SPICT-JP was useful.

> *Still, I think there is an importance for this [i.e. SPICT-JP]. […] there are not many people who think about palliative care [or advance care planning] as part of health maintenance […], and if this can generate an opportunity to 'change the gear' […] if it works as an educational tool to enable one health care professional to gain such views, then it would be very meaningful. (ID17, second interview)*

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[6] Family medicine trainees in Japan have to submit a series of portfolios to become JPCA-qualified family physicians.

He subsequently pondered on who would benefit most from the SPICT-JP during the interview. The answer was revealed in the following quote:

> *Regarding who would benefit by using this,[…] it's not that useful for people who have fully integrated a palliative care approach into their practice. When needed, they can automatically take a palliative care approach. But it'd be useful for people who have an interest in it [i.e. palliative care] and who provide some palliative care – but not at that level [of providing palliative care automatically]. For those who don't have any interest at all, they might not think of using it, but it may generate some awareness. So, I think it's meaningful. (ID17, second interview)*

Generally, the participants thought that family medicine education helped them to nurture insights into palliative care and how to initiate so-called end-of-life discussions. The participants had observed many doctors who did not have those sorts of insights, which made them feel concerned about such doctors' care for their patients. The participants thought that tools like the SPICT-JP and the education that accompanied it would help these doctors gain deeper insights into palliative care.

> *As for me, I myself was trained in family medicine including palliative care, the concept of frailty, so it's not new to me. But for doctors who've been working in internal medicine, they probably haven't learned much about frailty as a concept, or illness trajectories. They treat pneumonia without thinking much about such background. It'd be very useful to raise their awareness, it's not only about treating, but palliative care is also important. (ID05, second interview)*

8.6.2 Communication

Although not many participants used the SPICT-JP as a communication tool because of the limited timeframe for this research, the participants mentioned that the SPICT-JP has the potential to enhance communication between doctors and other healthcare professionals.

> *When I saw it [i.e. SPICT-JP] for the first time, my first impression was that I wouldn't have to be alone at the outpatient clinic. I wanted nurses or other co-medicals to use it. I thought that it would be important to verbalise [and*

> *discuss] ‘this patient is getting more unwell’ [with other professionals]. […] For example, nurses see the patients in the waiting room, and they could use it if they think the patients would benefit from it. (ID02, second interview)*

One participant actually used the SPICT-JP with his colleagues, including junior doctors and nurses. He said that it gave them opportunities to discuss the patients and their care.

> *ID08: […] we do home visits with nurses, one doctor and one nurse [go and see patients together]. We have different nurses at different times. Doctors normally remain the same [for the same patient for regular visits], but sometimes other doctors have to go and see [the patient]. So I thought it’d be useful for information sharing if we assess the patients [with the SPICT-JP] and attach it to their medical records. […]*
>
> *Interviewer: Did you have any problems in using it with others?*
>
> *ID08: No. No problems. On the contrary, I could ask nurses when I wasn’t sure about the criteria. I didn’t know how many times the patient fell, or how often they had a fever, for example. […] It’s also useful to have someone else in assessing if the patient had any suffering. It’s a bit tricky for me only to judge if the patient is receiving appropriate treatment or not, and if they are suffering or not.*
>
> *(second interview)*

As indicated in previous chapters, an understanding of palliative care often differs for each healthcare professional and sometimes it is difficult to agree on the care plan (see Section 6.3). The SPICT-JP was considered particularly useful in that sort of situation. ID07 explained that the SPICT-JP helped him to establish a shared understanding of who would benefit from palliative care with other professionals.

> *Another positive thing would be, it [i.e. SPICT-JP] would be an informative resource which tells other professionals that these kinds of patients would benefit from palliative care. (ID07, second interview)*

Another participant was working in a hospital where she often found it difficult to negotiate with her colleagues who were trained in internal medicine. She thought that using the SPICT-JP would make any discussion with them easier.

> *I think sharing it [i.e. SPICT-JP] with other doctors is very important. I'm currently working on a ward in a hospital with colleagues who are trained in internal medicine and who are more familiar with working as 'hospitalists'. And I sometimes find there is a gap between us in our understanding. I'm aware that I often think 'would you go further with aggressive treatment in this situation, now?' I'm not saying which is right or wrong, but it [i.e. using the SPICT-JP] would make that sort of discussion easier. (ID05, second interview)*

From these responses, it seemed that the SPICT-JP could not only help to trigger the discussion between healthcare professionals about patients but also function as a mediator for difficult communication when professionals have different views on palliative care.

8.6.3 Quality control

Another noteworthy comment from one participant about the potential roles of the SPICT-JP was that it might be useful at clinics where the expertise of the doctors was uncertain. There are clinics in Japan where locum doctors undertake the majority of the clinical workload. These doctors are not necessarily formally trained in family medicine or primary care, leaving in doubt the quality of their practice. The participant thought that patients who needed future care planning could be overlooked by such doctors who were not familiar with chronic disease management and patients' contexts. In such situations, nurses or other appropriate professionals could use the SPICT-JP to screen patients to identify those who might potentially benefit from further evaluation – including an assessment of the need for end-of-life discussions or future care planning.

> *In particular, it [i.e. using the SPICT-JP] would be useful where care is not quality-controlled. Where everybody takes care of patients with a shared view [which considers a palliative care approach as important], then patients would not be identified*

> *[by the SPICT-JP as being new palliative care candidates]. But, for example, in nursing homes, or where you have lots of locum doctors, in such situations the chances will be bigger that you would find patients who have not yet been considered for palliative care and also that you would change such care. (ID07, second interview)*

The conciseness of the SPICT-JP was considered as being important here. Because it was easy and simple enough, although some arrangements such as training might be preferable, he thought of nurses and other professionals using it.

8.7 Potential risks and challenges

The participants mentioned not only the potential roles but some potential challenges in using the SPICT-JP together with some possible solutions. Particularly, I intentionally asked the participants about their views regarding the risks of using the SPICT-JP in clinical practice to elicit the participants' non-biased opinions on the SPICT-JP. In this section, I will describe their responses to this question and other challenges reported in the interviews.

8.7.1 Risks of using a 'tool'

Even when asked directly, the participants could not identify any major risks in using the SPICT-JP in their practice. The only potential risk, they mentioned, might be the unnecessarily labelling of patients as 'terminal'. One participant articulated this point as follows:

> *I cannot think of any risks as long as it [i.e. SPICT-JP] will be used in the way it should be. […] if it's used mistakenly, like 'this person is terminal, isn't it? We don't have to treat them, do we?', then people needing treatment would not receive such treatment. It's like there might be healthcare professionals who wouldn't treat treatable diseases once it's written as DNAR. (ID07, second interview)*

The same participant added a potential solution for this risk:

> *As long as we understand the purposes written down in the user-guide, what it's for and what it's not for, and as long as we use the SPICT-JP based on a correct understanding, then*

> *that sort of mistake would not happen. […] So, it might be useful to have some blurb like ‘you should look at the user-guide first’ in the SPICT-JP itself. If only the sheet [of the SPICT-JP] is circulated and becomes available to everyone, there might be a possibility of a mistake as the nuances in the user-guide wouldn’t be available. (ID07, second interview)*

This response, as with those in the previous section (Section 8.5.4), indicated that providing a clear explanation of the purposes and appropriate ways to use the SPICT-JP was critical.

In addition, one participant reported the possibility of patients not being reviewed after having been once evaluated with the SPICT-JP. As shown in the following quote, he suggested that patients should be evaluated regularly.

> *I don’t think patients would get any disadvantages [by being evaluated by the SPICT-JP]. But in one instance, for example, […] if the patient doesn’t meet the criteria then you write that this patient was ‘negative’ [on the patient’s medical record], and then, the patient will never be identified unless you evaluate him again. You might think this patient is out of the issue. […] it might be better to evaluate [patients] regularly, annually or bi-annually. (ID08, second interview)*

Another participant pointed out the possibility of a ‘tick-box exercise’ and easily nominating patients for palliative care without careful consideration. However, interestingly, he did not necessarily regard it as a negative. He thought that SPICT-JP users would individualise care for the patients, so he considered that listing patients as ‘potentially’ needing palliative care would not harm anything even if it is premature. It was noteworthy how naturally he described his expectation for other healthcare professionals to take individuality into account in taking care of patients. Providing individualised care seemed to be a natural part of their practice.

> *ID06: Yes, we’d use it as a tick-box sheet, but I’m not sure if that’s right or wrong. There are many robust items and we may easily tick them and once the patient meets the criteria then we would think of palliative care more readily. I think that’s positive, too.*

> *Interviewer: Right, so it makes it a bit mechanical?*
>
> *ID06: Yes, indeed. It becomes a bit mechanical. I still think it's no problem at all if you use it to change your attitude a bit. […] In actual care, I think we would take the individuality into account.*
>
> *(second interview)*

8.7.2 Challenge to start using the SPICT-JP

Although many participants said that, overall, it was quick and easy to use the SPICT-JP, it was noteworthy that many participants found it difficult to 'start' using it. While some participants articulated their struggles in the interviews, it was already evident from their responses to my contacting them during the research period before the second interviews. Often, they had not used the SPICT-JP as yet when I contacted them. As I mentioned previously, I left them to decide when and with whom they would use the SPICT-JP. The degree of freedom given during the study seemed unhelpful for many participants. It was problematic for them to decide with which patients and when they should use the SPICT-JP. Interestingly, as one participant stated in the following quote, it was much easier for the participants to continue to use the SPICT-JP after their first use.

> *Once I knew what it was like after using it for the first time, it took off. Using it didn't bother me very much after using it for the first time as I've got the whole picture. (ID02, second interview)*

Another participant said that his clinic already had similar forms to evaluate newly admitted patients for medical homecare. Having the SPICT-JP on top of such forms seemed to be superfluous.

> *Yes, we have forms to check things which we think we should be checking for patients requiring medical homecare, which include future directions, advance directives, or similar items. So, we always see medical homecare patients from that point of view, and we go ahead and evaluate. (ID07, second interview)*

Some participants said that it would be easier to use the SPICT-JP if it was embedded in the medical record systems to align it with the regular practice.

> *Reminders [to start using the SPICT-JP would be helpful]. For example, if the patients' record has some paper or something inserted, or something to remind me, then I would be prompted to use it. And, if it were clearer with which kind of patients we'd be better using the SPICT-JP, then my motivation would have increased. (ID04, second interview)*

8.7.3 Setting factor

One participant mentioned that patients who should be identified for palliative care might be different in different settings. He practised in an urban area in Tokyo with lots of accessible hospitals around. In such an area, patients with serious medical conditions go to hospitals directly, bypassing family physicians in the community. This meant that patients who needed his attention were less physically serious but needed more psychosocial support which was not often provided by hospital specialists.

> *I realised that it depended on the cohort of patients. If we're seeing patients whose conditions are biologically serious, then the care would be signposted in that direction. But, when patients are less serious, then we'd be thinking more about psychosocial support or family care, or that sort of intervention. (ID14, second interview)*

In relation to this and the point raised in Section 8.1.5, the participants who used the SPICT-JP with medical homecare patients tended to say that the SPICT-JP was not helpful in identifying patients needing palliative care. From their point of view, almost all medical homecare patients had already required some form of palliative care, and they had been providing such care accordingly. One participant revealed in the following quote that the SPICT-JP would be useful for outpatients without cancer diagnoses because he thought that all medical homecare patients and cancer patients should be candidates for palliative care.

> *In particular, it's less meaningful for medical homecare and cancer patients [because they are already candidates for*

> *palliative care and so it has less meaning in evaluating them], and also it would be better to simply use it with outpatients without cancer. I simply think it'd be better. (ID20, second interview)*

As shown in the quote above, the participants in general thought that the SPICT-JP might be useful in outpatient clinics (See also the quote in Section 8.1.3). The heterogeneous characteristics of outpatients might conceal those who required more attention regarding palliative care. In such environments, the SPICT-JP might be more effective in helping family physicians to identify those who needed palliative care. This notion can be contrasted with the quote from ID15 in Section 7.3.1, reporting the difficulty of identifying patients needing palliative care in an outpatient setting.

There was an interesting contrast between how general indicators within the SPICT-JP would be dealt with for outpatients and inpatients. In the following quote, ID14 pointed out that some outpatients were not unwell enough to be identified by the SPICT-JP as they did not meet the general indicators, which is similar to the point suggested by ID15 in Section 7.3.1.

> *Again, for patients at outpatient clinics, it was unlikely to have deterioration in the general indicators. They are not extremely well but stable. For example, they do not rely on others for their activities of daily living, but still they have some problems. They are not in hospitals, but their health status is lower [than people with good health]. For these patients, the general indicators would not be met. (ID14, second interview)*

This participant did not identify many patients with the SPICT-JP. He questioned how doctors in different environments would find this tool.

> *I assume that family physicians who see more severe patients would identify more patients [with SPICT-JP], so I'm intrigued by the results [of this study]. Would I be the only one like this? (ID14, second interview)*

On the contrary, it was pointed out that all inpatients would meet the general indicators because they were admitted to hospitals for acute problems which caused some deterioration of their general conditions:

> *And inpatients were worse than usual, so they meet the general indicators. But, actually, they all meet [the general indicators]. (ID06, second interview)*

Evaluating patients' palliative care needs with the SPICT-JP at the point of admission was not deemed as being ideal, as it did not reflect the patients' general conditions.

8.7.4 Next steps after using the SPICT-JP

The greatest challenge suggested by the participants was the interpretation of and implications for having used SPICT-JP. Often, the participants were confused by what they should do after evaluating patients using the SPICT-JP, making them concerned about the ultimate purpose of using the SPICT-JP in practice.

Interpretation of the results

The participants often mentioned that it would be helpful if more explanations of the SPICT-JP outcomes and actions were available. It was sometimes difficult for them to discern the difference between people who were identified and those who were not, which led them not to change anything in the care for them (See also Sections 8.2). In particular, although they understood that the SPICT-JP was not to estimate patients' prognoses, they still wanted to know how much time patients had left when they were SPICT-JP positive.

> *I know it would be very difficult [for developers of the SPICT-JP], but it would be useful if the data was available to explain their prognosis or something for those who were identified [by the SPICT-JP] at certain stages. I know it'd be difficult and it's understandable there is no such data. But it's too vague and says nothing. I used it and am still not sure how those identified were different from those who were not. (ID18, second interview)*

As briefly discussed in Section 8.5.3, some participant tried to find a relationship between the number of met items and the severity of the patient's conditions.

> *It’s probably not like we don’t have to do anything for future care planning when patients didn’t get any ticks or they only got 3, is it? It doesn’t mean we don’t have to approach that patient, does it? I thought not. Or did I misunderstand? (ID16, second interview)*

> *I wasn’t sure if I could judge the results [of the SPICT-JP] like that. For example, if the patient meets a lot [of criteria] then this patient is really bad. I wasn’t sure if that sort of approach is appropriate. So I’m stuck with this. (ID16, second interview)*

> *It’s probably not correct to say patients with more criteria matched are more unwell. The judgement of how quickly we should act should be made clinically [not depending on the SPICT-JP]. […] it’s probably impossible to judge to what extent we should change our gear [for the patient care] by this paper [i.e. the SPICT-JP]. (ID02, second interview)*

SPICT-JP recommendations

While each indicator was considered as being concise and succinct, recommendations at the bottom of the SPICT-JP (See Appendix 1 and 2) were perceived as not easy to understand. Some participants said that the texts and information they contained were not readily comprehensible when they were busy seeing patients.

> *Well, they are alike each other. I first thought that it recommends us to do these five things in this order. For those identified, we would review the medications, refer if needed, and discuss the care plan, like that. I didn’t think we should pick up one of these, but should we? […] They overlap each other. For example, reviewing medications and referring to a specialist if needed and reviewing planning are all included within the latter three. (ID03, second interview)*

One participant said that he had already been doing most of what was recommended, so no actions were added to his practice except for gaining some insight into the risk of a loss of capacity:

> *I assume that the final part is what we should do. [Reviewing the recommendations one by one,] ‘Review current treatment and medication so the patient receives optimal care’. That’s what I always do. Then, ‘Consider referral for specialist assessment if symptoms or needs are complex and difficult to*

> *manage', this is obvious. 'Agreeing current and future care goals, and a care plan with the patient and family', this is again needless to say. I might not always be doing 'Plan ahead if the patient is at risk of loss of capacity'. […] 'Record, communicate and coordinate the care plan', is again obvious, and I'm doing this every day. So, I do most of the things recommended here. Surely, how to manage the risk of loss of capacity is a burning issue. It [i.e. using the SPICT-JP] wouldn't bring about any particular new actions, well, it didn't, though it made me think of this again. (ID20, second interview)*

In this quote, ID20 admitted that while the recommendations on the SPICT-JP made him think about them, they did not bring any particular changes in his practice. Other participants added that these recommendations should not only be for the patients who were identified by the SPICT-JP.

> *This, what's written at the bottom, such as reviewing supportive and palliative care plans, essentially should apply to all patients at all stages. So, it's an attitude we should have towards all patients rather than just those identified. (ID05, second interview)*

> *Plan ahead when the patients are at risk of losing capacity, or agree a care plan with the person and their family – I'm doing these without this tool. I cannot imagine a situation where we intentionally have to do these. (ID16, second interview)*

Some participants wanted clearer or more specific instructions as a recommended action after the evaluation. While the concept of these recommendations was not new to – and understandable for – them, extrapolating what they actually should do in their practice seemed challenging.

> *The intervention part [i.e. the recommendations] wasn't that specific. At the bottom, there are recommendations as to what to do when patients meet the criteria, but we had already done these, or sometimes although we could understand what it meant, we didn't know what specifically we should do for the particular patient. (ID08, second interview)*

One example of such situations was 'Consider referring patients to specialists'. Here, many participants were confused with the term 'specialists' in this context as palliative care specialists were not necessarily accessible in the community in Japan.

One particular participant showed her strong confusion on this part and wanted a much clearer description for this next step. She repeated words such as ‘difficult’ or ‘don’t know’ to describe her experience of using the SPICT-JP at this stage. The followings are the examples of her comments:

> *Well, it was a bit difficult. I might not have understood it well though..., I understood that it was not to lead to a prognosis, but then I couldn’t understand how I could use it in the practice. (ID16, second interview)*

> *For example, it might be easier for me to take these actions if it said ‘let’s make a plan like this when patients get five ticks’ or ‘if the patients were positive with all indicators then consider such patients are in crisis and share this with other people’. For example, it says ‘Review current medication’ but I didn’t know how to review. (ID16, second interview)*

> *It would be easier if it said ‘this and this meant this’ or ‘if this and this and this were like this and then it was reported this, so, if you were here and then let’s think this’. (ID16, second interview)*

It was thought that she apparently mistook the SPICT-JP for a diagnostic tool which would clearly signpost the care for patients with specific instructions. She seemed to be distinctive in this regard, but other participants did mention that additional information could be of help, although they did not necessarily insist that such information should be part of the tool itself. As ID17 said, this information was generally considered as ‘additional’.

> *[…] it’d be good if it would point users to background information about each item, which they can refer to. But that’s trivial and not the main thing. (ID17, second interview)*

Some participants stated that keeping the tool concise and simple was more important than it being comprehensive and complicated. ID20 suggested that having another booklet of case studies attached to the tool would be useful.

> *Well, I understand that the action plans at the end cannot avoid being generic, but I think they could be a little bit more specific. For example, within the range we can imagine, we may able to say when patients meet these criteria, then we should check this treatment and this medication or things like that. Such specific examples may make it [i.e. SPICT-JP] more attractive. I know it's no problem for people who know what to do, but even I am wondering how and what I could do before the patients lose their capacity, so something like samples or examples of suggestions on a separate piece of paper would be useful for those who don't know what to do when they recognise there's a problem. Then they could refer to these examples. Then they could offer palliative care. […] These could be case studies. […] Information such as 'this indicator suggests this', or some recommended guide, would make this easier to understand and to provide palliative care. (ID20, second interview)*

Balancing the comprehensiveness and the conciseness of the SPICT-JP tool seemed to be one of the critical points to consider for its improvement. This is not just limited to the practice recommendations at the end of the SPICT-JP, but this is pertinent to other aspects such as whether the SPICT-JP should include psychosocial aspects (See also Section 8.5.2). ID07 articulated this point as follows:

> *For the [SPICT-JP] sheet itself, I think if the contents were more concrete, we could refer to it more, particularly when other healthcare professionals use it for evaluation and act on the result. On the other hand, if you put too many contents onto the sheet it wouldn't function. If the user-guide becomes too thick then you'll have a problem of our not reading it. It's a difficult decision. […] If there are people who have a great knowledge in palliative care and who only look for identification, this would solve all such problems. (ID07, second interview)*

8.8 Chapter summary

This chapter reported the participating family physicians' perceptions of the utility of the SPICT-JP in their practice. The results were categorised into seven themes: pre-selection of patients; review, act and reflect; raising awareness; meaning of having the SPICT-JP; appropriateness of the SPICT-JP; potential roles of the SPICT-JP; and potential risks and challenges.

Generally, the participants selected the patients who they thought would be ‘SPICT positive’: in other words, needing palliative care. Eventually, they seemed to select the patients for the SPICT-JP in similar ways to how they identified palliative care patients, which was described in Chapter 7. After using the SPICT-JP with patients, they reviewed the patient care, and acted accordingly when needed, and reflected on their practice. This chain reaction raised the participants’ awareness for timely identification of patients for palliative care or future care planning. It was also noteworthy that this had a ripple effect on one of the patients’ families.

The participants also mentioned the value of having the SPICT-JP. The main value was that they could have objective criteria so that they did not have to rely on their vague instincts. The SPICT-JP also had a ‘confirming effect’ making them comfortable and confident. On the other hand, some participants were disappointed because they could not see any evident changes from using the SPICT-JP.

Regarding the appropriateness of the SPICT-JP, they discussed its practicality, coverage of psychosocial aspects, and some specific points regarding each of the indicators. In addition, it was suggested that the formatting of the SPICT-JP and the user-guide could be improved for an easier understanding and a better usage of the SPICT-JP.

The participants thought that the SPICT-JP would be useful to enhance education and communication around the end-of-life care and potentially for quality control. They also raised several challenges regarding implementing the SPICT-JP in Japanese primary care settings which included improvements of the recommendations at the bottom of the SPICT-JP sheet.

In my final chapter, I will summarise the findings from the three results chapters and other chapters, and provide an overall discussion of this research together with implications for future practice and research

Chapter 9 Discussion

In this concluding chapter, after summarising the findings of this study, I will address the research questions by integrating the findings with recent literature. Then, I will reflect on the strengths and limitations of this study, followed by implications for practice, policy and research. Finally, I will reflect on the conduct of this study and finish this thesis by providing concluding remarks. This chapter will show how I achieved the research aims to explore: the Japanese family physicians' understanding of palliative care; their identification of patients for primary palliative care; and their use of a specific tool for the identification of these patients (the SPICT-JP).

