

Psychosocial palliative care in Aberdeenshire: professional views and experiences.

Final report of the psychosocial palliative care project (August 2007-
August 2008)

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Action**

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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.

INTRODUCTION TO THE PROJECT

Project overview

This palliative care project ran from the end of August 2007 to the end of August 2008. It was funded by Aberdeenshire Council and hosted by Aberdeenshire Disability Action. The author met with the steering group (appendix 1) on a monthly basis.

The broad aims of this project are:

- To examine the available literature for evidence of issues and best practice in psychosocial palliative care.
- To identify the psychosocial needs of people who have or who are affected by life threatening illness.
- To identify existing services that meet the psychosocial needs of people who have or who are affected by life threatening illness.
- To identify gaps in current service provision for this client group.
- To draft plans for action to fill identified gaps in service provision.

This study covers the whole of Aberdeenshire and has a particular focus on people with a life threatening, non-malignant illness. However the study also examined the needs of people with a life threatening, malignant illness and the services that are in place to meet these needs in order to gain as accurate a picture as possible.

Some groups of people were not be included in this project. It is 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 this piece of work does not include children with palliative care needs. In addition to this people who have a chronic, but not life threatening, illness do not come under the remit of this particular piece of work.

Definitions

In this study, unless otherwise indicated, palliative care is

used to describe the care of people who have an advanced, progressive condition, whether malignant or non-malignant, that is incurable. (Based on a definition of palliative care by Aberdeenshire Council and NHS Grampian, 2006; and Watson, Lucas, Hoy and Back, 2005)

Psychosocial support is taken to mean

any formal or informal support or services, other than clinical care, which seek to address the needs of both an individual with an advanced, progressive condition, whether malignant or non-malignant, that is incurable and their family. Such needs may be identified by the individual, a family member or a professional (Based on Shipman, Levenson and Gillam's (2002) definition).

(Throughout this document the term 'family' is taken to mean anyone identified by the person with a life threatening illness as being important to them. Therefore for some people this term may mean a partner or a child; whereas for other people 'family' may mean their friends or neighbours.)

This can then be broken down into its component parts, although this is not a definitive list:

- 'Emotional support, including social activities, companionship and befriending.
- Personal care, help with bathing or providing massage and other complementary therapies.
- Assistance in securing financial support.
- Help inside and outside the home; for example, cleaning and shopping.
- Supplying practical aids such as wheelchairs and other equipment.

- Offering counselling and psychological support to help people come to terms with dying.
- Religious/spiritual support, whatever a person's beliefs.
- Practical support in preparing for death, including saying farewell, making end of life decision and arranging funerals.' (Shipman et. al., 2002, p. 14)

This definition can be simplified further, where necessary, into the following 'user-friendly' definition:

Psychosocial support is any formal or informal support or services, other than medical care, that help you and your 'family' deal with the impact of your illness on your everyday life.

LITERATURE REVIEW

Palliative care

What do we mean by palliative care?

The World Health Organisation (2007) define palliative care as an approach

'that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.' (WHO, 2007)

According to the Oxford Handbook of Palliative Care (Watson, Lucas, Hoy and Back, 2005) there are three spheres of concern in palliative care: symptom control, psychosocial care and disease management.



(Watson, Lucas, Hoy and Back, 2005, p. xxiv)

In the field of palliative care

'no single sphere of concern is adequate without considering the relationship with the other two. This usually requires genuine interdisciplinary collaboration.' (Watson, Lucas, Hoy and Back, 2005 p. xxiv)

Palliative care can be broken down into two levels: general palliative care and specialist palliative care (National Council for Hospice and Specialist Palliative Care Services, 2001). General palliative care is

'palliative care provided by the patient and family's usual professional carers as a vital and integral part of their routine clinical practice.....General palliative care is provided for patients and their families with low to moderate complexity of palliative care need,

whatever the illness or its stage, in all care settings.' (National Council for Hospice and Specialist Palliative Care Services, 2001, p. 3)

Whereas specialist palliative care is palliative care that is provided by health and social care professionals who specialise in palliative care and work within a multi-professional specialist palliative care team. Specialist palliative care should be available to patients with moderate to high complexity of palliative care need (National Council for Hospice and Palliative Care Services, 2001).

Palliative care and non-malignant illness

Audit Scotland (2007) comment that

'historically, specialist palliative care was established to address the needs of cancer patients. In recent years, the Scottish Executive has recognised the need to broaden access to palliative care to make it more widely available to those with non-malignant conditions (such as heart failure or chronic obstructive pulmonary disease (COPD)).' (p. 5)

This paradigm shift seems to have occurred as a result of the acknowledgment that

'much of what has been learned about palliative care for people with cancer is applicable to those with other diseases.' (Kristjanson, Aoun and Yates, 2006, p. 152)

According to Addington-Hall (1998)

'there is convincing evidence that many patients who die from non-malignant disease have unmet need for symptom control, psychosocial support, open communication, control over their final days and choice about the care they receive. These patients, and their informal carers,

facing considerable distress in the final months of life, need palliative care. For many, adoption of the palliative care approach to their care will be adequate. For others, with complex needs, specialist palliative care will be appropriate.' (p. 9)

However there do appear to be some difficulties in providing palliative care to patients with non-malignant illness. It is acknowledged by a number of authors that one such difficulty is the less predictable trajectory of non-malignant illnesses (Coventry, Grande, Richards and Todd, 2005; Oates, 2004; Travers, Jones and Nicol, 2007). Nonetheless in a recent article, Murray, Kendall, Grant, Boyd, Barclay and Sheikh (2007) have managed to discern characteristic social, psychological and spiritual end-of-life trajectories for people with heart failure as well as lung cancer. The authors conclude that

'typical trajectories may exist for other common diseases. Being aware of these trajectories may help clinicians anticipate times of increased social, psychological, and existential distress, and think proactively about ways of preventing or minimizing distress in their quest to help patients achieve death with dignity.' (p. 400)

Concerns have also been raised about whether existing services will be overwhelmed with referrals and that specialists in palliative care may not have the necessary skills to provide high quality care to patients with non-malignant illness (Addington-Hall, 1998). Therefore, although it is now widely acknowledged that palliative care services should be available on the basis of need rather than diagnosis (Addington-Hall, 1998) at present palliative care services continue to primarily provide care to patients with a cancer diagnosis only (Kristjanson et. al., 2006), as there is little funding available for people with non-malignant diseases in comparison to those with cancer (Higginson, 2007).

Furthermore questions appear to remain about the shape of palliative care services for people with non-malignant illness. Skillbeck and Payne (2005) argue that

'current approaches to specialist palliative care services, mainly adopted from cancer services, are not the most appropriate for addressing the complex problems experienced by the many patients with life-limiting illnesses. Indeed, the assumption that models of care developed for cancer patients are transferable to all patients, irrespective of diagnosis, is in our view deeply problematic.' (p. 326)

Similarly Fallon (2005) asks the question

'should specialists provide palliative care for non-malignant disease, or should the principles of palliative care be promoted and adopted for all non-cancer patients with chronic, progressive disease? From this question flow other questions-if palliative specialists both doctors and nurses, should be the ones providing the palliative care, is the time coming when we shall have to have sub-specialties for the many non-malignant conditions, within palliative care?' (p. 843-844)

It is therefore apparent that new models of palliative care and service delivery of palliative care for people with non-malignant conditions need to be developed.

Unresolved issues?

Throughout the literature it is apparent that there are a number of unresolved issues surrounding palliative care. It is difficult to answer the question what does 'life threatening' mean; or to define what is meant by 'life limiting.' Similarly what are the parameters of the term 'terminally ill' and the phrase 'end of life?' and what is meant by the word 'dying?'

