

Developing Evidence-Based Clinical Guidelines in Palliative Care for Home Care Setting in India

Jenifer Jeba, Jayarajan Ponissery¹, Akhileswaran Ramaswamy², Jeremy Richard Johnson³, Anu Savio Thelley⁴, Pheroza J Bilimoria⁵

Palliative Care Unit, Christian Medical College Hospital, Vellore, Tamil Nadu, ¹Department of Palliative Medicine, Specialist in Palliative Medicine, PD Hinduja Hospital, Mahim, ⁵Founder Trustee, Founder and Senior Management on Vision and Strategy, The Jimmy S Bilimoria Foundation, Mumbai, Maharashtra, ³Department of Education and Research, Bangalore Hospice Trust, Karunashraya, Bengaluru, Karnataka, ⁴Department of Palliative Medicine, Mahatma Gandhi Medical College and Research Institute, Pondicherry, India, ²Department of Geriatric Medicine, Khoo Teck Puat Hospital, Singapore

Abstract

Background: Clinical guidelines can improve care and reduce variations in practice. With the growth of The Jimmy S Bilimoria Foundation's PALCARE, a home-based palliative care service launched in December 2015, the foundation felt a need for locally relevant, clinical guidelines to ensure consistency and reliability of its service. A Clinical Consultative Committee (CCC) comprising of experienced palliative care professionals, from within and outside India, was constituted to help with the development of robust, evidence-based multidisciplinary clinical guidelines relevant to the delivery of palliative care for adults in a home care setting in Mumbai, India, which could be applied to other similar settings in India and elsewhere. **Methodology and Development:** The CCC developed 39 guidelines under eight categories; using a structured process from the initial draft to its finalization. The CCC vetted each of the guidelines over monthly Skype meetings for validity, relevance, local applicability and reproducibility. Feedback from the PALCARE team was also incorporated. Thirty-nine clinical guidelines relevant to adult palliative care services in home care setting were developed. These have been discussed and found useful by the PALCARE team. The guidelines are available on the PALCARE website for use by wider professional audience. **Conclusion:** Development of clinical guidelines locally for palliative care in a home care setting in response to a felt need to ensure quality care and reduce variation in practice has been beneficial in clinical care. It has proved to be a good teaching resource too. Regular audits to measure practice against these guidelines will ensure better patient outcomes.

Keywords: Clinical guidelines, home care, palliative care

INTRODUCTION

Clinical practice guidelines are defined as “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.”^[1] It is increasingly common to refer to clinical practice guidelines in routine patient care for clinical decision making. Clinical guidelines have the potential to improve clinical decision making, quality and consistency of care.^[2]

There are useful guidelines on palliative and end of life care; e.g. National Institute for Health and Care Excellence,^[3] the Scottish Intercollegiate Guidelines Network^[4] and many more. Although such guidelines provide useful guidance, there are unique challenges for their use in India. In India, palliative medicine, while still not widely available, is a speciality which is gaining recognition and acceptance. Problems exist relating to availability of essential medications including opioids, paucity

of trained health care professionals, continuity of workforce in palliative care and the lack of a robust network between primary care and palliative care physicians. Moreover, Mumbai is bursting at its seams, and its infrastructure is regrettably inadequate to serve its gigantic population, particularly for those of its citizens who live in one of its sprawling slums or cheek-to-jowl dwellings in chawls. Delivering palliative care at patients' homes in this city is not just a huge challenge but equally a dire need. Hence locally prepared clinical practice guidelines would prove to be a great asset.

Address for correspondence: Dr. Jenifer Jeba, Christian Medical College Hospital, Vellore - 632 004, Tamil Nadu, India. E-mail: jenifermugesh@yahoo.com

Submitted: 06-Sep-19 **Revised:** 02-Nov-19
Accepted: 31-Dec-19 **Published:** 29-Aug-20

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

How to cite this article: Jeba J, Ponissery J, Ramaswamy A, Johnson JR, Thelley AS, Bilimoria PJ. Developing evidence-based clinical guidelines in palliative care for home care setting in India. *Indian J Palliat Care* 2020;26:319-22.

