Special Article

Needs Assessments in Palliative Care: An Appraisal of Definitions and Approaches Used

Irene J. Higginson, BMedSci, BMBS, FFPHM, PhD, FRCP, Sam Hart, BA, MA, Jonathan Koffman, BA(Hons), MSc, Lucy Selman, BSc, MPhil, and Richard Harding, BSc (Joint Hons), MSc, PhD, DipSW
Department of Palliative Care, Policy & Rehabilitation, King's College London School of Medicine at Guy's, King's College and St. Thomas' Hospitals, London, United Kingdom

Abstract
We report a systematic appraisal of definitions and approaches to needs assessment in palliative care. Electronic databases were searched, and relevant individuals and organizations were contacted to identify needs assessments in palliative care. Over 200 articles were identified giving general information on needs assessment, and 77 articles comprised palliative care-related needs assessment reports. The reports originated from Africa (37), Australia (1), Europe (including former central/eastern European states) (35), USA (1), Latin America (5), and Asia (7). Two underpinning definitions of need were identified, that of Maslow from the field of psychology, and that of Bradshaw from sociology. However, in conducting needs assessments, these definitions were operationalized, and here the National Health Service Executive definition of need as "the ability to benefit from health care" is helpful. We identified three main categories of approach to needs assessment—epidemiological, corporate, and comparative—that can be used in combination. Careful consideration must be paid to any needs assessment data to ensure that the assessment is implemented. J Pain Symptom Manage 2007;33:500–505.

Key Words
Needs assessment, public health, palliative, review, methods

Introduction

An essential step to developing appropriate palliative care for a community is to define the need for palliative care of that community. Convincing arguments for prioritizing palliative care rely on rigorous needs assessments to propose the right services, appropriate in scale and type, to the needs within a community. However, there are different approaches to defining and assessing needs, with, to date, little analysis or comparison. Twenty years ago, speaking about health care generally, Soper stated, "There can be few concepts so frequently invoked and yet so little analysed as that of human needs."[1] Since then, some countries have developed systematic approaches to assessing the community need for palliative care. This paper reports preliminary

This study was funded by the Open Society Institute, New York, NY, USA.

Address reprint requests to: Richard Harding, PhD, Department of Palliative Care, Policy & Rehabilitation, King's College London School of Medicine, Weston Education Center, Cutcombe Road, London SE5 9RJ, United Kingdom. E-mail: richard.harding@kcl.ac.uk

Accepted for publication: February 1, 2007.

0885-3924/07/$—see front matter
doi:10.1016/j.jpainsymman.2007.02.007

findings from a global project to appraise the different definitions of and approaches to needs assessments in an attempt to define common useful methods. Our specific questions were the following: 1) What definitions of needs assessment are used in different contexts of palliative care? and 2) What approaches are used to determine palliative care needs?

Methods of Our Global Appraisal of Needs Assessments

Design

We conducted a systematic review, including published and unpublished (gray) literature, to identify and appraise needs assessments.

Search Strategies

Two search strategies were used: 1) identification of the scientific literature to establish the theoretical underpinnings, objectives, and approaches, and 2) identification of the gray literature (see Table 1).

Inclusion and Exclusion Criteria

Papers, reports, books, chapters, abstracts, and articles were included if they addressed any of the following six categories: 1) the science of needs assessment, 2) primary report of a needs assessments already conducted, 3) outlined a needs assessments tool, 4) were resource documents with needs assessments, 5) gave expert opinion of needs assessment, or 6) were general service development strategies, which included a component of needs assessment or discussion. For (1) we included articles on general and palliative care needs assessment; for (2) to (6) we focused only on articles that referred to palliative care, hospice care, terminal care, or progressive/end-stage/end-of-life care. We included all needs assessments provided that basic information about them could be translated into English.

Data Extraction and Analysis

In this paper, we contrast definitions and approaches in different contexts and have undertaken only a limited extraction of the needs assessments identified.

Results and Discussion

A total of 45 electronic searches were conducted, yielding over 1,250 articles. Of these, 69 papers met our inclusion criteria. A further 100 papers were yielded from the generic search "need$ assessment$ health care," with varying relevance. In addition, 70 further articles were collected through recommendations and hand searches.