Furthermore in practice who comes under the remit of specialist palliative care? And how can access be made more equitable for all patient groups with palliative care needs? At present there do not seem to be definitive answers to these controversies; yet it is still important to highlight that they exist to ensure that the complexity surrounding this topic is acknowledged.

Aberdeenshire palliative care strategy and action plan

In Scotland there is no one single strategy for end of life care (Higginson, 2007). However the Scottish Partnership for Palliative Care (2007) has recently recommended a cohesive approach to the Scottish Executive.

In North-east Scotland the Aberdeenshire Palliative Care Strategy and Action plan (Aberdeenshire Council, NHS Grampian, 2006) was published in January 2006. This document sets down the palliative care strategy for Aberdeenshire until March 2011. In this strategy it is highlighted that

'best practice suggests palliative care should not be exclusively associated with terminal care' (Aberdeenshire Council and NHS Grampian, 2006).

The scope of the strategy extends to all adults in Aberdeenshire with palliative care needs and their families and carers. It does not establish a strategy for children, as they are acknowledged as having their own needs, which it is envisaged will be addressed in a separate document. It is also highlighted that

A preferred model of care in Aberdeenshire is put forward in the document. This model of care focuses on:

- **Access to Services:** It is acknowledged that services should be offered on the basis of need, not diagnosis. Therefore individuals with non-malignant, as well as malignant illnesses should be offered palliative care services. It is also noted that there should be equity of service provision across the whole of Aberdeenshire.

- **Person Centred Services:** Services should be comprehensive, flexible, and tailored to meet individuals' needs.
- **Information:** Information about diagnosis, treatment, care, services and support should be readily available throughout the journey of illness. It is also noted that psychosocial support should be offered when information is being given to the individual, as appropriate. Furthermore it is suggested that a key worker is identified for each individual to act as a channel for information and a resource for accessing advice and services.
- **Communication and Inter-Agency Working:** There should be good communication between agencies and with service users and their carers. In addition to this shared planning should also be developed between primary and secondary care and social work. It is suggested that a multi-disciplinary inter-agency team approach should be developed. This team should consist of medical, nursing, allied health professionals, chaplaincy, pharmacy, independent sector and social work staff. The professionals in this team should be located in the same geographical area and should be responsible for the provision of palliative care to that area.
- **Joint Equipment:** The joint equipment services between health and the local authority should continue to be developed.
- **Training:** It is acknowledged in the strategy that all staff involved in the provision of palliative care should receive training appropriate to their needs.
- **Carers:** Carers should be listened to and their needs considered when developing care packages. In addition to this carers should have access to psychosocial support.
- **Shape of Future Provision:** It is envisaged that primary care should be the focus for co-ordination and delivery of palliative care services with support from acute and specialist palliative care services, where appropriate. At present the specialist palliative care team in Aberdeenshire is operated from Roxburghe House. However it is noted in the strategy that the development of this service should be considered to allow it to provide appropriate support in the development of community teams and community hospital services. (Aberdeenshire Council and NHS Grampian, 2006).

The strategy also identifies a number of gaps in current service provision, such as respite care and bereavement services. The action required to meet these needs is also noted. As part of this section it is acknowledged that there is a need for the development of psychosocial support. A number of action points are put forward to meet this need: increase the availability of appropriately trained staff able to provide emotional and social support to service users and their carers; develop self help and voluntary sector provision; develop proactive routine visiting of service users via their primary health team; and finally develop a key working system which offers advice, support and information throughout the period of palliative care (Aberdeenshire Council and NHS Grampian, 2006).

Towards the end of the document it is suggested that an implementation group should be created to take forward the strategy (Aberdeenshire Council and NHS Grampian, 2006).

'Psychosocial care'

Poorly defined?

A scan over the literature in this area highlights that, although psychosocial care is fairly frequently discussed, its parameters are poorly defined. According to Lloyd Williams (2003a)

'although much research has been carried out, there is still a lot that is not known about the psychosocial domains of palliative care and ensuring high quality research in these areas is a priority for the future.' (p.79)

It must be acknowledged that there are difficulties in defining psychosocial support, as every individual is different (Shipman, Levenson and Gillam, 2002). Therefore

'what one person sees as supportive, another may see as intrusive, inappropriate or oppressive.' (Shipman et. al., 2002, p. 12)

However the same can be said to be true of medical care and yet it appears that the clinical aspects of palliative care are better defined in the literature (O'Connor, Fisher and Guilfoyle, 2006). It, therefore, appears that whilst there is clarity about the medical aspects of palliative care, there is not yet agreement on what constitutes psychosocial support in this field.

Definitions of psychosocial support

An initial scan of the available literature suggests that psychosocial support is often used as a 'catch-all' term for everything that is not medical. At a basic level psychosocial support is seen as a sum of its parts: psychological and social care. According to the World Health Organisation in an article about developing services for HIV infected people, psychosocial support is described as addressing

'the ongoing psychological and social problems of HIV infected individuals, their partners, families and caregivers.' (WHO, 2007).

To this definition of psychosocial care, spiritual support is often also added (Lloyd Williams, 2003b). It is the opinion of O'Connor et. al., (2006) that psychosocial support is a

'concept that meshes emotional support, social support and, often, spiritual support, and one which is used interchangeably with psychological care and supportive care in the literature.' (p. 135)

Traditionally there has been a heavy emphasis on the psychological aspect of psychosocial support to the detriment of the social. In 1997 the National Council for Hospice and Specialist Palliative Care Services defined psychosocial care as

'concerned with the psychological and emotional well being of the patient and their family/carers, including issues of self esteem, insight into an adaptation to the illness and its consequences, communication, social functioning and relationships.' (Dix and Glickman, 1997, p. 3)

However as Beresford, Adshead and Croft (2007) acknowledge, in their recent publication, this emphasis is beginning to shift and there is now an acknowledgement of the social aspects of psychosocial support in the definition. In this vein the National Council for Hospice and Specialist Palliative Care Services produced a briefing in 2000, which conceded that

'the current use of the term 'psychosocial' is primarily defined in terms of psychological aspects of care and thus deflects attention away from social aspects of patient and family experiences.' (p. 2)

This briefing acknowledges that the 1997 definition of psychosocial care had failed to adequately address the social aspects of palliative care, such as family functioning and the influence of cultural beliefs and values (National Council for Hospice and Specialist Palliative Care Services, 2000). It is highlighted in this briefing that the social fabric of a person's life

'is central to how they make sense of their illness experiences, the meanings they draw upon to understand these, and the range of resources they can call upon to help them manage them.' (p.1)

Therefore both the social and the psychological aspects of palliative care need to be acknowledged.

There are those in the literature who broaden out the definition of psychosocial care still further. The Canadian Association of Psychosocial Oncology defines psychosocial oncology as including

'the formal study, understanding and treatment of the social, psychological, emotional, spiritual, quality of life and functional aspects of cancer as applied across the cancer trajectory from prevention through bereavement.' (Otfinowski, Christian, Mackenzie, Handman and Bultz, 2003, p. 108).

An MSc course in Professional Studies: Psychosocial Palliative Care at Southampton University (Southampton University, 2007) states that one of the aims of the course is to

'deepen the student's understanding of the psychological, social, spiritual, ethical and legal aspects of the care of people who are dying and bereaved.'

According to Sheldon (1997) if we accept the concept of 'total pain' then we have to take into account how the physical symptoms interact with the psychosocial aspects of care. In her opinion

'the patient's anxieties about who will look after their children when they are dead, even about how to pay the gas bill now, have an impact upon their experience of pain, and their understanding of what the whole experience of illness means certainly will.' (Sheldon, 1997, p. 10).

