Needs assessment and palliative care: the views of providers

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Abstract

Background: A key element within the programme of reform introduced into the UK National Health Service in the 1990s has been the concept of health needs assessment, which must be undertaken by health care purchasers as a guide to the planning process. As part of a wide-ranging study of the impact of the NHS reforms on hospices and specialist palliative care services, providers’ perceptions of needs assessment for palliative care were examined, including the extent to which needs assessments had been carried out in local districts, together with the implications.

Methods: The study comprised two key elements. In spring 1995 a postal survey was conducted among all UK hospices and specialist palliative care in-patient units (n = 203) to elicit factual information concerning needs assessment and contracting, together with perceptions and evaluations of the local impact of the NHS reforms. A total of 128 (63 per cent) questionnaires was completed and returned. In addition to the survey, 12 case studies were conducted with a stratified random sample of NHS, independent and large or small hospices and specialist palliative care units. Each of the 12 case study sites was visited by a member of the research team, who conducted interviews with senior staff and analysed financial, planning and management data. Thus the survey allowed a wide analysis of the impact of the NHS reforms, which was enhanced by the more in-depth qualitative data gathered from the case studies.

Results: In the survey 49 per cent of those responding reported that their main purchaser had conducted a needs assessment for palliative care in the last five years. Palliative care needs assessment was seen as valuable by providers; 73 per cent considered it very important and 28 per cent of hospices had gone so far as to request a needs assessment from their health authority. In an open-ended question seeking views on the impact of health needs assessment, 66 per cent of those responding (71/107) stated that the impact had been or would be positive. The case studies, however, revealed a more mixed picture. The 12 hospices or specialist palliative care units had contracts with a total of 24 health authorities, 12 of which had conducted some type of needs assessment for palliative care. On close examination the comprehensiveness of these was questionable. Few providers had participated in the design and there were low levels of knowledge about the findings. High expectations of the value of needs assessment were often not fulfilled. There was also a tendency for providers to view needs assessment in a purely instrumental light, as a vehicle to further promote their own interests.

Conclusions: Palliative care needs assessment has considerable potential to influence future purchasing and service provision, yet not all health commissions are undertaking it. There is a high level of provider enthusiasm for palliative care needs assessment, albeit coupled to low levels of technical knowledge and a lack of involvement in the process at local level. Purchaser–provider dialogue on needs assessment should focus on both raising awareness of appropriate techniques and debating ‘ethical neutrality’ about the outcome.

Keywords: health needs assessment, palliative care, National Health Service reforms

Introduction

The National Health Service (NHS) reforms of the 1990s have placed a growing emphasis upon the importance of health needs assessment as a cornerstone of planning and purchasing. Within the framework of the ‘purchasing cycle’, the assessment of health need becomes a fundamental platform upon which to develop and implement strategic plans, service specifications and contracts. Health needs assessment recognizes that communities and populations may have specific configurations of need, that these may change over time and that the task of the purchaser is to achieve the best possible fit between need and supply, so as to provide effective care within available resources. It has been argued that concepts of need provide a shaky foundation for health planning and that need is too elusive a notion to be useful in this context. Nevertheless, purchasers are charged with the responsibility to undertake needs assessments, to listen to ‘local voices’, and to produce data which can serve as a commissioning tool.

Within palliative care there has been some discussion of the most appropriate approaches for needs assessments. Strong

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arguments have been put forward for adopting the ‘aggregate’ model of health needs assessment, which seeks to give weight to epidemiological data, to the views of key stakeholders, and to the use of comparative service utilization and outcome data from different settings. Detailed guidance has been produced on the use of epidemiological evidence for assessing palliative care needs. In addition, some local examples of palliative care needs assessment used as a guide for purchasers have been forthcoming.

Needs assessment activity may serve as an important barometer of the NHS reforms more generally. The extent to which needs assessments are taking place may give some clue to progress in refining purchasing, to making the procurement of health care more relevant to local needs and to the development of an effective dialogue between purchasers, providers and users of services. In this sense, the study reported here, although focused on the rather specialized issue of palliative care, offers a wider perspective on the unfolding of the NHS reforms. Specialist palliative care delivered through hospices is of course a new feature in the quasi-market of health care. Hospices in the independent sector have proliferated since the early 1970s, but their pattern of growth has not necessarily reflected the distribution of identified need. Rather it has been based on the enthusiastic advocacy and initiative of aspiring providers. How then might specialist providers of palliative care regard the introduction of needs assessment? How far is needs assessment affecting hospice thinking? Is it perceived as an opportunity or threat and to what extent are purchasers and providers engaged in dialogue on the subject? Our study set out to answer these questions at a fairly early stage in the introduction of the NHS reforms; although the impact of needs assessment on service development is of course an important question, it lay beyond the boundaries of the present project.

