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Rural palliative care program national evaluation project: patient and carer experiences

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Abstract

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Rural Palliative Care Program National Evaluation Project: Patient and Carer Experiences

Introduction

Palliative care services in Australia are provided across a range of inpatient, outpatient and community settings by a mix of specialist and generalist providers from the public and private sectors. There is little evidence to guide the provision of palliative care in rural areas and few large scale studies that reflect on patient and carer experiences. The national Rural Palliative Care Program was implemented to provide support for palliative care interventions and to develop evidence on their effectiveness. An important part of that evidence is whether patients and their carers actually found the interventions to be helpful to them.

The Rural Palliative Care Program (RPCP) was built around a model initially developed in Griffith, NSW, known as the GAPS (Griffith Area Palliative Care Service) model. The GAPS model (Slide 4) is based around four aspects:

- Governance and Management
- Direct Care Delivery
- Management and Use of Patient Information
- Professional Participation and Development

An evaluation report by the Centre for Health Service Development (Eagar et. al. 2006) suggested that:

'for towns the size of Griffith, with around a dozen GPs, a regional hospital and community services, there appears to be no reason why the GAPS model of care could not be adopted'.

The evaluation subsequently proposed that further sites should test which components of the GAPS model are transferable to other rural and remote settings.

In response to this, the Department of Health and Ageing contracted the Australian General Practice Network in February 2003 to implement the RPCP. The aim was to support several rural Divisions of General Practice to develop and implement collaborative models that, over a three year period, would significantly improve rural community access to quality, coordinated palliative care. A total of \$5 million was made available to support this process.

After a competitive selection process eight sites around Australia were chosen to test how the GAPS model worked in different regions. A national evaluation framework, including an evaluation toolkit, was developed by the Centre for Health Service Development which aimed at evaluating the program at the consumer, provider and system levels. The evaluation framework and toolkit can be accessed at

http://chsd.uow.edu.au/Publications/2004_pubs/The%20Palliative%20Care%20Evaluation%20Tool%20Kit.pdf .

The tools selected were for the dual purpose of providing sites with clinical assessment and quality assurance data as well as data for the national evaluation.

Understanding the concerns of patients and carers is important in guiding clinical decisions if care and treatment are to deliver improved patient outcomes (Hopkinson et al. 2005). Senior and Perkins (2005) argued that direct input from patients and carers on what quality of life means to them is paramount to providing a service that is responsive to their needs.

This paper presents the combined results of patient and carer responses from the RPCP National Evaluation Project patient and carer experience survey tools, along with themes and comments on what influenced their quality of life. Each site was individually evaluated and a synthesis of all the evidence was produced as a final report on the program as a whole (Quinsey et. al. 2007).

Methods

Patient and carer experiences were collected from palliative care services in six of the participating study project locations. A total of 606 patients were enrolled, of which 87% had a diagnosis of cancer. Assertive follow-up of non-respondents was not appropriate in this context and there is some resulting selection bias. Questionnaires were collected from patients and carers enrolled in the service in early 2005 and patients enrolled in late 2006. All patients and/or carers of patients who were still alive and had been registered with the palliative care service for at least one month were invited to take part.

The service provider left the questionnaire in the home to be filled in by the patient and/or carer in their own time and it was left in a sealed envelope to be picked up at a later visit. The service provider then passed the questionnaire(s) on to the RPCP project officer. Questionnaires were forwarded to the National Evaluation Team at the end of the survey period, where they were entered into an Excel file. Data was then exported to SPSS for analysis. Results from the 2005 data collection were returned to each site to allow them to make comments and address any issues that may have arisen. Results from the 2006 data collection were included in the individual projects final reports.

Patient experiences

Patient experiences were collected by using a modified version of the Patient Outcome Scale (Hearn and Higginson, 1999). The first ten items in the questionnaire cover physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs. The original question 11 has been substituted with a question from the McGill Quality of Life Scale (Cohen et. al., 1995). This question is an open ended question about what made the patients' quality of life better or worse. A final question also asks if the patient needed any help filling out the questionnaire. The questionnaire also contained prompts to speak with their nurse or doctor if patients' scores were high on certain questions or they needed more help.

A staff rated version of the tool was also developed if the patient was unable or unwilling to fill out the questionnaire but were happy for a service provider to fill it out on their behalf. The most valuable feedback is from the patient, therefore, where possible, direct feedback from the patient was sought.

