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## Transforming community caring into improved health outcomes: lessons from the evaluation of a national palliative care program

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## Abstract

The Caring Communities Program (CCP) was a three-year national palliative care initiative of the Australian Department of Health and Ageing (2003-2006). It funded 37 diverse projects with the common goal of improving the knowledge and skills of families, carers and community groups so they could provide support during the palliative process and work through their own bereavement.

An independent national evaluation of the CCP considered outcomes and processes at three levels - consumers, providers and the system – as well as issues such as project sustainability, the transferability of any lessons learnt to other geographic areas or contexts, and the capacity in palliative care built as a result of the CCP.

This paper focuses on one aspect of the CCP - the processes at the project level which enabled and supported projects to achieve their goals - and presents some interim findings. The evaluation methodology is described and an overview of the program included, providing some context for the paper.

The 37 projects varied widely in their settings, scope and methods. For example, some aimed to bring specialist education in palliative care to health workers in rural and remote areas, while others built volunteer support networks and enhanced community understanding of palliative care. Projects also varied in structural aspects such as, for example, whether the officer was recruited for the project or was in a continuing role, and whether the project evaluation was conducted internally or externally. The evaluation provided an opportunity to examine characteristics at the project level which contributed to success in building capacity in palliative care.

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# **Transforming Community Caring into Improved Health Outcomes: Lessons from the Evaluation of a National Palliative Care Program.**

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The Caring Communities Program (CCP) was a three-year national palliative care initiative of the Australian Department of Health and Ageing (2003-2006). It funded 37 diverse projects with the common goal of improving the knowledge and skills of families, carers and community groups so they could provide support during the palliative process and work through their own bereavement.

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## **Introduction**

The Caring Communities Program (CCP) was funded by the Australian Department of Health and Ageing (DoHA) as part of the National Palliative Care Strategy. The program was designed to improve the quality of palliative care by assisting families, carers and health service providers to give better support to people with a terminal illness.

Tenders were invited in October 2002 for funding of between \$50,000 and approximately \$200,000. Approximately 270 submissions were received nationally. From these applications 37 projects were funded, totalling around \$4.7 million over four years. There were projects in every State and Territory, and in metropolitan, regional and remote areas. The 37 CCP projects addressed a number of themes associated with palliative care in the community, including:

- Improving community awareness of palliative care.
- Supporting dying people and their families.
- Increasing awareness of palliative care as an integral part of the health care system.
- Delivering education to support professionals providing palliative care services.
- Creating effective partnerships between palliative care providers, other health service providers and health systems, to coordinate care for dying people.

The program took a population health approach to promoting palliative care, with emphasis on the priority areas of Aboriginal health, rural and remote Australia, residential aged care and primary care. There was a strong focus on building community capacity and on building partnerships within the health care system.

In May 2003 the University of Wollongong was engaged to undertake the national evaluation of the CCP. The evaluation focused on six research questions, which were presented to projects in the following 'plain English' format:

1. What did you do? (Program and project delivery)
2. How did it go? (Program and project impact and outcomes)
3. What's been learned? (Capacity building)
4. Will it keep going? (Sustainability)
5. Are your lessons useful for someone else? (Generalisability)
6. Who did you tell? (Dissemination)

The results presented in this paper address the first of these six questions, with a specific focus on project delivery.

## **Methods**

### **Data collection**

Evaluation of the CCP had formative components. The national evaluation team (NET) played a capacity building role, developing a framework and tools for the evaluation, visiting the sites to discuss project plans and evaluation methods, attending National and State workshops and teleconferences, providing resources on a website and being available to consult by email or telephone. Risk assessments were carried out and NET members intervened to provide extra support in projects deemed 'at risk' of failing to meet their objectives.

Each NET member was assigned a number of projects to track and support. Division of the projects into groups was based mainly on location (State/Territory), but several projects involving Indigenous communities were assigned to a NET member with experience in working with Aboriginal people. In this way each NET member developed a detailed knowledge and understanding of a number of projects.

Process evaluation of projects encompassed the progress of individual projects and the support available to them from within their auspice bodies and other stakeholders. This aspect of the evaluation included initial and ongoing reviews of documentation and collection of qualitative and quantitative data on the ways in which projects were established, supported, run and evaluated. We drew on a variety of data sources:

- Initial review of project proposals (i.e. successful applications for funding).
- Examination of six-monthly progress reports by each project.
- Participation in, and evaluation of, two national workshops.
- Review of final reports and other documents (e.g., manuals, evaluation reports) produced by each project.
- Exit interviews with a representative of each project, usually the project officer.

## **Data analysis**

Large amounts of qualitative data were generated. The challenges of tracking and analysing the data were met through the use of standardised templates for data collection and presentation and ongoing analysis throughout the course of the evaluation project.

