Increasing access to cancer and palliative care provision in rural and remote areas in resource limited settings

Prof Julia Downing
Chief Executive
International Children’s Palliative Care Network
Professor Makerere University
Background

- In many countries PC has expanded, particularly in developed countries, and become part of mainstream service provision.
- For those living in rural or remote areas, access is sporadic, often resulting in patients having to leave their community to receive care, or receive suboptimal care,
Developed Countries

- 20% North Americans
- 25% Europeans
- 25% Canadians
- 11% Australians

- Does not take into account geographical differences
- In rural Scotland 18% population in areas covering 94% of the land mass, including islands
Developing Countries

- Many in SSA and India have high rural population
- Vast geographical areas
- Poor transport links
- Low numbers of healthcare workers
- Limited access to medications
- Poverty
- Transport and limitations in Infrastructure
PC in rural and remote areas

• Based on the premise that individuals wish, where possible, to die at home, and so models of PC need to embrace this.
Models

- Models for rural PC provision are evolving, particularly in SSA, which embrace the ‘culture’ of rural communities.
- Models demonstrate that PC can be effectively provided in rural and remote areas.
## Model of Rural PC development in Canada (Kelley et al 2011)

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<thead>
<tr>
<th></th>
<th>Having required antecedent community conditions, e.g. a sense of local empowerment, sufficient local health infrastructure, collaborative generalist practice, etc.</th>
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<td>Experiencing a catalyst for change, e.g. a local champion, policy or education.</td>
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<td>3</td>
<td>Creating a local palliative care team: important to get the right people involved.</td>
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<td>4</td>
<td>Growing the palliative care programme, e.g. strengthening the team, engaging the community and keeping community focused.</td>
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- Model uses a community capacity development perspective
- End-of-life care usually provided by generalist healthcare providers
- Various influencing factors e.g. socio demographic characteristics, distance from health services etc.
- Acceptance of PC team members easier if from the community
Model of Home Based Care in Rural SSA – Key Issues

1) PC provision amidst the face of poverty; patients need more than just medications.
2) Embedding palliative care within the community.
3) Embedding palliative care within the health service - Integration
4) Using a primary healthcare approach utilising volunteers.
5) The importance of PC being more than end-of-life care.
6) Cancer patients access proportionally less palliative care.
7) Resourceful approaches to new technology such as mobile phones.

(Grant et al 2011)
Cross-cutting issues

1) The uniqueness of each community

2) A model that is flexible and meets the diverse needs of rural communities

3) Community ownership and empowerment

4) A model that is embedded within the community and the health system

5) Need for timely communication, information and networking

6) A model that takes into account community health workers and volunteers

7) Clear and appropriate referral networks, with linkages between ‘generalist’ and ‘specialist’ PC

8) Where possible, ‘taking care to the people’, rather than ‘people to the place of care’.
Understanding the Patients Journey - Kenya

- Study looking at individuals experiences of PC and their ‘journey’
- Process prior to diagnosis and PC provision
- Place of Death is important
- Demonstrated the need to try and improve access to PC in the rural settings

- Interviews and FGDs
- 14 patients with diagnosis of cancer and <1 year to life
- 8 women and 6 men
- Aged between 36 – 90 years
- Range of tribes and employment status
The Patients Journey - Kenya

- Examples of issues identified:
  - Access to health services
  - Infrastructure
  - Cost of treatment
  - Spiral into poverty
  - Separation – physical, psychological, spiritual
  - Impact on family
  - Impact on future generations
Implementing Home Based Care in Rural Namibia

- Namibia
  - Small population
  - 90% rural and remote
  - Limited PC in Windhoek
- Integrated PC into Catholic AIDS Action (CAA) Home Based Care Programme
- APCA/CAA/PEPAR
HBC in Rural Namibia

- Components of integration:
  - Pain and symptom management
  - Referrals to a CAA nurse and MoHSS facilities
  - Clinical supervision of volunteers
- Training conducted for nurses and volunteers
- Part of a wider programme working at the national level to improve access to PC