We identified 77 palliative care-related needs assessment reports. They originated from Africa (37), Australia (1), Europe (including former central/eastern European states) (35), USA (1), Latin America (5), and Asia (7). Different countries/settings had taken slightly varying approaches to needs assessments, often depending on who had commissioned the needs assessment (e.g., policy makers or care providers). The analysis below

Table 1
Search Strategies

a) Scientific Literature

Electronic database searches were undertaken in August 2006 (Embase, Medline, Cinahl, and PsychInfo from 1980, 1966, 1982, and 1806, respectively, these being the start dates of the databases. In addition, we hand searched via the web and hard copy journals. Search terms facilitated a broad appraisal of assessments as well as a focus on palliative care (note: $ is a truncated search):

- need$ assessment$ in conjunction with: pallia$, pallia$ care, terminal, terminal care, end of life, end-of-life care, epidemiology, corporate, comparative, developing, developing country, global, health, health care, hospice
- rapid apprais$ in conjunction with: pallia$, pallia$ care, terminal, terminal care, end of life, end-of-life care, epidemiology, corporate, comparative, developing, developing country, global
- situation analys$ in conjunction with: pallia$, pallia$ care, terminal, terminal care, end of life, end-of-life care, epidemiology, corporate, comparative, developing, developing country, global

b) Gray Literature

Existing palliative care needs assessment reports were obtained through individual invitations to submit reports, with 1) 300 e-mails and follow-up telephone calls to relevant individuals; 2) searched conference proceedings and a public call for data at key conferences, in global newsletters and via website postings.

focuses on the main underpinning definitions and common approaches used.

What Is Need?

Two core definitions of need underpin most approaches to assessing need. Maslow, a U.S. psychologist and philosopher, proposed that human motivation can be understood as resulting from a hierarchy of needs.[2] These needs, starting with the most basic physiological demands (food, water), progress upward through safety needs, belonging needs, and esteem needs and culminate in self-actualization. Maslow argued that as lower-level needs are met, the motivation to meet the higher-level needs becomes active.[3,4] This theory is useful in reminding us that palliative care and symptom relief may not be wanted unless basic needs like food are already met. This is very relevant for the model of palliative care in developing contexts, for example, in Africa. However, Maslow's model implies an overly simplistic linear ordering of need, which may not apply. For example, it is not necessarily true that all higher needs, such as appreciation of relationships and art, cannot be important unless lower-level needs are already met.

In contrast, Bradshaw, a sociologist, considered need in the context of who defined it. He distinguished four types of need (Table 2).[5] His taxonomy is valuable in the context of palliative care because it draws attention to whom is assessing or defining the need. For example, many patients with progressive illness are not able (because of ill health) to actively express their need for palliative care or symptom relief. Thus, relying on expressed need to assess need for palliative care is likely to underestimate the level of need. However, relying on normative need will depend on the knowledge of professionals, which may be highly varied. Reliance on comparative need will depend on how well need is met in all the areas under consideration. Bradshaw's definition is helpful in identifying the different factors that might influence reported need, who determines it (professionals, politicians, or the general public), and what the cultural effects on need might be (e.g., social and media influences on knowledge of what is available, expectations, ability to express need). These factors should be considered when reviewing the results of any needs assessment.

Table 2
Taxonomy of Need According to Bradshaw?

Need can be:
• What the individual feels they need (felt need)
• What the individual demands (expressed need, i.e., felt need turned into action; this is also called demand in some contexts)
• What a professional thinks an individual wants (normative need)
• How we compare with others' areas or situations (comparative need)

From Reference 5.

Moving from Need to Needs Assessment

Whatever definition of need is used, it has to be operationalized to conduct an assessment of need. For this reason, Stevens and Raftery defined need in the context of health care, as "*the ability to benefit from health care.*" This was originally developed by the National Health Service (NHS) Executive (Department of Health) in the United Kingdom and is now used in several countries.[6] Recognizing Bradshaw's taxonomy, they sought to combine different approaches to determining what need was, but they added a very significant component—that of benefiting from health care. Thus, for need to exist in their definition, there must be an effective solution in health care; otherwise, there may be a need, but for something other than health care. In this definition, and highly relevant to the goals of palliative care, "need" is equated with "capacity to benefit." Benefit is not restricted to only clinical benefit, but can also include reassurance, supportive care, and relief of carers.[7]

Approaches to Assessing Need

The Epidemiological Approach. A well-established epidemiological approach is the protocol developed by Stevens and Raftery,[6] adapted for use in palliative care by Higginson (Table 3).[8] This has now been used in full or in part in several countries, including an adaptation of part of the approach by Tebbit in the UK's "Manual for Cancer Networks."[9] The epidemiological approach triangulates three sources of information—the size of the need (determined by information on incidence and prevalence of problems/symptoms), the services available locally, and the effectiveness and cost-effectiveness of potential services.