Access this article online

Quick Response Code:



Website:
www.jpalliativecare.com

DOI:
10.4103/IJPC.IJPC_161_19

The Jimmy S Bilimoria Foundation launched its PALCARE services in Mumbai, on December 1, 2015. The growth of the service and its vision to provide high quality and standardized home delivered care, prompted the need to develop clinical guidelines. In October 2016, the Founder Trustee of the Foundation approached a member of PALCARE’s Medical Advisory Board to help constitute and chair a Clinical Consultative Committee (CCC). By December 1, 2016, the CCC was formed with one of its members joining the Committee on November 1, 2017. It comprises experienced clinical and academic experts; palliative care specialists (4) and a specialist palliative care nurse (1) with representation from within India and Singapore, with a profound understanding of palliative care services in the Indian context, working in the community, hospital, and specialist palliative care services. PALCARE’s Chief Medical Officer (CMO) during that period, a seasoned palliative care physician was also appointed a member of the CCC and additionally played the role of researcher and coordinator. The CCC was committed to develop robust, evidence-based, multidisciplinary clinical guidelines in palliative care for a multidisciplinary team, which are relevant for the care of adult patients in a home care setting in India. The aim was to ensure evidence-based practice in the local setting, standardize care among the team, and tailor general evidence to local settings based on the need and availability of medications, expertise, and other resources. We intend to highlight the process of development of these clinical guidelines.

METHODOLOGY AND DEVELOPMENT

The clinical guidelines were to be developed for PALCARE under the guidance of the CCC. PALCARE’s CMO was to coordinate the entire process and develop the first draft for each guideline for deliberation by the CCC. The CCC was committed to ensure that the PALCARE guidelines were developed with rigor and meticulousness.

The CCC identified eight categories: symptom assessment, pain, gastro-intestinal, respiratory symptoms, palliative care emergencies, end of life care, nursing issues, and others [Table 1], with a total of 39 specific guidelines, that would be useful in the delivery of palliative care for adults in home care settings in India. The broad categories and clinical symptoms/conditions that needed development of clinical guidelines was discussed and identified, based on the symptom prevalence/complexity and need in adult patients requiring palliative care in home care settings.

The CCC members met on a monthly basis; the members being multi-locational this was conducted electronically over Skype. Each meeting lasted for 1.5–2 h. The scope of the CCC was to review, refine, and agree on the different symptoms/clinical conditions that needed guidelines to be developed, act as external peer review of the guidelines, and evaluate the evidence in the context of validity, relevance, feasibility, and applicability in the context of factors that would facilitate or hinder practice of the guidelines.

Table 1: Guidelines content

Category and topics
Symptom assessment
Symptom assessment
Pain
Pain assessment
Pain management
Neuropathic pain
Opioids
Gastro-intestinal
Nausea and vomiting
Constipation
Diarrhea
Malignant bowel obstruction
Ascites
Anorexia/cachexia
Nutrition and hydration
Oral care
Hiccups
Respiratory symptoms
Breathlessness
Cough
Palliative care emergencies
Haemorrhage
Seizures
Spinal cord compression
Superior vena cava obstruction
Hypercalcaemia
Delirium*
End of life care
Care in the last days of life
Severe uncontrolled distress
Anticipatory prescribing - at the end of life
Subcutaneous fluids
Syringe driver
Renal disease in the last days of life
Out of hours handover
Rapid transfer of terminally ill patient to the home
Nursing issues
Care of the bedbound patient
Wound care
Enteral feeding
Lymphedema
Others
Weakness/fatigue
Depression
Delirium*
Pruritis
Excessive sweating
Bladder care