One of the broadest, but most clearly defined, notion of psychosocial support, in the literature, is given by Shipman et. al., (2002). In their opinion psychosocial support is

'any formal or informal support or services for people who are dying that try to address the dying person's needs, as seen by the dying person himself/herself, other than needs for clinical care.' (Shipman et. al., p.13)

This is then broken down by the authors into its component parts:

'Psychosocial support and services may include any or all of the following:

- Emotional support, including social activities, companionship and befriending.
- Personal care, help with bathing or providing massage and other complementary therapies.
- Assistance in securing financial support.
- Help inside and outside the home; for example, cleaning and shopping.
- Supplying practical aids such as wheelchairs and other equipment.
- Offering counselling and psychological support to help people come to terms with dying.
- Religious/spiritual support, whatever a person's beliefs.
- Practical support in preparing for death, including saying farewell, making end of life decision and arranging funerals.' (p. 14)

It is apparent in the literature that there is not a single accepted definition of psychosocial care, but instead there are a number of interpretations. These range from a seeing psychosocial support as a sum of its parts, psychological and social care, to a concept that attempts to enable an individual to define their own needs from the perspective of the context of their own life.

Identifying psychosocial need

McIllmurray, Thomas, Francis, Morris, Soothill and Al-Hamad (2001) argue that

'identifying health needs is widely acknowledged to be fraught with difficulty, reflecting broader philosophical problems in understanding human 'needs' in general.....That cancer patients have health needs that encompass psychosocial as well as disease treatment needs has been officially acknowledged. However what these psychosocial needs actually are, and the prevalence and distribution of these needs amongst cancer

patients with different clinical and social characteristics, is less well understood.' (p. 262)

McIllmurray et. al., (2001) have generated a 48-item psychosocial needs inventory, which they suggest is a relevant, discriminatory and sensitive survey instrument. This research tool was developed by the authors from individual in-depth interviewing and focus group discussions with patients and informal carer who had experienced or were currently living with cancer. McIllmurray et. al., (2001) also drew on previous research into 'needs' conducted by a team of North American researchers.

The 48-item inventory groups together needs into seven categories: those related to health professionals; needs related to support networks; identity needs; emotional and spiritual needs; practical needs and child care needs. This inventory has been used by McIllmurray et. al., (2001) to identify the prevalence of psychosocial need, and the contributory factors to need, among cancer patients in the North-west of England. Their study revealed that

'there is at least one significant variable for all but one of the 48 need items, suggesting that need importance is differentially distributed by one or more clinical, sociodemographic or socioeconomic characteristic.'
(p. 267)

McIllmurray et. al., (2001) discovered that, even controlling for gender and age, breast cancer patients had a significantly higher level of needs for opportunities to participate in choices around treatment. The authors also comment that their research highlights that women had significantly higher levels of need than men for access to other sources of information and support from care professionals. Another interesting finding highlighted by McIllmurray et. al., (2001) is that

'patients not owning their accommodation, a marker of lower socioeconomic status, had significantly higher levels of need for all practical needs items than owner-occupiers, including: help with transport, advice about food and diet, dealing with tiredness, help with housework, help with financial matters, and help with filling out forms.'
(p 267)

Meeting psychosocial need: examples of service provision

Clarke (2007) argues that the way we deliver physical care

'goes a long way to satisfy patients' psychosocial needs-their needs for information, their needs for some control to combat their helplessness.'
(p. 150)

Care provision at the end of life should focus on: good timely information; pain and symptom control; being responsive to patient and family concern; addressing grief and sorrow; and managing depression and demoralisation (Clarke, 2007).

Jones (2007) describes an interesting project called 'Y Filltir Sgwar' ('Home Ground'), which involves an art therapist, clinical psychologist, complementary therapist and administrator together with an existing team of three Macmillan nurses and two Macmillan occupational therapists in rural Wales. The aim of the project is to enhance the existing palliative care service and to take the service to patients' homes or their immediate locality. Patients must have had a diagnosis of cancer to receive this service. Referrals are accepted from primary and secondary care and patients can also self-refer to the team.

A number of different services are on offer through the project: the clinical psychologist runs individual and group sessions in the ward and in patients' homes; the complementary therapist offers aromatherapy, reflexology, reiki and relaxation treatments and runs a joint relaxation session with the OT; the art therapist uses a psychodynamic approach and runs an art therapy group in the north and south of the county; and finally the team offers group and individual sessions for carers (Jones, 2007).

Recent research in Australia has highlighted the important role that community nurses play in meeting cancer patient's psychosocial, as well as physical, needs. McKenzie, Boughton, Hayes, Forsyth, Davies, Underwood and McVey (2007) argue that

'regular contact with generalist community nurses is associated with a strong sense of security about the immediate situation for home-based cancer patients and their primary carers. This sense of security is a

significant component of patient and carer physical and psychosocial well-being, and may have implications for health services utilisation.' (p. 352)

Chochinov, Hassard, Janson and McClement (2004) identify a number of psychotherapeutic approaches that can be used with patients with life-threatening or life-limiting disorders. According to Chochinov et. al., (2004)

'supportive therapy is the mainstay of psychological support for patients who are terminally ill. It is used to shore up or bolster established adaptive coping mechanisms, minimise maladaptive ones and decrease adverse psychological reactions such as anxiety or fear.' (p. 136)

In addition to this other forms of psychological support, such as interpersonal therapy, group supportive psychotherapy, existential supportive/expressive group psychotherapy, cognitive behavioural therapy, grief therapy, and life review can also be used with people at the end of life (Chochinov et. al., 2004).

According to Block and Kissane (1995) such therapies

'can not only promote psychological wellbeing, and thus improved quality of life, but also prolong survival. The Stanford work with group therapy for patients with metastatic breast cancer, the University of California, Los Angeles, intervention promoting active coping in patients with melanoma, and the follow-up in London of better outcomes for early breast cancer patients with certain mental attitudes are notable studies. (p. 1115)

Miller and Walsh (1991) suggest a number of services to meet people's psychosocial needs, which they have found helpful: family conferences which aim to be educative and supportive; a 24- hour hot line that the patient and family can call any time and speak with a nurse who has knowledge about their illness and care plan; counselling for the patient and their family; and training in home care for the family.

Meeting a person's information needs is another aspect of psychosocial service provision that is mentioned in the literature. According to Clarke (2007)

'good, clear information goes a long way to reducing anxiety, giving a sense of knowing the path ahead, and regaining a feeling of control. Patients do not always hear things the first time.....Printed 'fact sheets' and diagrams can be useful, as can referral to disease-specific community groups or websites.' (p. 150)

The importance of meeting a person's spiritual needs is also discussed by a number of authors. Oates (2004) argues that

'spiritual care is an integral component of palliative care, whatever a patient's diagnosis.' (p. 485)

Hirai, Morita and Kashiwagi (2003), in their study into psychosocial interventions for existential suffering of terminally ill cancer patients, classified psychosocial interventions effective for existential suffering into six categories: a supportive-expressive approach, providing comfortable environments, a meaning centred approach, being, education and coping skills training, and a religious approach.

Complementary therapies are also discussed in the literature. NICE (2004) in their publication 'Improving Supportive and Palliative Care for Adults with Cancer' comment that

'decision making regarding the provision of complementary therapy services for patients with cancer is complex. A considerable proportion of patients express interest in these therapies, but there is little conventional evidence about their effectiveness for the relief of physical symptoms and psychological distress.' (p. 12)

Nonetheless in their recommendations NICE (2004) state that

'commissioners and NHS and voluntary sector providers should work in partnership across a Cancer Network to decide how best to meet the needs of patients for complementary therapies where there is evidence to support their use. As a minimum, high quality information should be made available to patients about complementary therapies and services. Provider organisations should ensure that any practitioner delivering

complementary therapies in NHS setting conforms to policies designed to ensure best practice agreed by the Cancer Network. (p. 13)

Goelitz (2007) draws attention to the interesting, but understudied, field of dream work with the terminally ill. In Goelitz's opinion dream work is

'a psychosocial intervention that has been utilized with end-of-life patients, sometimes attracting patients who would not otherwise have accepted services' (Goelitz, 2007).