Table 3
The Epidemiological Approach: Six Key Steps

Development of General Categories
1) Statement of the problem: Define palliative care, terminal illness and palliative medicine and other relevant terms
2) Division into relevant subcategories: • Different palliative care services (e.g., hospice, generalist, specialist services) • Different diseases/groups of patients and families with need
Determining the Size of the Need
3) Incidence & Prevalence: For each of the subcategories, estimate incidence and prevalence figures and calculate likely need. In palliative care, this often involves using data on death rates (number of patients at the end of life and number of families affected) and symptoms experienced. Ideally, information on disease prevalence as well as mortality is useful. This can be made more detailed by using data on local populations (e.g., local death rates, standardized mortality ratios, deprivation index, ethnic composition, trends). Average estimates of death rates and symptom prevalence are available, but it is better to have local data when possible.
Determining the Current Level of Services
4) Nature and level of service currently provided: Current availability and use of services by subcategory. This can also involve local consultation on services available and views on opportunities for expanding certain services, and comparison of services available locally with those available elsewhere.
Determining Effectiveness and Cost-Effectiveness
5) Effectiveness and cost-effectiveness: Reviewing effectiveness of services in terms of palliative care outcomes, i.e., QoL, impact on family and carers. This usually involves consulting existing systematic literature reviews and any local evidence of effectiveness or cost-effectiveness. Where possible, this should be considered for the different subcategories.
Bringing the Information Together and Making Recommendations for Future Development of Services
6) Models of care: By bringing together the above sources of information on need, available services and effectiveness, gaps and mismatches of provision are identified.

Developed by Stevens and Raftery and adapted for palliative care by Higginson.

Contrasting these three sources of information, it is possible to see gaps and mismatches in provision of services and to identify priorities for change, which are then recommended in incremental steps, reviewing needs as change occurs.

Some limitations of the epidemiological approach are that it relies on the availability and accuracy of data, for example, of mortality data, including the correct record of cause of death, and of effectiveness data. Epidemiological needs assessments can include corporate and comparative assessments, potentially making these the most inclusive form of needs assessment.

Corporate Approaches. Corporate needs assessments engage directly with the receiving population to establish their needs and priorities. A series on needs assessment published in the British Medical Journal (BMJ) advocates inclusion of the question "What do patients want?"—in other words, including a corporate element to any needs assessment.[10]

The BMJ series laments that "many of the ways of assessing the health needs of a local population do not entail going anywhere near the population itself."[10] It argues that needs assessment models must include previously marginalized groups in order to ensure that needs of all groups are assessed, and that disempowered groups are suitably enabled to participate. A variety of possible methods of including users include citizens' juries (where members of the local community are presented evidence about need, perhaps from an epidemiological assessment), user consultation panels, focus groups, questionnaire surveys, and opinion surveys of standing panels. However, although needs assessment should be inclusive and integrate the views of local people,[11] there are particular challenges in ensuring meaningful involvement methods with palliative populations. In palliative care,

perhaps the most comprehensive instrument is that developed by Currow et al., which was used to survey 3,027 randomly selected South Australians on the need for, uptake rate of, and satisfaction with specialist palliative care services.[12] However, Currow et al.'s approach used the views of proxies, i.e., not directly the patients but bereaved carers or others.

Comparative Approaches. A comparative needs assessment contrasts the services received by a population in one area with those elsewhere. Thus, if one area has, for example, 40 hospice beds per million population, it might be seen as less well provided than an area with say 70 beds per million population.

Conducting and Implementing Needs Assessments

Any needs assessment is only as good as the data on which it is based. Care must be taken with any needs assessment to recognize the limitations of the data used. Further, any needs assessment, that relies on centrally generated data or senior experts can become too much of a "top-down" approach, with health care professionals defining what should be taken into account.

Needs assessment is an incremental process. It suggests ways in which the services might be modified, and can be reassessed as changes in services occur and when more local data become available.