*Delirium has been placed under two categories for ease of retrieval

Each month, the CMO as coordinator, in consultation with the chair of the committee, chose a few topics (1–2) to create an initial draft of the guideline after literature review/overview^[5] of other available guidelines on that particular topic (symptom or clinical conditions). With the local context in the background,

the draft was kept relevant, feasible, and appropriate for delivery of care within a home care setting in India, in particular the megalopolis of Mumbai. This initial draft was circulated by E-mail in advance to the CCC members before the teleconference discussion. Each member of the CCC took time to revisit evidence, other guidelines and sent back individual feedback/suggestions to the coordinator. This was incorporated in the next version and circulated to the CCC members prior to the Skype meeting. During the Skype meeting, the entire draft was vetted at length to ensure that it was evidence based and locally relevant and applicable to guide the final draft. Consideration to local availability of medications and expertise have been taken into account to make it locally relevant.

The details of the discussion were meticulously recorded by the CMO and minutes were circulated and confirmed. These discussions helped the coordinator to make the prefinal version of the guidelines. Further modifications were made into the guidelines after considering the inputs from the clinical team members. The draft was also read by a nonmedical person in the PALCARE team, the Founder Trustee, who was able to highlight ambiguity and lack of clarity in documentation. The guidelines were sent once again with the changes for a final discussion and approval by the CCC.

The CCC critically reviewed the guidelines before approving them for clinical use, to ensure validity, reproducibility, reliability, and local clinical applicability. The guidelines were developed and approved over a period of 28 months, from December 2016 to March 2019.

Challenges

The challenges during the process of clinical guidelines' development were many. With just a handful of palliative care specialists across India, finding the time and expertise needed for this task was not easy. There was a huge amount of commitment from the entire group to fulfil this process as it is a long endeavour, in this case 28 months. It is also a long-term commitment as guidelines need to be reviewed and updated.

A systematic literature review with structured appraisal, synthesis and analysis of resources, though would have been ideal for each of the 39 guidelines, given the enormity of the task and restricted time frame, this was felt not to be feasible. The other challenges were scarcity of evidence from within India and reproducibility of other international guidelines in view of challenges with nonavailability and cost of certain drugs within India.

There were instances of ambiguity or differences in opinions (e.g: evidence for a particular drug which is not available in India or lack of expertise locally); they were further debated, with opportunities for clarifications, changes, and amendments. Considering the discussion and evidence, it was the chair's prerogative to make the final decision.

These guidelines are a consensus of expert opinion on good practice, based on available evidence considering local factors, for adults with palliative care needs in the home

care setting. They are intended for use by a trained palliative care professional in a home care setting within India. As the term suggests, these are meant to guide and are therefore "recommendations" for "most common situations" in a home care milieu in India. We recognize that there will be exceptions to common situations, and it calls for clinical judgement and need for decision-making on an individualized basis.

DISCUSSION

Clinical guidelines offer many benefits to the patient, health-care professional, and health system.^[2] However if not combined with good clinical judgement it can result in harm. Rigorously developed guidelines can reduce such harm, which the PALCARE guidelines have strived to. Even with evidence based and relevant clinical guidelines it is the duty of the treating clinician to add to guidelines, clinical expertise and judgement to individualize care based on patient's wishes and values.

The guidelines have provided the PALCARE team an invaluable resource to ensure evidence based practice and standardise care to its ever growing base of patients. It has provided the team a tool that enables it to manage even the most complex patient situations with relative ease.

During the development of the 39 clinical guidelines over 28 months, the PALCARE team realised that it was possible to develop good multi-disciplinary, evidence-based clinical practice guidelines for delivery of palliative care for adults in the home care setting. The development of clinical guidelines has helped the participants in understanding the methodology behind this process. The need to critically assess the evidence base and its local relevance and applicability seem to be key. The CCC and the PALCARE team also realise that this is just the first step towards provision of quality consistent care. With new evidence emerging, clinical guidelines become outdated and require regular review and update and the The Jimmy S Bilimoria Foundation acknowledge the need for ongoing review and update of the guidelines on an annual basis to ensure they are relevant and new evidence is incorporated. The guidelines have been uploaded and available on the PALCARE website for access by wider professional audience.^[6]

The different attributes of a good guideline have been considered in its development process.^[7] The documentation, clarity and ease of understanding have been considered so it is easy for many to read and use. It would be ideal to have all stakeholders represented in the team involved in guideline development.^[8] Input towards the guidelines from the local PALCARE clinical team was obtained, however representation of patients or family caregivers was missing.