Methods

Data presented here form part of a larger enquiry into the impact of the NHS reforms on the hospice movement. The project was conducted in 1994–1995 and comprised a three-stage design: (1) detailed case studies of 12 hospices; (2) national survey by postal questionnaire of all in-patient hospices and specialist palliative care units; (3) interviews with national experts. This paper draws on the first two approaches.

Case studies were undertaken in autumn 1994 among a stratified random sample of 12 hospices and specialist palliative care units (SPCUs). The population of UK hospices and SPCUs was stratified on the basis of organizational status: NHS (48), Sue Ryder Foundation (9), Marie Curie Cancer Care (11) and independent (118), plus a separate category specializing in care for people with HIV/AIDS (11). The largest two categories (NHS and independent) were then further subdivided into large and small units, depending on whether they had below or above the mean number of beds (15.3) for UK hospices. The sample of 12 was then produced by selecting a representative number of hospices or SPCUs from each of the seven resulting categories; at this point, two units declined to participate on grounds of pressure of time, and these were replaced using random selection. Each of the 12 case study sites was then visited by a member of the research team and interviews with senior staff were conducted, together with an analysis of financial, planning and management data. A total of 32 interviews was conducted over the 12 sites.

By spring 1995 the number of UK hospices and SPCUs with adult in-patient facilities had risen to 203 and a postal questionnaire was sent to each of these. The questionnaire was designed to elicit both factual information on contractual arrangements and local implementation of ‘the purchasing cycle’; together with perceptions and evaluations of the impact of the recent NHS reforms upon hospices and SPCUs.

Results

We present first the national data derived from the survey, followed by the more detailed analysis which resulted from the case studies.

The survey

A total of 128 questionnaires was completed satisfactorily and returned, giving a response rate of 63 per cent. Of those responding, 27 were from NHS units and 101 from hospices in the independent sector.

Forty-nine per cent of those responding to the survey indicated that their main purchaser had conducted a needs assessment for palliative care in the last five years, and a further 14 per cent were unaware of whether or not one had been undertaken. Despite this, needs assessment was regarded by 73 per cent of respondents as very important, and 28 per cent had gone so far as to request that their main purchaser should conduct a needs assessment for palliative care.

Respondents were also asked how a needs assessment had (or would) affect their service. This open-ended question resulted in 107 free text replies (from 84 per cent of the respondents). These responses were then coded by two independent raters, with five distinct categories emerging (Fig. 1).

Sixty-six per cent of those responding to this question expressed a positive view of the impact of needs assessment. Benefits were seen in a number of ways. Information which would allow services to be tailored more carefully to patients’ and carers’ needs was considered particularly important. As one person noted on the questionnaire: ‘It would provide us with information as to what patients and carers want – not what professionals think they want.’ Some participants have also expressed the view that helpful quantitative data might also result, for example, relating to appropriate service volumes, particularly bed numbers. Other perceived benefits related to
contract formulation and negotiation, and providers were particularly alert to the possibility of using needs assessment to support the case for service expansion: 'It would have a vital role in the planning of future developments and improving existing services.' Finally, some saw it as an opportunity to promote collaboration both between providers and between purchasers and providers.

By contrast, only 6 per cent of responders took a negative view of needs assessment. Here one source of concern was that such an assessment might lead to a reduction in resources: '...very little provision is made for north of the river and therefore funds will be directed there. Our funding will be considerably reduced over the years because of this.' In two instances, reference was made to the wider uncertainties engendered by the NHS reforms, in particular the potential for disagreement between purchasers and providers about such issues as appropriate length of stay and funding: 'Two hospices in the wrong places - there are plans to move one. Lots of politics and negotiations about how to do this. Rumours flying round, local newspapers suspect conspiracies, fund-raisers hate uncertainty.'

In Table 1 we combine both negative and positive responses to needs assessment and rank them by frequency of response. A total of ten categories emerged, of which strategic-business planning and funding were the most frequently cited.

Beyond the positive and negative responses, a small proportion (6 per cent) did not know what the impact of a needs assessment would be, or considered the likely impact to be low (7 per cent). One of the latter commented: 'Needs assessment, though vital in theory, is very difficult in practice. There are so many different measures which change rapidly.' A further 15 per cent did not specify the impact, but included some interesting remarks, such as: 'One is being undertaken at present. I am not convinced that an effective methodology has been developed.'