Relevant data from projects' six-monthly progress reports were entered into an Excel spreadsheet and analysed by one NET member. The purpose of the analysis was to track the progress of each project to identify any in need of additional support. The reports also provided information on the prospects for sustainability, generalisability and capacity building from the projects and described dissemination strategies and results. This information was summarised in the NET's progress reports to the Australian Government at six-monthly intervals.

Templates were created for semi-structured exit interviews conducted by telephone or, occasionally, face-to-face. Notes were taken during interviews and written up as soon as possible afterwards by the person who conducted the interview. The data were later extracted into an Excel spreadsheet which provided a set of thematic charts for qualitative analysis. Analysis was conducted by several NET members and consisted of familiarisation with the data followed by identification of emergent themes. Patterns and clusters in the data were identified and interpreted.

NET members created a summary for each project drawing on all available data. The summaries were both descriptive and evaluative, providing a useful way to synthesise large amounts of information. The structure of the summaries facilitated systematic analysis of themes and issues across projects.

## **Results**

Interim findings about project processes are presented below, according to the themes that emerged.

### **Project goals and objectives**

Most projects were well defined with coherent objectives and strategies. Some projects had several streams or components and these were particularly challenging for project officers.

It was important that everyone involved had a shared understanding of what the project was about. Misunderstandings could arise, for example, when the project officer had not been involved in the design and planning phases. If the project officer's role was not clearly defined, they ended up doing things outside their role. This led to problems with excessive workloads as the officer struggled to complete project deliverables such as reporting while taking on other tasks they considered extremely important. For example, some project

officers with clinical experience in palliative care found it difficult to resist the temptation to become directly involved with clients.

There were also cases where project funds were seen differently by the host organisation and the funding body. Project managers saw the grant as a valuable way to top up or maintain an existing service, rather than to set up a discrete project. In these cases, the host organisations were resentful of what they saw as pressure to report outcomes.

### **Community needs addressed by the project**

Successful projects were well focused because they began with a careful needs analysis, or literature review, or consultation in the local community.

In one example of good practice, general practitioners (GPs) preparing for clinical placements with palliative care providers were given reading materials and written tasks, including a case scenario, and asked to list some topics relevant to their own caseload that they wished to learn more about. In this way, placements could be tailored to each GP.

In another project, which developed a self-directed learning package for community care workers, the scope was carefully defined at the outset. A literature review was conducted to investigate the role and education needs of care workers providing palliative care in the home setting. Interviews and focus groups were held with clients receiving palliative care, carers, care workers, allied health professionals and care coordinators to help determine the role of care workers in palliative care.

Several projects were very successful in meeting their objectives of recruiting and training palliative care volunteers but then found there was little demand for their services. Clients were difficult to contact, gatekeepers such as palliative care specialists were slow to start recommending the volunteer service, or the volunteers themselves were unwilling to travel far because of rising petrol prices. Some frustration was expressed by volunteers who had undertaken training and then, did not get the chance to put this into practice.

On the other hand, some projects were able to make subtle changes to their objectives and methods to ensure the outcomes would be relevant and useful. Several found that similar projects or services had been implemented locally and reassessed the need for their own project. In one case, a local health service employed a nurse to provide outreach services in palliative care, something the project was also planning to implement. In response, the project team refocused on co-ordination and referral to services, which they identified as an area of need.

### **Engaging stakeholders**

For community-based projects focused on making connections between providers, co-ordinating care, establishing referral pathways or implementing new models of care engaging stakeholders was essential. Some drew on the expertise of providers to create resources or provide education and training; others mapped local resources. It could be argued that these kinds of connections were among the most important achievements of the CCP, above and beyond the specific goals of individual projects. The success of community engagement has implications for project sustainability or at least its outcomes in the medium term.

Steering or reference groups for projects were generally made up of stakeholders from the community. These groups played a valuable role in creating and maintaining networks of support and gaining access to resources (e.g., potential recruits for volunteer services or for studies, distribution networks for promotional materials, relevant literature and clinical expertise, parking permits for volunteers visiting a hospice).

Projects that engaged with Aboriginal and Torres Strait Islander communities faced many common issues, particularly in rural and remote areas, such as dealing with staff turnover, identifying local champions and achieving genuine, ongoing consultation despite the distances involved.

Keys to maintaining relationships with stakeholders included regular contact via meetings or emails or newsletters and keeping an up-to-date list of names and addresses. Some projects started by compiling a register of local service providers and other stakeholders. One project officer remarked on how important it was to get agreements in writing, as this would help to buffer the project against staff changes in stakeholder organisations.

