Patient and Carer Experiences: the National Evaluation of the Rural Palliative Care Program

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Acknowledgements

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The Rural Palliative Care Program (RPCP)

- RPCP had its origins in the 2002 National Palliative Care Strategy.

- RPCP built on work done to develop the GAPS model (Griffith Area Palliative Care Service) in NSW.

- RPCP is aimed at developing palliative care in ‘towns the size of Griffith, with around a dozen GPs, a regional hospital and community services’.

GAPS Model of Care

- **Governance and Management**
  - Governance — clinical, scientific, organisational
  - Existing funding and payment arrangements
  - Agency partnership and collaboration
  - Role delineation and networking

- **Direct Care Delivery**
  - Common referral criteria
  - Shared service protocols
  - Access line
  - Patient held medical record
  - Multidisciplinary care planning

- **Management and Use of Patient Information**
  - Shared clinical information system

- **Professional Participation and Development**
  - Multidisciplinary participation — medical, nursing, allied pastoral, volunteer
  - Professional education and development
Location of Projects

Eight Divisions of General Practice were funded to run a Rural Palliative Care Project – testing the GAPS model in different regions.

- Adelaide Hills South Australia
- Eastern Goldfields (Kalgoorlie) Western Australia
- Eurobodalla (Moruya) NSW
- Mid North Coast (Coffs Harbour) NSW
- North West Tasmania (Burnie)
- Pilbara Western Australia
- South East Queensland (Kingaroy)
- West Victoria (Ararat)

The National Evaluation

- A national evaluation framework was used to evaluate the local projects at the consumer, provider and system levels
- A set of evaluation tools (the RPCP Evaluation Toolkit) was developed
- This presentation will present results from two consumer level tools: the patient and carer experience tools.
RPCP: Patient and Carer Experiences

- The tools selected were for the dual purpose of providing sites with clinical assessment and quality assurance data as well as evaluation data.
- The patient experiences questionnaire contained prompts to contact a physician if their scores were high.
- Patient and carer experiences were collected in 6 of the participating project locations.

Patient Experiences

- Patient experiences were collected by using a modified version of the Patient Outcome Scale (Hearn & Higginson, 1999; Cohen et al. 1995).
- A total of 186 surveys were collected from patients enrolled in the service in early 2005 and late 2006.
- Results from the 2005 collection were returned to participating sites for comments and the opportunity to address issues.
Patient 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.

Patient experiences over the past 3 days
Patient experiences over the past 3 days

- Information given
- Shared feelings
- Time wasted
- Matters addressed
- Decision involvement

What patient’s reported as making QOL worse

◆ Pain
  "It’s constant pain and it’s curbing it as it doesn’t go away."

◆ Lack of information or involvement
  "A skin growth is being treated by my doctor, but I do not feel that he has explained to me adequately what he is doing, why and what the options are."

◆ Lack of independence and isolation
  "Loss of independence has made life worse & frustrating for me"
  "Depression due to isolation from family, especially the children – wish to have family around. Distressed with loss of licence – felt a feeling of finality."

◆ Costs of medication etc.
  "The cost of all my medications are causing extreme problems"
What patient’s reported as making QOL better

◆ Pain management
  “Before seeing palliative care nurse 3 days ago I was in incredible pain …Until this time of consultation quality of life did not exist as I was consumed by pain and worry. After consultation and commencing steroids, pain decreased therefore the worry decreased.”

◆ Information and involvement in treatment
  “Everything has been explained to me which has also made quality of life better as I am now empowered with information.”

◆ Preservation of normalcy/ dignity
  “Knowing at the end of my life my dignity should be preserved.”

◆ Family close/nearby
  “Quality of family relationships and support makes my quality of life better.”

Carer Experiences

◆ Carer Experiences were collected using the *Care Experiences With Palliative Care Survey*.

◆ The questionnaire covers: Carer needs, information, equipment and support, relationship with palliative care staff, respite and grief support.

◆ Surveys were collected from carers of patients enrolled in the service in early 2005 and patients enrolled in late 2006.

◆ A total of 139 surveys from six projects were collected.
Carer Demographics

◆ The majority of carers (68.5%) were female

◆ Age 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).

Carer Experiences with Palliative Care Services

<table>
<thead>
<tr>
<th>Question</th>
<th>Agreed %</th>
</tr>
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<tbody>
<tr>
<td>Carer knows who to contact for help if needed</td>
<td>99.3</td>
</tr>
<tr>
<td>The palliative care staff are helpful and friendly</td>
<td>99.3</td>
</tr>
<tr>
<td>Carer comfortable with the palliative care staff visiting the home</td>
<td>98.5</td>
</tr>
<tr>
<td>Carer confident that care recipient is being kept pain free</td>
<td>97.8</td>
</tr>
<tr>
<td>Adequate attention is paid to carer’s needs</td>
<td>96.4</td>
</tr>
<tr>
<td>Carer feels secure that help and advice is available 24 hours a day</td>
<td>95.6</td>
</tr>
<tr>
<td>Carer has clear instructions about what to do in an emergency</td>
<td>89.7</td>
</tr>
<tr>
<td>Carer has been provided with all the equipment they need</td>
<td>87.5</td>
</tr>
<tr>
<td>Carer feels confident about using the equipment supplied</td>
<td>85.3</td>
</tr>
<tr>
<td>Carer knows who to contact for support after bereavement</td>
<td>82.8</td>
</tr>
<tr>
<td>Carer is aware that respite is available if needed</td>
<td>79.1</td>
</tr>
</tbody>
</table>
Carer Experiences with Help and Information

![Bar chart showing carer experiences with help and information]

Carers criticisms

- **Not enough respite/home support**
  
  “Respite could be more readily available, especially at short notice. Not all needs can be planned.”

  “I feel that people (families) in our position need more respite breaks ie. 4 day weekends. I feel that this would lighten the load.”

- **Difficulties for rural carer’s**

  “For country people should not have to fill in so much paperwork for travel and accommodation, all hospital appointments should be co-ordinated to be on same day.”

  “Due to small community, there are privacy issues.”

- **Hospitals/staff that are unresponsive to patient needs or insensitive**

  “I feel the way the person I care for was informed there was no more treatment options for him was done in a callous, off-hand manner. It caused undue stress and fear and should probably have been done by a palliative care doctor.”

- **Difficulty with Carer Payment**

  “Commenced Carer Pension one month ago, however have been carer for over 12 months. Possibly need to improve carers [knowledge] earlier of their entitlement.”
Carers praises

◆ Palliative care staff
   “I have been on carer allowance for approx. 4 years. My wife has cancer and cannot use her right arm. I don’t know how I could have got by without the help of the staff at (deleted)”

◆ Information, in home support and opportunity for discussion provided by palliative care staff
   “The palliative care nurses are a great support system that is priceless. For useful hints and help. Also the extremes they go to make sure things are rolling along smoothly. And very helpful. Nothing is a problem for them.”

◆ More praise for the palliative care staff
   “I have found the Palliative Care nurses and staff to be absolutely wonderful and as I don’t have a supportive family. Don’t think I could manage without them. They also feel like friends and I can discuss my needs with them. God bless them all.”

Conclusion

◆ For patients and carers the projects resulted in a greater range of service options.

◆ Patient and carer experiences indicated that palliative care services met their needs and that appropriate support, information and advice was provided.

◆ Movement towards an integrated model of care benefited those with a life limiting illness.