9.1 Summary of findings

9.1.1 Understanding of palliative care

A significant reason why I embarked on this PhD study was to understand the possible 'theory-practice gap' better and explore it further. I was becoming increasingly aware of this 'gap' in my clinical practice, which presented itself as the difficulty in translating the prevailing global definition of palliative care into everyday clinical practice. This theory-practice gap was also identified in the accounts from this study's participants. As shown in Table 6.2, in general, the participating family physicians considered the principles of palliative care as being broad, including all those patients with any cause or kind of suffering which could potentially impair their quality of life and that this made them candidates for palliative care. In addition, the participants considered that the principles of palliative care were congruent with the principles of family medicine, and so they practised palliative care in their everyday family practice without calling it 'palliative care'.

However, in their everyday conversations, the participants did not overtly use the term 'palliative care' to mean what they understood palliative care principles to be. Rather, the participants sometimes intentionally avoided using the term. This seemed to be because the global definition of palliative care was not embedded within Japanese medical practice or Japanese society in general. The participating family physicians avoided using the term ‘palliative care’ to prevent confusing the people with whom they were talking (these could be professionals, patients, or families). These findings indicated that there was a duality in these participants’ understanding of palliative care and that the definition of palliative care proposed by the WHO (the global definition) was not entirely useful or helpful in their everyday clinical practice.

9.1.2 Identification of patients for palliative care

In identifying patients for palliative care, the participating family physicians mentioned various factors that led them to consider applying palliative care principles (shown in Fig 7.1). These factors included: the underlying disease, time (*e.g.* estimated prognosis), patients (*e.g.* needs and preferences) and the environment (*e.g.* settings and carer factor). The participants also perceived the resulting phenomena, such as changing priorities and needing ‘beyond normal care’, as signs of a patient’s need for palliative care. The information needed for such identification was collected by direct observation of patients or by asking them or their families ‘how they were getting on’. However, the participants were often vague in describing how actually identified patients for palliative care and did not use any systematic methods. This was not surprising given that the participants did not have any clear or useable definitions of palliative care.

9.1.3 Translation and cultural adaptation of the SPICT

The SPICT was successfully translated into Japanese. There were some contentious or difficult expressions to translate, but these were resolved through discussions between the translators and with the developer. The expert committee members provided various suggestions not only for translation but also for improvements to the tool, including formatting, criteria in the tool, and who should use the SPICT-JP.

Some of the expert committee members’ comments revealed their understanding of palliative care. The expert committee members seemed to use the term ‘palliative care’ in a narrower sense when responding to the questions I sent them with the translated SPICT (see the right column of Table 6.2). For example, some of them wondered if the SPICT-JP should be used to identify patients for advance care planning or for ‘palliative care’ as they understood the term. They also commented that some patients felt abandoned after having been recommended for ‘palliative care’. This may be one of the reasons why the expert committee members used the term ‘palliative care’ in a narrower sense. It was unclear what the expert committee members’ understandings of palliative care principles actually were, as this was not the focus of the expert committee consultation. However, it was confirmed by them that, in general, doctors in Japan found it difficult to consider ‘palliative care’ for those who were medically stable in their practice. Some of the expert committee members also suggested that cultural and healthcare system differences between Japan and the UK could affect the implementation of the SPICT-JP.

9.1.4 Use of the SPICT-JP in practice

The participating family physicians selected patients for assessment using the SPICT-JP in a similar manner to that which they normally used when they identified patients for palliative care. In other words, they used the SPICT-JP with patients whom they already considered would need palliative care. This meant that using the SPICT-JP did not necessarily change the participants’ actions in their patient care. However, using the SPICT-JP raised their awareness of identifying patients for palliative care and the value of doing that more systematically. Regarding further improvement of the SPICT-JP, the participants suggested several points, which were similar to those raised by the expert committee.

9.2 Integration of the findings and comparison with literature

This section integrates the findings from this study and compares them with the existing literature to answer the four research questions as follows:

RQ1: How do the Japanese family physicians understand palliative care?

RQ2: How do the Japanese family physicians identify patients with palliative care needs?

RQ3: Can the SPICT be translated for and adapted to Japanese primary care settings?

RQ4: How would the Japanese version of the SPICT be utilised by family physicians, and what are their perceptions of its impact?

These all four questions are highly interrelated, and some answers to one question might also be relevant to other questions. In particular, the first two (RQ1 and RQ2) and the last two (RQ3 and RQ4) are closely related. Furthermore, RQ4 is contingent on the first three research questions, and the integration of the findings for the last question built upon my discussion for RQ1 to RQ3. For example, many findings from Phase I of the study were relevant to RQ3, but some were useful in answering other questions, and vice versa. Thus, it was difficult to demarcate completely between the research questions.

However, I will now present a summary for each of the four questions separately to provide a clearer representation of my key findings, while acknowledging the interrelationship between them and integrating data from the different phases and interviews.

RQ1: How do the Japanese family physicians understand palliative care?

Finding 1: The gap between an understanding of the principles and the use of the term in everyday practice

One important finding, shown in my earlier ‘Prologue to the analysis results’ in Chapter 6, was that many participating family physicians were unsure of the definition of palliative care, which was in keeping with previous reports in the international literature (Phillips, Davidson and Willcock, 2009; Mitchell *et al.*, 2013; Wallerstedt *et al.*, 2019). Not only these participating family physicians but also some of the expert committee members expressed similar confusion about the definition of palliative care. This confusion was also evident in previous reviews which explored meanings and definitions of palliative care in papers, books and online websites (Pastrana and Ostgathe, 2008; Hui *et al.*, 2014; Kozlov and Carpenter, 2017) and among the general public (McIlfatrick *et al.*, 2014) or patients with advanced cancer (Akiyama *et al.*, 2012).

Furthermore, there was a gap identified between the participants’ understanding of palliative care principles and the use of the term ‘palliative care’ (Table 6.2), which seemed to occupy a spectrum with two ends. When discussing their understanding of the definition of palliative care, they tended to consider it to be a broad concept, with the purpose of ‘reducing patients’ suffering’. Therefore, all those patients whose suffering could potentially impair their quality of life should be able to receive palliative care, and so ‘palliative care’ should be a part of normal family practice. This finding resonates with current literature which argues that generalists – including the participants in this research – should or do take active roles in providing palliative care (Schneider, Mitchell and Murray, 2010; Quill and Abernethy, 2013; Ankuda *et al.*, 2017; WHO, 2018c).

Notwithstanding their broader concept of palliative care principles as outlined above, the participants had a tendency not to use the term ‘palliative care’ in their everyday practice. This tendency has been observed in previous studies with family physicians or other healthcare professionals in the community (Claessen *et al.*, 2013; Mitchell *et al.*, 2013; Beernaert *et al.*, 2015; Nowels *et al.*, 2016; Wallerstedt *et al.*, 2019). Such studies reported that the participants considered labelling patients as ‘palliative’ too early not to be beneficial or even potentially harmful (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). This perception was also observed in Japan, where it has led to the practice of late referrals to specialist palliative care services (Morita *et al.*, 2005, 2009). The reasons for such delays were reported as being the negative image or misconceptions of palliative care or the patients’ wishes. (Morita *et al.*, 2005; Miyashita *et al.*, 2008). This echoes the findings of my research: that the participating family physicians discussed the prevailing negative connotations of palliative care; and they considered the ‘needs and preferences’ of their patients when determining an indication for palliative care. This could be because the participants were culturally sensitive in their approaches to providing care. In addition, the current study identified the influence of healthcare structures and specialist palliative care services as possible reasons for the gap between the participants’ understanding of principles and their use of the term palliative care. From the perspective of the participating family physicians, these contextual factors, such as culture, care settings, and healthcare structures, including specialist palliative care services, should be considered when identifying patients for palliative care.

All of these findings highlighted that the participating Japanese family physicians struggled with the tension between their understanding of the principles of palliative care and how they could practically use the term ‘palliative care’. Sawatzky *et al.* (2016) have pointed out such a tension between a philosophy of palliative care and how palliative care was enacted in healthcare services. Similarly, Wallerstedt *et al.* (2012) highlighted a possible moral conflict felt by healthcare professionals between what they thought should be provided as palliative care and what they could offer. A more recent study identified that while the majority of primary care physicians strongly agreed with the idea of early palliative care, only a half of them reported having sufficient resources for it (Sorensen *et al.*, 2020). These tensions have yet to be addressed in Japanese primary care.

Finding 2: Palliative care: to reduce patients' suffering and to improve their quality of life, *i.e.* going beyond physical symptom management

The participating family physicians discussed several important aspects of their practice of palliative care beyond physical symptom management. All of these aspects were intended to achieve the main goals of palliative care suggested by the participant: to reduce patients' suffering and to improve their quality of life.

The first such aspect was symptom management. One participant clearly stated that family physicians were better at symptom management than other doctors, so family physicians should be responsible for it. Furthermore, some participants seemed to perceive symptom management as a prerequisite for holistic palliative care – and they appeared to consider the existence of symptoms to be an important indicator for palliative care. Symptom management was also considered to be very important in the literature (Groot *et al.*, 2005; Borgsteede *et al.*, 2006; Evans *et al.*, 2014; Liu *et al.*, 2018; Mitchell, Senior, Johnson, *et al.*, 2018). Other papers reported that patients and carers did not necessarily expect family physicians to be responsible for symptom management and that they would rely instead on specialists (Oishi and Murtagh, 2014; Green *et al.*, 2018).

Although the study participants listed symptom management to be first in the requirements of palliative care, they often moved on quickly to other, non-biomedical or holistic aspects, *e.g.* psycho-social or spiritual support, and spent more time explaining about them. The participating family physicians were aware that it was impossible for family physicians to deal with patients' multi-faceted problems alone and that interprofessional collaboration was essential. It was important for participants to 'pave the way' for solving psycho-social problems even when they themselves could not find the way forward. This emphasis on such non-biomedical or holistic aspects of palliative care and interprofessional collaboration by the participants was consistent with the literature (Hanratty *et al.*, 2006; Van Mechelen *et al.*, 2012; Beernaert *et al.*, 2014, 2015) and with the philosophy of primary care (Charlton, 2002).

An emphasis on holistic aspects in addition to symptom management was also in line with the findings from an exploration of patients' experiences of living with advanced illnesses, which revealed their wish to retain their normality as much as possible (Kendall *et al.*, 2015). However, one paper detailed sceptical views among family physicians on whether they should be responsible for psycho-social care while not mentioning the possible use of interprofessional collaboration in dealing with psycho-social problems (Beernaert *et al.*, 2015).

Another important aspect identified in this study was communication. In particular, clarifying information about patients' medical conditions was deemed important for good future care planning. Some participants suggested that patients and their families were often unaware of the patient's deteriorating health, a factor which hindered effective future care planning. In relation to this, one participant reported the importance of translating information provided by specialists into a more readily understandable form of language for patients to prevent unnecessary anxiety and confusion. These perceptions demonstrated the participants' views that family physicians should act as mediators between patients and hospital specialists, thus facilitating a better understanding of current medical knowledge for patients and families. Such communication, including interpreting information from specialists, was also identified as an important role for family physicians in providing palliative care by some studies (Beernaert *et al.*, 2015; Green *et al.*, 2018). It was emphasised particularly that family physicians should fulfil their patients' expectations of them as the being well placed to explain the diagnosis made by the specialists and so help such patients understand the implications of their illness (Beernaert *et al.* 2015).

Within the overall topic of communication, this study identified that communication between healthcare professionals was critical for interprofessional collaboration and coordinating care. It was noteworthy that one participant affirmed that family physicians should function as ‘a care coordinator in the community’. The participants’ focus in coordinating care was rather on *seikatsu* (day-to-day living) than on medical care, which was in accordance with their main holistic goals of palliative care. These views were in contrast to some literature which suggested the possibility of delegating the task of coordination (Groot *et al.*, 2005; Brännström, Forssell and Pettersson, 2011; Waterworth and Gott, 2012; Oishi and Murtagh, 2014). The participants’ views in this study probably reflect the Japanese healthcare situation in which no other healthcare professionals are in a position where they can coordinate the care for patients needing palliative care adequately.

Finally, one aspect not discussed by the participants in this study was continuity of care – a significant difference between this study and some existing literature. While continuity of care was often acknowledged in the previous literature (Groot *et al.*, 2005; Borgsteede *et al.*, 2006; O’Connor and Lee-Steere, 2006; Dahlhaus *et al.*, 2014; Green *et al.*, 2018), it was not identified by many participants in this study. There are two possible reasons for infrequent references to continuity of care as opposed to coordination of care in this study. Firstly, the participating family physicians did not have their patients registered with them in the Japanese healthcare system, which leads to a lack of continuity of care in general in Japan. Secondly, the participants were relatively young and did not have substantial practice experience, and so they did not have a long-term relationship with patients. The lack of continuity could result in an undesirable situation which was described by some participants as being when patients in a ‘palliative’ phase had just been referred by specialists as ‘new’ patients. In this context, these participants found it difficult to establish a good relationship with such patients in a limited timeframe, but they seemed to take this situation for granted and did not discuss it in the interviews.

RQ2: How do the Japanese family physicians identify patients with palliative care needs?

Finding 1: Complex nature of identification: a 'limited prognosis' is not everything

The participants considered various factors when identifying patients for palliative care. The possible interactions between such factors are shown in Figure 7.1, which is what makes the identification process complex.

A diagnosis, typically of an advanced cancer with limited prognosis, was often a starting point in the interview when discussing 'Who would be candidates for palliative care?' This seemed to reflect the participants' archetypal image of patients for palliative care which was linked to their everyday use of the term 'palliative care' shown in Table 6.2. However, once the discussion progressed further, it was revealed that the participants considered other factors described in Chapter 7 as important. The participants reported that diagnoses and estimated prognoses were not the only factors to consider. The participants implied that while they acknowledged diagnoses such as an advanced cancer or neurodegenerative diseases as important indications for palliative care, not having such diagnoses did not exclude the possibility of the patients having palliative care needs. They deemed other factors as equally important to maintaining a patient's quality of life. This notion was related to their broader concept of palliative care (*i.e.* understanding of palliative care principles shown in Table 6.2). All of the factors were inextricably intertwined and caused these resulting phenomena: changing priorities of patients; and patients needing 'beyond normal care'. The participants sometimes only perceived these resulting phenomena, and often could not explain the relationships between the causal factors and the phenomena that resulted from them.

Despite limited evidence on how family physicians identify patients for palliative care, the vagueness and the lack of straightforwardness in such identification suggested in this study have also been highlighted in the existing literature (Harrison *et al.*, 2012; Claessen *et al.*, 2013; Mitchell *et al.*, 2013; Nowels *et al.*, 2016; Pocock *et al.*, 2019). This echoed the findings for RQ1, where a vague and unclear understanding of palliative care explained some of the difficulty in defining which patients needed palliative care. Some previous studies also suggested that while some family physicians considered imminence of death as an important indicator for palliative care (Beernaert *et al.*, 2015), family physicians' identification, in general, was more based on the patients' needs such as increased care dependency than their diagnosis or prognosis (Claessen *et al.*, 2013; Mitchell *et al.*, 2013). These published findings were in line with this study, and also confirmed the purpose of palliative care identified in RQ1; to maintain a patient's quality of life.

Regarding what the diagnoses meant to the participants, there were distinctive differences between cancer and non-cancer chronic diseases. The participants claimed that cancer patients had often thought about themselves as needing palliative care at some point, whereas non-cancer chronic disease patients had not. In addition, some participants suggested that all cancer patients should be considered for palliative care regardless of their stage of illness, whereas they did not have such clear ideas for non-cancer patients. These distinctions between cancer and non-cancer diagnoses and the perceived difficulty around timely identification of non-cancer patients needing palliative care due to uncertain illness trajectories have been discussed repeatedly in the literature (Murray *et al.*, 2002; Shipman *et al.*, 2008; O'Leary *et al.*, 2009; Harrison *et al.*, 2012; Kendall *et al.*, 2015; Wichmann *et al.*, 2018; Pocock *et al.*, 2019). The current study confirmed that the Japanese family physicians held similar beliefs about cancer versus non-cancer diagnoses in relation to palliative care, and that these notions were highly prevalent among them.

Among the other suggested factors to consider when identifying patients for palliative care, some were particularly notable. One of them was the 'accumulation of palliativeness' which represented the gradual and chronological nature of the patients acquiring palliative care needs.

According to the participants' accounts, palliative care needs did not happen suddenly. This has similarities to what Newall *et al.* (2006) have described as an accumulation of seemingly trivial events in old age which built up together to cause progressive debility until the person's overall health deteriorates, often rapidly. A gradual shift to the 'palliative process' was also mentioned in some other papers (Claessen *et al.*, 2013; Mitchell *et al.*, 2013), and it was more pronounced in non-cancer chronic diseases (Murray *et al.*, 2002; Kendall *et al.*, 2015). All of these have some links to the idea of a gradual 'transition' to palliative care in the illness trajectory (Boyd and Murray, 2010; Gott *et al.*, 2011; Gardiner *et al.*, 2015).

Finding 2: Contextual factors influencing identification

The findings of this study were generally consistent with the existing evidence, suggesting that Japanese family physicians shared similar views with family physicians in other countries. Nonetheless, there were several contextual factors which were unique to Japan. These were not necessarily explicitly identified as direct findings of this study, however, consideration of these factors is important when interpreting the findings. Some of the contextual factors are related to healthcare systems, while others include some cultural components.

The first thing we should consider is the absence of palliative care registers of patients in Japan, like many other countries. The palliative care register in the UK does have some impact on family physicians' practice of identifying patients for palliative care. In fact, there is some evidence that the register seemed to be useful for timely identification (Harrison *et al.*, 2012; Mitchell *et al.*, 2013; Zheng *et al.*, 2013; Pocock *et al.*, 2019). The Japanese family physicians do not have to identify patients formally for palliative care. This probably affected the meaning of the identification of patients for palliative care and might have made the meaning of identification even more vague as opposed to the situation where a palliative care register exists.

In addition, as I discussed earlier, the available specialist palliative care resources affected the participants’ recognition of patients needing palliative care. The palliative care units, which are the main source of specialist palliative care in Japan, only accept cancer patients, and there are very limited specialist palliative care services available in the community. This is likely to impact on identification practices in primary care in Japan. For example, one participant struggled to find a meaningful explanation of palliative care which was consistent with what the local specialist palliative services, *i.e.* a palliative care unit for people with advanced cancer could offer, while she herself believed that palliative care should be available for everyone.

Another notable factor relating to the contextual background was ‘needs and preferences’ presented in Chapter 7. Sometimes the participating family physicians seemed to be keener to protect patients’ hopes or preferences than providing what might be considered as ‘appropriate’ medical treatment. In addition, patients’ personal experiences and the culture they live in could shape their preferences in relation to medical care. The phrase ‘patient-centred initiation of palliative care’ by one participant echoed the finding from a recent study which suggested that the timing of early palliative care intervention should be determined based on patients’ individual needs (Fliedner *et al.*, 2019). However, the same study also proved that early palliative care intervention was, in the end, perceived as being reassuring and beneficial by the patients (Fliedner *et al.*, 2019). Several studies confirmed that the Japanese healthcare professionals’ tendency not to tell cancer patients their diagnosis, seemingly stemmed from Japanese culture (Uchitomi and Yamawaki, 1997; Seo *et al.*, 2000; Morita *et al.*, 2006). One international systematic review suggested that avoiding honest discussions with patients could have harmful results (Hancock, J M Clayton, *et al.*, 2007). However, there is as yet scant evidence to guide changes to the views of Japanese patients with advanced illnesses about early palliative care interventions. The possible influence of culture on physicians’ practice will be discussed further in Finding 4 in RQ4.

Finding 3: Collecting subtle signs: no systematic ways for collating information to identify patients with palliative care needs

One of the things which this study could not clarify fully was how the participating family physicians collected the information they needed to enable them to identify patients with palliative care needs consistently. I was intrigued by how family physicians would look for triggers for palliative care because knowing how they did this could determine the skills that family physicians should acquire for better identification of patients. Despite my persistent questioning, the participating family physicians were not clear about how they gathered information needed to identify patients with palliative care needs except for asking patients directly, along with their own observations and professional judgements. Considering the listed factors relating to the identification process and how explicitly they described them in the interviews, the participants must have been able to identify these triggers by some means in their consultations. In hindsight, it is possible the participants were using ways other than by asking patients directly and observations, but I could not elicit these with any clarity. Nevertheless, it was evident that the participating family physicians did not use any systematic ways to identify patients with palliative care needs.

While there is some research available regarding triggers for palliative care, there is scarce information on how doctors, particularly family physicians, actively look for such triggers. Only one study from the Netherlands categorised those signals the family physicians perceived as signs for palliative care (Claessen *et al.*, 2013). They classified such signals as: 1) subtle signals given by patients; 2) signals from close relatives; and 3) reports by other professionals (Claessen *et al.*, 2013). The participants of the current study might have picked up on the signs for palliative care in similar ways.

RQ3: Can the SPICT be translated for and adapted to Japanese primary care settings?

Finding 1: Not many challenges in the translation

While several words and phrases in the original SPICT were highlighted as challenging to translate (See Table 4.9), only a few of them were related to conceptual equivalence, and others needed grammatical or vocabulary considerations to retain the equivalence. The original SPICT used in this study was itself revised frequently before the period of this study, incorporating the views from clinicians from many countries as part of a peer-learning and consensus-building approach to its development. Thus, the original SPICT already had an adaptable format for international use. For example, in the translation of the SPICT into Spanish, they changed the phrase ‘NHS continuing care unit’ in the November 2013 version of the SPICT (Fachado *et al.*, 2018). Such locally specific expressions were already eliminated in the version used in this study (April 2015 version). Even the expressions requiring considerations for conceptual equivalence were easily solved by rephrasing them.

Finding 2: Possible perceptions of expert committee members towards palliative care – the narrow concept

Notably, the expert committee members’ comments suggested that they seemed to verbalise a narrower concept of palliative care (see the right column of Table 6.1). While I did not ask them directly for their understanding of palliative care, as this was not within the scope of the expert committee, their responses suggested the possibility of narrower concepts of palliative care being prevalent among Japanese healthcare professionals. This finding echoed the finding of RQ1, which highlighted the gap between an understanding of the principles of palliative care and the use of the term in everyday practice. The expert committee members seemed to have adopted the narrower concept of palliative care intuitively when answering questions about the translation of the SPICT.

Finding 3: Comparison with other language versions

While the SPICT has been translated into many languages which are available on the SPICT website, only three language versions (German, Spanish and Swedish) of the SPICT and their translation process were published in academic papers (Afshar *et al.*, 2018; Fachado *et al.*, 2018; Pham *et al.*, 2019). These studies suggested that the translated version of the SPICT had ‘face validity’ and clinical relevance in identifying patients who need palliative care, which differed in some respects from the findings of this study. This will be discussed further in Finding 3 for RQ4.

Finding 4: Who should use the SPICT-JP?

The expert committee members expressed some concerns about the differences between the Japanese and UK healthcare systems which potentially affect how the SPICT-JP should be used. In particular, one member thought that the original SPICT was for the GPs in the UK where primary care was at the centre of its healthcare system. Whereas in Japan, primary care is less well established, and thus people with palliative care needs are not necessarily seen by family physicians. For this and other reasons, some members suggested that the SPICT-JP might be more useful for doctors other than family physicians who had less expertise in palliative care or future care planning with patients who are approaching death. This is comparable to the accounts of some of the participating family physicians that doctors who were inexperienced in identifying patients for palliative care and in initiating conversations about future care planning would benefit from the SPICT-JP more than they themselves. The participating family physicians consider that they had received adequate training in palliative care during their family medicine residency.