Project officers spent time building trust, negotiating and finding common ground between stakeholders. This was more difficult where there was a great deal of change happening in the palliative care sector, or more generally in the health system. Several projects that dealt with stakeholders over long distances or in large regions commented on the need to find a local champion to look after the interests of the project and maintain momentum.

## **Project management**

The way in which projects were managed had a substantial impact on their potential to achieve successful outcomes. Projects were small in scale and generally staffed by one key officer. Sometimes this person was supported by a small team, which might include help with administration, budgeting, or networking.

Because projects had so few staff, the skills, experience and enthusiasm of project officers were crucial to success. Diverse technical expertise was required, including project design, data collection and analysis, report writing, and specialist skills such as designing websites, promotional materials or education packages. Some project officers also had high levels of clinical knowledge and experience in palliative care. In addition, they required skills in project management (e.g., running a budget), negotiation and community engagement. This was a great deal to ask from one person, especially as many were employed part-time on short-term contracts.

There was at least an initial advantage for projects where the officer was already employed by the host organisation and took part in designing the project. Where necessary, providing project officers with training (e.g. in project management) was a good investment. Another useful approach was bringing in outside expertise. For example, some project officers who were conducting internal evaluations sought advice from local university staff to design the evaluation. Good relationships between project officers and their hosts could create mutual benefits, such as an exchange of skills and knowledge.

Time management was a challenge, especially for project officers who were already part of the host organisation and took on the project part-time in addition to their previous role.

Project officers talked about the need to be able to 'borrow' from one job and 'pay back' the time later.

Extra support was needed for those in rural and remote areas. These were the projects most likely to be at risk due to difficulties with staff recruitment and turnover or lack of support in the host organisation. Finding ways to provide this support is an ongoing challenge for program managers.

While a few project officers saw the six-monthly progress reports as a bureaucratic nuisance, others used it to their advantage. The reports provided an opportunity for project staff to reflect on their achievements and consider whether strategies were effective. If progress was slower than expected, they could consider changing their methods or asking for more resources.

Adapting to the environment was a key strategy for success. There were many examples of projects that encountered unexpected difficulties, such as failure of initial recruitment, or the unfortunate coincidence that some other service had just started doing what they were planning to do. In order to achieve their outcomes, they were forced to innovate and adapt. For example, several projects providing specialist palliative care awareness training to primary care providers found it very difficult to involve GPs. One project got around this by offering GPs a one-to-one appointment for academic detailing, rather than a workshop. This was such a successful approach that the project continued and expanded it.

## **Project evaluation**

Some project officers incorporated evaluation into their project plans and saw it as essential and integral to the project. They believed it was important to obtain baseline information and to monitor progress to provide feedback to staff and the community. A rigorous evaluation process provided an opportunity to identify and acknowledge successes.

Others felt the evaluation had been imposed on them, that they now had to divert valuable time and money from project work to something unnecessary and intrusive. In some cases, active resistance to evaluation and reporting meant that evaluation strategies were implemented mid-way through the project and the opportunity to collect baseline data was lost. With help from the NET and DoHA officers, some of the projects that had been resistant were able to collect evaluation data and therefore report outcomes.

In many cases, project officers came to see the value of evaluation as time went by, when they realised that data could be used to demonstrate the effectiveness of their project and support applications for future funding.

Although all projects were expected to allocate 10% of their budgets to evaluation, only six took up the option of engaging an external evaluator. For these projects, external evaluation was an excellent investment. It separated evaluation tasks from project tasks, freeing staff to concentrate on making the project work, and at the same time ensuring that evaluation tasks were given priority. There was also the potential for some transfer of knowledge and skills from the evaluator to the project team and visa versa. Importantly, external consultants brought an independent and objective perspective to project evaluation.

## **Discussion**



The qualitative data available from the CCP national evaluation provide an insight into the challenges faced by organisations undertaking palliative care projects over one, two or three years in a variety of community settings and how these difficulties were overcome.

Distance and isolation presented major challenges for projects in rural and remote areas. Difficulties were also encountered with human and other resources within host organisations. Because these were small-scale operations, the illness or personal crisis of one staff member could have a disproportionate effect on the achievement of project goals, as could a lack of key skills (e.g. evaluation, budget management). Such problems were exacerbated when project officers had insufficient support from their host organisation. Some opportunities were missed because project staff did not recognise the value of evaluation, or did not realise that part of the project budget could be used to fund an external evaluator. Project evaluation data were used positively to inform stakeholders and the community, acknowledge successes and enhance prospects for sustainability. A few projects had overly ambitious goals, or their expectations were unrealistic; most, however, were clearly defined and well managed. Recruitment of participants and/or engagement of stakeholders was commonly much more difficult than anticipated. When their proposed methods for community engagement failed, some projects were able to adapt and innovate, with excellent results.

## **Acknowledgement**

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