It emerged from this part of the study therefore that needs assessment was viewed as a positive and worthwhile activity by a majority of providers, but some reservations existed, particularly concerning the efficacy of needs assessment, in practice, to facilitate improvements in patient care.

The case studies
Detailed work in 12 hospices or specialist palliative care units enabled us to gain a more complete picture of providers' perceptions of needs assessment. This part of the study drew on a range of recommended qualitative methods, including in-depth interviews, documentary analysis and observational data gathered on site visits. Interviews were conducted with 32 senior staff across the 12 settings; these were tape-recorded, transcribed and subjected to a thematic content analysis. Similar analytical procedures were used for the documentary evidence, which took the form of business plans and strategies as well as service specifications. Observational data provided a contextual understanding of each hospice or palliative care unit, but were not utilized in detail. The 12 units used for the case studies included one in Northern Ireland, one in Wales and two in each of four English health regions; no Scottish units were drawn in the sample. The units had contracts with a total of 24 health authorities: five had one contract, two had two contracts, one had three contracts and three had four contracts. In the interviews, respondents were asked if any of the purchasers with whom they had contracts had undertaken a palliative care needs assessment. The proportion of health authorities which had undertaken a needs assessment (12/25) was very similar to that reported in the survey. It was found, however, that interpretations and understandings of the term 'needs assessment' could vary considerably, and in some instances this might be used to denote a more general review of services as part of the planning process. For example, the matron of one hospice remarked: '... what they did was an assessment of what was there rather than an assessment of need. A big piece of work but it looked much more at what was being provided than what was needed.' If such needs assessments are widespread, this could...
have the effect of overestimating the level of needs assessment work in existence, and may have a bearing on the survey finding, reported above.

The main needs assessment techniques reported in the case studies are shown in Table 2. These could range from informal conversations through to advanced geographical mapping of service uptake. Purchasers typically adopted three main approaches, using service utilization data, mortality data (especially relating to cancer) and national guidelines for in-patient provision. It was notable that little prominence was given to methods which focus on user experiences and community viewpoints. Most respondents, however, had only partial or superficial knowledge of the relevant techniques in needs assessment.

The needs assessments referred to were usually carried out internally by the respective purchasers, though two had made use of external expertise. Few hospices had participated in setting the agenda for the needs assessment. Nevertheless, despite this rather partial involvement and relative lack of knowledge about needs assessment, it was clear that the process did inspire a good deal of speculation about effects and implications.

From the individual case studies examined, there was little evidence that needs assessment had resulted in a direct impact on services. There was, however, a contrast between this and the high expectations concerning the importance of needs assessment in relation to future developments: ‘the impact it has when we’re planning our future – that’s perhaps where the impact is most full’. Several of those interviewed identified scope to capitalize on needs assessment so as to promote the local palliative care service in some way. So, for example, there was a fairly widespread belief that the process would identify areas of need previously recognized by hospices, but still unattended to. Thus, one matron thought a need for home care might be demonstrated, as ‘that’s the way I see palliative care going’. Another thought needs assessment could point up the importance of day care, as ‘I feel sure that the people are there, but the referrals are not being made’. One medical director had recommended that a needs assessment be conducted and admitted to having a ‘hidden agenda’ that the district had too few hospice beds. There was therefore a widespread view among those interviewed that needs assessment could be used to promote the case for more funding.

Against the potential for needs assessment to be used in this way there were also the dangers of less supportive findings. For example, evidence might result that local need was not being met by the current providers of palliative care; one hospice raised this in relation to the local Asian population. Frequently, there was the concern that the purchaser’s priorities may not be those of the hospice – for example, in relation to diagnostic groups or the model and place of care. Two hospices mentioned that needs assessment data showing a high rate of hospital deaths were construed as a criticism of their local palliative care service. In another, there was concern that the service could become less patient-focused. Here the chairperson of a hospice remarked: ‘the first person you think about is the person receiving the service, the patient and their family, but very quickly on the back of that it’s the purchaser as well and I don’t think that was the case a couple of years ago.’

Discussion

It must be remembered here that the survey findings are based on a response rate of 63 per cent. For various reasons this was considered satisfactory: for example, the questionnaire was lengthy and detailed; many hospices are relatively small organizations with limited administrative structures to respond to such requests; and some may have considered the policy orientation of the survey less relevant than the immediate pressures associated with fund-raising. However, the non-responses were slightly weighted towards NHS units (46 per cent of which did not return the questionnaire) rather than independent hospices (where the non-response was 34 per cent), and smaller NHS units with less than 15 beds were particularly likely not to respond.