Interestingly, this point, about who should use the SPICT, was neither mentioned nor discussed in the previous papers on translating the SPICT into other languages. This might be because all of these papers are from European countries which have similar healthcare systems putting primary care at the centre or because the SPICT is promoted for use in all care settings by different professionals and specialities.

RQ4: How would the Japanese version of the SPICT be utilised by family physicians, and what are their perceptions of its impact?

Finding 1: Not changing their practice, but raising awareness and providing a sense of being supported

It was already suggested in the previous sections that the participating family physicians' understanding of palliative care was not homogeneous, and the identification of patients for palliative care was a 'messy business'. In general, the SPICT-JP was welcomed positively by the participating family physicians to help them deal with this 'messy business'. They had found that the tool itself was easy and quick to use.

In most cases, the participants pre-selected patients who were likely to need some sort of palliative care for assessment with the SPICT-JP and used it to confirm their clinical judgement rather than to uncover previously unidentified palliative care needs. They selected patients for the SPICT-JP in a similar manner to that already being used to identify patients for palliative care. Some participants used the SPICT-JP with patients on whom they thought they had been spending a lot of energy or resources, suggesting that high workload was a sign for them to consider palliative care. In addition, the participants often had some ideas about what they had to do for such patients already. Therefore, it was difficult to see the apparent changes in their practice after introducing the SPICT-JP. Given this, it was noteworthy that many participants acknowledged the positive impact on their attitudes or perceptions that came from using the SPICT-JP. There were several possible reasons for their positive perceptions towards the SPICT-JP identified in this study.

Firstly, the participants particularly liked its inclusion of non-cancer conditions in the list of disease categories. Palliative care for people with non-cancer illnesses was discussed repeatedly throughout this study by the expert committee members and the participating family physicians, indicating that this was a significant issue for them. Using the SPICT-JP in their practice might have helped confirm their existing perceptions that palliative care should be for people with all conditions.

Secondly, the systematic nature of the tool comprising a set of clear criteria was favoured by some participants. They believed that having a ‘checklist-like’ tool would decrease the chances of overlooking patients, and as a result reduce the discomfort of dealing with uncertainty. The participants’ comments, which suggested that having specific clinical indicators was useful, might show their need for guidelines for identifying patients who need palliative care. Indeed, some authors have argued that clinicians should be able to evaluate patients in a systematic manner to identify their palliative care needs so that they do not have to rely on vague instincts (Harrison *et al.*, 2012; Beernaert *et al.*, 2014).

Finally, but most significantly, using the SPICT-JP seemed to encourage more reflective practice which culminated in enhanced understanding of the identification of patients for palliative care among these family physicians. The fact that the participants valued the opportunity for self-reflection and reviewing patients suggested that they may have experienced time constraints in their practice and a lack of support to deal with such patients. The SPICT-JP seemed to offer the participants some sense of reassurance and made them feel better supported in their clinical practice. Meanwhile, it was also suggested that for those who were already comfortable and confident in identifying patients for palliative care, adding the SPICT-JP into their normal practice could be superfluous.

However, the possible influences of the research activities prior to the second interviews on the participants’ views on the SPICT-JP should be considered in interpreting these findings. These activities included: the participants’ receiving education by the researcher, their keeping of case logs and ‘quick contacts’ by the researcher (See Section 5.3.3). Indeed, some participants admitted that having the first interviews had some positive influences on their understanding of palliative care which in turn may have affected their views on the SPICT-JP. Therefore, the participants’ positive views on the SPICT-JP might not have been engendered by the SPICT-JP itself, but could have been engendered by these research activities.

In the existing literature, similar findings were shown with regard to the general acceptability of the tools to identify patients for palliative care. Gómez-Batiste *et al.* (2013) reported that the doctors’ awareness was sharpened by implementing the NECPAL CCOMS-ICO© (NECPAL), although they did not report the details of the qualitative data in their paper. Another study published in Ireland looked at how the SPICT would be used in primary care along with an additional information booklet for patients (Dunphy *et al.*, 2016). In this study, the participating family physicians seemed to find the SPICT acceptable despite its additional complexity as compared with a simpler question based on prognostic judgement (Dunphy *et al.*, 2016). However, these views were not formally collected as part of the study (Dunphy *et al.*, 2016). A critical review of the Gold Standards Framework (GSF) suggested that implementing the GSF, which contained the GSF-Prognostic Indicator Guidance, was considered by some users as merely administrative work for efficient record-keeping, while others welcomed it as a way to improve care, and their motivation influenced the implementation (Shaw *et al.*, 2010). These findings are broadly in line with the findings of this study, but these studies failed to explore the barriers and facilitators to routine use of structured tools to support identification of people for palliative care.

Finding 2: Misconceptions about the SPICT-JP as being a prognostic tool

Often the participants showed their confusion about how to interpret the guidance of the SPICT-JP. The participants seemed to have assumed that the SPICT-JP could make a cler distinction between patients needing palliative care and those who did not, or be used primarily as a prognostic indicator. One of the potential reasons for this could be that the majority of healthcare professionals may be accustomed to using diagnostic tools designed to label patients as positive or negative. In one-to-one, brief lectures with the participants, I explained the purpose of the SPICT-JP as ‘to identify patients at risk of deteriorating health and dying’ in line with the description in the original SPICT. This seemed to be understood incorrectly by some participants as meaning that the SPICT-JP was to be used as a prognostic tool. In addition, some of the participants and the expert committee members said that it would be useful if the evidence about the accuracy or effectiveness of the SPICT was available. When they discussed this, they often confused identifying patients who have palliative care needs with predicting these patients’ prognosis.

However, Coventry *et al.* (2005), in their systematic review, concluded that all the available prognostic models had poor discrimination, particularly for people with non-cancer illnesses. The lack of accuracy in prognostication at the individual patient level was reiterated in a more recent review (Campbell *et al.*, 2015). Furthermore, a study from Australia demonstrated that screening tools including the SPICT were no more accurate than intuition at predicting patients’ prognosis (Mitchell, Senior, Rhee, *et al.*, 2018). Similarly, low specificity of the SPICT (0.579 to 0.67) compared to its sensitivity (0.841 to 0.87) in predicting six- to twelve-month mortality have been reported (De Bock, Van Den Noortgate and Piers, 2018; Woolfield *et al.*, 2019). Mitchell, Senior, Rhee, *et al.* (2018) added that screening for predictable deaths was not the best way to recognise patients who could potentially benefit from palliative care and they concluded that recognising the burden of illness was a better way to identify patients with the greatest unmet needs. The Lancet Commission has highlighted a global imperative to focus on alleviating the burden of health-related suffering associated with advanced progressive illness by improving access to palliative care and pain relief (Knaul *et al.*, 2018). On the basis of these findings and arguments, the value of the SPICT-JP is not in the provision of accurate prognostication. Some of the participants inappropriately expected the SPICT-JP to be a prognostic tool and the limitations of prognostication using such tools need to be clarified.

The SPICT-JP can be used to identify people with a great burden of illness and this may be more appropriate.

Finding 3: Including fewer psychosocial aspects was acceptable

While the SPICT-JP was consistent with the participants' understanding of palliative care principles in many ways, some participants commented that the SPICT-JP did not include other aspects of patient needs apart from those relating to diseases or physical conditions. Interestingly, despite this suggestion, they did not recommend that the SPICT-JP should include them. There are several possible reasons for these participants' views. Firstly, they preferred a simpler tool for easier use. The conciseness of the tool seemed to outweigh any disadvantages of its narrower scope for such participants. Secondly, the participants might have felt more responsible for the medical aspects of the patients' problems rather than for other aspects. They thought that whole person care should be provided by interprofessional collaboration, which may have led them to concentrate on medical aspects of the patients' problems in their role as doctors. Furthermore, one participant stated that considering psychosocial factors separately from medical factors enabled him to recognise the patients' complex situations more clearly. All of the reasons listed above did not minimise the participants' view that psychosocial aspects of patients' problems were as important as medical problems when providing palliative care. We should be aware of the possibility of marginalising psychosocial aspects by having only a few of them in the SPICT-JP.

The suggestion about the SPICT not covering the psychosocial aspects contrasted with the findings from other studies. All of the three existing papers which translated the SPICT into other languages reported that medical professionals (including family physicians, internal medicine physicians, palliative care physicians, and nurses with or without primary care specialisation) agreed that the translated SPICT covered relevant indicators to identify patients who might benefit from palliative care (Afshar *et al.*, 2018; Fachado *et al.*, 2018; Pham *et al.*, 2019). Only the Spanish study discussed the option of combining the SPICT with other tools for greater comprehensiveness (Fachado *et al.*, 2018). This difference between the previous studies and the current one may be due to the difference in the methods of collecting the participants' views. While the participants in this study used the SPICT-JP in their practice with actual patients, the participants in other studies expressed their views via expert committees or in focus group discussions with or without clinical vignettes. The views obtained in this study were based on and reflected the participants' experiences in clinical practice more directly.

In relation to the point that non-medical aspects should be considered when identifying patients' palliative care needs, some studies with patients who had heart failure showed that patient-reported symptom status or physical conditions reflected their overall health-related quality of life and so indicated a need for palliative care (Heo, Doering and Widener, 2008; Campbell *et al.*, 2018). These findings support the concept of the SPICT-JP mainly focusing on the physical indicators of patients' health conditions. These authors also suggested that it would be preferable to use patient-reported health status measures rather than healthcare professionals' ratings. The SPICT is not a patient-reported outcome measure *per se*, and the relationship between patient-reported outcomes and introduction of the SPICT is not clear from this or other published studies. There is a version of SPICT written in more accessible lay language that is aimed at social care workers, families and patients but this has not yet been evaluated in research studies (SPICT programme, 2018a).

Finding 4: Physicians' avoidance of having discussions: personalised care, a fear of taking away hope, or cultural sensitivity?

Notably, some participants revealed that they sometimes intentionally withheld the discussion of future care planning after using the SPICT-JP because such discussion could worsen the patient's anxiety. It was impossible to conclude from the available data whether the participants compromised due to the difficulties of overcoming the negative connotations around palliative care or if they were purely providing personalised care based on an appropriate assessment of a patient's mental and psychological status. It could also be argued that it may be because a truth-telling culture is not prevalent in Japan (Uchitomi and Yamawaki, 1997; Seo *et al.*, 2000; Morita *et al.*, 2006). Furthermore, studies about what is meant by 'a good death' in cancer care in Japan found that among the Japanese people there is a preference for remaining unaware of impending death and disengaging from death (Hirai *et al.*, 2006; Miyashita *et al.*, 2007). Hirakawa (2012) added that older Japanese people might have a 'fatalistic acceptance' in deciding their future. All of these findings can explain why the participating family physicians in this study were reluctant to start the conversation about future care planning, especially aspects relating to the patient's end of life. It has also been reported that personalised care tended to be prioritised over effectiveness in Japan compared to the UK (Asano, 2017), which may also explain the participants' tendency of not following guidance about care planning.

One systematic review has highlighted that the emotional nature of patient-professional interactions required for advance care planning acts as a barrier (Lund, Richardson and May, 2015), while other studies reported patients' perceived benefits from early future care planning despite unpleasant feelings caused by such difficult discussions (De Vleminck *et al.*, 2013; Glaudemans, Van Charante and Willems, 2015; Fliedner *et al.*, 2019). The authors concluded that the initiation of such conversations should be personalised (Fliedner *et al.*, 2019) and training of family physicians for this challenging task was required (De Vleminck *et al.*, 2013).

However, all such evidence is from European or North American countries. Even systematic reviews about patient perceptions or cultural acceptance of advance care planning did not include any studies from Asia (Johnson *et al.*, 2016) or had a little data from Asian populations (McDermott and Selman, 2018). It has been reported that not only research on advance care planning, but the majority of research into palliative care more broadly has come from

European and North American countries (Walshe, Ahmed and Preston, 2020). This suggests that much of the currently available evidence about provision of palliative care might not reflect the situations in other areas of the world.

Looking at the evidence from East Asia, one study reported that Korean people would generally be more tolerant of lying ‘for a friend’ while Americans would emphasise telling the truth (Park *et al.*, 2018). Cheng (2018) recommended using indirect communication approaches with Chinese seniors to determine their readiness for advance care planning. This was similar to a proposal suggesting the possibility of a communication-focused approach (rather than formal documentation) being useful to address culturally diverse populations (McDermott and Selman, 2018). One recent study reported a low documentation rate of advance care planning in Japanese primary care, which may have reflected the cultural sensitivity of this area of practice (Hamano *et al.*, 2020). All of these papers provided explanations for the participating family physicians’ apparent reluctance to initiate discussions for end-of-life care planning, and the need for further investigation to identify a better way to address this.

Finding 5: Inconsistent views on the stringency of the criteria

While the participants embraced having a set of criteria for a systematic review of patients, their views on the stringency of the current criteria in the SPICT-JP varied. The participants often expressed a view that the SPICT-JP criteria were too stringent as a prompt for them to start a broader approach to future care planning. The participants thought that discussions about future care planning, which they considered to be part of the principles of palliative care, should be initiated before patients showed clear signs of deterioration. This view contrasted with the participants’ reluctance to start formal advance care planning with patients, which was explored in the previous section. On the other hand, some participants claimed that the clinical indicators, particularly those listed under ‘frailty/dementia’ in the SPICT-JP, identified too many patients so that they could not pay special attention to those who were identified. This dilemma probably reflected the tension they faced in identifying patients for palliative care and in providing care for those who were identified, leading to the difficulty in translating their understanding of the principles of palliative care into their practice.

Finding 6: Potential to enhance communication and education
Regarding the potential roles for the SPICT-JP, the participants suggested that it would be useful in enhancing communication among healthcare professionals. As explored earlier, the understanding of the term ‘palliative care’ varied in clinical practice, so that it was sometimes difficult to agree on the direction of care for the patients among different healthcare professionals. The SPICT-JP could be used to reach consensus among them. The SPICT-JP also has the potential to be an educational tool if sufficient background information is provided. Some participants did introduce or wished to introduce the SPICT-JP to their junior colleagues for educational purposes. The SPICT-JP was deemed more useful for doctors with less experience than those with more experience. These aspects: the potential use of the SPICT in communication between healthcare professionals and in education have rarely been discussed in the existing literature, while trials of implementing similar tools often did have some educational elements (Thomas and Noble, 2007; Gómez-Batiste *et al.*, 2013; Thoonsen *et al.*, 2016).

9.3 Strengths and limitations of this study

9.3.1 Strengths

This is the first study undertaken to investigate Japanese family physicians’ understanding of palliative care and their views on identification of patients for palliative care. The dearth of research, particularly qualitative research, in primary care in Japan has been highlighted (Kaneko *et al.*, 2018, 2019). The findings from this study can be an invaluable resource for the development of primary palliative care in Japan and to increase the evidence base for Japanese primary care.

This study provides detailed accounts on the actual use of the SPICT-JP. There have been several studies examining the SPICT or similar tools, or a programme which incorporates such a tool (Gómez-Batiste *et al.*, 2013; Highet *et al.*, 2014; Thoonsen *et al.*, 2015; Dunphy *et al.*, 2016; De Bock, Van Den Noortgate and Piers, 2018; Mitchell, Senior, Rhee, *et al.*, 2018; Mudge *et al.*, 2018; Woolfield *et al.*, 2019), and studies translating the SPICT into other languages (Afshar *et al.*, 2018; Fachado *et al.*, 2018; Pham *et al.*, 2019). However, none of them succeeded in reporting the users' views in the form of rich qualitative accounts. The nuances and stories contained in this study could be useful in clarifying the mechanisms behind the observed findings and determining the best possible way to help family physicians provide better palliative care for their patients.

None of the three studies which translated the SPICT into other languages tested the translated SPICT in actual clinical practice to obtain healthcare professionals' views about its use in routine care (Afshar *et al.*, 2018; Fachado *et al.*, 2018; Pham *et al.*, 2019). In addition, this is the first study to translate the SPICT into non-Anglo-Saxon language. The description of the process of translation and cross-cultural adaptation of the SPICT into non-Anglo-Saxon languages and non-Western cultures provides valuable evidence for those interested in using the SPICT in their own contexts throughout Asia.

I am cognisant of how my position as both an insider and an outsider shaped the way that the research was carried out and enriched the study findings (Wilkinson and Kitzinger, 2013; Berger, 2015). Through the interviewing process, I recognised that I was accepted as a fellow colleague, working in a similar environment which enabled the participants to feel confident and safe enough to reveal their candid views and opinions. However, my outsider position as a UK researcher gave me additional skills to re-evaluate and sense-check the 'objective' realities about the participants' perceptions and Japanese culture (Wilkinson and Kitzinger, 2013). Indeed, less rich findings might have been obtained by a researcher who was: non-Japanese; not working in family medicine; or a colleague of the study participants without wider academic expertise.

Finally, I have received several emails from Japanese clinicians asking for permission to use the SPICT-JP in their practice. Most participants also showed positive responses at the end of the interviews. This positive interest from other clinicians and feedback from the participants indicates that this study is highly relevant to Japanese primary care clinicians and could potentially have a significant impact on the practice of palliative care in Japan.

9.3.2 Limitations

The main limitation of this study relates to the selection of study participants. Firstly, this study only included formally trained family physicians, who were still few in number in Japan, and recruited from only a small number of practices. These participants provided palliative care in their normal practice, whereas other medical doctors who engage in primary care in Japan might not do so. Additionally, given the short history of family medicine training and accreditation in Japan, the participants tended to be young and had limited experience in medicine overall. Some studies have reported that family physicians' perceptions of palliative care could be different between physicians with shorter and longer careers (Burt *et al.*, 2006; Rhee *et al.*, 2008; Mitchell, Senior, Johnson, *et al.*, 2018). Thus, we might have missed the helpful insights that more experienced doctors could potentially provide.

Secondly, many of the participants mentioned that they were interested in implementing a new tool and in improving their practice of identifying patients for palliative care. Their expectations might have affected their impressions of the SPICT-JP, which might have caused a difference in the results from the views of mainstream family physicians in Japan. However, their expectations made their views rich and significant. Because this was the first study to investigate Japanese family physicians' views on this topic, I wanted the participants to have rich and relevant insights.

The third limitation related to data collection methods. I offered the participants the option of having a group discussion, although nobody chose this option. Conducting one-to-one interviews allowed me to spend sufficient time with each participant to elicit their accounts in response to the research questions. However, during the interviews, many participants asked me how other participants had answered the interview questions. Focus group discussions might have enabled me to obtain richer or deeper insights resulting from interactions between the participants.

Another limitation is that the interviews were done in Japanese, but this thesis was written and produced in English. As detailed in Chapter 5, I paid careful attention to preserve the nuances expressed in the original interviews in Japanese when analysing and reporting the findings in English. However, there is a possibility that some subtle meanings were lost in such translation. Such risk could have been partially avoided by having other co-researchers who were also fluent in Japanese, which proved impossible within the remit of a PhD study. This issue will be revisited as part of my reflection on conducting this study (See Section 9.5.1).

Finally, the application of the findings and discussion of this study to the policy and clinical practice in low- and middle- income countries should proceed with caution. This study was undertaken in Japan which like the UK is among the more economically developed countries in the world. In addition, the majority of the previous literature is from high-income Western countries, although a version of the SPICT has been developed for low- and middle- income countries (SPICT programme, 2018b). We need to develop better strategies and solutions for such low- and middle-income countries as noted by the recent Lancet Commission (Knaul *et al.*, 2018), along with the WHO endorsement of palliative care in universal health coverage (WHO, 2014).

9.4 Implications and recommendations

9.4.1 Practice and education

Understanding of palliative care

Whole person care was identified as being at the centre of palliative care principles in this study. Whole person care was required to achieve the goal of palliative care defined by the participants: to maintain patients’ quality of life and retain as much normality in their lives as possible. It was natural for the participants that psychosocial support was included as part of palliative care, considering that psychosocial aspects also constitute an integral part of patients’ quality of life. Family physicians do not necessarily have to solve all the psychosocial problems of patients. However, they should be at least sensitive enough to detect them and be able to consult with other appropriate professionals to signpost the patients to access necessary support.

The identified gap between the principles of palliative care and the everyday use of the term ‘palliative care’ could be a burden for family physicians when providing palliative care. It was notable that the participating family physicians were not necessarily aware of this gap. Clinicians should be aware that they are facing a dilemma between the principle of palliative care and the everyday use of the term ‘palliative care’ as this awareness could potentially reduce the stress arising from the gap. Education for clinicians and undergraduate medical students should also consider this gap.

Identification of patients for palliative care

The nature of identifying patients for palliative care was very complex. This complexity was intensified among non-cancer patients whose illness trajectories were filled with uncertainty. Furthermore, a gradual accumulation of the patients’ palliative care needs blurred the transition. Family physicians should be aware that the factors listed in Chapter 7 could affect their identification of those needing palliative care. The listed factors could help organise the information gathered by physicians about the patients in order to identify their possible palliative care needs more systematically.

The factors identified in this study also indicated that the meaning of the identification could be highly context-dependent. For example, healthcare systems, characteristics of patient populations, culture and perceptions of death and dying among the general public could influence how the clinicians identify patients for palliative care. It would be useful for clinicians and policymakers to be aware of these factors.

The practice of palliative care

The principles of palliative care, according to the participants, were similar to those of family medicine. It was reported that there was a tendency for experienced family physicians to perceive palliative care as being more familiar and less burdensome (Burt *et al.*, 2006; Groot *et al.*, 2007; Rhee *et al.*, 2008). Potentially, the skills and competencies needed to be a good family physician could also be adapted to provide good palliative care, although this adaptation has not yet been investigated or explicitly described. Family physicians should be aware of this potential, and family medicine education curriculums should consider how effectively the principles of family medicine can be incorporated into the provision of palliative care in primary care. This also should be included in undergraduate education in family medicine and palliative care.

It is not clear who would be most appropriate to coordinate patients’ care in the provision of palliative care in the current and previous studies. However, family physicians could be the most appropriate professional for coordinating patients’ care in current Japanese primary care settings. Therefore, family physicians should consider taking the initiative to coordinate the care when they cannot identify a more appropriate coordinator.

Communication about future care planning

This study observed a tendency among family physicians to withhold future care planning conversations for fear of removing hope and causing unnecessary anxiety, while this was not yet confirmed from the patients’ point of view. Further research is needed to explore Japanese patients’ preferred communication styles. It would be useful to develop education for clinicians with a particular focus on how to address their concerns about dealing with clinical uncertainty and the risk of taking away hope from patients. This would enable the effective initiation of discussions about aspects of future care planning relating to death and dying. Available guidance on this largely relates to Western settings (Jackson *et al.*, 2013; Coleman and Thomas, 2014; Parry, Land and Seymour, 2014; Kimbell *et al.*, 2016) so it needs to be tested and adapted for other health systems and cultures.

Education

The implications for education, including both under- and post-grad education and in-service training, would be an important outcome of this study. Several implications for education were already mentioned in the above sections. However, further research focusing on education is necessary to generate more specific recommendations. Such research should include patients and educationists to ensure the future education is in line with patients' preferences and educational theory.