Carer experiences

Carer experiences were collected using the *Care Experiences with Palliative Care Survey*. The tool was designed to be brief and simple in order to minimise the burden on the respondent. The questions in the first section were based on interviews with carers in the Griffith Area Palliative Care Service (GAPS) (Senior and Perkins, 2005), and were field tested by the RPCP National Evaluation Team. Carers are asked if they agree or disagree with a series of statements about how well their needs are being met for practical assistance, confidence in their caring role and

knowing who to ask for more assistance. They are also asked to rate overall support and assistance on a four point scale from excellent to poor.

The second page contains questions from the then most recent version of the Ongoing Needs Identification (ONI) tool (Owen et. al., 2004). It is more specific on rating the carer's experience with practical help, financial tasks, information and managing medicines, aids and equipment, including space to record their comments.

Results

A total of 186 patient experience surveys and 139 carer experience surveys from six projects were collected.

Demographics

Of those who completed the patient experiences questionnaire, approximately 56% were male and 44% were female. Patient ages ranged from 38 to 90 with an average age of 71 years. No patients described themselves as being of Aboriginal or Torres Strait Islander background, and only four identified with any specific ethnic origin.

The majority of carers who completed a questionnaire (68.5%) were female. Their ages ranged from 32 to 90 years and averaged 66.5 years. Only two carers described themselves as being of Aboriginal or Torres Strait Islander background, and three others identified with a specific ethnic origin (English, Greek and German).

Patient Experiences

Patient experiences were measured over the past three days. They are presented below as a set of health related experiences and a set of social experiences.

Figure 1 (slide 10) presents patients health related experiences. When asked if they had been affected by pain, 63.9% of patients described their recent pain levels as either slight or moderate. Slight or moderate symptoms (eg, feeling sick, having a cough or constipation) were reported by 61% of patients. Overall, there were more patients who reported anxiety and worry occasionally or sometimes. Indications are that patients perceived that their families & friends were more anxious about them than they were themselves. Finally 54.7% of patients reported depression sometimes or occasionally.

Figure 2 (slide 11) presents patients social experiences with palliative care. Overall, nearly two thirds of patients reported that they had received full information in the previous three days. When asked if they had been able to share how they were feeling with their family or friends, 80.6% of patients reported sharing feelings as much as they wanted or most of the time. Almost all patients (92.1%) reported wasting no time on appointments relating to health care, such as waiting around for transport or repeating tests.

Overall, there was little evidence of problems being encountered by patients in having their financial and personal affairs attended to, with only 4% of patients reporting that these matters were not being addressed. Almost 80% of patients reported high levels of involvement in decision making.

Patients were asked to write down what made their quality of life better or worse. Those things that made patients' quality of life worse were often amenable to change. Selected quotes illustrating each of these points are included in slide 12 of the presentation.

Those factors described by patients that made their quality of life worse include:

- Pain
- Lack of information or involvement
- Lack of independence and isolation
- Costs of medication and other aspects of care.

What made a patient's quality of life better were often the reverse of factors that made patient's quality of life worse. Comments that illustrate improvements to quality of life are included in slide 13. What made patient's quality of life better included:

- Pain management
- Information and involvement in treatment
- Preservation of normalcy/ dignity
- Family being close or nearby

Carer Experiences

Carers were asked about their experience with the palliative care service as well as their own experiences as carers.

Carers' reports of their experiences with palliative care services (Table 1 – slide 16) were overwhelmingly positive, although carers appeared to know less about respite and bereavement support. Carers' awareness of the availability of respite was lower relative to other aspects of carer experience with the remaining proportion mostly taken up by carers who didn't know if respite was available. There were also fewer carers who knew who to contact after the person they are caring for had died.

Carers' experiences with help and information received were also reported by carers as largely positive (Figure 3 – slide 17). The majority of carers responded to questions about whether they had help with practical tasks and being given information about the carer payment with a 'Yes' or 'Not Needed'.

Although the majority of carers said that they received information on support services or that the information was not needed, 13% indicated that they had not received enough information about support services. Also noted is the 21% of carers who reported that they did not receive practical training on lifting, managing medicine or other tasks, although almost half of carers said that they did not need training for these things.

Carers were also asked to rate the overall support and assistance as excellent, good, satisfactory or poor. Almost all carers (94%) rated the overall support and assistance received as either excellent or good with the remainder rating overall support as satisfactory.