- Evaluation
  - Baseline and post intervention
  - Quantitative and qualitative methods
  - Structured questionnaire
  - APCA African POS
Evaluation HBC in Namibia - Results

- Improvements made in PC provision
- Support of nurse to the volunteers is essential and enables them to provide more comprehensive care
- Working closely with other organisations
- Volunteers felt empowered and supported through comprehensive system of mentorship and supervision
- Developed referral processes and networks to enable continuum of care
- Statistically significant improvement in patient outcomes was seen e.g. pain control.
Developing CPC in Rural India

- Two country project funded by DFID – in Maharashtra India and Malawi
- Goal was to improve the quality of life of children with life-limiting conditions and to gain government commitment
- Sites in Maharashtra:
  - Sion Hospital – Urban
  - Jawhar Hospital – Rural
  - MHM Hospital - Rurban
Example....

Activities:
- Advocacy
- Training and sensitisation
- Children’s rights
- Child Protection Policy
- Networking
- Fundraising
- Media and awareness activities

Training
- Health Professionals
- ASHA workers
- ANMs
- Community Health Workers

Implementation
- Home visits
- Children’s Groups
- Improving care in the hospitals
Findings…

- HCWs assessing holistically and not just physically
- Commitment to PC provision in children
- Team discuss care
- Information provided
- Improvements seen across physical, emotional, social and school functioning using PedsQl
- ASHA workers and CHWs provide care where the child is.
- Strengthened referral networks
- Prevention of poverty cycle – more research needed on this
## Key Challenges for PC in Rural and Remote Areas

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<tr>
<th>Programmatic</th>
<th>For health professionals</th>
<th>For patients</th>
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<td>Lack of resources</td>
<td>Separating personal and professional life for healthcare team: lack of anonymity</td>
<td>Travelling significant distances for care</td>
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<td>Community resistance to palliative care</td>
<td>Working alone in isolated roles</td>
<td>Limited access to multidisciplinary team</td>
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<td>Nature of the rural environment</td>
<td>Need to be both specialist and generalist</td>
<td>Unemployment</td>
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<td>Limited access to services</td>
<td>Shortage of health professionals in the rural setting</td>
<td>Poverty</td>
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<td>Poorly co-ordinated care</td>
<td>Difficulty in managing symptoms</td>
<td>Lack of access</td>
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<td>Limited access to multidisciplinary team, particularly physicians</td>
<td>Limited access to continuing educational opportunities</td>
<td>Personal health beliefs and culture</td>
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<td>How to provide palliative care in the face of poverty</td>
<td>Communication</td>
<td>Lack of family caregivers</td>
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<td>How to encourage early identification of patients</td>
<td>Needing to be multiskilled</td>
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<td>How to develop effective and integrated referral systems</td>
<td>‘Surviving’ in palliative care</td>
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<td>Lack of understanding of the philosophy and principles of palliative care</td>
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<td>and recognition of its importance</td>
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<td>Provision of out-of-hours services</td>
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<td>Local and health systems politics including trends towards centralization of</td>
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<tr>
<td>services</td>
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<td>Caring for marginalized groups</td>
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<td>Inadequate medical facilities and access to medication such as analgesics</td>
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(Downing and Jack 2012)
Issues in establishing effective PC for rural and remote communities

• Some issues are region/country specific:
  • Cultural issues
  • Geography
  • Resources

• Some generic:
  • Supporting clinical staff
  • Recognising isolation and difficulties in attending education events
Summary

• Rural areas have their own specific individual needs
• There are challenges facing rural PC settings
• Many models of rural palliative care services, particularly in SSA, use a local volunteer system.
• The emergence of new technologies provides potential methods to support rural teams and access patients.
• Must find ways of taking PC to the patient, wherever they are.
• Need to continue to ‘Think outside of the Box’