9.4.2 The SPICT-JP and its implementation

When introducing the SPICT-JP into clinical practice in Japan, active guidance and education to support SPICT-JP users are necessary. The guidance should be provided in accordance with their practice environments, such as its alignment with established ways of identifying people for palliative care. The SPICT-JP could be embedded in their electronic medical record system for effective use and to avoid additional complexity, which has already been examined in Scotland (Mason *et al.*, 2015, 2018; Finucane *et al.*, 2020). The difficulties of understanding how to use the SPICT-JP at the beginning could easily be resolved by providing a clear explanation in the user-guide and perhaps by offering access to advice from colleagues with more experience in its use. It would also be important to provide clearer recommendations and guidance on how to start conversations about future care planning after the SPICT-JP has been used to identify people for palliative care and care planning. How to plan the implementation and its evaluation will be discussed further in Section 1.4.4.

The confusion I found in interpreting the SPICT-JP screening process could be resolved by providing more background information for the SPICT-JP. For example, the SPICT-JP is not a quantitative tool to allocate patients into two categories: negative or positive, which was not easily understood by the participants. Although many participants expected some background information such as expected survival time for people with each item, such information is of limited value as I have discussed. This should have been probably stated more clearly in the user-guide and in the SPICT-JP itself. More recent versions of the SPICT and the supporting guides on its use clearly state that the SPICT does not ‘give a “prognosis” or a time frame’ which will help users understand the tool better.

It might be useful for the users if they could stratify the patients according to the level or urgency of their patients’ need for palliative care. The participants did look at the number of indicators in the SPICT-JP that were present and related these to the severity of their patients’ health conditions (See Section 8.5.3) suggesting that identifying patients for palliative care in practice seemed to be akin to stratifying patients according to the level of their palliative care needs. In some cases, this helped reinforce their existing practice of making assessments of need by integrating diverse factors. For others, the tool was seen as too narrow and potentially excluding people for early care planning. This tension between the concept of introducing palliative care gradually over time and having ways to prioritise people at greatest need of palliative care is similar to other priority setting in primary care. As I noted in my discussion about contextual factors, the patient populations and what specialist palliative care and primary care could offer vary depending on the situation, so the identification process needs to vary and be flexible too. Whilst there are studies into how to identify patients needing specialist palliative care (Lidstone *et al.*, 2003; Ahmed *et al.*, 2009; Campbell *et al.*, 2018), the SPICT-JP was used in this study to identify patients needing palliative care within primary care settings, which could be even more problematic (Nevin, Smith and Hynes, 2019). Although there was an attempt to devise standard sets of criteria for general and specialist palliative care (Lüthi *et al.*, 2020), it was very challenging to establish standardised criteria. Being able to stratify patients, rather than dichotomously dividing the patients into those who do, or do not, need palliative care at this time, could also help address the difficulty in translating principles of palliative care into practice and the gradual accumulation of ‘palliativeness’ found in this study and a UK study using an electronic version of the SPICT (Mason *et al.*, 2018).

The participants pre-selected patients for the SPICT-JP evaluation in a similar manner to the one they used in identifying patients with palliative care needs, resulting in not many changes in their actual practice. While this might suggest that the participants were already providing appropriate care for their patients, the pre-selection of patients might have generated a number of patients who would not be selected for the evaluation by the SPICT-JP despite their potential undiscovered needs for palliative care. It is worth considering how we could encourage practitioners to use the SPICT-JP as a screening tool.

The relationship between patient-reported outcomes or the patients’ experiences and the use of the SPICT-JP is as yet still unclear. A study – investigating patient-reported outcomes and experiences of care incorporating the SPICT-JP – would be useful to further understanding about how the SPICT-JP could contribute to patients’ quality of life.

In the translation and cross-cultural adaptation of the SPICT into Japanese, there were only modest challenges. This suggested that the SPICT could be relatively easily translated and culturally adapted into other languages including non-Anglo-Saxon ones, and for other countries including non-Western ones.

9.4.3 Policy and public health strategy

According to the findings of this study, the definition of palliative care as set out by the WHO was not translated into clinical practice in Japanese primary care. Not only the participants but also other healthcare professionals and the general public in Japan held negative connotations of palliative care, inhibiting open communication about future care planning. In fact, it has been discussed whether changing the name of ‘palliative care’ would be helpful or confusing in promoting its scope and benefits (Boyd *et al.*, 2019; Sorensen *et al.*, 2020). In Scotland, the SPICT has been used nationally to identify people for early palliative care (defined more broadly by professionals). However, it is presented to patients as ‘anticipatory care’ planning for changes in health that are recorded in a national electronic record called a ‘Key Information Summary’ used for a wide range of people who may need urgent or unscheduled care (Finucane *et al.*, 2020; Healthcare Improvement Scotland, 2020). This is probably helping patients accept a broader approach to proactive primary palliative care without necessarily calling it ‘palliative care’ (Mason *et al.*, 2018).

Discussions around such nomenclature also exist in Japan. ‘Supportive care’ and ‘palliative care’ have been used interchangeably by many clinicians while the former is less common. Some clinicians insist that ‘supportive care’ is less confronting and more appropriate. In 2018, the Ministry of Health, Labour and Welfare (MHLW) in Japan decided to rephrase ‘advance care planning’ as ‘*jinsei-kaigi* (life meeting)’ to be more acceptable and understandable. However, when the MHLW published a poster in 2019 to promote ‘*jinsei-kaigi*’ with a comedian incorporating some contentious phrases to urge people to make end-of-life decisions, it drew public criticism as being inconsiderate and insensitive. Although there have been signs of increasing awareness and openness among the general public about end-of-life issues (Oishi and Hamano, 2015), public consultation is necessary to find a way forward to tackle the negative connotations of ‘palliative care’ and to promote open conversations about the benefits of future care planning. In fact, a trial of the regional interventions involving public education in Japan was reported as being effective (Morita *et al.*, 2013; Akiyama *et al.*, 2016). When developing a policy to improve the care for those who are in the last phase of their life, we should be sensitive to the words and phrases we use and ensure that they are culturally acceptable to the general public.

9.4.4 Research and knowledge exchange

A limitation of this study stemmed from its narrow selection of participants. Research with a wider range of people as participants, or even as researchers, would be beneficial to extend the implications of this study. Particularly, studies with a wider range of family physicians would be needed to determine the degree to which the findings are generalisable. Similar studies with other groups of doctors or other professionals could inform how interprofessional collaboration in promoting best practice in palliative care should take place. These studies would also help answer the question as to who should use the SPICT-JP. Some expert committee members mentioned that doctors other than family physicians should use the SPICT-JP for the effective identification of patients needing palliative care.

Similarly, in this study, we could only assume the family physicians' identification of patients for palliative care from their accounts in the interviews. Having a wider range of people as participants or employing other kinds of data generation (such as medical records data or direct observations of their practice) would help understand the identification process from multifaceted perspectives.

It was understood that the principles of family medicine and palliative care were similar. However, it remains unclear how family physicians can take advantage of this linkage in clinical practice and education. Research investigating how the principles of primary care could be adapted in the provision of palliative care in primary care settings would be useful.

It remains unclear if the implementation of the SPICT-JP could improve quality of care and patients' experiences. In addition to the evaluation of the effect of implementing the SPICT-JP, we also need to investigate patients' or the general public's views on this issue: their understanding of palliative care and their preferred communication styles in future care planning, particularly for the end of their life. This would determine how family physicians should address patients when future care planning is needed. Such studies would also inform education in family medicine.

The SPICT-JP could be implemented as part of a complex intervention by referring to relevant guidelines such as Medical Research Council guidance on complex interventions (O'Cathain *et al.*, 2019). Relevant existing theories could be drawn from when developing an intervention. For example, a hypothesis for mechanisms of impact could be formulated and confirmed by using Theory of Change (De Silva *et al.*, 2014). Another theory, Normalisation Process Theory (Murray *et al.*, 2010) could help to develop a successful intervention which would be accepted in clinical practices. The findings from this study could also be referred to.

While acknowledging the importance of measuring effectiveness quantitatively, appropriate measurable outcomes for the SPICT-JP or similar tools are as yet unclear. Therefore, a process evaluation using mixed methods would be more suitable to evaluate the SPICT-JP implementation (Moore *et al.*, 2015). Moreover, the process evaluation would ensure the external validity of the study, which allows the obtaining of findings applicable to more diverse clinical settings (Minary *et al.*, 2019). This is particularly important for Japanese primary care as the settings are widely diverse across the country. The complex intervention including the SPICT and its process and outcome evaluation have already been planned and in progress in Germany (Afshar *et al.*, 2019). The findings of this study could be also referred to in planning any future research in Japan.

The SPICT-JP could be used in research to define 'palliative care' patients or those who need future care planning. Its relatively clear criteria and conciseness can be an advantage. Several papers have already been published using the SPICT-JP (Hamano, Oishi and Kizawa, 2018, 2019; Hamano *et al.*, 2020).

I employed Skype (VoIP) as a means of communicating with the participants, which proved useful for both the researcher and the participants. As long as safe, natural and rich communications are secured, and ethical consent gained, the VoIP has the potential to decrease the burden on those participating in and conducting interviews and so enhance research activity.

Disseminating the findings and the implications of this study is particularly important in developing better primary palliative care in Japan. In addition to publishing this study in Japanese, developing educational workshops based on the findings of this study might be helpful for Japanese clinicians to scale up primary palliative care.

9.5 Reflections on conducting a study between two countries as both a researcher and a clinician

I am the first Japanese family physician to conduct a PhD study registered in the UK with the field study undertaken in Japan, making both my standing and this study unique. In addition, I continued my clinical practice on a part-time basis while conducting this study after returning to Japan following the first year of my PhD study in Edinburgh. The decision to return was made to maintain my clinical career while developing as a researcher and ensuring my academic work remained grounded in clinical practice. My reflections on my PhD study as a whole stem from this dual role of being a researcher and a clinician, and being based in Japan while studying at a UK university. Conducting this study offered me a significant opportunity to understand the research culture in both countries, which will help contribute to UK-Japan collaboration specifically and international knowledge exchange in the future. A major challenge in the earlier stages of the project was obtaining ethics committee approvals in both Japan and Scotland, which I have discussed in some detail in Chapter 5 so will not revisit here.

9.5.1 Interviewing in Japanese, reporting in English

Not only the interviews, but all of the communication with the participants in this research was done in Japanese. There were several possible approaches to this challenge. For example, Sarfraz (2015) translated all the transcripts from Punjabi to English before analysing them, which was a considerable task. There was also some risk of losing the nuances in the interviews. As opposed to this approach, I decided to use Japanese at the beginning of my analysis and to introduce English incrementally towards the end when defining the identified themes. On reflection, my approach proved successful that, given that I am a native Japanese speaker, this was the most natural and efficient way to report the participants' accounts without losing subtle nuances.

A further reflection concerns the more significant challenge which was posed by sharing the process of analysis with other English-speaking researchers and reporting the findings in English. As I had anticipated, translating the Japanese quotes into English with careful attention to keeping the original meaning took considerable effort and time. However, on reflection, this whole process deepened my own understanding of the research topic and the many differences between the two languages and cultures, adding more value to this study.

9.5.2 Doing a qualitative research as a medical doctor

Although it was a natural decision to conduct a qualitative study with a constructivist approach given the nature of my research inquiry, it required me to depart from the prevailing Japanese medical culture. I have constructed my medical knowledge in a positivist way since medical school. Thus, conducting a research in a medical field from a different epistemological position sometimes posed challenges. My awareness gained through my clinical practice that the nuances and stories could have a significant impact on patient care helped overcome these challenges. Moreover, in Japan, qualitative studies are yet to be approved as scientific as quantitative ones are in healthcare research, which sometimes made communications about this research with other clinicians in Japan difficult.

Notwithstanding, my remaining in clinical practice in Japan had positive impacts on my research. First, it enabled me to access a family medicine researcher network where I could share my experience. This will be helpful to distribute the findings of this study in the near future. Second, I could gain some inputs from my clinical practice into research – and vice versa. I believe that this helped my study to be valid and relevant in improving actual clinical practice in Japan.

9.5.3 Analysing the data

I coded the interview manuscript data myself in order to maintain management and continuity and therefore the reliability of the coding process and outcomes, because having co-coders proved to be unfeasible due to the data being in Japanese and due to limited resources. However, had I co-coded the data with experienced qualitative researchers it would have extended my research experience and made the coding process more transparent. Also, having additional perspectives might possibly have deepened my understanding of the data and illumined more clearly my values and beliefs towards the research topic.

As a family physician in Japan, I could relate to and the participants could relate to me. On reflection, I sometimes noticed myself automatically or subconsciously judging their accounts. This was because I had cultivated my values and beliefs regarding the research topic. As I had been passionate about the topic, my values and beliefs had become strong, and I was aware that these influenced how I interpreted the data. Whenever I was aware of these potential influences while analysing the data and reporting the findings, I went back to the interview transcripts to ensure that my analysis and writing did not diverge from what the raw data actually said. On reflection, through this process, I became more aware of the values and beliefs that I held, which was very useful in my development as both a clinician and a researcher.

9.6 Concluding remarks

This study explored the Japanese family physicians' understanding of palliative care and their identification of patients with palliative care needs in addition to their perceptions of the SPICT-JP, a tool to support the identification of such patients. The study identified several important findings and implications for clinical practice, the SPICT-JP implementation, public health strategy, and research.

The family physicians' use of the term 'palliative care' seemed to be context-dependent and sensitive to its public association with the imminence of death, as opposed to their understanding of palliative care principles. Their identification of patients for palliative care is a complicated process incorporating many intricate factors. These made the practice of palliative care challenging for family physicians. In planning policies for primary palliative care, we should be conscious of this gap, and the challenges arising from it. When implementing the SPICT-JP within Japanese primary care settings, active guidance and education will be needed. We also need to tackle the negative connotation of the term 'palliative care' to enhance the identification of patients needing palliative care, which is a prerequisite for timely initiation of a gradual process of future care planning.

Finally, future measures to improve primary palliative care and the identification of more patients who can benefit from palliative care by family physicians should be in line with the views and perceptions of patients, families and the wider general public on this topic, which were beyond the remit of this study. I hope that this study provides the basis for taking new steps forward to improve the quality of care for all patients in the community who are living and dying with advanced health conditions.

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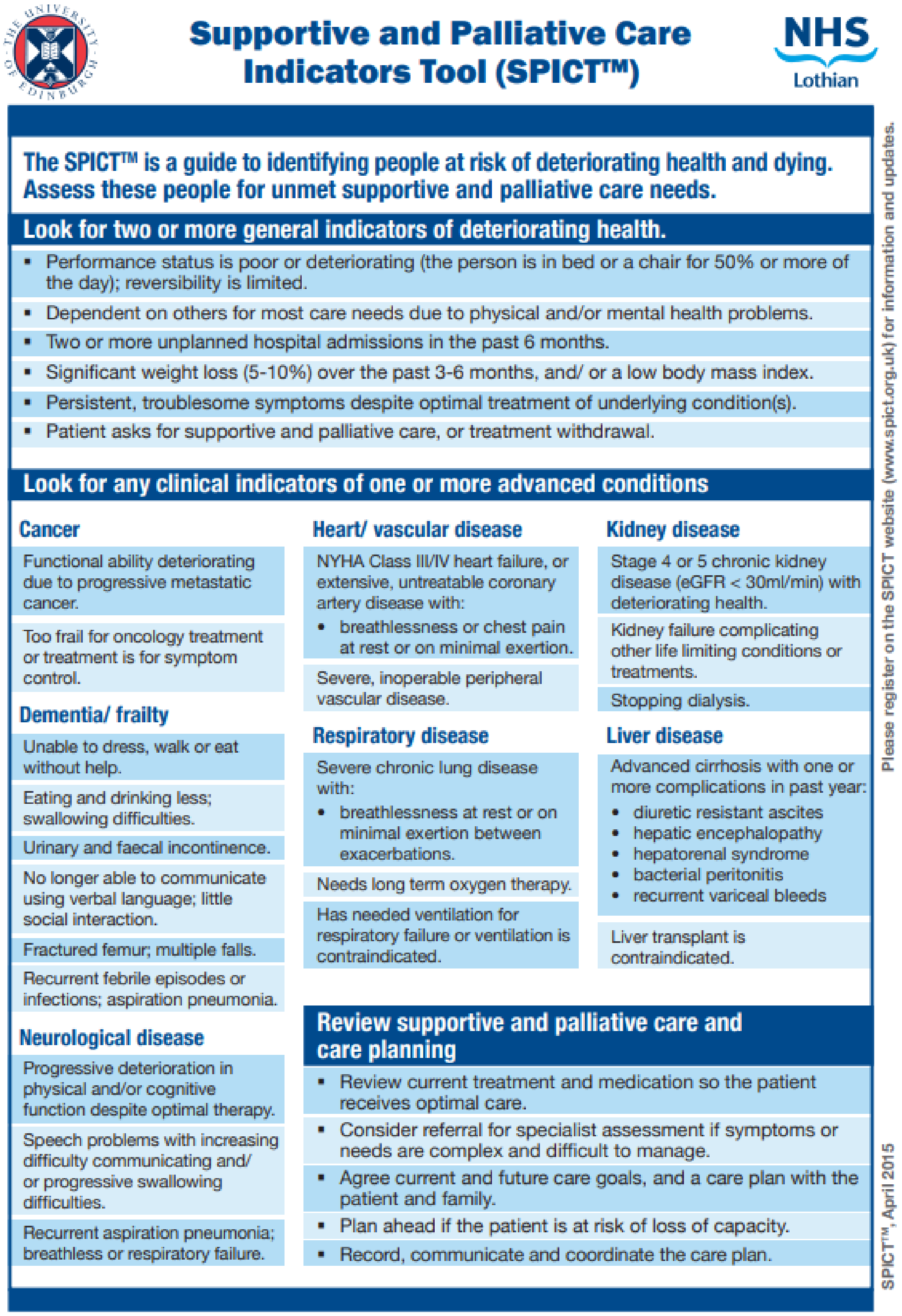
Appendices

Appendix 1: The Supportive and Palliative Care Indicators Tool (SPICT)

(April 2015 version)



THE UNIVERSITY OF EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:
- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:
- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:
- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2015

Appendix 2: The SPICT-JP and user-guide

Supportive and Palliative Care Indicator Tool (SPICT-JP)

SPICTは健康状態が悪化するリスク、あるいは亡くなるリスクのある方を同定し、その方々の支持療法・緩和ケアにおける満たされていないニーズを評価するガイドです。

健康状態の悪化を示す全般的な指標のうち2つ以上が当てはまるか確認する

パフォーマンス・ステータス（PS）が低いか低下しつつあり、改善の見込みが限られている（目安としてPS3以上、つまり日中の50%以上の時間を臥位または座位で過ごしている）	
身体的・精神的問題により、日常生活動作のほとんどを他人のケアに頼っている	
過去6か月間に2回以上の予定外入院があった	
過去3-6ヶ月間に顕著な体重減少（5-10%）があり、かつ／またはBMIが低い	
原疾患の適切な治療にも関わらず、苦痛となる症状が続いている	
患者が、支持・緩和ケアを求めている、または原疾患の治療中止を求めている	

進行した状態を示す臨床指標が１つ以上あるか確認する

がん疾患

進行性の転移性がんによる生活・身体機能の低下がある	
体力低下のため抗がん治療（化学療法および放射線治療）ができない、または症状緩和のための抗がん治療を受けている	

認知症／フレイル（虚弱）

介助なしには着替え、歩行や食事ができない	
経口摂取量の低下、嚥下困難がある	
尿失禁や便失禁がある	
発語によるコミュニケーションができない、社会的交流がほとんどない	
大腿骨骨折や複数回の転倒を経験している	
反復する発熱のエピソードや感染症（誤嚥性肺炎など）がある	

神経疾患

適切な治療にも関わらず進行する身体機能や認知機能の悪化がある	
発語の問題に伴いコミュニケーションが困難になってきている、あるいは、進行性の嚥下困難がある	
反復する誤嚥性肺炎、息切れ、呼吸困難感または呼吸不全がある	

心疾患・血管疾患

NYHA Class III/IVの心不全、または広範囲にわたる治療不可能の冠動脈疾患があり、安静時もしくは軽度の労作で呼吸困難や胸痛が生じる	
重症で手術不能な末梢血管疾患がある	

呼吸器疾患

重症慢性肺疾患があり、かつ、急性増悪でないときにも安静時またはわずかな労作で呼吸困難感を生じる	
在宅酸素療法を含む長期の酸素療法を必要とする	
呼吸不全のために人工呼吸器管理が必要だったことがある、または現在も必要としている	
人工呼吸器管理が予後およびQOLを改善しないため適応にならない	

腎疾患

慢性腎臓病（CKD）の Stage 4または5（推算糸球体濾過量（eGFR）<30ml/min）で健康状態の悪化を伴う	
腎不全によって、他の予後規定疾患や治療が複雑になっている	
透析を中止した、または中止が検討されている	

肝疾患

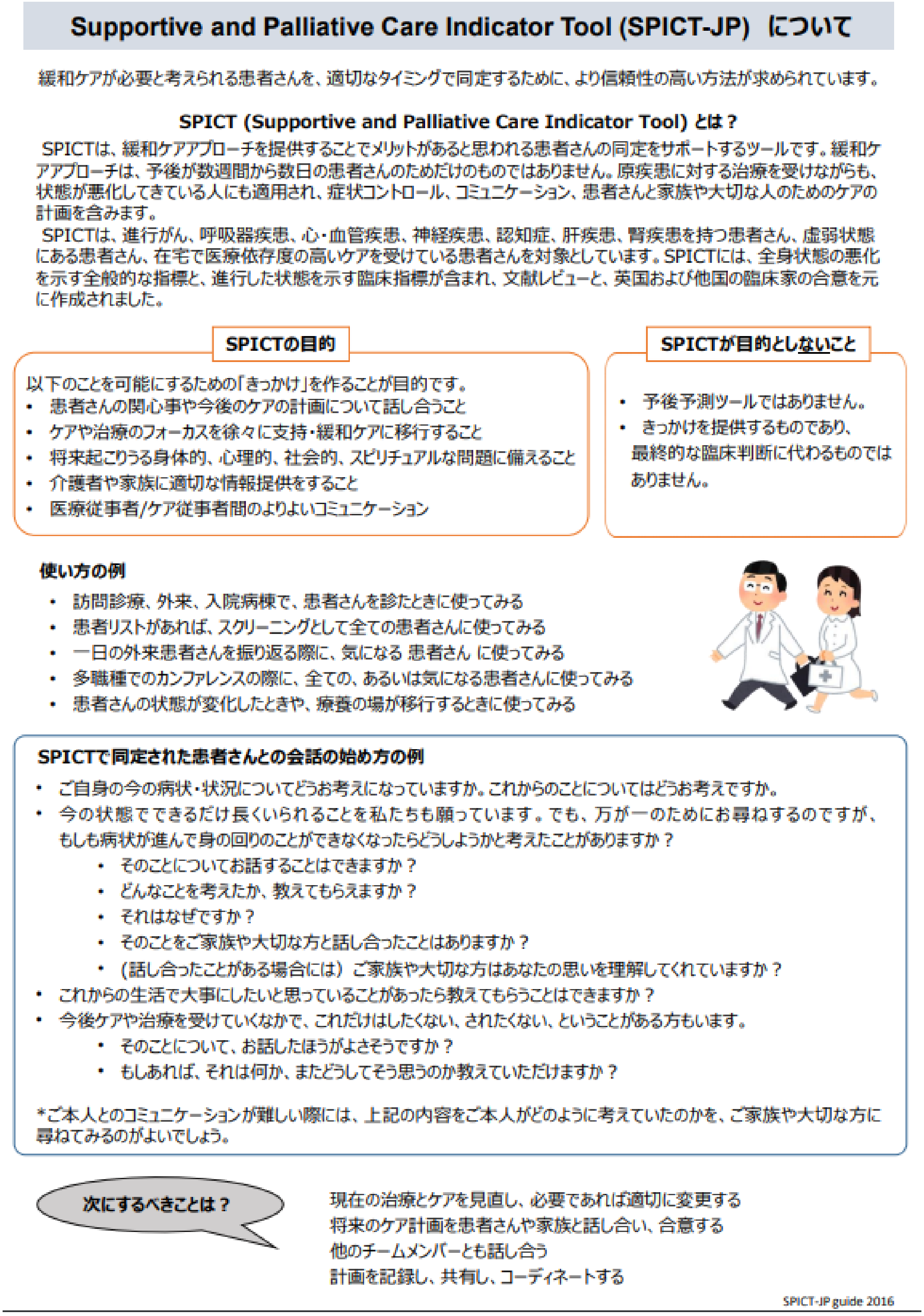
進行性肝硬変があり、以下の一つ以上を1年以内に併発している • 利尿薬に反応しない腹水 • 肝性脳症 • 肝腎症候群 • 細菌性腹膜炎 • 反復する静脈瘤出血	
肝移植が予後およびQOLを改善しないため適応にならない	

