

Psychosocial palliative care in Aberdeenshire: professional views and experiences.

EXECUTIVE SUMMARY

Project overview

Background to the project

This project has run from August 2007 to August 2008. The project is set against both a national and a local policy context.

- At a national level there has been a move towards broadening access to palliative care for people with non-malignant conditions.
- At a local level the Aberdeenshire Palliative Care Strategy and Action Plan (2006) recognized the need for the development of psychosocial support. In addition to this bereavement services, respite care, home based care and complementary therapies were all also highlighted as identified needs.

It was recognized that further information about psychosocial palliative care in particular was needed before further services could be developed. Once the need for this project had been recognised, funding was provided by Aberdeenshire Council and Aberdeenshire Disability Action was chosen as the host organisation. A steering group was then convened.

Project's aims

- Review current literature
- Identify what is understood by psychosocial care
- Identify psychosocial needs of service users and their carers
- Map current service provision (both malignant and non-malignant)
- Identify gaps in current service provision
- Draft proposals for development of services to fill identified gaps

Defining the boundaries of the project

During the first few months of the project the boundaries had to be defined. It was agreed with the steering committee that the project would cover malignant and non-malignant illness, but would pay particular attention to non-malignant illness.

Some groups of people are not included in this project. It was acknowledged in the Aberdeenshire Palliative Care Strategy and Action Plan (2006) that children who require palliative care services have their own distinct needs and therefore should be considered separately. Therefore it was decided that this piece of work would not include children with palliative care needs.

A decision also had to be taken as to who would be interviewed as part of this project. After careful consideration, it was decided that this project would only involve professionals working in the field, given the available time and the potential ethical implications of interviewing service users.

Who was involved in this project?

Ethical approval was sought for the study from the North Scotland Research Ethics Service. Permission was granted to go-ahead with the work in early January 2008. Participants were drawn from a wide variety of professional backgrounds, including representatives from the local authority, NHS Grampian and the voluntary sector.

Interview sample:

- 18 individual interviews were conducted
- 8 focus groups were conducted
- Data was also collected, as a field note, from an informal meeting with 2 further groups and used in the final write up.

Findings

What is psychosocial care?

Participants found psychosocial care difficult to define.

- The initial reactions from people involved in this project, when asked to define psychosocial care, demonstrated a lack of confidence in being able to explain what it means.
- However the majority of participants did go onto suggest what psychosocial care is. Therefore it seems that, whilst this is not a term people are confident with, most workers do have a sense of what it means.
- No one definition of psychosocial care emerged from the responses given by participants, instead different aspects were highlighted. These include social, emotional, wellbeing, financial, coping and quality of life aspects of care.
- This, rather nebulous, definition reflects the literature on this subject, as it is difficult to locate a definitive definition of psychosocial care in the literature.

What are the psychosocial needs of a person with a life threatening illness?

According to participants psychosocial needs vary from person to person and are not always easily understood or expressed. Nonetheless common psychosocial needs can be identified.

Amongst others, the following psychosocial needs were identified by participants:

- Support: what was meant by this was often a bit vague and seemed to overlap with other needs such as practical needs.
- Practical needs: included assistance with care and the activities of daily living.

- The need to talk and be listened to: people need to feel safe to ask questions.
- Sourcing information and assistance: professionals need to know what is out there for different patients.
- Time: participants commented that people with a life threatening illness need time and space.
- Financial needs.

Carers were identified as having their own psychosocial needs. These include: support, information and space away from the patient.

What needs do workers meet?

Workers meet a variety of needs, which include carers' support, information and advice, support, bereavement support, practical care, training, talking and listening and financial needs. There is a notable degree of crossover between the psychosocial needs of people with a life threatening illness identified by participants and the needs that they said they met.

Unmet psychosocial needs.

It was recognized that some psychosocial needs go unmet:

- Even needs that workers identified that they met, may not be met across all illnesses and all areas of Aberdeenshire.
- Specific needs that were identified as being unmet by participants included care, place of death and spiritual needs.
- People involved in this project suggested that the psychosocial needs of people with a non-malignant illness went unmet more frequently.

A number of suggestions were put forward as to why psychosocial needs go unmet:

- Lack of time
- Lack of resources
- Stoical culture of the area
- Professionals fault
- The sidelining of psychosocial needs.

In specific regard to non-malignant illness, the trajectory of non-malignant conditions was put forward as a reason why psychosocial needs go unmet.

Service provision

Participants were able to identify a large number of services to meet the psychosocial needs of people with a life threatening illness in Aberdeenshire. A few themes emerged when participants discussed current service provision:

- Amongst workers there was a general feeling that good multi-disciplinary working took place across Aberdeenshire, which contributed positively to service provision.
- There was a strong feeling amongst some people that structure was lacking and services had developed in a haphazard way. As a result good service provision was reliant on the expertise and experience of the worker, rather than because of the structure that was in place.
- Participants also pointed out that there were inequalities in service provision. Some workers felt that their area of Aberdeenshire was left out, whereas others pointed to differences in service provision for those with malignant and non-malignant illnesses.

The inequalities in service provision for those with malignant and non-malignant illnesses were further highlighted by participants when they spoke about gaps in service provision.

- There was a perception that people with a non-malignant life threatening illness do not get specialist palliative care. Instead they are cared for by carers and the emphasis is very much on the physical.
- There was also a feeling that there is a lack of resources that people with a non-malignant illness can access.

Services workers would like.

Participants identified a number of services that they would like to see to meet the psychosocial needs of people with a life threatening illness:

- A number of participants called for a difference in the way care is provided.
- Workers would like earlier and ongoing contact with people with a life threatening illness.
- Participants also put forward the idea of a palliative care team or workers whose remit would be to meet the psychosocial needs of people with a life threatening illness. This service would be for anyone affected by an advanced, progressive illness.
- Psychological support and counselling.

The way forward

As this project has progressed it has become apparent that there are no easy solutions to fill the gaps that have been identified and that further research is required in this area. Nonetheless tentative suggestions can be made as to how things could be taken forward.

- Agreement and education across all services (health, local authority, voluntary and private sector) as to what psychosocial care means and who is responsible for providing psychosocial care to people with a life threatening illness.

- Clarification should be provided as to whether all workers are expected to provide a level of psychosocial care and when someone should be referred on for more specialist psychosocial care.
- Creation of a clear referral pathway so that workers are aware of what assistance is available in their area and how it can be accessed.
- Creation and publication of a map of service provision, so that workers and people with a life threatening illness are aware of what services are available across Aberdeenshire.
- There needs to be an acknowledgement of the services organizations, such as CLAN and Macmillan, provide to people with malignant conditions and a consideration of how the services that they offer can be replicated for all people with a life threatening illness, including those non-malignant conditions.
- Dialogue needs to be sought with these organizations to ascertain if they plan to follow Marie Curie's example and widen their remit to include the care of people with a non-malignant illness. However if this is not going to happen in the foreseeable future, then other forms of service provision need to be examined to sit alongside these services.

One way of providing a more equitable service for people with a malignant and a non-malignant condition in all areas of Aberdeenshire would be to establish a mobile psychosocial palliative care team who will work with anyone with a life threatening illness. This would be to complement existing services, not to replace them.