Future plans

Development of clinical guidelines in itself is not the end, but the beginning. The benefit of clinical guidelines depends on successful implementation. Adherence to guidelines by everyone across the team is not an easy task. There is need

for hard work within the team for ongoing education and teaching; and remaining motivated to practice in accordance with the guidelines when appropriate. Every member of the team has access to the guidelines both as hard copy and online access. There is regular review of guidelines by individuals and collectively as a team when difficult or complex scenarios arise. The team members have verbally acknowledged the usefulness of the guidelines in their clinical work. The team intends to also conduct regular audits that incorporate patient centered outcomes, keeping these guidelines as standard to promote quality of care and identify challenges in its implementation to further refine them.

The development of these guidelines was a response to a need within PALCARE team; however, we hope they reach palliative care professionals within India and other developing countries in similar settings as an educational tool that empowers and promotes quality care. The clinical guidelines may not have global relevance especially to the developed world at this point, as these have taken into consideration the constraints of availability of different opioids and other medications used in palliative care within India. To disseminate this resource, the website with the guidelines was launched during the Indian Association of Palliative Care Conference, 2019.^[6] We also hope that such guidelines will help to provide consistent care, even in situations where there is a frequent change in the health care work force as is the case in many places across India.

CONCLUSION

Locally relevant and appropriate clinical practice guidelines can be developed meticulously after rigorous evaluation of evidence, with commitment of few health professionals. The guidelines should be used as a tool in clinical practice and must be always coupled with good clinical evaluation and reasoning. Such guidelines which are developed in a local context can be an asset to the team and can ensure good and consistent standard of care. The role of evidence-based care within

palliative care services should be encouraged. Ongoing quality improvement efforts through audits, education and training should be promoted to improve adherence to guidelines.

Acknowledgement

We acknowledge the work and effort of Elaine Fernandes, PALCARE's Communications Executive and Medical Team Coordinator, who assisted the CMO on documentation.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Field MJ, Lohr KN; Institute of Medicine, Committee on Clinical Practice Guidelines, Division of Health Care Services. Guidelines for Clinical Practice: From Development to Use. Washington: National Academy Press; 1992.
2. Woolf SH, Grol R, Hutchinson A, Eccles M, Grimshaw J. Clinical guidelines: Potential benefits, limitations, and harms of clinical guidelines. *BMJ* 1999;318:527-30.
3. NICE Guidance. End of Life Care. Available from: <https://www.nice.org.uk/guidance/health-and-social-care-delivery/end-of-life-care>. [Last accessed on 2019 Jul 09].
4. Scottish Palliative Care Guidelines. Available from: <https://www.palliativecareguidelines.scot.nhs.uk/>. [Last accessed on 2019 Jul 09].
5. Grant MJ, Booth A. A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Info Libr J* 2009;26:91-108.
6. PALCARE. Palliative Care Guidelines for a Home Setting in India. Available from: <https://guidelines.palcareindia.com/>. [Last accessed on 2019 Jul 09].
7. NHS Centre for Reviews and Dissemination. Implementing Clinical practice Guidelines: Can Guidelines be Used to Improve Clinical Practice? *Effective Health Care Bull* 1994. No. 8. Available from: <https://www.york.ac.uk/inst/crd/EHC/ehc18.pdf>. [Last accessed on 2019 Jul 09].
8. Haroon M, Ranmal R, McElroy H, Dudley J; Royal College of Paediatrics and Child Health Clinical Standards Committee. Developing clinical guidelines: How much rigour is required? *Arch Dis Child Educ Pract* 2015;100:89-96.