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Project to Improve Management of Terminal Illness: Summary of Findings from **PROMOTE**

Julia M. Addington-Hall, Fiona Aspinal,
Rhidian Hughes, Maria Dunckley,
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**National Council
for Palliative Care**



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The clinical governance and quality committee of the National Council for Palliative Care has given encouragement to this important project from its inception and is pleased to be associated with this publication and its findings.

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BACKGROUND

Despite the growth in hospices and specialist palliative care services over the past thirty five years, population-based studies have shown that some cancer patients still receive inadequate care, and have unmet needs for symptom control and psychosocial support (Addington-Hall & McCarthy, 1995). People who die from chronic diseases are less likely than cancer patients to receive specialist palliative care (Addington-Hall, 1998) and there is growing evidence that the care they receive in the last weeks and months of life is often poor.

There is, therefore, no room for complacency about the quality of care provided for people in the last months of life with cancer, or other progressive diseases. To improve the quality of services for dying people, and their relatives, it is necessary to assess and seek to improve the care provided to all patients with palliative care needs and their families, irrespective of diagnosis or care setting. The methods and techniques of quality assurance have an important role to play in this.

Quality assurance has become an explicit formal priority of managers, funders and policy-makers in the NHS (Black, 1990). Recent government policies that call for user and public participation in evaluation and development of the NHS are intended to enhance accountability and improve the patient experience (DoH, 2001a; DoH 2001b; DoH, 2002; DoH, 2003).

They highlight the important contribution of user views to quality assurance. The Project to imPRove Management Of Terminal illness (PROMOTE), which focused on developing methods for quality assurance in palliative care, was therefore timely as its findings are highly relevant to this debate (Hughes et al., 2001).

PROMOTE sought to develop suitable mechanisms for monitoring regularly the quality of care provided to patients with progressive or terminal illnesses, and for their families, and to investigate the best ways of feeding back this information to service providers and commissioners. The objectives of PROMOTE were therefore to:

- *Develop and assess the POS (The Palliative Care Outcome Scale), a questionnaire used prospectively to evaluate the palliative care needs, problems and outcomes of care of patients in different healthcare settings, and their families.*
- *Develop and evaluate the Views Of Informal Carers: Evaluation of Services (VOICES) questionnaire, a retrospective questionnaire designed to evaluate the quality of care provided to patients, and to their families, in the last year of life, irrespective of diagnosis.*
- *Develop and evaluate systems of regular feedback about quality of care to health care commissioners and providers.*

PROMOTE also investigated ways of improving accessibility to both POS and VOICES for members of minority groups.

The Palliative Care Outcome Scale (POS) was developed to prospectively evaluate the needs, problems and outcomes (results) of care for patients who have progressive illness. It also includes items relevant to their families' concerns. Like other outcome measures, POS results can be helpful in determining the effectiveness and outcome of treatments and interventions, in guiding patient care, and in highlighting areas where improvements in care are needed (Carr and Higginson, 2001). Outcome measures such as POS are becoming increasingly established as integral components of clinical practice and research (Department of Health, 1998; 2000).

The POS (Hearn and Higginson, 1999) was developed following a systematic review of palliative care outcome measures, consultation with an expert panel (which included two user representatives), piloting in a number of settings, and feedback from patients on its content.

It encapsulates the central tenets of palliative care: physical and psychological symptoms; spiritual, emotional and practical concerns; and social needs. It includes an open question about patients' main concerns. There are currently two scales, one completed by patients (when they are well enough to do so) and a mirror scale for health professionals.

The POS has been widely used, has been translated into a number of languages and tested for validity and reliability in a variety of specialist palliative care settings.

Developing the POS

A survey of registered POS users showed that it had been used successfully in a variety of specialist palliative care settings (Hughes et al., 2003), however, the scale had not been widely used in non-specialist palliative care settings. PROMOTE wanted to ascertain whether the POS could be introduced and used effectively and successfully in non-specialist settings. Therefore, the team aimed to monitor the utility of using the POS over a six month period in nursing homes, community settings, general wards and oncology wards.