Finally carers were asked to write down any comments about their experiences that they would like to share. Below is a summary of their comments.

Carers had some criticisms of palliative services. Comments that illustrate each of these summary points are included in slide 18 of the presentation.

- Not enough respite or home support
- Difficulties for rural carers
- Hospitals or staff that are unresponsive to patient needs or insensitive
- Difficulty with Carer Payment

Carers were also forthcoming in praise for the palliative care services they received, in particular, the availability and professionalism of palliative care staff. Information, in home support and opportunity for discussion provided by the palliative care staff was seen as invaluable by many carers'. Comments illustrating what carers' praised are included in slide 19 of the presentation.

Discussion

There are inherent difficulties in undertaking this kind of research and any analysis has to consider response biases as well as the ethical issues of research using the time of people at the end of their life. Carers will be strongly involved and likely to be satisfied with any assistance they receive at an extremely difficult time, leading them to answer questions in a more positive way. Follow up studies asking similar questions at a later time may capture different responses that result from a period of reflection on their experiences.

With those caveats, the number of responses to the patient and carer experiences surveys was modest but the analysis has shown some interesting results. There were very few patients who responded that they had wasted time on health care or that their financial and personal affairs had not been addressed. In general, patients indicated a high degree of involvement in decisions about their treatment. Approximately two thirds of patients indicated that they had experienced a degree of depression in the preceding three days. Depression can be difficult to diagnose and is often under treated in the terminally ill as the symptoms are common to those in pain and in end stage disease (Fischer, 2006).

Carers' experiences show a high degree of agreement that palliative care services are meeting their needs and that appropriate support, information and advice is being provided. Fischer (2006) found that a palliative care service that is able to anticipate and provide interventions and an explanation of symptoms is highly valued by families. Study members the GAPS evaluation (Senior and Perkins, 2005) emphasised the importance of a round the clock support program that they could call for help at home after hours or for information at any time.

Patient quality of life appears to be affected by those factors that can be addressed as part of the RPC model. Pain management, providing information, opportunities for the patient to be involved in decision making, fostering normalcy, preserving dignity and encouraging family contact and support were important for patients. These findings are similar to those of Senior and Perkins (2005) who found that patients and carers emphasised the need to maintain a sense of normality and family contact as being most important to their quality of life. In a review of palliative care services in rural Australia, Sach (1997) found that patients and their carers want symptom and pain management, experienced care and family support in a model that aims to deliver services in the home or in a home like setting with the family near by.

Factors affecting carers' quality of life were similar to those for patients but more focussed on support. The provision of in home support that is responsive and sensitive to both patient and carer needs was an important factor improving carer quality of life. Carers were often vocal when these aspects of care were problematic or inadequate.

Palliative care services are most appreciated when they work in the background, empowering the carer to undertake as many of the caring tasks as they can manage (Fischer, 2006). Unobtrusive in home support and respite where appropriate should be given importance in future palliative care models.

While the number of patients and carers returning a questionnaire was modest, results show that patients and carers were often happy to provide information about their experiences. This supports work done by Hopkinson et.al. (2005) that challenged the notion that, for practical and ethical reasons, it is inappropriate to study people who are approaching the end of life and that in fact patients are often supportive of work that may help others.

Hopkinson et.al. (2005) also argued that participation in research was a way of developing practice. The RPC project collected patient and carer experiences as part of a formal set of tools developed to both inform evaluation and clinical practice.

The patient and carer experiences questionnaires provide a structured format for feedback to palliative care services. The use of a standardised tool can help professionals overcome barriers to sensitive issues and access unfamiliar territory while ensuring relevant topics are addressed (Osse et. al., 2007). The use of the patient and carer experiences questionnaires provided patient and carer input to the evaluation but also provided an avenue for feedback to the palliative care service on issues that are relevant to patients and carers.

Conclusion

The RPC projects began in late 2003 and ran for three years. For palliative care patients and their carers, the projects resulted in a greater range of service options. Service providers reported that the projects were effective in increasing continuity of care, particularly between the public and private sectors, due to services working together better as a team, improved communication and better information sharing. Carers' experiences show agreement that palliative care services met their needs and that appropriate support, information and advice was provided.

The projects were judged to have made valuable contributions to local systems. There were professional development opportunities and training resources created for providers that no doubt contributed to positive patient and carer experiences. For the wider system, the projects achieved some limited measures of structural and cultural change and some movement towards more integrated models of care for those with a life limiting illness.

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