However Goelitz (2007) does go onto caution that

'dream work can produce even more vulnerability if a safe enough space is not created. Care needs to be taken to ensure that individuals do not plunge in too soon, reveal more than they are ready to, and/or discuss issues that require more trust.' (p. 167)

Therefore it seems that more research is needed in this area.

It is important to acknowledge that a number of services to meet the psychosocial needs of carers are also mentioned in the literature. In addition to the aforementioned psychological interventions, which may also be used by some carers, the provision of home care, respite care (Harding and Higginson, 2003) and carers support groups (Henriksson and Andershed, 2007) are all important elements of service provision for the informal carers of people with palliative care needs.

Kelley, Sellick and Linkewich's (2003) research into rural non-physician providers' perspectives on palliative care services in Canada highlights a number of suggestions for improvement or innovations to palliative care service delivery in the area. According to Kelley et. al., (2003) respondents wanted more education for service providers; improved availability of palliative care services; more counselling/supportive services for bereavement and to meet the emotional and care needs of patients and their carers and greater availability of respite beds.

Who provides psychosocial support?

Shipman et. al., (2002) acknowledge that informally

'most psychosocial care is provided by family and friends and other support networks within the community.' (p.7)

Formally psychosocial support appears to be a shared realm, provided by a number of different professionals. In the literature it is acknowledged that a range of professionals are involved in providing psychosocial care. Shipman et. al., (2002) identify the part played by GPs and District and Community Nurses; Botti, Endacott, Watts, Cairns, Lewis and Kenny (2006) highlight the role that nurses play, whilst acknowledging the contribution of other professionals in this field, and Davis (2004) focuses on the role played by social workers. The American Psychological Association (2001) argues that psychologists also have an important role to play in the provision of psychosocial support in palliative care.

David Oliver, a Consultant in Palliative Medicine and Donal Gallagher, a Specialist Social Worker, in a letter to the British Medical Journal (1998), argue that

'all professionals involved in the care of the patient and family will provide psychosocial care. Some families, however, may require more specialised and skilled specialist psychosocial care. This care will need professionals with further training and experience, including social workers, clinical psychologists, and trained (and supported) counsellors.

Although it is acknowledged elsewhere in the literature that the need frequently arises for specialised and skilled specialist psychosocial care agreement has yet to be reached about which professionals should be involved in such support.

O' Connor et. al., (2006) argue that

'traditionally, psychosocial and spiritual support in palliative care was provided by nursing and medical staff, which has resulted in some resistance to allied-health professionals playing a major role.' (p. 135)

Gill Luff, Chair, Association of Hospice and Specialist Palliative Care Social Workers in a letter in response to a previous article in the British Medical Journal

brought attention to the way in which the role of social workers in the provision of psychosocial support can be overlooked. In this letter Luff (1998) stated that

'the Association of Hospice and Specialist Palliative Care Social Workers is alarmed to see the marginal role that the authors give to social workers in the column indicating sources of support for carers.'

Therefore it seems that there is yet to be agreement on who should do what in the provision of psychosocial support in palliative care.

Is psychosocial care effective?

Although there appears to be a general feeling that psychosocial support is an important component of holistic care, a search of the available literature reveals that psychosocial aspects of care are often under researched and under evaluated and psychosocial aspects of palliative care even more so. According to Thompson, Rose, Wainwright, Mattar and Scanlan (2001)

'what providing psychosocial care means is vague and under-researched.'
(p. 229)

Therefore it is important to at least acknowledge the question 'do psychosocial interventions actually make a difference to the person with a life threatening illness and their family?'

Meyer and Mark (1995) in their meta-analysis of randomized, controlled studies of psychosocial interventions with adult cancer patients argue that

'that the cumulative evidence is sufficiently strong that it would be an inefficient use of research resources to conduct more studies in the United States to ask the simple question: Is there an effect of behavioural, educational, social support, and nonbehavioural counselling and therapy interventions on the emotional adjustment, functional adjustment, and treatment-and disease related symptoms of cancer

patients? There interventions have a consistent beneficial effect on all three areas.' (p. 106).

However Meyer and Mark do go onto argue that

'more direct comparisons of different treatments should be made. We believe it would be premature to conclude that there is no difference between treatment categories on the basis of the present meta-analysis, given possible confounds.' (p.106)

A review of the available literature highlights that the question as to whether psychosocial intervention among cancer patients has a beneficial effect is still unresolved (Ross, Boesen, Dalton and Johansen, 2002; Rehse and Pukrop, 2002). It therefore appears that further research into this area is required. In addition to this further research is needed to establish the effectiveness of psychosocial interventions beyond the realms of cancer patients into the domain of palliative care.

There also appears to be a lack of credible research into the effectiveness of psychosocial interventions for carers. Harding and Higginson (2003) comment on the lack of experimental evaluations in the field of palliative care and caregivers.

According to Harding and Higginson (2003)

'there are a handful of unevaluated descriptions of interventions, which are valuable in terms of providing information about the design and format of interventions. However evaluations (especially rigorous ones) are rare, with only two (quasi-) experimental evaluations indentified in the present review. (p. 72)

They go on to argue that

'the provision of supportive interventions may be detrimental to carers, and this proposition has as yet not been refuted due to the lack of evaluation data in services for carers.' (p.72)

Whilst this may seem an unlikely assertion it is important to note that without well designed and evaluated studies it is impossible to say with any certainty that supportive interventions are to the benefit, and not to the detriment, of carers.

Therefore in light of the above it seems that further research, which is well thought out and evaluated, is required in order to ensure that psychosocial support in palliative care is evidence based and auditable. This may, in turn, result in psychosocial care gaining a more prominent place on the agenda, thus ensuring holistic care for those requiring palliative care services.

Is psychosocial support considered to be important?

An overview of the available literature suggests that in the field of palliative care psychosocial support is often only briefly mentioned and sometimes even overlooked.

Badger, Ackerson, Buttell and Rand (1997) argue that

'primary care physicians, both urban and rural, infrequently address the social, emotional and psychological needs of their patients, despite the stated goal of providing a holistic approach to patient care.' (p. 20)

This view is supported by the American Cancer Society (2007) who suggest that

'the psychosocial burden of cancer is well recognised but seems to be poorly managed by many physicians.'

According to Pascoe, Neal, Allgar, Selby and Wright (2004)

'the identification and treatment of psychosocial issues occur in primary care but are not formally recognised or integrated into existing structures.' (p. 439)

In the Scottish Partnerships for Palliative Care's recent report, 'Palliative and End of Life Care in Scotland: The Case for a Cohesive Approach' (Scottish Partnership for Palliative Care, 2007), it is acknowledged that psychosocial issues are not covered in depth within the report.

