

Original Article

Population-Based Quality Indicators for Palliative Care Programs for Cancer Patients in Japan: A Delphi Study

Yoko Nakazawa, RN, MSH, Masahi Kato, MD, Saran Yoshida, PhD, Mitsunori Miyashita, RN, PhD, Tatsuya Morita, MD, and Yoshiyuki Kizawa, MD, PhD

Division of Medical Support and Partnership (Y.N., M.K., S.Y.), Center for Cancer Control and Information Services, National Cancer Center, Chuo-ku, Tokyo; Department of Palliative Nursing (M.M.), Health Sciences, Tohoku University Graduate School of Medicine, Sendai, Miyagi; Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka; and Division of Palliative Medicine (Y.K.), Department of Internal Related, Kobe University Graduate School of Medicine, Kobe, Hyogo, Japan

Abstract

Context. Cancer control programs in Japan strongly endorse the dissemination of palliative care, and various policy measures have been implemented; however, indicators for evaluating palliative care programs have not been defined.

Objectives. The aim of this study was to develop quality indicators for palliative care programs taking a population-based view to meet the challenge of cancer control in the Japanese population.

Methods. We conducted a modified Delphi survey. The panelists rated a list of indicators over three iterative rounds according to four perspectives: 1) consistency with the policy target, 2) relevance to the problem, 3) clarity of expression, and 4) measurement feasibility. The criterion for adoption of candidate indicators was set at a total mean score of 7 or more. Finally, the most relevant and important indicators were selected; consensus was defined by agreement of panelists at the panel meeting.

Results. Among 49 panelists surveyed, 48 (98%), 39 (80%), and 43 (88%) responded over the three rounds, respectively. The 15 indicators were identified from 11 domains: patient-reported quality of life, bereaved family—reported quality at the end of life, family care, place of death, bereaved family—reported quality of palliative care, specialized palliative care services, opioid utilization, public perceptions about palliative care, palliative care education to primary care providers, specialist palliative care services, and regional palliative care.

Conclusion. Comprehensive quality indicators for palliative care programs were identified. The indicators are currently being used, and the feasibility of measuring change over time will be examined. It is expected that the indicators will be used effectively in the future. It is important to evaluate outcomes of the program, to improve weaknesses, improve outcomes, and promote the welfare of cancer patients. *J Pain Symptom Manage* 2016;51:652–661. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Quality indicator, program evaluation, palliative care, cancer, public health, Japan

Introduction

Palliative care is an approach that relieves suffering and improves quality of life for both patients and families throughout an illness experience, not just at the end of life.¹ It is considered an indispensable part of

public health care.^{2,3} However, globally, there is a significant unmet need for palliative care, which will further increase as a result of the growing number of older people with incurable chronic disease. Further development in palliative care can, therefore, be seen as a public health priority.^{4–8}

Address correspondence to: Yoko Nakazawa, RN, MSH, Division of Medical Support and Partnership, Center for Cancer Control and Information Services, National Cancer Center, 5-1-1

Tsukiji, Chuo-ku, Tokyo 104-0045, Japan. E-mail: ynakazaw@ncc.go.jp

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In Japan, the National Cancer Act was implemented in 2007. The cancer control programs based on this Act strongly support the dissemination of palliative care as one of the highest priority issues.⁹ The main aims of the Act are as follows: 1) improving the quality of life of cancer patients and families by providing relief of pain and other symptoms, 2) basic education about palliative care for primary care providers, 3) creating a specialist palliative care team in designated cancer hospitals and improving access to specialist palliative care services for patients, and 4) providing home care services that meet the wishes of cancer patients and their families.

More than five years have passed since the cancer control programs began. It is time to address ways to improve palliative care programs and achieve outcomes desired by cancer patients and families; however, indicators for evaluating palliative care programs have not been defined. In the second term in 2012, the Basic Plan to Promote Cancer Control Programs issued a plan to formulate indicators that evaluate the cancer control programs, by 2015.¹⁰

The development of indicators of care from a population-based view to meet the challenge of cancer control in the Japanese population has been identified as essential to improving the quality of palliative care.¹¹ Developing and measuring end-of-life cancer care has been done using administrative databases in the U.S. and Canada.^{12–14} In Japan, only hospital-based studies using quality indicators of end-of-life cancer care from medical chart reviews have been done; the systematic development of quality indicators for palliative care using a population-based view has not been attempted. However, there are many tools and measurement points for the evaluation of palliative care programs, including outcome measurements, quality indicators, and metrics.^{15–18}

The Donabedian model, “structure, process, and outcome,” is used as a framework for evaluating quality of care.¹⁹ However, the best indicators are not defined. In addition, there is no gold standard as to who should select the indicators. The indicators must be selected considering balance validity with measurement feasibility. Structural indicators are easier to measure and interpret, but they only indirectly measure the quality of palliative care. In contrast, outcome indicators evaluate the quality of palliative care directly, but it is not clear whether these indicators are a direct effect of a palliative care program, and they are also more difficult to measure. The selection of indicators cannot be determined only by palliative care specialists and researchers. We believe that judging the balance described previously is beyond the scope of researchers and that judgment by consensus of the people concerned, including

cancer specialists, academic experts, cancer patients, bereaved families, and palliative care specialists, is required.

The aim of this study was to collect the opinions of people involved in the Cancer Control Program using a modified Delphi method²⁰ to develop quality indicators for palliative care programs, taking a population-based view to meet the challenge of cancer control in the Japanese population. In this study, we defined population-based quality indicators as statistical measures that give an indication of the quality of palliative care throughout the entire country. This study was done as part of a research project that develops indicators, which is a task of the second-term Basic Plan to Promote Cancer Control Programs.

Methods

We used a modified Delphi method to build systematic consensus. The study protocol was approved by the National Cancer Center institutional review board in Japan.

Selection of Panelists

We selected the panelists for the Delphi survey to assess the validity of the indicators. To collect the opinions of people involved in the Cancer Control Programs, the following policy makers and experts in palliative care were included as panelists:

- 1) Members of the National Council for Cancer Control Program Promotion, the National Committee for Palliative Care Promotion (2012–2013), and the National Working Group for Palliative Care Field Investigation (2013) in Japan. These three organizations were established by the Ministry of Health, Labor, and Welfare to promote cancer control programs; members were appointed by the Ministry of Health, Labor, and Welfare as representative of major professional and academic organizations and patient groups with an interest in cancer care in Japan. The number of panelists in Group 1 was 32.
- 2) Multidisciplinary experts: a physician, a psychoncologist, a nurse, a pharmacist, and a medical social worker. The experts had to meet two criteria: 1) health professional who specializes in palliative care with at least five years of post-qualification clinical experience, and 2) at least one of the following: board certification or the equivalent in palliative care or oncology, published in the area of palliative care or oncology in the last 10 years, or involved in national

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