支持療法・緩和ケアとケアの計画を見直す

患者が適切な治療を受けられるように現在の治療と投薬内容を見直す
症状またはニーズが複雑でマネジメントが困難な場合には専門家への紹介を検討する
現在および将来のケアのゴールやケアの計画について、患者や家族と合意する
患者が意思決定能力を喪失するリスクがある場合には、前もって計画するようにする
プランを記録し、共有し、ケアをコーディネートする

SPICT-JP based on SPICT™, April 2015

User-guide



Supportive and Palliative Care Indicator Tool (SPICT-JP) について

緩和ケアが必要と考えられる患者さんを、適切なタイミングで同定するために、より信頼性の高い方法が求められています。

SPICT (Supportive and Palliative Care Indicator Tool) とは？

SPICTは、緩和ケアアプローチを提供することでメリットがあると思われる患者さんの同定をサポートするツールです。緩和ケアアプローチは、予後が数週間から数日の患者さんのためだけのものではありません。原疾患に対する治療を受けながらも、状態が悪化してきている人にも適用され、症状コントロール、コミュニケーション、患者さんと家族や大切な人のためのケアの計画を含みます。

SPICTは、進行がん、呼吸器疾患、心・血管疾患、神経疾患、認知症、肝疾患、腎疾患を持つ患者さん、虚弱状態にある患者さん、在宅で医療依存度の高いケアを受けている患者さんを対象としています。SPICTには、全身状態の悪化を示す全般的な指標と、進行した状態を示す臨床指標が含まれ、文献レビューと、英国および他国の臨床家の合意を元に作成されました。

SPICTの目的

以下のことを可能にするための「きっかけ」を作ることが目的です。
- 患者さんの関心事や今後のケアの計画について話し合うこと
- ケアや治療のフォーカスを徐々に支持・緩和ケアに移行すること
- 将来起こりうる身体的、心理的、社会的、スピリチュアルな問題に備えること
- 介護者や家族に適切な情報提供をすること
- 医療従事者/ケア従事者間のよりよいコミュニケーション

SPICTが目的としないこと

- 予後予測ツールではありません。
- きっかけを提供するものであり、最終的な臨床判断に代わるものではありません。

使い方の例

- 訪問診療、外来、入院病棟で、患者さんを診たときに使ってみる
- 患者リストがあれば、スクリーニングとして全ての患者さんに使ってみる
- 一日の外来患者さんを振り返る際に、気になる 患者さん に使ってみる
- 多職種でのカンファレンスの際に、全ての、あるいは気になる患者さんに使ってみる
- 患者さんの状態が変化したときや、療養の場が移行するときに使ってみる

SPICTで同定された患者さんとの会話の始め方の例

- ご自身の今の病状・状況についてどうお考えになっていますか。これからのことについてはどうお考えですか。
- 今の状態でできるだけ長くいられることを私たちも願っています。でも、万が一のためにお尋ねするのですが、もしも病状が進んで身の回りのことができなくなったらどうしようかと考えたことがありますか？
    - そのことについてお話することはできますか？
    - どんなことを考えたか、教えてもらえますか？
    - それはなぜですか？
    - そのことをご家族や大切な方と話し合ったことはありますか？
    - (話し合ったことがある場合には) ご家族や大切な方はあなたの思いを理解してくれていますか？
- これからの生活で大事にしたいと思っていることがあったら教えてもらうことはできますか？
- 今後ケアや治療を受けていくなかで、これだけはしたくない、されたくない、ということがある方もいます。
    - そのことについて、お話したほうがよさそうですか？
    - もしあれば、それは何か、またどうしてそう思うのか教えていただけますか？

*ご本人とのコミュニケーションが難しい際には、上記の内容をご本人がどのように考えていたのかを、ご家族や大切な方に尋ねてみるのがよいでしょう。

次にするべきことは？

現在の治療とケアを見直し、必要であれば適切に変更する
将来のケア計画を患者さんや家族と話し合い、合意する
他のチームメンバーとも話し合う
計画を記録し、共有し、コーディネートする

SPICT-JP guide 2016

Appendix 3: Ethics approval

The University of Edinburgh

THE UNIVERSITY *of* EDINBURGH

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POPULATION HEALTH SCIENCES
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The University of Edinburgh
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Fax +44 (0)131 650 6909
www.ed.ac.uk
email: cphs.ethics@ed.ac.uk

05 April 2016

Dr Ai Oishi

Dear Ai

Re: Identifying patients for palliative care approach in primary care settings in Japan

Thank you for resubmitting your documentation with the amendments that were requested by the CPHS ethics committee, and the Japanese language version. I am therefore pleased to be able to inform you that the above study has now been granted ethical approval.

Please be aware that this ethical approval is in respect of the protocol and methods as described in the documents submitted to the committee (with amended documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check whether this means your level 2 application form needs to be revised, and submit to the committee (via me), any documents that have been revised (study materials/protocol/level 2 form), using tracked changes. You should make clear in your covering email whether:

(i) you are requesting ethical review of a study amendment; or
(ii) you are not sure whether such is needed and, in the first instance, would like the committee's opinion on whether a formal approval is needed of the amended design/methods.

We would like to take this opportunity to compliment you on your diligence and perseverance in revising the process and documentation for this study, so that ethical approval could be given. Hopefully the changes made will also reward you with enhanced recruitment and retention of participants, and better quality study data collected, all making for more powerful findings for your very important research.

Very best wishes for the data collection and analysis/writing up phases of your research.

Yours sincerely

Diane White
Ethics Review Group Administrator

Usher Institute
Population Health Sciences & Informatics

CPHS: http://www.cphs.mvm.ed.ac.uk
Ethical Review Group : http://www.cphs.mvm.ed.ac.uk/intra/research/ethicalReview.php (Staff & PGR Students only)

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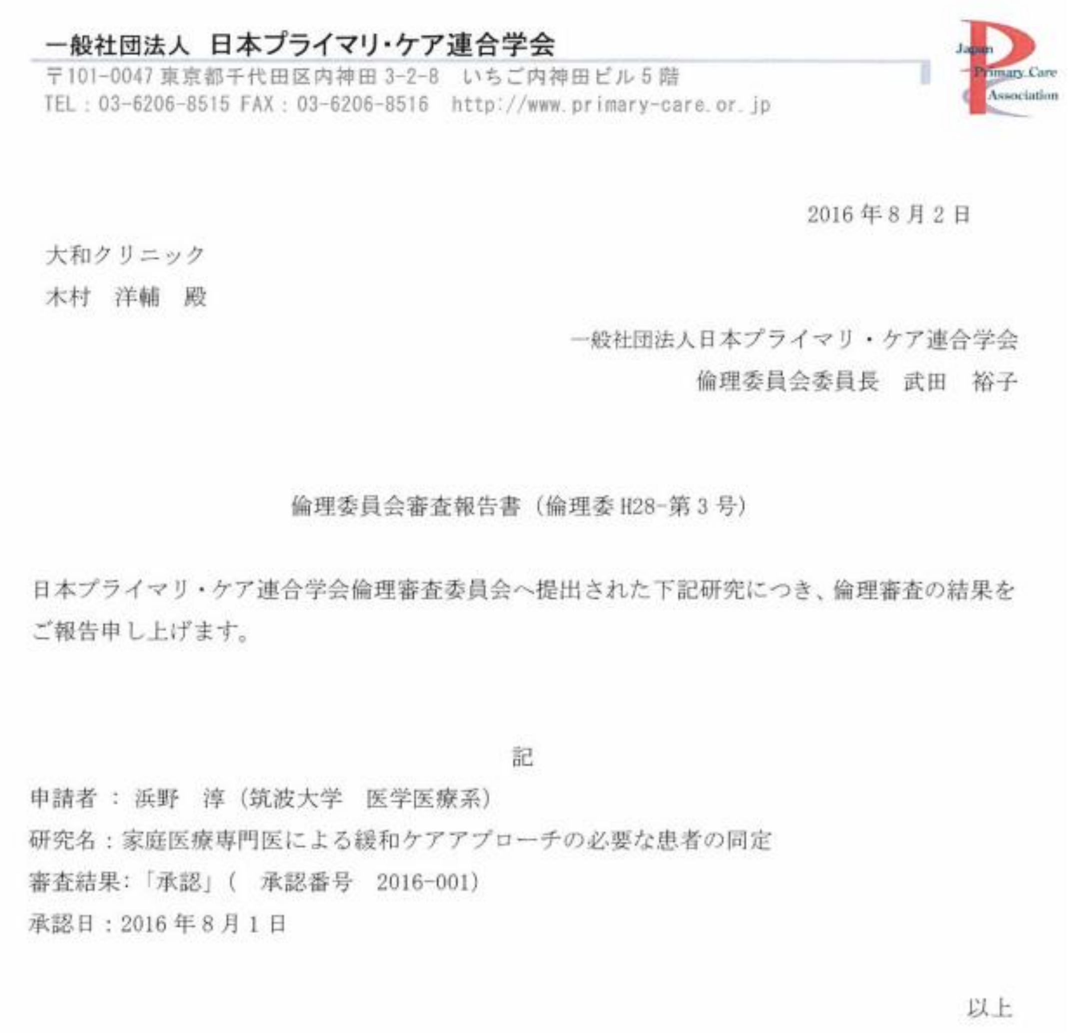
Japan Primary Care Association



一般社団法人　日本プライマリ・ケア連合学会
〒101-0047 東京都千代田区内神田 3-2-8　いちご内神田ビル 5 階
TEL：03-6206-8515 FAX：03-6206-8516　http://www.primary-care.or.jp

2016 年 8 月 2 日

大和クリニック
木村　洋輔　殿

一般社団法人日本プライマリ・ケア連合学会
倫理委員会委員長　武田　裕子

倫理委員会審査報告書（倫理委 H28-第 3 号）

日本プライマリ・ケア連合学会倫理審査委員会へ提出された下記研究につき、倫理審査の結果をご報告申し上げます。

記

申請者 ： 浜野　淳（筑波大学　医学医療系）
研究名：家庭医療専門医による緩和ケアアプローチの必要な患者の同定
審査結果:「承認」(　承認番号　2016-001)
承認日：2016 年 8 月 1 日

以上

Appendix 4: Information sheet

(English version)

Identifying patients for palliative care approach in primary care settings in Japan (for family physicians)

My name is Dr Ai Oishi and I am a JPCA certified family physician (JPCA FP) with a special interest in palliative care. I am interested in how we as family physicians might provide better palliative care in the community, and clearly the first step on this path is *identifying* which of our patients would benefit from palliative care. I am conducting a PhD project in this area at the University of Edinburgh and would like you to consider participating. This study is partly funded by the JPCA, Japan Hospice Palliative Care Foundation and Great Britain Sasakawa Foundation. This study was approved by the ethics committees at the University of Edinburgh and the JPCA.

Before you decide whether to take part in this study, it is important that you understand why it is being done and what it will involve. Please contact me if you want more information. Contact information is provided at the end of this information sheet.

Purpose of the study

Identifying patients who would benefit from palliative care is a challenging and important issue for health care professionals working in the community. Palliative care doctors, family physicians and researchers at the University of Edinburgh have developed the Supportive & Palliative Care Indicator Tool (SPICT), for identifying patients who would benefit from palliative care approach. The SPICT has now been translated into Japanese (SPICT-JP) in collaboration with other Japanese doctors in palliative care, homecare and family medicine.

This study has two aims;

1. To understand JPCA FPs' and family medicine registrars' understanding of identifying patients for palliative care approach
2. To investigate if the SPICT-JP is acceptable for JPCA FPs and family medicine registrars and how they will use it.

In this study, palliative care approach is defined as a way to integrate palliative care methods in all health care settings which includes communication such as decision making and goal setting.

Why have I been invited?

You have been invited because you are a JPCA FP or receiving training to be a JPCA FP practising in the community settings working for family medicine institutions which is I have chosen against pre-set criteria; 1) belongs to an established research network or universities or 2) has a JPCA accredited family medicine programme.

What does taking part involve?

When you agree participating, you will be asked to sign a consent form. The research has four main steps;

i. Pre-intervention Interviews or focus groups: First, you will take part in a focus-group interview or a personal interview. You can choose which ever suits you better. I will let you know the date and place of focus-group separately. You also will be asked to answer several questions about your background on a registration sheet.

ii. Induction session: After that, you will attend an induction session which offers update of identifying patients for palliative care and training on how to use the SPICT-JP. You will have a chance to ask questions and discuss. This induction session will also be audio recorded.

iii. The use of the SPICT-JP: You will be asked to use the SPICT-JP in your practice for about three months. I have developed the SPICT-JP from the original SPICT with other Japanese doctors in palliative care, homecare and family medicine. During these three months, you will also be asked to keep logs for 6 cases, about how you found using the SPICT-JP in these cases. Only the 6 case logs will be collected in, after the interview (see iv). Also, I will touch base with you fortnightly. Each contact will be about 20 minutes. You can access the on-line SPICT-JP forum where you can post questions, thoughts or anything you would like to share with other participants and me. Also, you can access to me anytime if you have any questions about the use of the SPICT-JP.

iv. Post-intervention interviews: After the period of use of the SPICT-JP, I will have a personal interview with you. I will ask you to have your Case Logs with you during the interview, and we will discuss your experience of using the SPICT. The interview will take about 20 to 40 minutes and can be done in person or on Skype, whichever suits you better. You will be able to choose the date, time and place of your interview. This interview will be audio-recorded.

You will have a chance to see how I analyse the data and give me feedback. You will receive 2000 Japanese Yen Amazon gift card for participation. I will send you a summary of the final results on your request.

Do I have to take part? What if I have any complaint or concerns during the study?

No. Taking part in this research is entirely up to you and your decision will not affect your job or any work-related evaluations or reports. If you have any complaint or concerns about any aspect of the study, you can contact the researchers at any time. If you are not comfortable to contact me, please use another contact provided at the end of this sheet. You are free to withdraw from the study at any point without giving a reason.

Will my participation be confidential? What will happen to my personal information?

At group sessions, other participants will see you there, so your participation cannot be entirely confidential. Also an assistant may attend the group session to help take field notes. However, all information that is collected about you during the study will be kept strictly confidential and will be stored in a locked filing cabinet or on a password-protected computer, and will not be made available to anyone apart from the researcher. The recording of your interview will be typed up, but any names, details or other information which could possibly identify you will be removed or changed. When I write up the study’s findings, I will also make sure that it will not be possible to identify you from any of these findings. All files and information will be destroyed by five years after the completion of the study.

You are not obligated to join the on-line SPICT-JP forum discussion while participating the study. However, if you do join the discussion, you can use your ID number to hide your name, and if you do this, your participation will remain confidential to others visiting discussion board.

What might be possible benefits and disadvantages of taking part?

You will have a chance to reflect and learn about palliative care and identifying patients for palliative care by participating this study. The time needed for the study can be an added pressure on your practice.

What happens when the study stops?

You will still be able to use the SPICT-JP in your practice if you wish.

Contact information

Dr Ai Oishi

Primary Palliative Care Research Group, Centre for Population Health Sciences, University of Edinburgh, Medical School, Teviot Place, Edinburgh, EH8 9AG, UK

Tel: 080-6255-3383 (Japan), +44-75-23251703 (UK)

Dr Jun Hamano

Faculty of Medicine, University of Tsukuba, 1-1-1 Tennodai, Tsukuba 305-8575

Tel: 029-853-3189,3101

Email: junhamano1012@gmail.com

[Ver 8, March 2016]

(Japanese version)

家庭医療専門医・専攻医は、
緩和ケアが必要な患者さんをどのように同定しているか?

家庭医が地域においてより良い緩和ケアを提供するには、緩和ケアを提供すべき患者を適切に「同定」することが最初のステップとなります。現在、このことについてエジンバラ大学で博士研究を行っており、皆様のご協力をいただければ幸いです。この研究は、日本プライマリ・ケア連合学会、日本ホスピス緩和ケア財団、グレイトブリテン・ササカワ財団の助成を受けています。この研究は、エジンバラ大学および日本プライマリ・ケア連合学会の倫理委員会の承認を得ています。

以下の内容をご理解のうえ、研究参加の可否を決めていただくことが大切です。より詳しい情報が必要な方は、お気軽にお問い合わせ下さい。

研究目的

緩和ケアの提供が望ましい患者さんを同定することは、地域で働くケア従事者にとって重要な課題です。エジンバラ大学の緩和ケア医、家庭医、研究者によって開発された Supportive & Palliative Care Indicator Tool（SPICT）は緩和ケアの必要な患者さんを同定するためのツールであり、日本の緩和ケア医、在宅医、家庭医の協力のもと、日本語版 SPICT（SPICT-JP）を作成しました。

この研究は以下の二点を目的とします

1. 家庭医の緩和ケアアプローチの必要な患者の同定についての理解を探る
2. SPICT-JP が日本の家庭医にどのように受け入れられ、どのように使われるかを探る

なお、本研究において、「緩和ケアアプローチ」とは、あらゆるセッティングにおける緩和ケアの手法すべてを指し、意思決定や目標設定などのコミュニケーションも含むものとします。

研究対象者の条件は？

1)研究ネットワークないし大学に属する、2)日本プライマリ・ケア連合学会認定の家庭医療プログラムを持っている、のいずれかの基準を満たす施設に所属しており、地域で診療している日本プライマリ・ケア連合学会認定家庭医療専門医もしくは家庭医療専攻医を対象としています。

研究に参加したら何をするんですか？

まず、参加同意書にサインをしていただきます。研究は、主に 4 つのステップからなります。

i. **介入前インタビュー**： フォーカスグループインタビューまたは個別インタビューに参加していただきます。ご自身の背景についていくつかの質問にも答えていただきます。対面もしくはスカイプを選択できます。内容は録音します。

ii. **導入セッション**： 緩和ケアの必要な患者さんの認識についての情報提供および SPICT-JP についての説明をします。質問をする機会もあります。内容は録音します。

iii. **SPICT-JP の使用**： SPICT-JP を診療で 3 ヶ月ほど使っていただきます。

   1. 3 ヶ月の間に、SPICT-JP を使ってみてどうだったか、6 症例分の振り返りを記録していただきます。この振り返り記録は iv. 介入後インタビューの際に回収します。
   2. 期間中 2 週間ごとに電話・スカイプなどで連絡を差し上げて、状況についてお尋ねします。所要時間は 20 分程度の予定です。
   3. SPICT-JP 使用期間中、SPICT-JP オンラインコミュニティに参加し、質問などを投稿することによって、他の参加者と意見を交換共有することができます。
   4. いつでも研究者に連絡して SPICT-JP についての質問をすることができます。

iv. **介入後インタビュー**: SPICT-JP 使用期間後、個人インタビューをします。その際には、振り返り記録を手元に用意していただきます。およそ 20－40 分の予定で、対面またはスカイプを選択できます。内容は録音します。

分析の結果を見てフィードバックができる機会を設けます。参加謝礼として Amazon のギフトカード 2000 円相当とエジンバラ大学のステッカーをお渡しします。

参加しなくてはなりませんか？

いいえ、参加は義務ではありません。本研究への参加は全く自由であり、参加の有無が職務やあなたの評価に影響することはありません。いつでも辞退可能で、その際に理由を伝える必要もありません。

参加は内密に扱われますか？

グループインタビューを行う場合には、他の参加者およびアシスタントが同席する可能性があり、また、診療中に SPICT-JP を使用していただくことから、あなたの研究への参加を厳密に誰にも知られないようにするのは難しいと考えます。ただし、研究中に集めた個人情報は厳密に扱い、鍵のかかったキャビネットもしくはパスワードで保護したコンピューターに保存します。これらの情報は研究者以外の誰も閲覧できません。インタビューの録音は、あなたの許可のもと、書き起こします。書き起こす際、個人を特定する可能性のある氏名、詳細その他の情報はすべて省略または変更します。研究の記述にあたっても、内容から個人を特定することができないようにします。すべてのファイル及び情報は、当該論文等発表後 10 年で廃棄します。

SPICT-JP オンラインコミュニティに参加するときは、氏名を隠せるよう ID 番号を入力します。SPICT-JP オンラインコミュニティへの参加は辞退してもかまいません。

研究に参加することによって生じうる利益、不利益はありますか？

緩和ケアについて、および緩和ケアの必要な患者さんを同定することについて振り返る機会を得ることができます。研究のための時間が負荷となる可能性があります。

もし研究が中止になったらどうなりますか？

研究が中止になった場合でも、SPICT-JP を使用し続けることができます。

研究者: 大石 愛

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Medical School, Teviot Place, Edinburgh, EH8 9AG, UK

Tel: 070-4084-9114 (Japan), E-mail: ai.oishi@ed.ac.uk Skype ID: aioishi

共同研究者: 浜野淳 筑波大学医学医療系 つくば市天王台 1-1-1 E-mail: junhamano@md.tsukuba.ac.jp

[Ver 10, Aug 2016]

Appendix 5: Informed consent form

(English version)

Identifying patients for palliative care approach in primary care setting in Japan

Family Physician Participant ID:

Researchers: Dr Ai Oishi (University of Edinburgh), Dr Jun Hamano (Tsukuba University), Prof Yoshiyuki Kizawa (Kobe University), Professor Scott Murray, Dr Liz Grant, Dr Kirsty Boyd (University of Edinburgh)