The marginalisation of psychosocial support in palliative care is also highlighted by Beresford et. al. in their recent research into social work and palliative care. According to Beresford et. al., (2007)

'it was evident from many of the service users' accounts that psychological need had not led to referral. It seemed as if referral only happened once the severity of physical symptoms had caught up with the severity of emotional distress. Still less was there evidence that social problems, for example housing or financial difficulties, had played any part in bringing about a referral. Yet services users told us that these were sometimes the very issues that had caused them the most difficulty and suffering and made their illness particularly hard to deal with.' (p. 140)

However the picture is not altogether bleak. There is evidence that psychosocial support is beginning to make it onto the palliative care agenda. The Calman-Hine report, 'A policy Framework for Commissioning Cancer Services,' includes the need for psychosocial support in its recommendations (McIllmurray, Thomas, Francis, Morris, Soothill and Al-Hamad (2001). Similarly the importance of psychosocial care is emphasised in the NHS cancer plan (McIllmurray et. al., 2001). Psychosocial needs are also emphasised throughout the NCPC's most recent publication (National Council for Palliative Care, 2008)

Carers in palliative care

Soothill, Morris, Harman, Francis, Thomas and McIllmurray (2001) argue that

'historically, the needs of informal carers of cancer patients have been neglected within cancer services. However in the UK, alongside the growing policy awareness of the valuable role played by informal carers in the community in general, there has been an increasing recognition in the cancer services of the importance of informal carers-both as supporters of cancer patients and as people who have psychosocial needs of their own.' (p. 464)

The role of informal carers in palliative care is ambiguous. Informal carers both provide care and need support themselves (Henriksson and Andershed, 2007; Harding and Higginson, 2003). According to Ferrell, Ervin, Smith, Marek and Melancon (2002)

'in general, findings highlight the chronic and consuming nature of care giving and show that caregivers have diminished quality of life. Frequently given to feelings of depression, family caregivers typically experience fear of loneliness, a sense of helplessness, lifestyle disruption, and uncertainty.' (p. 270)

This view is supported by others in the literature (Henriksson and Andershed, 2007; Mystakidou, Tsilika, Parpa, Galanos and Vlahos, 2007). However alongside the more negative and difficult aspects of caring for someone who is terminally ill, positives are also identified (Ferrell et. al., 2002). Henriksson and Andershed (2007) comment that

'positive experiences may emerge in the context of regarding the remaining time with the patient as a gift and as an opportunity to communicate and show love through caring.'

Research conducted by Mystakidou et. al., (2007) has identified that caregivers' hopelessness is predicted by the cancer patient's characteristics and that a patient's depression is correlated to that of their caregiver. These findings demonstrate that the lives of the patient and the caregiver are closely entwined and therefore cannot be understood in isolation from each other.

Although the range of carers' needs is vast, three main needs can be identified in the literature: information, communication and support (Henriksson and Andershed, 2007; Harding and Higginson, 2003). According to Henriksson and Andershed (2007)

'a number of studies have identified a need for information and communication for relatives who are close to someone near death.' (p. 175)

The authors go onto argue that

'information can fill a number of needs for relatives, such as easing feelings of loneliness and vulnerability and also strengthening relatives' sense of control.' (p.175)

Caregivers also need to be affirmed in what they are doing and seen as active participants in care (Ferrell et. al., 2002; Henriksson and Andershed, 2007).

Unfortunately, according to Harding and Higginson (2003),

'current provision for informal carers (i.e., those unpaid carers providing one or a combination of physical, practical and emotional care and support) has been described as crisis intervention, in that services ignore successes and reward failure. Those carers who appear to be coping in their role and do not request services are assumed to have no unmet needs, and it is only in the crisis situations of imminent or apparent breakdown of informal care that services respond.' (p. 2003)

A systematic psychosocial assessment of patients and primary carers has been proposed by Powazki and Walsh (1999). However it is still not clear how best to meet assessed need (Harding and Higginson, 2003). Henriksson and Andershed (2007) describe a support group programme at a palliative care unit in Stockholm, Sweden, that relatives were invited to take part in during the late palliative phase of their family member. The support group was found to have six key constituents: confirmation, insight, sense of belonging, participation, rest and strength. According to Henriksson and Andershed (2007)

'in all key constituents there was a recurring and common meaning-safety-that made up the overall essence of the experience and the importance of support groups for relatives of patients in palliative care.'
(p. 178)

This sense of safety enabled participants to care for their relatives in a more assured manner than before and helped caregivers to feel more capable of handling the situation (Henriksson and Andershed, 2007).

Ferrell et. al.,s (2002) research, which examined 1100 pieces of correspondence written by family caregivers of ovarian cancer patients to *Conversations!: The*

International Newsletter for Those Fighting Ovarian Cancer, also illustrates the importance of emotional support for carers. Their findings highlight the value of peer support and the sharing of common experiences.

Similarly Grassi (2007), in her work on bereavement in families with relatives dying of cancer, comments that

'participating in support group interventions may be extremely important for family members so that they can be given information, education, active listening, a sense of cohesion, as well as being able to express their emotions and confront their imminent loss.' (p. 44)

The needs of people with neurodegenerative conditions and their families are highlighted by Kristjanson, Aoun and Yates (2006) in their recent study. According to Kristjanson et. al., (2006)

'those who receive more tailored services and more palliative care services were the most satisfied.' (p.151)

It appears that for people with neurodegenerative conditions and their families there needs to be individually tailored and flexible models of care, which take into consideration the trajectory of the illness and the need to move from rehabilitative approaches to a greater emphasis on palliative care approaches, as the illness progresses. In addition to this, the considerable demands that these illnesses put on carers should be noted (Kristjanson, Aoun and Yates, 2006).

Harding and Higginson (2003) in their systematic literature review of interventions and their effectiveness identified 6 types of intervention: home care, respite services, social networks and activity enhancement, problem solving and education and group work. However according to Harding and Higginson (2003)

'a considerable body of knowledge was identified with respect to need, but little on interventions and their evaluation.' (p.64)

It appears that in order for carer's needs to be fully met more research needs to be done into what are the most effective supportive services (Harding and Higginson, 2003).

Palliative care in a rural setting

Wilson, Justice, Sheps, Thomas, Reid and Leibovici (2006) argue that rural end of life research is uncommon. As a result there is little evidence of the availability, efficiency and effectiveness of palliative care services or programmes in the literature. However a few common themes do emerge from the limited literature into rural end of life care: it is apparent that palliative care is overwhelmingly provided by generalists outside of metropolitan areas (Kelley, Sellick and Linkewich (2003). It is also clear that the demands on informal carers are considerable in rural areas (Clarke, 2007; Kelley et. al, 2003). This can result in informal care givers feeling overwhelmed by their responsibilities (Kelley et. al., 2003).

There are a number of challenges in the delivery of palliative care in rural areas. Geographic isolation and transportation problems are one of the most significant barriers to accessing palliative care services for people living in a rural area (Otfinowski, Christian, Mackenzie, Handman and Bultz (2003). In addition to this recruitment and retention of health care professionals in rural areas is also a significant issue (Kelley et. al., 2003), as is the lack of local services and a lack of awareness of local services (Kelley et. al., 2003; Otfinowski et. al., 2003).

A number of suggestions as to how these barriers can be overcome are noted in the available literature. The aforementioned 'Y Filltir Sgwar' ('Home Ground') project has attempted to overcome the transportation and distance difficulties experienced by many rural communities by finding suitable venues in strategic areas of the county, which the team visits, in order to give equality of service and reduce travelling time for patients (Jones, 2007). The team has also made use of new video conferencing technology to access expertise and support for the team (Jones, 2007).

End of life care in rural areas cannot be modelled on service delivery in urban areas, but instead needs to grow up from and reflect the distinctive needs of rural people (Kelley et. al., 2003; Wilson et. al., 2006). In order to improve palliative care in rural areas there needs to be ongoing interdisciplinary education for generalists who undertake end of life care in rural areas (Kelley et. al., 2003). Practitioners working with terminally ill people in rural areas also need to be able to

access specialists for consultation (Kelley, et. al., 2003; Wilson et. al., 2006). This can be done through travelling clinics, on-call telephone consultation or through the use of new technology, such as video conferencing (Kelley et. al., 2003; Jones, 2007; Wilson et. al., 2006).

Otfinowski et. al., (2003) found that

'ninety-five per cent of health care providers who responded to our survey felt that it was important for their cancer patients to have access to psychosocial care. However only 18% were satisfied with the support services available in their community.' (p. 107)

It is, therefore, apparent that an improved model of palliative care in rural areas should also include greater access to psychosocial support for patients and carers and to better psychosocial education of practitioners working in this field (Kelley et. al., 2003; Otfinowski et. al., 2003).

