Review Article

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Delphi Process and Evidence-Informed Palliative Care: Making ends Meet

Nisha Rani Jamwal*, Senthil P. Kumar**

Author's Affiliation: *Senior Physiotherapist, Department of Physiotherapy, Fortis Super Speciality hospital, Phase-VIII, Mohali, Punjab **Professor & Principal, Maharishi Markandeshwar Institute of Physiotherapy and Rehabilitation (Maharishi Markandeshwar University), Mullana - Ambala-133207, Haryana.

Corresponding Author: Senthil P. Kumar, Professor & Principal, Maharishi Markandeshwar Institute of Physiotherapy and Rehabilitation (MMIPR), Maharishi Markandeshwar University (MMU), Mullana University Road, Mullana, Ambala, Haryana- 133207.
E-mail: senthilparamasivamkumar@gmailcom

Abstract

Evidence-informed palliative care (EIPC) denotes thoughtful integration of recent scientific evidence with patient/caregiver preferences to individualize care plan and process for terminally ill patients and their families. The proponents of EIPC claim that practice decisions and communication should be evidence-based or evidence-informed, whereas evidence for most palliative and end-of-life care is insufficient and/or inconclusive. The demand to establish evidence, together with limitations in conducting clinical trials on palliative care patient population had necessitated the introduction of Delphi process as a means of evidence. The Delphi process utilizes expert opinion for conflicting decisions, arrive at a consensus and establish levels of evidence for various care recommendations. Herewith this review article highlighted the role of Delphi process and Delphi studies in providing scientific information which bridges the evidence-to-practice gap in EIPC. We grouped identified studies qualitatively under palliative care practice, education, research and administration. There is scope for future research to develop better treatment guidelines for palliative care utilizing the Delphi approach.

Keywords: Evidence-Informed Palliative Care; Practice-Based Evidence; Expert Panel Guidelines.

Introduction

Evidence-informed palliative care (EIPC) denotes thoughtful integration of recent scientific evidence with patient/caregiver preferences to individualize care plan and process for terminally ill patients and their families. The proponents of EIPC claim that practice decisions and communication should be evidence-based or evidence-informed, whereas evidence for most palliative and end-of-life care is insufficient and/or inconclusive.

The demand to establish evidence, together with limitations in conducting clinical trials on palliative care patient population had necessitated the introduction of Delphi process as a means of evidence. The Delphi process utilizes expert opinion for conflicting decisions, arrive at a consensus and establish levels of evidence for various care recommendations. Herewith we write this letter to highlight the role of Delphi process and Delphi studies in providing scientific information which bridges the evidence-to-practice gap in EIPC. We organized the identified studies under palliative care practice, education, research and administration.

Practice

Diagnosis

Patient Classification

Sigurdardottiret al [1] on behalf of PRISMA group conducted a five-step international Delphi exercise to obtain consensus among 117 experts on a basic set of core variables to describe or classify a palliative care cancer population according to guidelines put forth by European Association for Palliative Care. A total of 18 clinical variables were introduced after an elaborate literature review in the first round, and the choice of including new/old variables was performed in second round. Upon 70% agreement which was defined as consensus, the three last Delphi rounds focused on how the agreed variables should be recorded. The final consensus-based evidence identified 31 variables in two forms: 'patient form' - date of birth, gender, living situation, education, ethnicity and 12 symptoms - and a 'health-care personnel form' - patient's date of birth, principal diagnosis, date of the principal diagnosis, stage of the cancer disease, site of metastases, present anticancer treatment, main additional diagnoses, stage of the additional diagnoses, medication, weight loss, performance status, cognitive impairment, place of care and provision of care. The three variables which did not adequately receive consensus was ethnicity, vomiting and weight loss.

Assessment Tools

Biondoet al[2] used the Delphi technique for development of two palliative pain assessment tools: the Edmonton Classification System for Cancer Pain (ECS-CP) and the Alberta Breakthrough Pain Assessment Tool for Research (ABPAT-R). Their study established validity of the tools based upon expert experience, challenges in using the tools- sampling, study and survey design, consensus setting and response rates, and, suggestions for improvement through national and international collaborations. The study found that international inputs assure relevance in diverse clinical settings and practice cultures, and also the use of the Delphi technique in palliative care tool development may thereby facilitate international collaborations, rapid knowledge transfer, and effective uptake of novel tools across diverse palliative care settings.