One important part of conducting a needs assessment is to ensure that it is implemented. This should be planned well in advance. In the course of the appraisal, we identified guidance. Steps should be taken to ensure maximum potential to impact on policy, often achieved through involving policy makers from the inception of a methodologically sound and community-involved needs assessment plan.[13]

Palliative Care Needs Assessments in Developing Countries

Deciding what constitutes palliative care in a developing country setting has to take into account different types of need (e.g., food, money), different levels of need (many have poor access to basic health care), and different demographic and disease profiles (e.g., HIV/AIDS).[14] Good end-of-life care requires attention to domains of socioeconomic deprivation usually considered outside the original remit of specialist palliative care.

The debate has important implications for developing a palliative care needs assessment tool—until there is agreement on what it is you are trying to assess, it cannot be properly assessed. Aside from this debate, there is little literature considering appropriate methods for conducting palliative care needs assessments in developing countries. A particular concern is whether adequate data are available for epidemiological approaches. Wright and Walley[15] specifically address health needs assessments in developing countries. Principal considerations are the availability of accurate information, community involvement, local evidence of effectiveness, and the use of novel methodologies among nonliterate populations.

Conclusion

Needs assessment for palliative care is a fundamental activity in identifying the population-level need for care and provides a robust scientific basis for lobbying for resources and policy response. This article has focused on the definitions and main approaches found in the literature.

An essential first step is to conduct an assessment with a clearly defined definition of need, which was rarely undertaken in the reports we identified. We found the definition of need as *the ability to benefit from health care* (NHS Executive, UK) a useful definition, which is applicable in the palliative context of "total well-being." However, in countries with few economic resources, the term "ability" to benefit may be more problematic, as the matter becomes one of access, delineated by socioeconomic conditions, and structural and process indicators.

Once need is defined, the three approaches to needs assessment can be used, ideally in combination. This includes the comparative approach, the corporate approach, and the epidemiological approach. However, any needs assessment must take into account the limitations of the data used, and here the underlying definitions of need, such as those by Bradshaw, are valuable. Needs assessment is part of the process of developing services; its results need to be implemented and planned from

the outset. Subsequently, results can be improved and the needs assessment further developed.

Our review to date identified 77 needs assessments, in developing and developed contexts. While we have presented here some of the general issues in developing a needs assessment, a next step will be to extract and appraise those needs assessments found and ideally to follow up on how they have been implemented.

Acknowledgments

The authors thank the Open Society Institute for funding this study. We also acknowledge the useful comments on the project provided by Marie Coughlin, Liliana De Lima, and Lukas Radbruch. They are also very grateful to all those individuals and organizations that helped to disseminate our requests for participation and to those who provided us with materials for review.

References

1. Soper K. On human needs. Hassocks: Harvester Press, 1981.

2. Maslow AH. A theory of human motivation. Psychol Rev 1943;50:370–396.

3. Maslow AH. Motivation and personality. New York: Harper & Row, 1954.

4. Maslow AH. Toward a psychology of being. New York: John Wiley & Sons, 1968.

5. Bradshaw J. A taxonomy of social need. New Soc 1972;30:640–643.

6. Stevens A, Raftery J. In: Health care needs assessment: The epidemiologically based needs reviews. Oxford: Radcliffe Medical Press, 1994.

7. Stevens A, Gillam S. Needs assessment: from theory to practice. Br Med J 1998;316(7142): 1448–1452.

8. Higginson IJ. Health care needs assessment: palliative and terminal care. In: Stevens A, Raftery J, eds. Health care needs assessment: The epidemiologically based needs reviews. Oxford: Radcliffe Medical Press, 1997, pp. 1–45.

9. Tebbit P. Population-based needs assessment for palliative care—a manual for cancer networks. London: National Council for Palliative Care, 2004.

10. Wright J, Williams R, Wilkinson JR. Development and importance of health needs assessment. Br Med J 1998;316(7140):1310–1313.

11. Mirando S. Palliative care needs assessment. Int J Palliat Nurs 2004;10(12):602–605.

12. Currow DC, Abernethy AP, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliat Med 2004;18(3):239–247.

13. Jordan J, Wright J, Ayres P, et al. Health needs assessment and needs-led health service change: a survey of projects involving public health doctors. J Health Serv Res Policy 2002;7(2):71–80.

14. Harding R, Higginson IJ. Palliative care in Sub-Saharan Africa. Lancet 2005;365:1971–1977.

15. Wright J, Walley J. Assessing health needs in developing countries. Br Med J 1998;316(7147): 1819–1823.