METHODOLOGY

Background

Between September 2007 and January 2008 database searches were undertaken for literature related to the topic. The databases searched during this period were:

- 1) Ovid Medline (R) to January week 1 2008
 - Search 1 terms: palliative care and psychosocial care;
 - Search 2 terms: effectiveness of psychosocial interventions;
 - Search 3 terms: palliative care and effectiveness of psychosocial interventions;
 - Search 4 terms: palliative care and randomized controlled trials and psychosocial;
 - Search 5 terms: palliative and randomized controlled trials and psychosocial support;
 - Search 6 terms: palliative care and randomized controlled trials and psychosocial care;
 - Search 7 terms: palliative care and randomized controlled trials and psychosocial interventions;
 - Search terms 8: randomized controlled trials and psychosocial support;
 - Search terms 9: psychotherapy OR social OR psychosocial combined with intervention AND cancer.
 - Search terms 10: psychotherapy OR social OR psychosocial OR psychological combined with intervention or intervention studies AND withholding treatment/or ethics/, medical/or palliative care/or terminal care/or end of life care.
 - Search terms 11: effectiveness AND intervention or intervention studies AND palliative care/ or terminal care/ or end of life care AND social support/or psychosocial care AND social support/or psychosocial support.
- 2) Journals @Ovid Full Text September 14, 2007
 - Search terms: palliative care and psychosocial care

- 3) Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations
Search terms: palliative care and psychosocial care
- 4) Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1950 to Present
Search terms: palliative care and psychosocial care
- 5) NHS Scotland Journals@OVID
Search 1 terms: psychosocial and palliative care and rural; Search 2 terms: palliative care and psychosocial care.
- 6) AARP Ageline 1978 to October 2007
Search terms: palliative care and psychosocial care.
- 7) AMED (Allied and Complementary Medicine) 1985 to October 2007
Search terms: palliative care and psychosocial care
- 8) British Nursing Index 1994 to October 2007
Search terms: palliative care and psychosocial care
- 9) British Nursing Index Archive 1985 to 1996
Search terms: palliative care and psychosocial care
- 10) CINAHL - Cumulative Index to Nursing & Allied Health Literature 1982 to October Week 4 2007
Search terms: palliative care and support AND psychosocial OR psychosocial care
- 11) EMBASE 1996 to 2007 Week 43
Search terms: palliative care and psychosocial care
- 12) ERIC 1965 to September 2007
Search terms: palliative care and psychosocial care
- 13) HMIC Health Management Information Consortium November 2007
Search terms: palliative care and psychosocial care
- 14) PsycINFO 2000 to October Week 4 2007
Search terms: palliative care and psychosocial care

Once articles were identified the title of each article was read and abstracts were sought for relevant articles. Finally the full text of the identified articles were read where possible. During this process any articles that referred to paediatric care were rejected. Relevant literature was also identified from the Robert Gordon University library and other sources, such as Aberdeenshire Council.

As part of the project a search of current service provision across Aberdeenshire was also carried out. The database 'Grampian Caredata' was searched using the following terms:

- 1) Support groups, Aberdeenshire
- 2) Cancer
- 3) Non-Malignant Illness
- 4) COPD
- 5) Chronic Respiratory Failure
- 6) Multiple Sclerosis
- 7) Huntington's
- 8) Chest, heart and stroke
- 9) Dementia-Aberdeenshire
- 10) Heart Failure
- 11) Heart Disease

The internet search engine 'Google' was also searched using the following terms (only the first page of results was examined for each search):

- 1) Cancer Support Groups, Aberdeenshire, Scotland
- 2) Cancer, Aberdeenshire, Scotland
- 3) Non-Malignant Illness, Aberdeenshire, Scotland
- 4) Huntington's, Aberdeenshire, Scotland

Narrowing down the study

Initially the project's parameters were broad and ill defined. However as the project progressed decisions were taken in conjunction with the Steering Group to define the boundaries of the work more clearly. It was decided in December 2007 that the project should focus on a review of current service provision. The aims of this project would be to identify the services that currently exist to meet the needs of people with life threatening illness throughout Aberdeenshire, to locate the gaps in service provision and suggest how these gaps could be filled. Although the project would seek to identify the needs of people with life threatening illness this was only one aspect of the study. A decision was taken that the project would not tackle issues, such as which psychosocial interventions are the most effective or who should provide such services, in any great depth.

Therefore it was decided at this point to conduct research with professionals only. Although it is acknowledged that involving service users in research is good practice and would have been likely to have yielded interesting results a number of factors precluded the project from moving in this direction. Whilst questioning service users to ascertain what their psychosocial needs are and what services they would like to see to meet these needs could have provided interesting insights it raised too many ethical dilemmas. This project does not have the scope to offer service users any guarantee that the needs that they identified would be met and the services that they suggested would come to fruition. Therefore a situation might have arisen where expectations could have been raised, only to have been dashed.

Furthermore in order to have got a representative sample of service users' opinions a large number of service users would have had to have been questioned. The constraints on this project were such that questioning on this scale would not have been possible given the time and resources available. Therefore it was agreed at the Steering Committee that questioning of professionals only would be more ethically sound in this situation and would provide an adequate insight into the issues for the purposes of this particular project. However this does not close the door to research in the future, which does question service users directly about their needs and service delivery.

Study design

Study setting

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.

The research tools

A number of methodologies for data collection were considered and discussed with members of the Steering Committee. Initially attention turned to questionnaires

as a way of canvassing the opinion of a significant number of people. However it is argued by Gillham (2000) that

'questionnaire data are necessarily thin and do not help you understand or explore answers.' (p. 10)

Therefore a decision was made not to use questionnaires as the primary method of data collection, but instead to consider other methods of data collection.

According to Gillham (2000)

'the overpoweringly positive feature of the interview is the richness and vividness of the material it turns up.' (p. 10)

Similarly it is argued by Morgan (1998) that

'focus groups are fundamentally a way of listening to people and learning from them.' (p. 9)

Rich and vivid data and hearing the voices of stakeholders are two key components of this project. Therefore it was decided that face-to-face interviews with individuals and focus groups with key groups would be the most appropriate method of data collection for this piece of work.

Following this decision individual interview and focus group schedules were formulated (see appendices 2-6). After further consultation with members of the Steering Group Committee it was acknowledged that some interview and focus group schedules would need to be carefully focused, as some stakeholders had already indicated that they would only be available to interview for a limited period of time due to time and resource constraints.

Oppenheim (1992) highlights the importance of piloting research tools. Therefore a pilot was conducted with a worker who had been previously involved in palliative care in a neighbouring local authority. After this pilot the questions were further refined to take in the feedback from the pilot interview.

Recruitment

During the initial months of the project time was spent identifying stakeholders. These stakeholders were then contacted with an introductory letter and were kept up-to-date with the progress by a newsletter that was produced in December 2007. Once ethical approval was granted a list of people to interview and conduct focus groups with was drafted. Due to time and financial constraints it was acknowledged at this stage that only a certain number of people could realistically be interviewed. Therefore priority was given to people who come into regular direct contact with people with a life threatening illness, especially those with a non-malignant life threatening illness. This list was then agreed by the Steering Committee.

In the following months stakeholders were contacted by letter, email or telephone to ask if they would be prepared to take part in an individual interview or a focus group. A mutually convenient time was then arranged to conduct the interview or focus group.

Data collection

All the interviews and focus groups in this project were conducted by JK. All but one of the interviews was conducted face-to-face. The one interview that was not conducted in person was conducted over the telephone. Interviews and focus groups were conducted at a mutually agreed venue, which was usually the stakeholders' place of work to avoid travel costs and time to the interviewee. At the start of each interview a brief outline of the aim of the session was given and it was explained to the participant that the interview would be tape recorded and direct quotations may be used in the write up, although all responses would be anonymous. The same process was used for the focus groups.