Treatment

Disorders

Dementia

van der Steen et al[3] used the five-round Delphi method on a core group of 12 experts from 6 countries to provide EAPC recommendations for optimal palliative care in dementia. 89 invited experts from 27 countries evaluated and provided consensus for two round survey and feedback, followed by core team decision in fourth round, and EAPC inputs in the fifth round. Eight out of 11 domains had immediate and full consensus: "person-centred care, communication and shared decision-making; optimal treatment of symptoms and providing comfort (these two identified as central to care and research); setting care goals and advance planning; continuity of care; psychosocial and spiritual support; family care and involvement; education of the health care team; and societal and ethical issues." Whereas, prognostication and timely recognition of dying reached full consensus after revision, and only moderate consensus was reached for nutrition and dehydration (avoiding overly aggressive, burdensome or futile treatment) and on dementia stages in relation to care goals (applicability of palliative care).

Depression

Rayner et al[4] used the two-round Delphi method of 18 international, multi-professional experts on choice of screening tool, choice of antidepressant and choice of psychological therapy for depression in order to develop European Palliative Care Research Collaborative clinical practice guideline on managing depression in palliative care. The study results indicated better benefits of screening using 'routine formal asking' than screening questionnaires; anti-depressant medications of choice were Mirtazapineand citalopram; and, beneficial role of cognitive-behavioral therapy.

Developing a Care Protocol

Mendes and Justo da Silva[5] aimed to develop consensus among neonatologists using a three-round online Delphi technique for neonatal palliative care by assessing 57 neonatologists' willingness to build a palliative care and end-of-life protocol with nationwide acceptabilityin Portugal. Neonatologists were found to agree on 7 specific areas: "(1) planning (medical education, resources, and local), (2) prenatal palliative care, (3) neonatal palliative care criteria, (4) the parents (presenting neonatal palliative care to parents, including then in the daily care of newborns and in family-centered care), (5) physicians' needs, (6) pain and symptom management, and (7) end-of-life care (withholding / withdrawing ventilation and hydration / nutrition)."

Developing a Clinical Guideline

Morita et al[6] constructed a clinical guideline for palliative sedation therapy using the three-round Delphi technique on a national multidisciplinary committee (five palliative care physicians, four nurses, two oncologists, two psychiatrists, two anesthesiologists, two bioethicists, a medical social worker, and a lawyer). The developed guideline included definitions of palliative sedation therapy, description of the ethical basis of palliative sedation therapy, recommendations about clinical practices in continuous-deep sedation, and diagrams illustrating the clinical application of continuous-deep sedation.

Education

Medicine

Kizawaet al [7] conducted a modified three-step Delphi study (first step: a workshop to produce the draft syllabus; second step: a survey-based provisional syllabus; third step: Delphi rounds and a panel meeting (modified Delphi method) to produce the working syllabus. of 32 people (28 educators and experts in palliative medicine, one cancer survivor, one bereaved family member, and two medical students) to develop a nationwide consensus syllabus of palliative medicine for undergraduate medical education in Japan. The final consensus syllabus consisted of 115 learning objectives across seven sections: “basic principles; disease process and comprehensive assessment; symptom management; psychosocial care; cultural, religious, and spiritual issues; ethical issues; and legal frameworks.”

Paes and Wee [8] carried out a three-round Delphi study among 43 experts from Britain and Ireland to develop a consensus syllabus of Association for Palliative Medicine (APM) for undergraduate palliative medicine in medical education. 75% agreement was achieved and the new syllabus comprised of: following sections: basic principles, physical care, psychosocial care, culture, language, religious and spiritual issues, ethics and legal frameworks. Two learning outcomes were identified-essential and desirable, which allowed prioritization of resource allocation among the medical schools.