Results showed that the POS was most successfully implemented in nursing homes, where both nurses and residents embraced the POS and reported wide-reaching benefits, including increased understanding between residents and nurses.

THE POS

However, recruitment was much lower than expected in other settings. Interviews with nursing staff in each of the sites identified reasons for the low response. Although nurses thought that use of the POS raised ward profiles within the Trusts and contributed to professional development, a number of factors acted as barriers to its use.

These included: general issues of time available for patient care; time needed to undertake a palliative assessment and to record this; lack of confidence in recruiting patients; concerns about raising palliative issues with patients and a lack of ability to deal with these issues; concerns about effects of using a palliative assessment with very ill patients; and staff turnover.

This component of PROMOTE highlighted general concerns about being able to integrate outcome measures into routine clinical practice (Hughes et al., in press).

Implementing outcome assessment in routine practice

To investigate these barriers further and to identify facilitators to the implementation of outcome assessments in clinical practice, an action research study was undertaken in a nursing home and a hospice.

This study identified ways of successfully implementing the POS, but the findings can also be related to other outcome measures. The facilitators to outcome measure implementation are shown in Table 1.

Table 1: Facilitators to outcome measure implementation

Outcome measure specific issues	<ul style="list-style-type: none"> ● Easy to use to reduce time needed to complete ● Flexible so can ensure that organisational priorities are assessed ● It should not be used too frequently ● Benefits should be easily and quickly observable ● The measure should have an obvious relevance to clinical palliative care
Organisational issues	<ul style="list-style-type: none"> ● A 'cascade' management style with nominated co-ordinator eases implementation of outcomes measures ● All staff should be involved in decision-making processes ● Existing working structures should be utilised, e.g. team nursing ● The time needed to implement and use clinical tools must be acknowledged ● It must be possible to analyse results using existing resources ● A link with a research/audit group gives advice, support and training ● It is important that data are used i.e. that data collection is not merely a paper exercise ● Staff should be encouraged to accept outcome assessment as integral to clinical care

THE VOICES QUESTIONNAIRE

Assessing the quality of services for dying people can be very difficult as many patients are too ill to be interviewed or complete a questionnaire (Small and Rhodes, 2000). To address these problems the VOICES questionnaire was developed. This allows evaluation of services to be made after the patient's death by bereaved relatives, friends or care staff who act as proxies for the patient, as well as recounting their own experiences. Although there are some concerns about the use of proxy data, evidence from studies that have investigated the validity of using bereaved relatives as proxy informants suggests good validity for service evaluation and for some symptoms (Addington-Hall and McPherson, 2001). The views of bereaved relatives have their own validity, as it is these that live on. The VOICES questionnaire enables the respondent to provide information on the care and services that they themselves received and also on the care the patient received.

It was devised as a postal questionnaire by Addington-Hall et al. (1998), based on the interview schedule used in the Regional Study of the Care for the Dying (RSCD) (Addington-Hall and McCarthy, 1995). The question domains covered in the initial VOICES questionnaire were originally based on important issues and ideas surrounding end-of-life care in the 1960s (Cartwright et al., 1973). As a result of advances in research and in palliative care provision, and the changing political dimensions of health, it was considered important for VOICES to be revised to address contemporary issues surrounding death and dying.

Developing the VOICES questionnaire

To inform the content and format of the revised VOICES, extensive literature reviews were undertaken to identify appropriate ways of measuring service satisfaction (Aspinal et al., 2003) and to review the literature of concepts of a good death. Interviews were then held with 36 professional 'stakeholders' such as palliative care commissioners, nurses and general practitioners, to ascertain issues they thought important to measure at the end of life and which should, therefore, be included in VOICES.

THE VOICES QUESTIONNAIRE

Analysis of these interviews identified five key issues: information and communication; choice and control; access to services; symptom control; and well-being. These findings were supported and supplemented with focus groups involving patients, bereaved relatives, and professionals.