Each interview and focus group was tape recorded. Wengraf (2001) argues that

'post interviewing debriefing is central to your understanding the interview and to advancing your professional competence....This record of interview experience and what memories, ideas, anythings, it stimulated

in you is vital for your subsequent analysis of this particular interview.'
(p. 142)

Therefore after each interview and focus group time was taken to reflect upon it and any initial thoughts or impressions were noted. At this stage the tape was also checked to ensure that the interview had been recorded and any hand-written notes were read to verify that they were legible.

Analysis

Miles and Huberman's (1994) qualitative analysis approach informed the analysis of data collected by this project. Rather than adhering to a pattern of completing data collection before undertaking an analysis of the data collected, early analysis of each interview and focus group was undertaken. Following each data collection session, the tape recorded interview or focus group was listened to and detailed notes, including quotations, were made. Themes and codes were then generated as part of this process. To ascertain that there were not gaps in the coding process, SL, also reviewed a selection of the transcriptions.

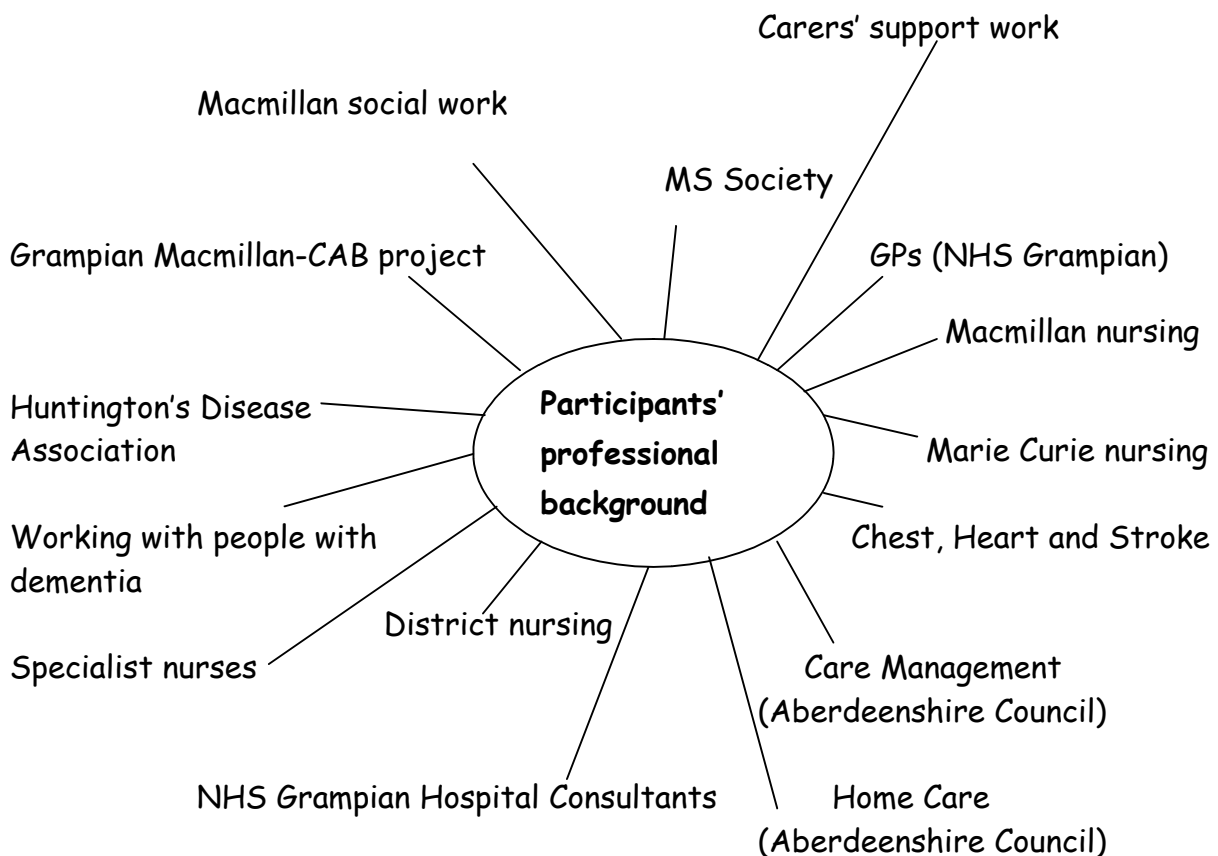
Following Collie and Lawton's (2006) data display, codes were then entered into a summary grid and further collapsed and grouped. At this point the final summary grid was created, which included an illustration based on quotations identified in the coding process.

FINDINGS

Please note that throughout the findings section participants are described in the feminine form. This does not denote the gender of the participants, as both male and female workers took part in this project; rather it is to ensure that all responses are anonymous.

The project's participants

Participants' professional background



(Figure 1)

Participants were drawn from a wide range of backgrounds for this project (figure 1) including those who worked with predominantly with people with malignant illness and those who worked predominantly with people with a specific non-malignant illness, as well as those who worked with both group of people. Although participants were not asked directly to classify themselves as specialists in palliative care or generalists whose work involved an element of palliative care, a number of participants commented on their role in their responses. The majority of those who indicated whether they fulfilled a specialist or generalist role identified them self as generalists.

One group of participants who were interviewed for this project did not view their role as coming under the remit of palliative care. According to one worker from this group

'We don't tend to get involved with people who are dying. That's not our role.'

A number of participants involved in this project managed and/or supported staff as part of their remit. This had an impact on some of the answers that they gave, as they were able to draw not only on their own experience of working with people with a life threatening illness, but also on the experiences of the staff that they managed and/or supported.

Tasks project participants do

Throughout the interviews and focus groups participants mentioned a variety of tasks that they were involved in as part of their work with people with a life threatening illness. The most mentioned task was 'support.' This involved supporting the person with a life threatening illness and, in many cases, the carer of a person with a life threatening illness. The term 'support' covered a large range of activities, including emotional and practical support, which is illustrated by the following responses:

According to one worker she offers

'the opportunity for someone to explore their needs, articulate them and identify them.'

During a focus group another participant commented that they

'see the silly things like 'who's going to look after my budgie?' which may be very important to someone. They may not mention this in hospital.'

Another worker drew attention to the weight of responsibility they felt of providing practical support, such as the setting up of care for someone who is in the palliative stage of their illness.

'If an individual wants to be at home, an awful lot of weight falls on our shoulders.'

The second most mentioned task, by those involved in the project, was 'referring on.' Participants appear to refer on to others to meet needs that they are unable to meet or to access services that they are unable to provide.

One worker described her role as the 'link' by

'putting people in contact with and referring people to the different figures.'

Another participant saw it as part of their role to make service users aware of what was available in the locality.

A number of those involved in the project mentioned that another task that they did was 'talking with people' or providing some sort of counseling to people with a life threatening illness. By talking with people, participants were able to encourage service users to look to the future and consider the issues that may arise. Some workers were also involved in providing counseling and advice to those caring for a person with a life threatening illness.

One worker commented that it is

'relatively normal to talk about and encourage people to talk about concerns about advancing illness and end of life care.'

This view is supported by another worker who stated that

'we are able to give somebody the time to be able to discuss their fears.'

'Care' was mentioned frequently during interviews and focus groups. A number of participants were either involved in setting up care for someone with a life threatening illness or undertook physical care and nursing tasks as part of their remit. Caring for people with a life threatening illness appeared, at times, to go beyond the completion of purely physical tasks, which is illustrated by the following responses:

One group of participants commented during a focus group that they

'use physical interventions to get to know people and to build up relationships.'

Another worker commented that

'when carers are in doing personal care they intentionally and perhaps unintentionally will build a relationship, reassure the person, which will help the person.'