Please initial box

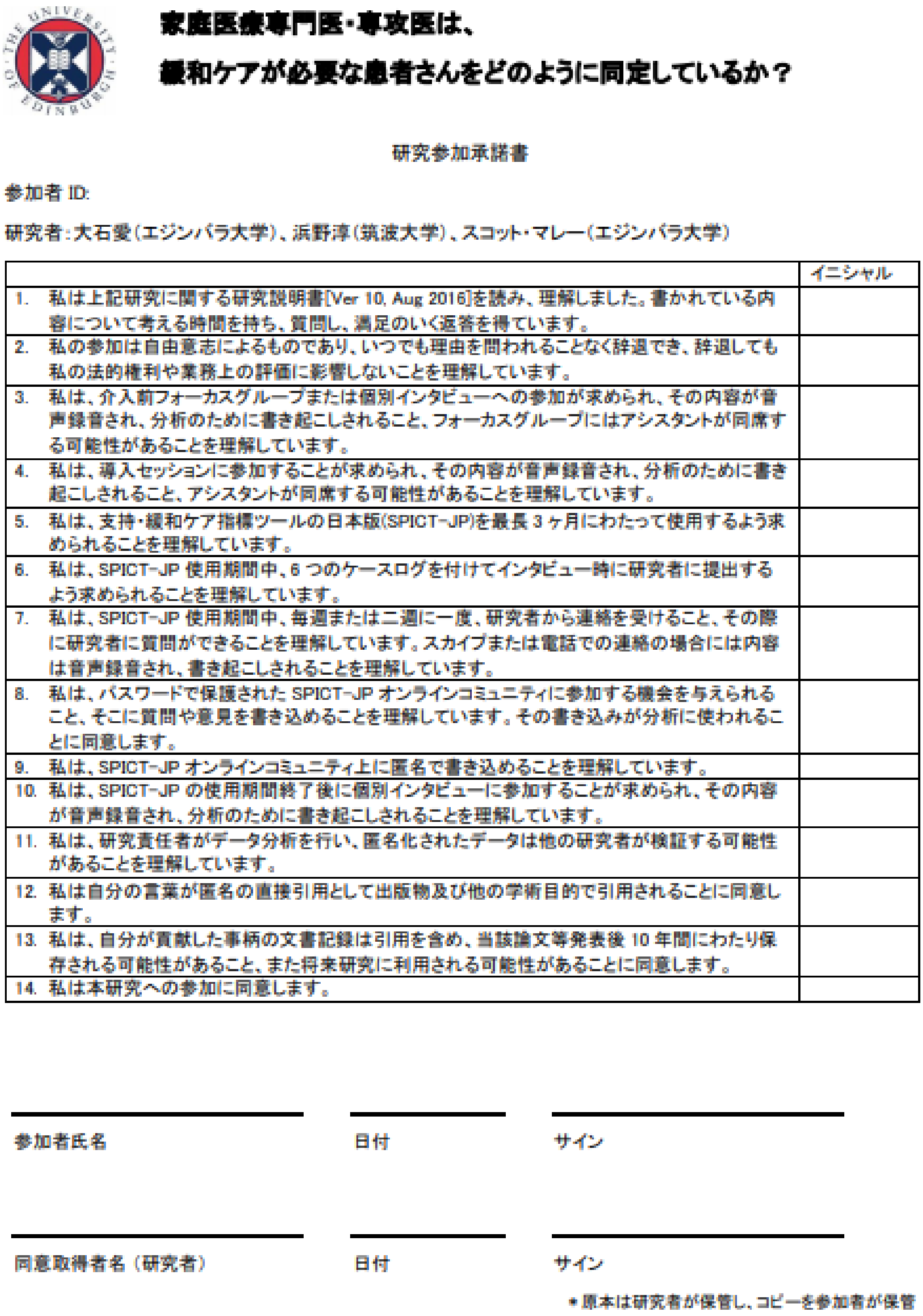
1. I confirm that I have read and have understood the information sheet dated [Ver 8, March 2016] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without any reason, without my legal rights or work-related evaluation being affected.	
3. I understand that I will be asked to participate in a pre-intervention focus-group or personal interview, and agree that it will be audio recorded and transcribed for analysis, and that an assistant may attend the focus group to help take field notes.	
4. I understand that I will be asked to participate in an induction session, and agree that it will be audio recorded and transcribed for analysis, and that an assistant may attend the session to help take field notes.	
5. I understand that I will be asked to use the Japanese version of Supportive & Palliative Care Indicator Tool (SPICT-JP) for up to 3 months.	
6. I understand that I will be asked to complete 6 Case Logs while I am using the SPICT-JP, and to hand them in to the researcher after the end-of-study interview.	
• I understand that the researcher will contact me weekly or fortnightly while I am using the SPICT-JP and will be free to ask any questions. I agree that this conversation will be audio recorded and transcribed when I choose to be contacted by phone or Skype.	
• I understand that I will be offered an opportunity to join the on-line SPICT-JP forum in a password protected area on the SPICT website, and will be free to share any questions and thoughts there. I agree that my posts there will be used for analysis.	
• I understand that I can choose anonymise myself when posting in the on-line SPICT-J community.	
• I understand that I will be asked to participate a personal interview after using the SPICT-JP and agree that it will be audio recorded and transcribed for analysis.	
• I understand that the researcher will conduct data analysis, and that some anonymised data may be examined by other researchers.	

• I agree for anonymised direct quotations to be used in publications and other reports.	
• I agree that the anonymised written record of my contribution, may be kept for 5 years after the completion of the study and used for future research.	
• I agree to take part in the study.	

______________________	_________	_______________________
Name of participant	Date	Signature
______________________	_________	_______________________
Person taking consent (Researcher)	Date	Signature

Original to be retained by the researcher. Copy (x1) to be retained by the participant.

(Japanese version)



家庭医療専門医・専攻医は、
緩和ケアが必要な患者さんをどのように同定しているか？

研究参加承諾書

参加者 ID:

研究者：大石愛（エジンバラ大学）、浜野淳（筑波大学）、スコット・マレー（エジンバラ大学）

	イニシャル
1. 私は上記研究に関する研究説明書[Ver 10, Aug 2016]を読み、理解しました。書かれている内容について考える時間を持ち、質問し、満足のいく返答を得ています。	
2. 私の参加は自由意志によるものであり、いつでも理由を問われることなく辞退でき、辞退しても私の法的権利や業務上の評価に影響しないことを理解しています。	
3. 私は、介入前フォーカスグループまたは個別インタビューへの参加が求められ、その内容が音声録音され、分析のために書き起こしされること、フォーカスグループにはアシスタントが同席する可能性があることを理解しています。	
4. 私は、導入セッションに参加することが求められ、その内容が音声録音され、分析のために書き起こしされること、アシスタントが同席する可能性があることを理解しています。	
5. 私は、支持・緩和ケア指標ツールの日本版(SPICT-JP)を最長 3 ヶ月にわたって使用するよう求められることを理解しています。	
6. 私は、SPICT-JP 使用期間中、6 つのケースログを付けてインタビュー時に研究者に提出するよう求められることを理解しています。	
7. 私は、SPICT-JP 使用期間中、毎週または二週に一度、研究者から連絡を受けること、その際に研究者に質問ができることを理解しています。スカイプまたは電話での連絡の場合には内容は音声録音され、書き起こしされることを理解しています。	
8. 私は、パスワードで保護された SPICT-JP オンラインコミュニティに参加する機会を与えられること、そこに質問や意見を書き込めることを理解しています。その書き込みが分析に使われることに同意します。	
9. 私は、SPICT-JP オンラインコミュニティ上に匿名で書き込めることを理解しています。	
10. 私は、SPICT-JP の使用期間終了後に個別インタビューに参加することが求められ、その内容が音声録音され、分析のために書き起こしされることを理解しています。	
11. 私は、研究責任者がデータ分析を行い、匿名化されたデータは他の研究者が検証する可能性があることを理解しています。	
12. 私は自分の言葉が匿名の直接引用として出版物及び他の学術目的で引用されることに同意します。	
13. 私は、自分が貢献した事柄の文書記録は引用を含め、当該論文等発表後 10 年間にわたり保存される可能性があること、また将来研究に利用される可能性があることに同意します。	
14. 私は本研究への参加に同意します。	

参加者氏名　日付　サイン

同意取得者名（研究者）　日付　サイン

＊原本は研究者が保管し、コピーを参加者が保管

Appendix 6: Case log sheet

(English version)

Case log sheet

The Case Log covers the main aspects that will be discussed during the interview. Please use the Case Log to make reflective notes about SPICT use – one Log for each of at least 6 patients.

Important note

The 6 Case Logs will be collected by the researcher after the final interview, so:

- Please do NOT write the patient's name (nor practice identifier) anywhere on this sheet.
- If you need to give some clinical context for an action/ decision, please keep your wording general (eg aged over 90), rather than specific (eg aged 96 years 4 months).
- Until collected in, please keep your completed Case Logs in secure storage (in a locked filing cabinet for a paper sheet, and on a password-protected computer for an electronic file).

Family physician Participant ID:

Date: **Research SPICT-use Case number: 1 2 3 4 5 6 7 8 9 (circle one)**
Using the SPICT Why did you decide to use the SPICT to assess this patient? How did you use the SPICT with this patient? Did you use the SPICT for this patient with any other health care professionals? If so, with who? Comment on how useful you think the SPICT was in assessing this patient?
About the patient Did using the SPICT to assess this patient affect how you then managed their treatment and care? What sort of discussions did you have with patients you identified using SPICT, if any? What happened to this patient?
Any further reflection or other comments?

(Japanese version)

Case log sheet

SPICT-JP を使ってみての振り返りを 1 症例につき 1 振り返りを記載し、最低 6 症例分記録してください。

重要事項：このケースログは、最後のインタビューの際に**回収します**。したがって、以下の点にご注意ください。

- 患者さんの氏名その他の個人が特定される情報は記載しないでください。
- 臨床情報や背景情報が文脈上必要な場合も、できるだけ一般的な表現にとどめてください。
- 回収されるまで、ケースログは厳密に保管してください（鍵付きのキャビネットまたはパスワードで保護されたコンピュータ）

参加者 ID：

日付　　：

症例番号：　1　2　3　4　5　6　7　8　9

SPICT-JP の使用について

どうしてこの患者さんに SPICT-JP を使おうと思いましたか？
どのように SPICT-JP を使いましたか？
SPICT-JP を他の医療従事者と一緒に使いましたか？誰とですか？
この患者さんを評価するにあたって、SPICT-JP はどれだけ役に立った／立たなかったか、何かコメントはありますか？

患者さんについて

SPICT-JP を使ったことによって、患者さんのケアに何らかの影響があったと思いますか？
SPICT-JP で同定された患者さんと、何か話し合いをしましたか？
この患者さんはどうなりましたか？

他に何らかの振り返りやコメントがあればご記載ください。

Appendix 7: Interview schedules

The first interview

Can you describe the patients you give palliative care to and the care you provide to them?

What actions do you take as a first step in your practice when you see a patient who needs palliative care?

Are you working with anyone to provide palliative care to patients? Who?

When do you realise that a patient needs palliative care?

From your own experience, are there any ways to identify people for palliative care that work well? Can you tell me about these?

What makes it easier or more difficult to recognize patients for palliative care?

Do you see a difference between cancer patients and non-cancer patients in terms of recognizing a need for palliative care?

Does the point when you start palliative care coincide with the patient’s prognosis of weeks, months or years? Why?

Are there cases where you start palliative care many months, or even years, before death is expected?

Nowadays, palliative care is often seen as more than simply terminal care. Based on this, we decided to use the term ‘palliative care approach’. It is sometimes suggested that palliative care starts as soon as a life-threatening condition is diagnosed. What are your views on this?

How would you define palliative care?

The second interview

Introduction: Before the interview begins, I would like to remind you that for the sake of your patient confidentiality you should not mention any identifiable patient information, such as name.

How was your overall experience of the use of the SPICT-JP?

Are there any impressive cases? Why?

In what settings and how did you use the SPICT-JP?

What triggered you to use the SPICT?

How useful were the SPICT-JP?

When or in what points do you think the SPICT-JP was not useful?

What would you suggest to improve the SPICT-JP?

Was the user-guide useful? If so, how?

What do you think is the potential danger and risk of using such tool to identify patients for palliative care approach? Do you think there are any ways to prevent such risk?

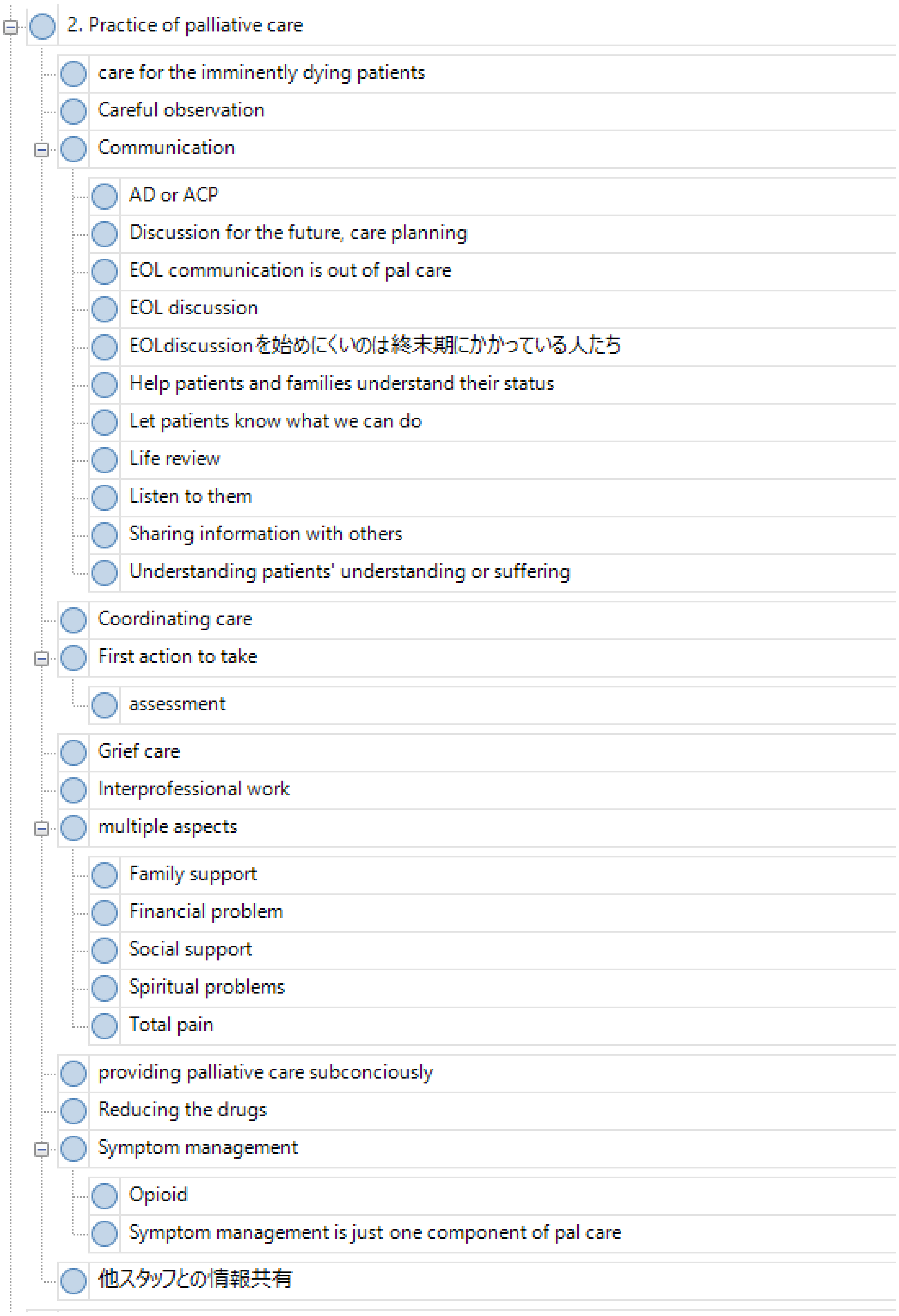
Has participating this research changed your practice? If it has, how?

Do you think taking part in this study has changed your practice? If so, how?

Appendix 8: Coding tree excerpt

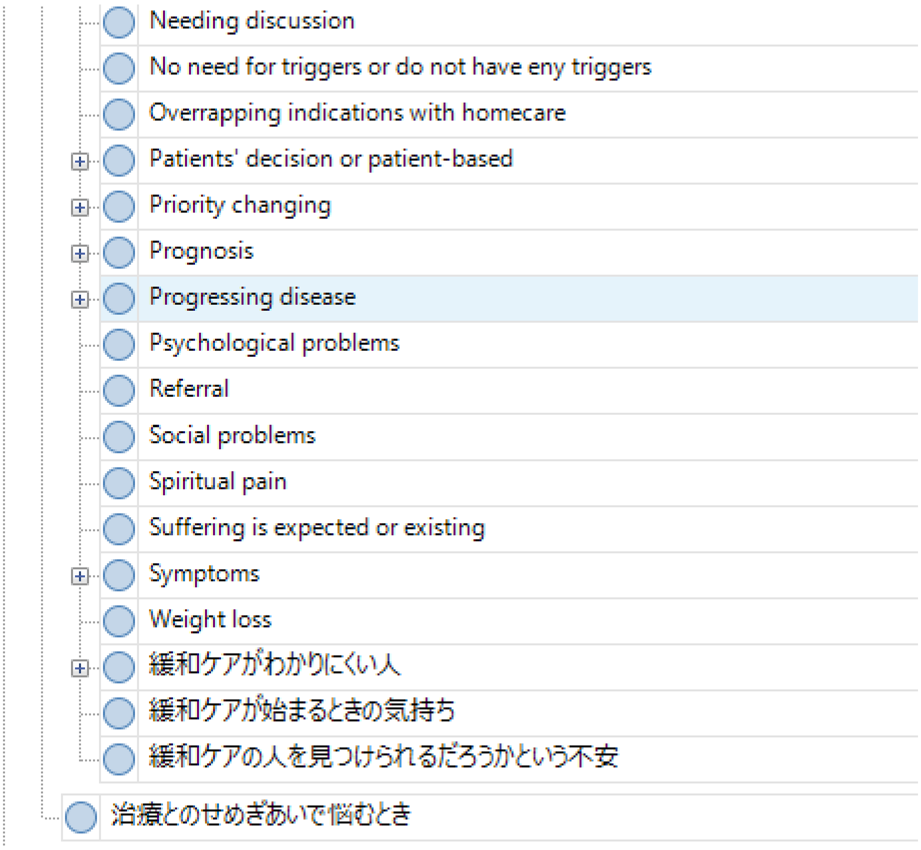
A coding structure of the first three categories on NVivo 12

- 1. Understanding of palliative care
  - 1. Principles of palliative care
    - Concept of palliative care
      - Broader palliative care
      - Double definition of palliative care
      - Early palliative care
      - EOLd vs palliative care approach
      - Everyone needs palliative care
      - Textbook definition of palliative care
      - 狭義の緩和ケア
      - 色々な緩和ケアがあるので、それを一色田にするのは意味がない
    - Definition of palliative care
      - Being with them
      - Improve their quality of life
      - multi-disciplinary
      - Not only cancer
      - Palliative care as comprehensive care
      - Preparing for death
      - Unclear definition of palliative care
    - Different phases in palliative care
    - Embedded to family practice
    - Family medicine and palliative care
    - Influencing factors on understanding of palliative care
    - Target is to reduce patients suffering
    - Wiggle or oblique line to palliative care
    - 死と向き合っていけるように助ける
  - 2. The term palliative care
    - Discussing palliative care in the interview
    - Image of palliative care
    - Misunderstanding of illness trajectory of frail elderly
    - The term palliative care
    - 緩和ケアをしている実感があるときとないとき



- 2. Practice of palliative care
  - care for the imminently dying patients
  - Careful observation
  - Communication
    - AD or ACP
    - Discussion for the future, care planning
    - EOL communication is out of pal care
    - EOL discussion
    - EOLdiscussionを始めにくいのは終末期にかかっている人たち
    - Help patients and families understand their status
    - Let patients know what we can do
    - Life review
    - Listen to them
    - Sharing information with others
    - Understanding patients' understanding or suffering
  - Coordinating care
  - First action to take
    - assessment
  - Grief care
  - Interprofessional work
  - multiple aspects
    - Family support
    - Financial problem
    - Social support
    - Spiritual problems
    - Total pain
  - providing palliative care subconciously
  - Reducing the drugs
  - Symptom management
    - Opioid
    - Symptom management is just one component of pal care
  - 他スタッフとの情報共有

- 3. Identification of palliative care patients
  - Collecting information
    - Actively asking
    - Grasping the whole picture is important
    - Input from other people
    - Observation
    - Scores
    - 診察の中で気づく
  - Diagnosis
    - Diagnosis is important
    - Diagnosis less important
    - Diagnosis of advanced cancer
    - Diagnosis of cancer, but not advanced
    - Diagnosis of non-cancer diseases
    - 診断や病期
  - Difficulty of capturing tiny changes at outpatient settings
  - Factors influencing identifying patients for palliative care
    - Factors influencing identification
    - Social factors influencing care
    - Speed of progression
  - Needs based
  - Triggers for and indications of palliative care
    - accumulation of palliativeness
    - Acute events
    - Age
    - Beyond normal care
    - Changes in ADL or life
    - Complexity
    - Family's suffering
    - Indicated 'best supportive care'



- Needing discussion
- No need for triggers or do not have eny triggers
- Overrapping indications with homecare
- Patients' decision or patient-based
- Priority changing
- Prognosis
- Progressing disease
- Psychological problems
- Referral
- Social problems
- Spiritual pain
- Suffering is expected or existing
- Symptoms
- Weight loss
- 緩和ケアがわかりにくい人
- 緩和ケアが始まるときの気持ち
- 緩和ケアの人を見つけられるだろうかという不安

治療とのせめぎあいで悩むとき

A set of categories and themes created on 2018/12/7

Understanding of palliative care:

1. Wide conception of palliative care
    1. Goal – to reduce sufferings
    2. Management of suffering
        1. Physical symptom
        2. Other problems
    3. Communication
    4. Organising care
    5. Early and for all conditions
        1. Blurred boarder between chronic care
    6. Embedded to family practice
2. Palliative care as a narrow concept
    1. Stratifying patients
    2. Use of the term ‘palliative care’
    3. Avoid negative connotations
    4. Keep the pace with other professionals

Identification of palliative care patients:

1. Accumulation of ‘palliativeness’
2. Changing priority

About the SPICT:

1. Not changing action, but raising awareness
2. Offering a time to stop and think
3. Potential educational & communication tool
4. Challenges: environment, tool factors, attaching education

Additional:

1. Haven’t had chances to verbalise

Appendix 9: Consolidated criteria for Reporting Qualitative research (COREQ) checklist

No. Item	Guide questions/description	Reported in Chapter or Section
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	5.3.1
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	5.3.1
3. Occupation	What was their occupation at the time of the study?	5.2, 6
4. Gender	Was the researcher male or female?	-
5. Experience and training	What experience or training did the researcher have?	5.3.1
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	5.6.2
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5.6.2
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	1, 5.6
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5.1
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5.2
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	5.2
12. Sample size	How many participants were in the study?	6
13. Non-participation	How many people refused to participate or dropped out? Reasons?	5, 5.3.4
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	5.3.2

15. Presence of non-participants	Was anyone else present besides the participants and researchers?	5.3.2
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	6
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5.3
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	5.3
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	5.3
20. Field notes	Were field notes made during and/or after the interview or focus group?	5.3, 5.4
21. Duration	What was the duration of the interviews or focus group?	5.3
22. Data saturation	Was data saturation discussed?	5.2.1
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	-
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	5.4
25. Description of the coding tree	Did authors provide a description of the coding tree?	Appendix 8
26. Derivation of themes	Were themes identified in advance or derived from the data?	5.4
27. Software	What software, if applicable, was used to manage the data?	5.4.2
28. Participant checking	Did participants provide feedback on the findings?	5.4.3
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6, 7, 8
30. Data and findings consistent	Was there consistency between the data presented and the findings?	6, 7, 8, 9
31. Clarity of major themes	Were major themes clearly presented in the findings?	6, 7, 8
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	5, 6, 7, 8

Appendix 10: Conference presentations

The 8th annual academic conference of the JPCA, May 2017

Developing a Japanese version of the Supportive and Palliative Care Indicators Tool™ (SPICT-JP)

Ai Oishi[1], Jun Hamano[2]
Kirsty Boyd[1], Liz Grant[1], Scott Murray[1]

1) Primary Palliative Care Research Group,
Usher Institute of Population Health Sciences and Informatics,
University of Edinburgh, Scotland

2) Faculty of Medicine, University of Tsukuba

1

Background

- Timely introduction of palliative care approach in all illnesses is beneficial for patients.
- Identifying patients for palliative care approach is recognized as challenging by family physicians.
- Several tools have been developed to identify patients needing palliative care approach in primary care.