The focus groups were conducted using the nominal group technique (Carney et al. 1996) which enabled importance to be ascribed to each of the issues raised within the groups. Fourteen themes emerged from the analysis: symptom management; choice and control; communication; information; dignity; quality of life; maintaining a normal life; carer support; access to services; preparation; co-ordination and continuity; questioning; relationships; and safety and security.

The most important themes were symptom management; preparation; dignity; co-ordination and continuity; quality of life; choice and control; and relationships.

The initial VOICES had covered some of these themes, but with little emphasis on choice and control, dignity and relationships. This confirmed the decision to re-develop the questionnaire. Questions were then devised to address each of these themes. The new VOICES questionnaire was then pre-tested with bereaved relatives using cognitive testing techniques.

Relatives were asked their opinions of the questionnaire as a whole, and about individual questions. Participants were positive about the questionnaire, and thought it was a valuable way of assessing services. Many reported that completing the questionnaire was cathartic. The pre-testing also identified questions which respondents found upsetting, particularly questions about patient anxiety. Questions that had caused distress to respondents were removed, restructured or reworded, as were questions that were misunderstood, or seemed irrelevant to participants. The revised questionnaire was then used in two Primary Care Trusts (PCTs) in London.

Methods of identifying respondents were substantially modified in light of current data protection legislation and involved close partnership with the Office for National Statistics.

VOICES is now available for use in local quality assurance studies, as well as in research studies.

INCREASING ACCESSIBILITY

Given the changing demographic structure of society in the UK (Evandrou, 2000) and the need to include under-served groups in service evaluation, the POS and the VOICES questionnaire have been translated. Literature reviews were undertaken to discover relevant issues and identify appropriate methods for translation of outcome measures and other service assessment tools (Dunckley et al., 2003a). These reviews were supplemented with interviews held with professionals (Dunckley et al., 2003b).

The POS

Translation was conducted in line with established guidelines (Cull et al. 1998). The POS has been translated into two languages: Punjabi and Urdu, and has been tested for use with people who read these languages. Key findings from Urdu interviews were that some of the words used in the translation were too complicated and unfamiliar for general use and that some words were incorrect. For example, in a question about nausea, a word meaning 'general malaise' was used rather than one that specifically referred to 'nausea'.

Similarly, findings from Punjabi interviews indicated that translation of some of the questions could have been made shorter and more simple.

Despite the use of a skilled translator and participants praising the high quality of the translation, a couple of words on the information sheet were written in Urdu rather than in Punjabi. Furthermore, participants did not understand the question about 'self worth' even though they reported that the translation was accurate.

INCREASING ACCESSIBILITY

VOICES

The VOICES questionnaire has been translated into Bengali, again using high quality translators, back and forward translation and reconciliation, and has been tested with members of the Bengali community. Organisations representing these communities facilitated access to community members and conducted many of the interviews on our behalf. The study showed that the translation was accurate but was 'text book' and 'academic'. As such, those who could read the questionnaire in Bengali would most likely be able to read it in English. The questionnaire was felt to be too long, an issue that was not identified when pre-testing the revised questionnaire. Some words and phrases were unfamiliar, such as 'hospice' and 'carer' and needed to be explained. As such, it was thought that some people may need a facilitator to complete the questionnaire with them and some of the questions were irrelevant to the Bengali community for cultural or religious reasons.

General Comments

Participants also made general comments about translation. Participants involved in POS translation felt that interpreter delivered or self-complete outcome measures were preferable to audio-taped administration, but the Bengali participants thought that having the questions spoken on audiotape would increase participation. They also agreed that it was important to bear in mind that although people could speak a language, often they could not read it.

The translated questionnaires were revised as suggested and are now available from the Department of Palliative Care and Policy, King's College London. Recommendations for accessing minority groups in palliative care, and of translating outcome measures have been developed.