Nursing

Liu and Yuan [9] conducted a two-round Delphi study on a 36-member expert panel on 93 training-related items to construct palliative-care-related training contents for Chinese clinical nurses. ”The expert panelists reached consensus on 69 training items that belonged to 6 modules; these were (1) 8 items for the palliative care overview, (2) 24 items for symptom care, (3) 15 items for psychological care, (4) 13 items for communication and exchange, (5) 5 items for ethics and laws, and (6) 4 items for terminal care.” The authors also developed a six-module training program comprising of core palliative care knowledge and competency skills for Chinese nurses.

Research

Prioritization

Steele et al [10] performed a Delphi survey of 14-16 interdisciplinary researchers and/or clinicians in Canada, to achieve consensus on potential areas of pediatric palliative care research. The study identified four research questions as priority: “What matters most for patients and parents receiving pediatric palliative services? What are the bereavement needs of families in pediatric palliative care? What are the best practice standards in pain and symptom management? What are effective strategies to alleviate suffering at the end of life?”

Administration

Policy Development

Jüngeret al [11] conducted a two-round online consensus Delphi study of multi-professional expert panel of board members of national hospice and palliative care associations in Europe to develop standards and norms for palliative care for advocacy and health policy decision making.96 experts from 35 national hospice and palliative care associations in 22 countries reached high-very high level consensus on common values and principles of palliative care (e.g., autonomy, dignity) and the provision of different levels of palliative care, whereas only low level consensus was arrived for demand of services and the composition of palliative care teams.

Behmannet al [12] conducted a three-round Delphi study (First round: proposing actions for each of the key targets; second round: assessment of the actions regarding their relevance; third round: ranking of the actions) of 107 stakeholders to identify and prioritize actions to achieve key targets for public health initiatives to improve palliative care in Germany. Three actions (out of total 37 identified actions in first round) obtained highest level of ranking in the final round: “close collaboration between specialist palliative care services, general practitioners and community nursing services”, and “Implementing specialist palliative care in the community consequently” and “Strengthening generalist palliative care through training and education of general practitioners and nursing services”.

Quality of Care

Woithaet al [13] used a modified two-round RAND Delphi study of20 multi-professional palliative care teams in seven European countries (the Europall project) to validate a set of 110 structure and process indicators for Quality of care in palliative care settings. The study identified 56 quality indicators as useful and they concerned the following domains: "the definition of a palliative care service (2 quality indicators), accessibility to palliative care (16 quality indicators), specific infrastructure to deliver palliative care (8 quality indicators), symptom assessment tools (1 quality indicator), specific personnel in palliative care services (9 quality indicators), documentation methodology of clinical data (14 quality indicators), evaluation of quality and safety procedures (1 quality indicator), reporting of clinical activities (1 quality indicator), and education in palliative care (4 quality indicator)."

Sasaharaet al [14] used a modified Delphi method on 27 multi-professional panelists who rated the appropriateness of 37 statements to develop evaluative standards for hospital-based palliative care consultation teams. The 37 identified statements were grouped in four areas: "philosophy and policy," "structure for care provision," "contents of activities," and "quality assurance and care improvements."

Discussion and Conclusion

There were Delphi studies published on practice (on diagnosis- patient classification, assessment tools; and on treatment- disorders such as dementia and depression, developing a care protocol and developing a clinical guideline), education (for medicine and nursing fields), research (for prioritization), and administration (for policy development and quality of care). These studies provide valuable evidence that would bridge the knowledge-translation gap through an evidence-informed model of palliative care.

The application of Delphi method to generate palliative care evidence should be cautiously considered keeping in mind the following limitations and issues; selection of expert panel, communication with experts, decision selection, and report writing. It is a qualitative method and it cannot be objectified or quantified, with limited internal and external validity, due to increased chance of expert-related bias, and less applicability due to involvement of few experts.

The Delphi process would pave way for an effective generation of evidence along a 'practice-based evidence' model, and in a long way would significantly influence evidence-based palliative care in developing countries' palliative care settings. In lieu of limited evidence being generated from published research in India, generation of evidence by consulting experts in palliative care delivery would bridge the need for successful implementation of Evidence-informed palliative care.

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