13/05/2017 The 8th JPCA academic conference in Takamatsu 2

2

Supportive and Palliative Care Indicators Tool (SPICT)™

- Identified as most useful in a recent systematic review
- Developed by researchers and clinicians in Scotland
- Available at: http://www.spict.org.uk/

The 8th JPCA academic conference in Takamatsu 3

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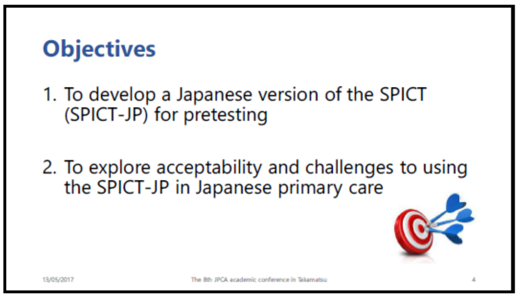

Objectives

1. To develop a Japanese version of the SPICT (SPICT-JP) for pretesting
2. To explore acceptability and challenges to using the SPICT-JP in Japanese primary care

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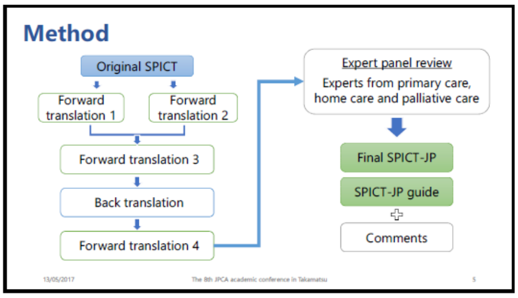

Method

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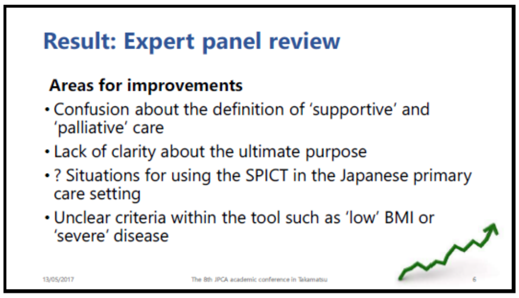

Result: Expert panel review

Areas for improvements

- Confusion about the definition of 'supportive' and 'palliative' care
- Lack of clarity about the ultimate purpose
- ? Situations for using the SPICT in the Japanese primary care setting
- Unclear criteria within the tool such as 'low' BMI or 'severe' disease

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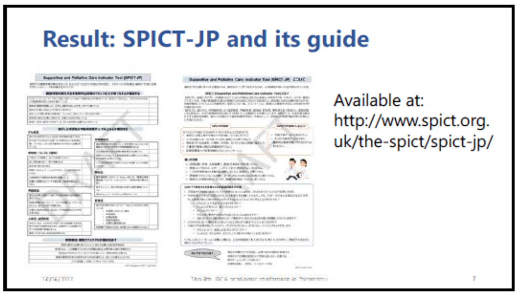

Result: SPICT-JP and its guide

Available at: http://www.spict.org.uk/the-spict/spict-jp/

7

7

Conclusions

- Valuable insights were gained from the expert panel enabling the SPICT-JP and its guide to be developed for pretesting.
- More insights from family physicians are needed for further improvements.
- We are now conducting a study to assess its usability with family physicians in Japan.

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8

WONCA Asia Pacific regional conference, May 2019

Supportive and Palliative Care Indicators Tool (SPICT) to identify patients for palliative care; Perspectives of Japanese family physicians

Ai Oishi[1], Jun Hamano[2]
Kirsty Boyd[1], Liz Grant[1], Scott Murray[1]

1) Primary Palliative Care Research Group,
Usher Institute of Population Health Sciences and Inform
University of Edinburgh, Scotland

2) Faculty of Medicine, University of Tsukuba

1

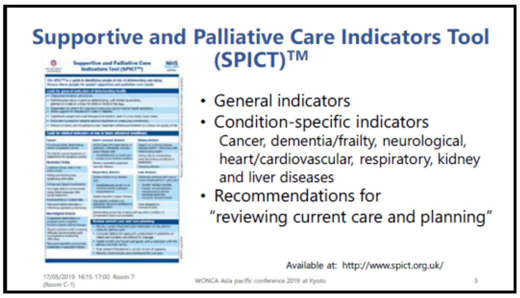
OA4

Background

- Timely introduction of a palliative care approach is beneficial for all patients (Walsh et al. 2015).
- Identifying patients for a palliative care approach is recognised as challenging by family physicians (Beernaert 2014).
- Several tools have been developed to identify patients who would benefit from a palliative care approach in primary care (Maas et al. 2015).

17/05/2019 16:15-17:00 Room 7 (Room C-1) WONCA Asia pacific conference 2019 at Kyoto 2

2



Supportive and Palliative Care Indicators Tool (SPICT)™

- General indicators
- Condition-specific indicators
  Cancer, dementia/frailty, neurological, heart/cardiovascular, respiratory, kidney and liver diseases
- Recommendations for "reviewing current care and planning"

Available at: http://www.spict.org.uk/

17/05/2019 16:15-17:00 Room 7 (Room C-1) WONCA Asia pacific conference 2019 at Kyoto 3

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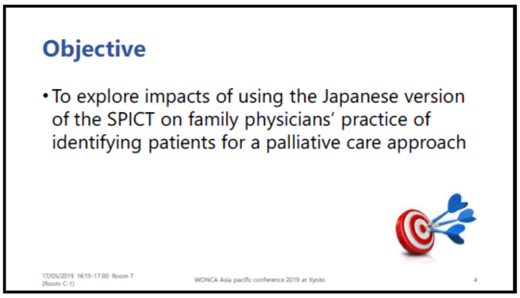

Objective

- To explore impacts of using the Japanese version of the SPICT on family physicians' practice of identifying patients for a palliative care approach

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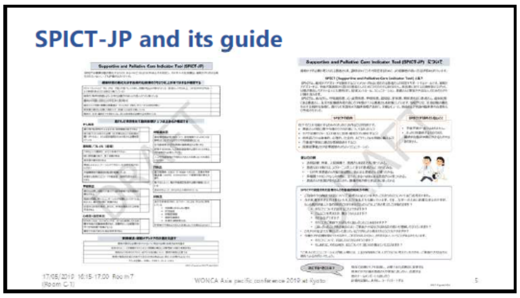

SPICT-JP and its guide

17/05/2019 16:15-17:00 Room 7 (Room C-1) WONCA Asia pacific conference 2019 at Kyoto 5

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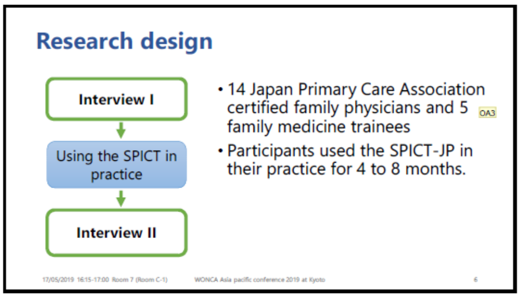

Research design

Interview I
Using the SPICT in practice
Interview II

- 14 Japan Primary Care Association certified family physicians and 5 family medicine trainees
- Participants used the SPICT-JP in their practice for 4 to 8 months.

OA3

17/05/2019 16:15-17:00 Room 7 (Room C-1) WONCA Asia pacific conference 2019 at Kyoto 6

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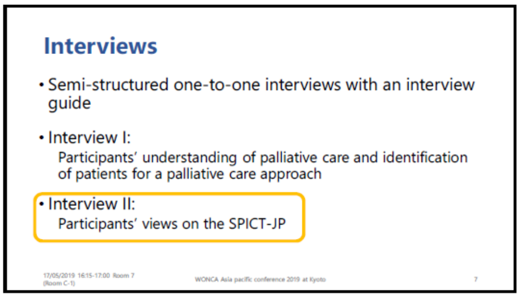

Interviews

- Semi-structured one-to-one interviews with an interview guide
- Interview I:
  Participants' understanding of palliative care and identification of patients for a palliative care approach
- Interview II:
  Participants' views on the SPICT-JP

17/05/2019 16:15-17:00 Room 7 (Room C-1) WONCA Asia pacific conference 2019 at Kyoto 7

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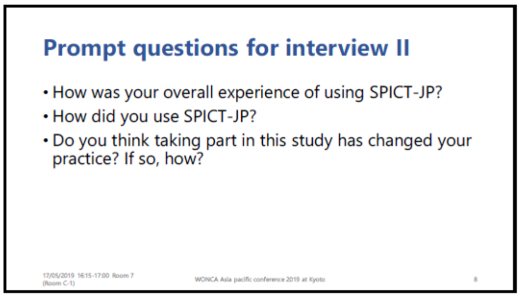

Prompt questions for interview II

- How was your overall experience of using SPICT-JP?
- How did you use SPICT-JP?
- Do you think taking part in this study has changed your practice? If so, how?

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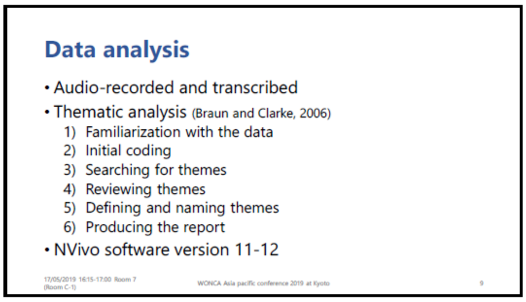
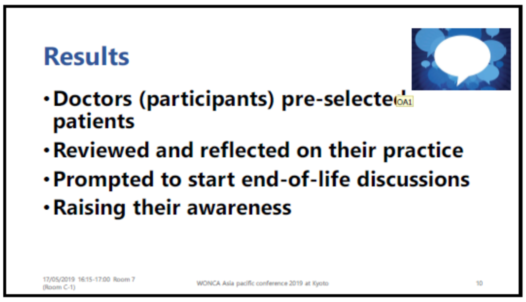


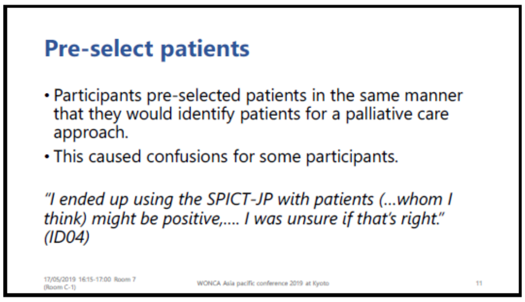
Data analysis

- Audio-recorded and transcribed
- Thematic analysis (Braun and Clarke, 2006)
  1) Familiarization with the data
  2) Initial coding
  3) Searching for themes
  4) Reviewing themes
  5) Defining and naming themes
  6) Producing the report
- NVivo software version 11-12



Results

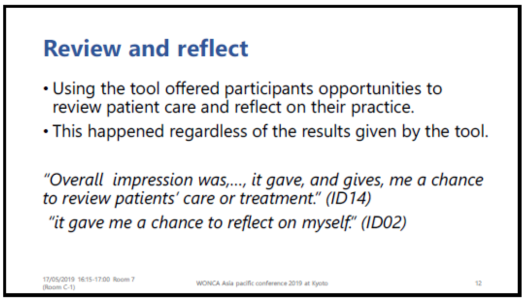
- **Doctors (participants) pre-selected patients**
- **Reviewed and reflected on their practice**
- **Prompted to start end-of-life discussions**
- **Raising their awareness**



Pre-select patients

- Participants pre-selected patients in the same manner that they would identify patients for a palliative care approach.
- This caused confusions for some participants.

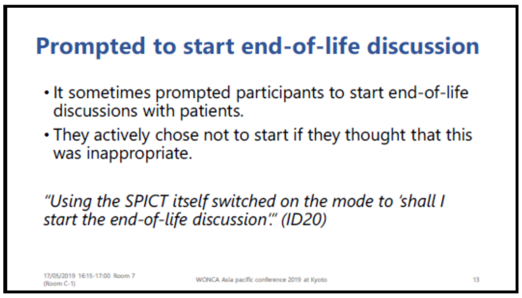
"I ended up using the SPICT-JP with patients (...whom I think) might be positive,.... I was unsure if that's right." (ID04)



Review and reflect

- Using the tool offered participants opportunities to review patient care and reflect on their practice.
- This happened regardless of the results given by the tool.

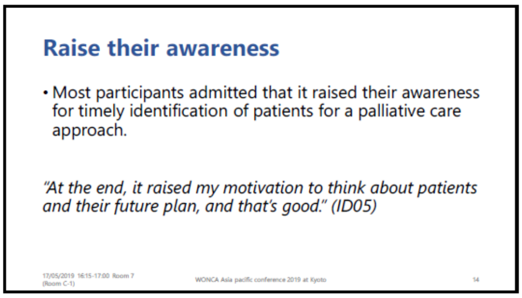
"Overall impression was,..., it gave, and gives, me a chance to review patients' care or treatment." (ID14)
"it gave me a chance to reflect on myself." (ID02)



Prompted to start end-of-life discussion

- It sometimes prompted participants to start end-of-life discussions with patients.
- They actively chose not to start if they thought that this was inappropriate.

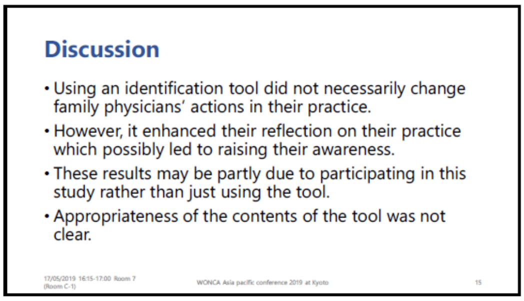
"Using the SPICT itself switched on the mode to 'shall I start the end-of-life discussion'." (ID20)



Raise their awareness

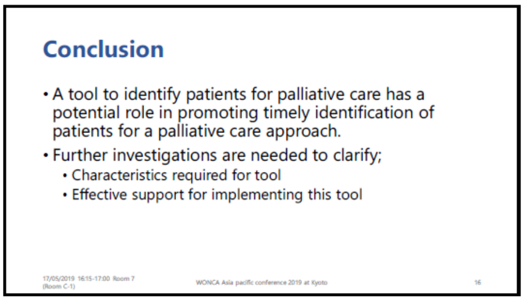
- Most participants admitted that it raised their awareness for timely identification of patients for a palliative care approach.

"At the end, it raised my motivation to think about patients and their future plan, and that's good." (ID05)



Discussion

- Using an identification tool did not necessarily change family physicians' actions in their practice.
- However, it enhanced their reflection on their practice which possibly led to raising their awareness.
- These results may be partly due to participating in this study rather than just using the tool.
- Appropriateness of the contents of the tool was not clear.



Conclusion

- A tool to identify patients for palliative care has a potential role in promoting timely identification of patients for a palliative care approach.
- Further investigations are needed to clarify;
  - Characteristics required for tool
  - Effective support for implementing this tool

Appendix 11: Publications

Good deaths for all in Japan: the potential role of primary palliative care

So far, palliative care in Japan has focused on specialist care for cancer patients in hospitals. The country is now faced with the challenge of helping a growing number of older people and non-cancer patients achieve a 'good death', explain **Ai Oishi** and **Jun Hamano,** both trained family physicians in their country

Japan has entered the 'fifth stage' of its demographic transition, in which the death rate exceeds the birth rate.[1] We have more deaths than before and the average age at death is also increasing. Hospitals face the challenge of coping with the increasing numbers of people who die in their care. Many people wish to die at home, so palliative care in the community, which is often called 'primary palliative care',[2] potentially has a significant role to play. Here, we describe the current status of primary palliative care in Japan and its potential to address this public health issue.

Primary palliative care in Japan

In Japan, no clear organisational boundaries exist between primary and secondary care. Healthcare has a greater focus on hospital care and tends to be categorised according to where the care takes place rather than its function, which makes the position of 'family medicine' and 'primary care' unclear. Because of this, and for other historical reasons, family medicine has not been recognised as an established specialty, unlike in many other countries. However, to tackle the current challenges in healthcare, the government has announced that family medicine will be a recognised medical specialty from 2017.

Meanwhile, the development of specialist palliative care has gained considerable momentum since the first palliative care unit (PCU) opened in 1973. The numbers of PCUs and palliative care consulting teams have increased dramatically.[3,4] The government has supported this through the accreditation of PCUs and good medical remuneration rates for those providing palliative care.

However, the focus of palliative care in Japan has been cancer. Medical remuneration for cancer patients in PCUs is more than twice as high as for non-cancer patients. Owing to this tariff difference and to a lack of resources, most PCUs do not take non-cancer patients.[5] For the same reasons, hospital palliative care consulting teams accept only a few non-cancer cases.[6] Not only is most clinical care about cancer, but this is also the case of most palliative care research.

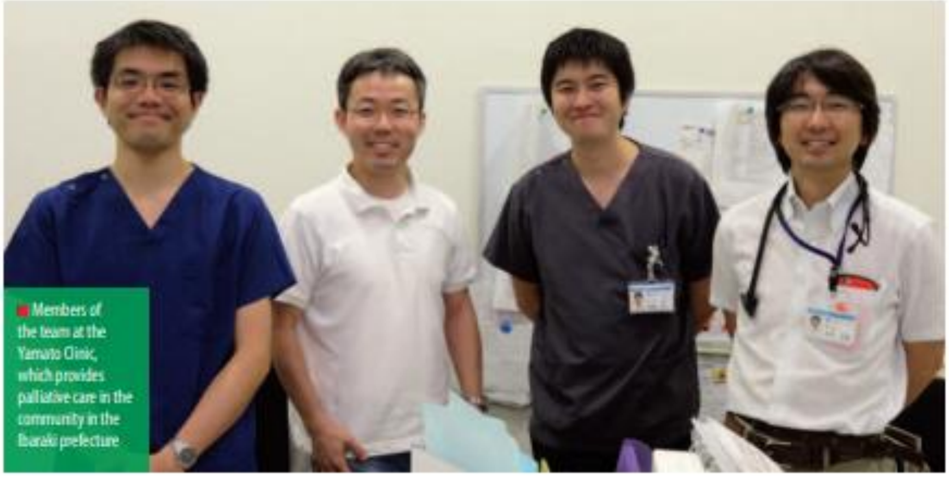
In addition, reflecting the fact that PCUs in Japan are usually hospital wards rather than community-based hospices, palliative care specialists tend to stay in hospitals and not provide services in the community. Organisational barriers and lack of resources prevent them from offering outreach services.

A majority of older people in Japan die from non-cancer conditions. Most of them cannot access specialist palliative care and hence cannot benefit from the support and planning that this would offer.

While specialist palliative care has been concentrated in hospitals, home care has recently been developed as a specialty. Doctors who specialise in home care have wider palliative care knowledge and skills than their counterparts in general medicine or family

Key points

- The number of deaths in Japan is increasing and many people wish to die at home, which presents a public health challenge.
- Specialist palliative care services in Japan have traditionally been based in hospitals and reserved for cancer patients.
- Recent developments in government, clinical organisations, academia and the general public contribute to a recognition of the palliative care needs of older people and non-cancer patients.
- Palliative care in the community has a potentially significant role in meeting the challenges posed by the increasing number of deaths.



Members of the team at the Yamato Clinic, which provides palliative care in the community in the Ibaraki prefecture

medicine. Some palliative care specialists have even moved their practice from PCUs to home care and to the community, in order to offer direct care to patients.

However, access to, and availability of, specialist palliative care in the community remain patchy. Most family doctors (either formally trained in family medicine or not) who are actively caring for the dying in the community are left without support from specialists, and without training on how to provide good palliative care.

Focusing on cancer patients in hospitals has led to many achievements, but there is an increasing need for community palliative care, with more focus on non-cancer patients and older people. The 67th World Health Assembly in May 2014 resolved that palliative care should be integrated into all healthcare settings, with an emphasis on primary care and community and home-based care.[7]

Interest in end-of-life issues is increasing among the general public in Japan

Signs of change

There are signs of an emerging awareness of the need for palliative care outside of hospitals and beyond cancer care. In 2010, a session on palliative care for older people and non-cancer patients was held for the first time at an academic conference of the Japanese Society for Palliative Medicine (JSPM). In recent years, the number of presentations and reports on palliative care for non-cancer patients has been increasing at conferences organised by the JSPM and the Japan Primary Care Association (JPCA).

This increasing interest in palliative care for non-cancer and older patients has led to organisational changes within the JSPM and the JPCA. The JSPM has set itself medium-term action goals for education in palliative care for non-cancer patients and older people. In August 2014, the JPCA created both a palliative care and a home care committee, with the aim of developing palliative care education for family physicians and primary care teams, and of improving the quality of palliative care in the community, respectively.

Since 2008, a nationwide educational programme in palliative care for community and hospital physicians has been deployed via a project called the Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE).[3,4] Although the PEACE project focuses on cancer care, the two-day interactive courses encourage participants to discuss 'end-of-life care' in general. By October 2014, the total number of participants had risen above 50,000. The PEACE programme has been highly valued by participating physicians and has contributed to the promotion of palliative care.

In 2010, a consensus syllabus in palliative medicine for medical undergraduates was developed.[8] The syllabus innovatively involves the views of patients and families. Unfortunately, there have been no concrete plans so far to integrate it into any medical curricula, which would be a huge step forward for palliative care in medical education.

Increasing public awareness

Interest in end-of-life issues is also increasing among the general public. Preparing for death is becoming more common among middle-aged and older people. This is sometimes playfully referred to as 'shukatsu',[9] which entails preparing for one's funeral and sorting out what to do with one's possessions. The term was coined by a magazine and the movement has been led mainly by publishing companies and funeral directors. It could potentially be the basis for a national discussion around death and dying; however, because it is mostly an industry-led phenomenon, end-of-life healthcare issues are not necessarily addressed adequately.