The diversity of views about needs assessment exhibited in both the survey and the case studies is a striking finding, and shows how a single element of policy guidance can be widely interpreted. Any follow-up study in this area would benefit from the inclusion of both an operational definition of needs assessment and a parallel investigation of the views of purchasers. Nevertheless, several points emerge from this enquiry into specialist providers’ views of palliative care needs assessment.

First, it was noted from the survey that almost a half of the hospices’ main purchasers appeared to have conducted a palliative care needs assessment. Health needs assessment is the bedrock of the purchasing process in health commissions. That so many purchasers had not carried out such an assessment for palliative care is problematic, although not surprising if one considers that palliative care is not a major spending priority. It is beyond the scope of this study to scrutinize why a needs assessment had or had not been undertaken, but clearly such information would be of value. Our immediate concern is the disparity between the 49 per cent who had undertaken a needs assessment and the figures for strategic plans (56 per cent), service specifications (65 per cent) and contracts (98 per cent),

Table 2 Case studies: types of needs assessment approaches in evidence

| Adoption of national guidelines for in-patient beds |
| Analysis of cancer statistics |
| Analysis of Macmillan nurse data and comparison with local provision |
| Service utilization data |
| Interviews with providers |
| Questionnaire survey of GPs |
| Informal conversations with providers |
| User and local opinion |

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found elsewhere in the survey. This perhaps reflects purchasers’ priorities in the early phases of the internal market, when contracting arrangements were given precedence over needs assessment. Nevertheless, if we also take into account the fact that the figure of 49 per cent palliative care needs assessments conducted is likely to be an overestimate, then clearly a great deal of work is still to be done.

Second, both the survey and the case studies revealed a high level of enthusiasm among specialist palliative care providers for the idea of needs assessment. More than three-quarters of hospices or specialist palliative care units consider health needs assessment very important; over a quarter have gone so far as asking their main purchaser to undertake such an assessment. This enthusiasm, however, appears to be driven by a conviction that health needs assessment can be used to promote sectional interests or that its findings can be expected to confirm providers’ existing suspicions and perceptions. This is an understandable reaction by providers in the context of an emergent health care market, but it is one to be guarded against. Hospice care has a history of service development leaning heavily on emotive appeals and reflecting the enthusiasms and energies of local lobbyists and advocates. The evidence-based approach of health needs assessment calls for services to be grounded in a more thoroughgoing analysis of what is required to provide optimal care in a particular setting. To prejudge its outcome is to run the risk of missing an opportunity to respond to unmet need, when this is identified.

Third, it appears that knowledge about the technical aspects of health needs assessment is still underdeveloped within the UK health care system. Specialist providers of palliative care report low levels of involvement in the design of relevant studies. The range of approaches being adopted by purchasers appears narrow and predictable, with the emphasis being placed on traditional epidemiological measures, at the expense of more innovative approaches. Palliative care research poses many methodological challenges, but these do not constitute a reason for avoiding attempts to reach a rigorous and research-based assessment of local need. There are, none the less, some published examples of needs assessment studies which incorporate user views, employ rapid appraisal techniques or seek to contrast and compare the views of key stakeholders in the health care system.

Several implications for public health and for purchasing emerge from this discussion. Greater dialogue between purchasers and providers is called for if palliative care needs assessment is to improve in range and quality. An emerging literature on the subject should be of use in promoting debate between different stakeholders. Purchasers must refine their needs assessment techniques, to ask the kinds of questions which can lead to more sensitive purchasing. This will call for greater clarity of purpose and a better understanding of available approaches. Providers, for their part, must adopt greater ethical neutrality vis-à-vis health needs assessment, recognizing that it may provide a mechanism for uncovering important, if painful truths, rather than serve merely as a vehicle for reinforcing existing assumptions. There should also be far greater attention to the involvement of user perspectives in the design and dissemination of health needs assessments for palliative care. Purchasers and those involved in public health can do a great deal to promote better understanding of the value of needs assessment activity; the evidence from this study of palliative care is that providers will be eager to participate in such discussions. The extent to which this occurs will serve as at least one indicator of whether the purchaser-provider relationship is maturing and the purchasing cycle is becoming effective.

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References

Nottingham: Nottingham Health, Department of Public Health Medicine, 1992.


12 Tranter, G. *Assessing need for palliative care in a rural area: a report of the research to gather evidence in Dyfed*. Dyfed Health Authority and Marie Curie Cancer Care, 1995.


19 Clark D. What is qualitative research and what can it contribute to palliative care? *Palliative Med* 1997; 11(2): 159-166.


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