A review was undertaken of literature on how to ensure that research findings are incorporated in policy and practice. An initial scoping round of interviews was conducted with professional stakeholders to identify what type of information they would like to receive. This scoping study showed that both quantitative and qualitative information would be useful to inform policy decisions. A second in-depth exploratory study using vignettes illustrating alternative feedback methods was conducted to understand professionals' views on how survey findings should be fed back. Analysis of ten interviews with professionals, working within the two Primary Care Trusts where the VOICES survey had been conducted and their respective Cancer Networks, identified a number of issues that can be located within two key themes.

Key themes

Professionals felt that there was no single right way to present research and audit findings. They recognised that different people preferred, and were influenced by, different styles of data presentation; some may like graphs, charts or tables whilst others prefer words. As such, the professionals interviewed recommended the use of feedback packages that could include reports and presentations.

A feedback package, presenting data from the VOICES pilot surveys, has been prepared and its format has been guided by these recommendations from professionals. Although this part of PROMOTE used VOICES data, the recommendations are applicable to feeding back findings from the POS or, indeed, any other audit or research findings about end of life care.

Table 2: Key Themes

Report structure and presentation	<ul style="list-style-type: none"> ● Present data in a clear, comprehensive and chronological order ● Present data in a positive way ● Use text boxes to identify important conclusions or recommendations ● Summarise each section of the report providing clear “take home” messages ● Use boxes of text, blocks of text and different colours to maintain interest ● Use illustrations, tables and graphs to represent data ● Ensure colours are distinguishable in graphs
Contextualise data	<ul style="list-style-type: none"> ● Consider the pressure on professionals time to deliver services and engage in feedback ● Represent data fairly and within the context of existing literature, policy and practice, acknowledging that reasons may exist for poor results ● Deliver feedback in ways that maximise data ownership amongst professionals i.e. demonstrate a relevance of the data to their clinical environment

CONCLUSION

The PROMOTE has further developed and tested two independent but complimentary questionnaires to assess the quality of service provision for dying people: the Palliative care Outcome Scale (POS) and the Views of Informal Carers: Evaluation of Services (VOICES) questionnaire. The successful translation of the questionnaires helps ensure that people from different communities within the UK can also make their views known. The project has also identified the type and style of information that are likely to impact on service providers and commissioners. In summary, it has demonstrated that:

- *outcome measures intended for use in routine practice need to be quick to complete, flexible and have an obvious relevance to palliative care; criteria which the POS fulfils. PROMOTE has also shown that there are critical organisational issues which need addressing if outcome measures are to be used routinely in practice, including management style, staffing levels, the involvement of staff in decision making, a clear, shared, rationale for its use, and rapid analysis and use of the gathered data.*
- *issues which are particularly important to measure from the perspective of patients, bereaved relatives and health professionals include symptom management, choice and control, preparation, dignity, co-ordination and continuity, quality of life and relationships. The VOICES questionnaire has been extensively revised in the light of these findings and provides a valuable mechanism to capture bereaved relatives' views of these important areas.*
- *translation is possible of both short outcome measures such as the POS and of longer survey instruments such as VOICES. Translation can be done in a culturally sensitive way and, although further work is needed on the testing of such translated measures, it is a feasible way of improving cultural accessibility.*
- *that health service providers and commissioners want information to be fed back to them in ways which are, where possible, positive about the findings, easy to understand, include clear 'take home' and summary messages, and which follow basic design principles. Qualitative information is valued, whilst the presentation of numerical data needs to be particularly well presented. Both presentations and reports are valued, with there being no one 'right way' to feed back information.*

CONCLUSION

These findings have an important contribution to make to the continuing debate about how best to promote evidence-based practice and policy making in palliative care.

Further information about the POS, the VOICES questionnaire, copies of the full reports of each component of PROMOTE, and an up-to-date publication list are available from: Department of Palliative Care and Policy, Kings College London, Weston Education Centre, Denmark Hill, London, SE5 9RJ.

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