A recent national survey showed that 70% of Japanese people agreed with the idea of having a living will, but only 3.2% actually had one. The same survey also showed the need for open discussions on end-of-life care and the need to promote what good community palliative care can provide.

In response to these developments, some healthcare professionals, from both primary and palliative care, actively host events to discuss end-of-life issues with the public. Although these activities have not been well documented or investigated, such discussions with the general public can potentially inform a better model of primary palliative care.

The Yamato Clinic

There are some clinics providing palliative care for everyone in the community. One of them is the Yamato Clinic in the Ibaraki prefecture. It is located in a rural area with a population of around 50,000 people, of whom a quarter are aged 65 years and above.

The clinic's staff comprises four family doctors and five practice nurses who provide home and ambulatory care. All doctors and nurses have had palliative care training (varying from three months to one year). In addition, the clinic has an adjacent home nursing station staffed with ten visiting nurses, which collaborates with other healthcare professionals in the area and provides training for them, as well as for medical students.

The Yamato Clinic is unique in that it is run by four doctors trained in family medicine, whereas the majority of clinics in Japan are run by a single doctor trained in hospital medicine. Clinics with family doctors and with connections to medical schools and other local healthcare organisations will have an important role to play in meeting palliative care needs in the community.

■ Multidisciplinary conference at the Yamato Clinic

Summary

There are unmet palliative care needs in Japan, particularly in the community. To tackle the challenges, there are emerging movements from the government, academia, clinical organisations and the general public. These are moving forward in parallel towards the goal of achieving better deaths for all in Japan.

Declaration of interest

The authors declare that there is no conflict of interest.

Acknowledgement

The authors would like to thank Professor Scott Murray for his comments.

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Brief Report

Prevalence and Characteristics of Patients Being at Risk of Deteriorating and Dying in Primary Care

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Abstract

Context. Understanding the prevalence and characteristics of primary care outpatients being at risk of deteriorating and dying may allow general practitioners (GPs) to identify them and initiate end-of-life discussions.

Objectives. This study aimed to investigate the prevalence and characteristics of primary care outpatients being at risk of deteriorating and dying, as determined by the Supportive and Palliative Care Indicators Tool (SPICT™).

Methods. A multicenter cross-sectional observational study was conducted at 17 clinics with 22 GPs. We enrolled all patients aged ≥65 years who visited the GPs in March 2017. We used the Japanese version of the SPICT to identify patients being at risk of deteriorating and dying. We assessed the demographic and clinical characteristics of enrolled patients.

Results. In total, 382 patients with a mean age of 77.4 ± 7.9 years were investigated. Sixty-six patients (17.3%) had ≥2 positive general indicators or ≥1 positive disease-specific indicator in the SPICT-JP. Patients with dementia/frailty, neurological disease, cancer, and kidney disease showed a significantly elevated risk of deteriorating and dying, whereas patients with other specific disease did not. The patients at risk were significantly older and less likely to be living with family at home. They also had a higher Charlson Comorbidity Index score and a lower Palliative Performance Scale score.

Conclusion. Among primary care outpatients aged over 65 years, 17.3% were at risk of deteriorating and dying regardless of their estimated survival time, and many outpatients at risk were not receiving optimal multidisciplinary care. J Pain Symptom Manage 2019;57:266–272. © *2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Identification tool, SPICT™, primary care, outpatients

Introduction

Most patients with chronic illnesses are managed in primary care over a long period.[1] Appropriate identification of such patients who may be at risk of deteriorating and dying would allow general practitioners (GPs) to assess them and identify the unmet supportive and palliative care needs of these patients and their families.[2]

Assessment of unmet supportive and palliative care needs could also lead to initiation of end-of-life discussions among patients, family members, and GPs, which is essential for high-quality end-of-life planning,[3–6] although GPs consider that they lack sufficient knowledge and skill to appropriately assess such unmet needs.[7,8]

A recent study demonstrated that use of a systematic method or tool could facilitate efficient identification of patients who may be at risk of deteriorating and dying.[9] Several methods or tools have been developed for use in the primary care setting,[10] such as the Gold Standards Framework Prognostic Indicator Guidance,[11] Supportive and Palliative Care Indicators Tool (SPICT™),[12] Palliative Necessities CCOMS-ICO (NECPAL),[13] and RADboud indicators for PAlliative

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Accepted for publication: November 2, 2018.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2018.11.006

Care Needs.[14] A recent systematic review found that the SPICT is the most suitable tool for introduction and adoption in various primary care clinical settings.[15]

The SPICT is designed to identify patients with chronic progressive diseases who are at risk of deteriorating and might benefit from palliative care. Unlike other methods or tools, the SPICT is not restricted to specific diseases and has been tested in different settings (e.g., primary care, home care, and hospitals).[12,16–18]

Knowing the prevalence and characteristic of patients who may be at risk of deteriorating and dying in primary care should help GPs to identify such patients. Timely identification also could overcome the barriers to initiating end-of-life discussions.[8] Subsequently, GPs can organize appropriate care to achieve each patient's care goals.

Therefore, this multicenter observational study was performed to investigate the prevalence and characteristics of primary care outpatients who may be at risk of deteriorating and dying, as determined by the SPICT.

Methods

This multicenter cross-sectional observational study was conducted at 17 clinics with 22 GPs in Japan. In March 2017, each clinic set an arbitrary day for each GP in advance and we enrolled the outpatients over 65 years old who were seen by those GPs on that day. This study was conducted in accordance with the ethical standards of the Declaration of Helsinki and the ethical guidelines for epidemiological research issued by the Ministry of Health, Labour and Welfare of Japan. The institutional review board of the University of Tsukuba approved this study (no. 1089).

Supportive and Palliative Care Indicators Tool

The SPICT was originally developed in Scotland and was based on the American National Health Observances guideline for eligibility of patients for hospice care combined with a further literature review and expert consensus input.[16,19] The SPICT consists of a combination of general clinical indicators (e.g., poor performance status, unplanned hospital admissions, or persistent symptoms despite optimal treatment of the underlying condition) relevant to patients with any advanced illness and disease-specific indicators for common advanced conditions (e.g., cancer, dementia, and cardiac, pulmonary, or renal disease).

The development, structure, and evaluation of the original English version of the SPICT have been described elsewhere,[12] as well as its use as a guide to help physicians recognize people at risk of deteriorating and dying.[17,18]

Development of the Japanese Version of SPICT

The Japanese version of SPICT (SPICT-JP) was developed according to an international standard translation and back-translation procedure.[20] The English-language items were initially translated by two native Japanese speakers who had experience with community palliative care and knew how words and phrases would be understood by general practitioners in Japan. Then the two translations were reconciled by discussion. Any disagreements and unclear points were recorded, and we sought clearer explanations from the developer of the original version. The synthesized version was back-translated by a professional Japanese translator, and the appropriateness of the English expressions was subsequently checked by a native English speaker. Then an independent professional proof-reader compared the completed synthesized version and the back translation and provided comments. Subsequently, an expert panel with nine members (general practitioners with or without a special interest in palliative care, home care physicians, and palliative care physicians) reviewed the synthesized version. The final version of the SPICT-JP was developed by incorporating the comments of the expert panel.

Data Collection

We recorded demographic and clinical characteristics of the patients, including the age, sex, living situation, main underlying disease, use of care services, and level of care needed.[21] We assessed the Charlson Comorbidity Index (CCI) score,[22] the Palliative Performance Scale (PPS), and the six general clinical indicators and 25 disease-specific indicators in the SPICT-JP (Appendix 1).

Statistical Analysis

According to previous reports,[23] we defined patients as being at risk of deteriorating and dying if they had ≥2 positive general indicators or ≥1 positive disease-specific indicator in the SPICT-JP. We calculated descriptive statistics for the prevalence of patients being at risk of deteriorating and dying. Characteristics of the participants were described as proportions for categorical variables and were analyzed by Pearson's χ^2 test or Fisher's exact test, whereas continuous variables were analyzed by Student's t-test. In all statistical evaluations, a *P*-value of less than 0.05 was considered significant. Analyses were conducted with SPSS-J software (version 24.0; IBM, Tokyo, Japan).

Results

A total of 382 patients were included in this study, and their characteristics are summarized in Table 1. The mean age was 77.4 ± 7.9 years. Most of the patients lived at home with their families (78.0%), had

Table 1
Patient Background Factors and Characteristics
($N = 382$)

Background Factors and Characteristics	*n*	%
Age (mean ± SD)	77.4 ± 7.9	
Gender		
Male	141	36.9
Female	241	63.1
Living situation		
At home with family	298	78.0
At home alone	59	15.4
Care facility	8	2.1
Main underlying disease		
Hypertension	122	31.9
Dementia/frailty	58	15.2
Cardiovascular disease (not hypertension)	38	9.9
Diabetes	30	7.9
Hyperlipidemia	19	5.0
Neurological disease	18	4.7
Cancer	14	3.7
Respiratory disease	13	3.4
Musculoskeletal disease	8	2.1
Mental disease	6	1.6
Gastroesophageal reflux disease	6	1.6
Kidney disease	5	1.3
Liver disease	3	0.8
Others	42	11.0
Charlson Comorbidity Index score		
0	301	78.8
1	35	9.2
2	23	6.0
3	3	0.8
4	4	1.0
5	1	0.3
6	1	0.3
7	2	0.5
Palliative Performance Scale		
100	202	52.9
90	51	13.4
80	49	12.8
70	20	5.2
60	33	8.6
50	22	5.8
40	5	1.3
Level of care need		
No certified care need	290	75.9
Support need Level 1	8	2.1
Support need Level 2	11	2.9
Care need Level 1	13	3.4
Care need Level 2	14	3.7
Care need Level 3	9	2.4
Care need Level 4	1	0.3
Care need Level 5	1	0.3
Current care services		
No care service	311	81.4
One or more care services	71	18.6
Type of care service (multiple answers)		
Home nursing	11	2.9
Home help service	16	4.2
Home pharmacist	1	0.3
Day care/day service	54	14.1
Specialized palliative care service	2	0.5

a CCI score of zero (78.8%), PPS≥80 (79.1%), no certified care needs (75.9%), and no use of care services (81.4%). The most common main underlying disease was hypertension (31.9%), followed by dementia/frailty (15.2%) and cardiovascular disease excluding hypertension (9.2%). Only two patients (0.5%) used a specialized palliative care service.

Prevalence of Patients Being at Risk of Deteriorating and Dying

The most common general indicator for a higher risk of deteriorating and dying was "The person or family asked for palliative care, treatment withdrawal/limitation, or a focus on quality of life" (25.4%). The major clinical indicator was "No longer able to communicate using verbal language; little social interaction" ($n = 23$), followed by "Urinary and fecal incontinence" ($n = 13$) and "Unable to dress, walk or eat without help" ($n = 12$) in patients with dementia/frailty (Table 2).

Characteristics of Patients Being at Risk of Deteriorating and Dying

The characteristics of the patients being at risk of deteriorating and dying are shown in Table 3. Sixty-six patients (17.3%) had ≥2 positive general indicators or ≥1 positive disease-specific indicator. Patients with dementia/frailty, neurological disease, cancer, and kidney disease had a significantly higher risk of deteriorating and dying, whereas patients with other specific diseases did not. The patients at risk were significantly older than those not at risk, were less likely to be living at home with family members, and had higher CCI scores and a lower PPS. The care services used by patients at risk were mainly home nursing, home help service, and day care/day service.

Discussion

To our knowledge, this is the first large-scale cross-sectional survey investigating the prevalence and characteristics of primary care outpatients being risk of deteriorating and dying according to the SPICT.

The first important finding was that 17.3% of primary care outpatients over 65 years old were at risk of deteriorating and dying. This was a much higher prevalence than that shown by a previous smaller study, in which the prevalence was 9.2% according to the SPICT.[23] One possible reason for this difference was that our study was conducted at 17 clinics and enrolled the patients of 22 GPs, while the previous study was confined to a single clinic with one GP. Thus, our results seem to be more reliable with regard to the prevalence of patients in primary care who are at risk of deteriorating and dying. In addition, our prevalence was about twice that determined by a cross-sectional population-based study conducted in Spain, which identified 8.0% of patients over 65 years old with palliative care needs by using the NECPAL.[24] The NECPAL-positive patients were defined as positive for the "surprise question" ("I would not be surprised

Table 2
Prevalence of Patients at Risk of Deteriorating and Dying

Patients at Risk of Deteriorating and Dying	n	%
General clinical risk of deteriorating health ($n = 382$)		
Two or more unplanned hospital admissions in the past six months	1	0.3
Performance status is poor or deteriorating, with limited reversibility	24	6.3
Dependent on others for care due to physical and/or mental health problems	26	6.8
Significant weight loss over the past three to six months, and/or a low body mass index	18	4.7
Persistent symptoms despite optimal treatment of underlying condition(s)	16	4.2
Person or family ask for palliative care, treatment withdrawal/limitation, or a focus on quality of life	97	25.4
Specific disease-specific risk for deterioration of specific conditions		
Cancer ($n = 14$)		
Functional ability deteriorating due to progressive cancer	3	21.4
Too frail for cancer treatment or treatment is for symptom control	2	14.3
Dementia/frailty ($n = 56$)		
Unable to dress, walk, or eat without help	12	21.4
Eating and drinking less; swallowing difficulties	9	16.1
Urinary and fecal incontinence	13	23.2
No longer able to communicate using verbal language; little social interaction	23	41.1
Fractured femur; multiple falls	10	17.9
Recurrent febrile episodes or infections; aspiration pneumonia	2	3.6
Neurological disease ($n = 18$)		
Progressive deterioration in physical and/or cognitive function despite optimal therapy	7	38.9
Speech problems with increasing difficulty communicating and/or progressive swallowing difficulties	2	11.1
Recurrent aspiration pneumonia; breathless or respiratory failure	1	5.6
Cardiovascular disease ($n = 38$)		
New York Heart Association Class III/IV heart failure, or extensive, untreatable coronary artery disease with breathlessness or chest pain at rest or on minimal exertion	4	10.5
Severe, inoperable peripheral vascular disease	0	0.0
Respiratory disease ($n = 13$)		
Severe chronic lung disease with breathlessness at rest or on minimal exertion between exacerbations	2	15.4
Needs long-term oxygen therapy	1	7.7
Has needed ventilation for respiratory failure or ventilation is contraindicated	0	0.0
Kidney disease ($n = 5$)		
Stage 4 or 5 chronic kidney disease (estimated glomerular filtration rate < 30 mL/minute) with deteriorating health	3	60.0
Kidney failure complicating other life-limiting conditions or treatments	3	60.0
Stopping dialysis	0	0.0
Liver disease ($n = 3$)		
Advanced cirrhosis with one or more complications in past year: diuretic resistant ascites	0	0.0
Advanced cirrhosis with one or more complications in past year: hepatic encephalopathy	0	0.0
Advanced cirrhosis with one or more complications in past year: hepatorenal syndrome	0	0.0
Advanced cirrhosis with one or more complications in past year: bacterial peritonitis	0	0.0
Advanced cirrhosis with one or more complications in past year: recurrent variceal bleeds	0	0.0
Liver transplantation is contraindicated	2	66.7

if this patient were to die in the next 12 months.") and had at least one general or clinical indicator. Taken together with our result, it seems that a certain proportion of primary care outpatients are at risk of deteriorating and dying regardless of their estimated survival time.

The second important finding was that outpatients with dementia/frailty, neurological disease, cancer, and kidney disease had a significantly elevated risk of deteriorating and dying, whereas patients with other specific diseases did not. This finding suggests that outpatients over 65 years old with these diseases should be carefully assessed for the risk of deteriorating and dying. However, SPICT cannot identify patients with a risk of deteriorating cognitive function, although it evaluates the symptoms and behavioral disorders of dementia patients. Therefore, our finding that 67.9% of patients with dementia are at risk of deteriorating and dying requires careful interpretation. In the future, there is a need for a method that can evaluate the risk of deteriorating the cognitive function of dementia patients.

With respect to reviewing current treatment and care, primary care outpatients with dementia/frailty, neurological disease, cancer, and kidney disease could be regarded as a target population for active communication about the goals of care, such as "Jumpstart-Tips intervention."[25] However, GPs often feel that they lack sufficient knowledge, skills, and experience to talk about existential needs and may not actively ask about nonphysical/disease-related care needs.[26] Thus, to improve the quality of active communication about goals of care, it is important to identify the multidimensional needs of patients and the kinds of conversations that occur among patients at risk of deteriorating and dying, family members, and GPs.[27]

The third important finding was that almost half of the patients who were at risk of deteriorating and dying were not using a care service. This result implies that many outpatients at risk were not receiving

Table 3

Characteristics of Patients With or Without an Elevated Risk of Deteriorating and Dying

	With Two or More General Indicators or One or More Disease-Specific Indicators (*n* = 66)		Without Two or More General Indicators or One or More Disease-Specific Indicators (*n* = 316)		
Characteristics of Patients	*n*	%	*n*	%	*P*-Value
Age (mean ± SD)	84.6 ± 7.9		75.9 ± 7.0		<0.001
Gender					0.858
Male	25	37.9	116	36.7	
Female	41	62.1	200	63.3	
Living situation					0.001[a]
At home with family	47	71.2	251	79.4	
At home alone	11	16.7	48	15.2	
Care facility	6	9.1	2	0.6	
Main underlying disease					
Dementia/frailty	38	57.6	20	6.3	<0.001
Cardiovascular disease (not hypertension)	5	7.6	33	10.4	0.479
Neurological disease	7	10.6	11	3.5	0.022[a]
Cancer	6	9.1	8	2.5	0.020[a]
Respiratory disease	2	3.0	11	3.5	0.272[a]
Kidney disease	3	4.5	2	0.6	0.038[a]
Liver disease	2	3.0	1	0.3	0.078[a]
Others	3	4.5	230	72.8	<0.001
Charlson Comorbidity Index score					<0.001[a]
0	40	60.6	261	82.6	
1–4	19	28.8	46	14.6	
≥5	3	4.5	1	0.3	
Level of care need					<0.001
No certified care need	24	36.4	266	84.2	
Any level of certified care need	38	57.6	34	10.8	
Current care services					<0.001
No care service	31	47.0	279	88.3	
One or more care services	35	53.0	36	11.4	
Types of care service (multiple answers)					
Home nursing	9	13.6	2	0.6	<0.001[a]
Home help service	11	16.7	5	1.6	<0.001[a]
Home pharmacist	1	1.5	0	0.0	0.173
Day care/day service	26	39.4	28	8.9	<0.001
Specialized palliative care service	2	3.0	0	0.0	0.030[a]

[a] Fisher's exact test.

optimal multidisciplinary care, which would be a barrier to initiating end-of-life discussions to achieve the care goals of patients. Thus, it seems important to implement systematic evaluation methods for identifying patients at risk and promoting interprofessional collaboration in primary care,[28] such as the Gold Standards Framework in the U.K.[29]

It is noteworthy that only 3% of the patients who were at risk of deteriorating and dying used specialized palliative care. A retrospective study performed in the U.K. revealed that 30% of primary care patients were referred to specialized palliative care before death, although referral tended to be late and the median time until death after referral was only 4.9 weeks.[2] Because our study was cross-sectional, it is difficult to compare the frequency of referral to specialized palliative care. Thus, it would be worthwhile examining the level of palliative care delivered or offered in Japanese primary care practice in the future.

This study had several limitations. First, we only enrolled patients over 65 years old who visited each clinic on a day selected in advance. Therefore, we only assessed part of the patient population who may be at risk of deteriorating and dying in each clinic. However, we minimized the influence of this methodology on the results by registering multiple doctors at multiple facilities. We consider that this approach is most feasible for obtaining evidence in the primary care setting, although there is unavoidable sample bias. Second, our study was only carried out in Japan, although it was a multicenter investigation. Therefore, caution is needed when interpreting the results, which might be influenced by the Japanese health care system and cultural background. Third, observer bias might exist because assessment was conducted by the GPs of the patients. However, the SPICT was developed for assessment of patients by care team staff based on clinical indicators.[12] Therefore, observer bias should only have a small influence on the results.

In conclusion, among primary care outpatients over 65 years old in Japan, 17.3% were at risk of deteriorating and dying regardless of their estimated survival time, and almost half of those patients were not using a care service. To organize appropriate care to achieve each patient's care goals, it is important to determine what multidimensional needs exist and to implement a systematic approach for promotion of interprofessional collaboration in primary care.

Disclosures and Acknowledgments

This study was conducted in accordance with the ethical standards of the Declaration of Helsinki and the ethical guidelines for epidemiological research issued by the Ministry of Health, Labour and Welfare of Japan. The institutional review board of the University of Tsukuba approved this study (no. 1089).

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The authors have declared no competing interests.

This project received funding from the Japan Hospice/Palliative Care Foundation. The funder had no role in the design and conduct of the study; the collection, management, analysis, and interpretation of data; the preparation, review, or approval of the manuscript; or the decision to submit the manuscript for publication.

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Appendix 1. Supportive and Palliative Care Indicators Tool (SPICT™), April 2015

Look for two or more general indicators of deteriorating health

- Performance status is poor or deteriorating (in bed or a chair for ≥50% of the day); reversibility is limited
- Dependent on others for most care needs due to physical or mental health problems
- Two or more unplanned hospital admissions in the past six months
- Significant weight loss (5%−10%) over the past three to six months or a low body mass index
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s)
- Patient asks for supportive and palliative care or treatment withdrawal

Look for any clinical indicators of one or more advanced conditions

Cancer

- Functional ability deteriorating due to progressive metastatic cancer
- Too frail for oncology treatment or treatment is for symptom control

Dementia/frailty

- Unable to dress, walk, or eat without help
- Eating and drinking less or swallowing difficulties
- Urinary and fecal incontinence
- No longer able to communicate using verbal language or little social interaction
- Femur fracture or multiple falls
- Recurrent febrile episodes or infections, or aspiration pneumonia

Neurological diseases

- Progressive deterioration in physical or cognitive function despite optimal therapy
- Speech problems with increasing difficulty communicating or progressive swallowing difficulties
- Recurrent aspiration pneumonia, breathlessness, or respiratory failure

Heart/vascular disease

- NYHA Class III/IV heart failure or extensive untreatable coronary artery disease with breathlessness or chest pain at rest or on minimal exertion
- Severe inoperable peripheral vascular disease

Respiratory disease

- Severe chronic lung disease with breathlessness at rest or on minimal exertion between exacerbations
- Needs long-term oxygen therapy
- Has needed ventilation for respiratory failure or ventilation is contraindicated

Kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30 mL/minute) with deteriorating health
- Kidney failure complicating other life-limiting conditions or treatments
- Discontinuation of dialysis

Liver disease

- Advanced cirrhosis with one or more complications in the past year:
  Diuretic resistant ascites
  Hepatic encephalopathy
  Hepatorenal syndrome
  Bacterial peritonitis
  Recurrent variceal bleeding
- Liver transplantation is contraindicated

NYHA = New York Heart Association; eGFR = estimated glomerular filtration rate.