There were also a number of other tasks that were mentioned by participants during the interviews and focus groups. These included assessment, review, advising and educating other professionals and problem solving. However each of these responses was only mentioned by one worker.

Definition of psychosocial care

What is psychosocial care?

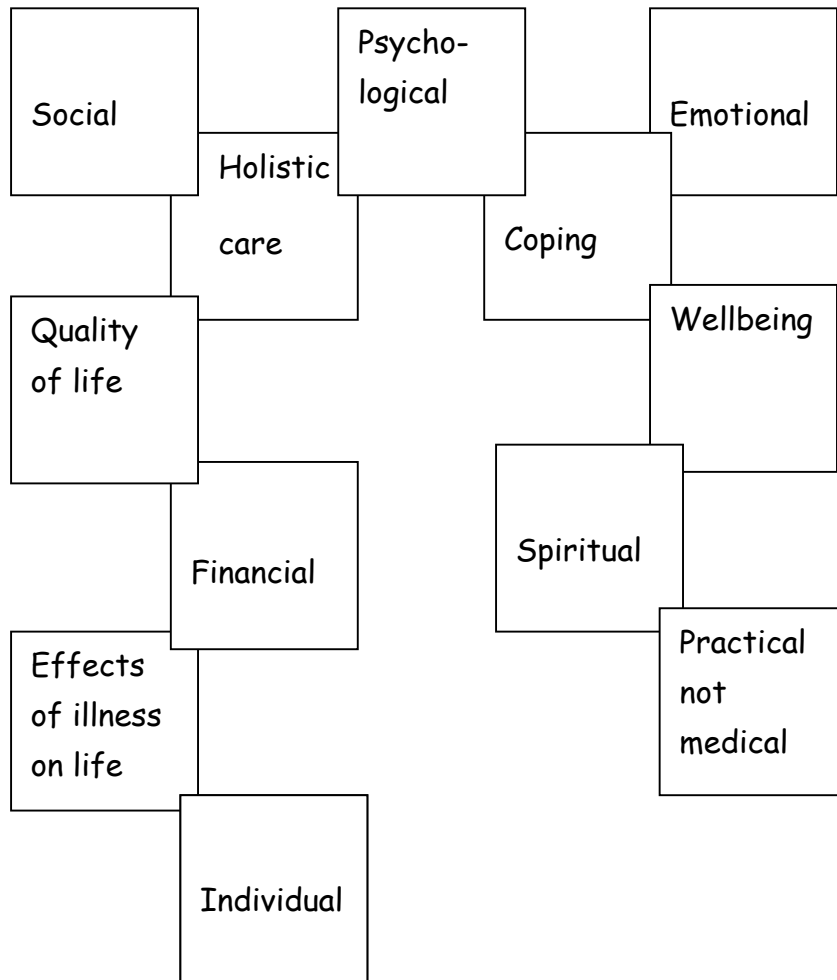


Figure 2

Difficult to define?

When participants in this project were asked to define 'psychosocial care' it was apparent that this was not an easy task. Before giving their answer, the vast majority of participants looked blank, hesitated, said um, um or laughed nervously. This uncertainty was put into words by some people.

One participant responded to the question by saying

'I don't know.'

Another worker replied

'that's a big question isn't it?'

The following answer summarizes the general response to the concept of 'psychosocial care:'

'It's difficult to define, difficult to classify and therefore difficult to do anything about.'

Definitions of 'psychosocial care'

No one definition of 'psychosocial care' emerged from the responses given by participants in this project. Instead, as figure 2 demonstrates, a number of aspects, which when put together appear to give a more complete picture, were each mentioned a few times by those involved. One participant articulated this in their answer, arguing that 'psychosocial care' is

'multi-dimensional, so one individual may not feel as if it is all their job to sort out.'

Therefore from the responses of those involved in this project it appears that the term 'psychosocial care' is a compound concept rather than an absolute term.

Although no participants mentioned all the identified aspects (figure 2) in their answer, those who took part in the project tended to combine a varying number of the aspects illustrated in figure 2 in their definition of 'psychosocial care.'

A number of people described 'psychosocial care' as a sum of its parts, by highlighting the psychological and/or the social aspects of the term. One participant described 'psychosocial care' as 'anxiety management, whereas another suggested that it was 'psychological support.'

When discussing the social aspects of the term one participant argued that it is the

'social aspects of illness that effects them and their family.'

Similarly another person thought that

'Psychosocial care looks at the social factors that impact on a person's sense of self'

A few participants explicitly combined aspects of the term, arguing that

'it is the psychological wellbeing and the social wellbeing of the individual-putting the two together.'

The emotional aspects of 'psychosocial care' were also amongst the most identified meanings of the term. One participant commented that the term can be partly understood as the

'emotional aspects of illness that effects them and their family.'

Whereas another person described this aspect of 'psychosocial care' as

'encouraging individuals to show feelings and name their losses; validating their feelings.'

'Psychosocial care' was also described by some participants as treating people holistically. One person who took part in the project argued that 'psychosocial care' is

'something that encompasses most things that my patients require, something that they do not all get..... I cannot say it is part of one thing. It is important that we see these things as a whole rather than start to divide them up.'

When asked to define 'psychosocial care,' some participants raised the notion of 'coping' in their answer. According to one focus group 'psychosocial care' is about

'how someone is coping with their illness-some people will cope better, their resilience is better.'

Another group highlighted carers in their answer, arguing that 'psychosocial care' is

'looking at how the family is coping and the support that they need to continue to do that.'

Wellbeing was also mentioned by some participants in their definition of 'psychosocial care.' One person viewed 'psychosocial care' as being about the

'wellbeing of the individual and their family-the one interacts with the other.'

Similarly one group suggested that the term was

'about wellbeing aspects, about how someone feels in themselves, and how they feel about their situation.'

Financial concerns, including benefits, were mentioned by a few people when they were asked to define 'psychosocial care.' Similarly spiritual needs were also mentioned by a few people who took part in this project. One worker commented that 'psychosocial care' should encompass the

'spiritual, not religion, the big questions of life, which can effect someone's psychological wellbeing.'

Some participants in this project discussed other aspects of 'psychosocial care,' such as the effect of an illness on someone's life and the notion of quality of life. One person argued that

'taking away some of the stress helps people focus on the time they have left.'

Similarly another participant thought that one meaning of 'psychosocial care' was

'working with people.... there can be a future, they can have potentially a good quality of life for a period of time.'

The notion that 'psychosocial care' is practical not medical was mentioned a couple of times by people who took part in this project, as was the idea that the term was to do with the individual. A handful of other suggestions were also made by participants, such as the idea that 'psychosocial care' is reflected in complex casework. However each of these was only mentioned by one person and therefore has not been included in the definition of 'psychosocial care' illustrated by figure 2

How do the responses given in this project tie in with the definition of 'psychosocial care' identified at the start of this project? A search of the relevant literature highlights the difficulty that there is in defining 'psychosocial care.' No one definition appears to emerge as the accepted understanding of what constitutes 'psychosocial care.' This is borne out by this project and is perhaps one of its most significant findings. Throughout the project it was apparent that participants were hesitant and, in many cases, initially felt uncertain about the meaning of 'psychosocial care.' However most people did go onto provide a definition of 'psychosocial care' and an understanding of the term did emerge.

At the start of this project a definition of 'psychosocial care' based on Shipman et. al.'s (2002) definition was agreed by the steering group committee (see page 13). A number of similarities can be identified between the agreed project definition and the way in which participants defined 'psychosocial care.'

The spread of answers given by project participants captures the nebulous nature of this term. Shipman et. al.'s (2002) definition and the suggestions made by the participants of this project indicate that 'psychosocial care' does not appear to be an absolute term. Rather 'psychosocial care' seems to be a concept that is made up

of a number of component parts, of which all or only some may be applicable at any one time.

Psychosocial needs of people with a life threatening illness

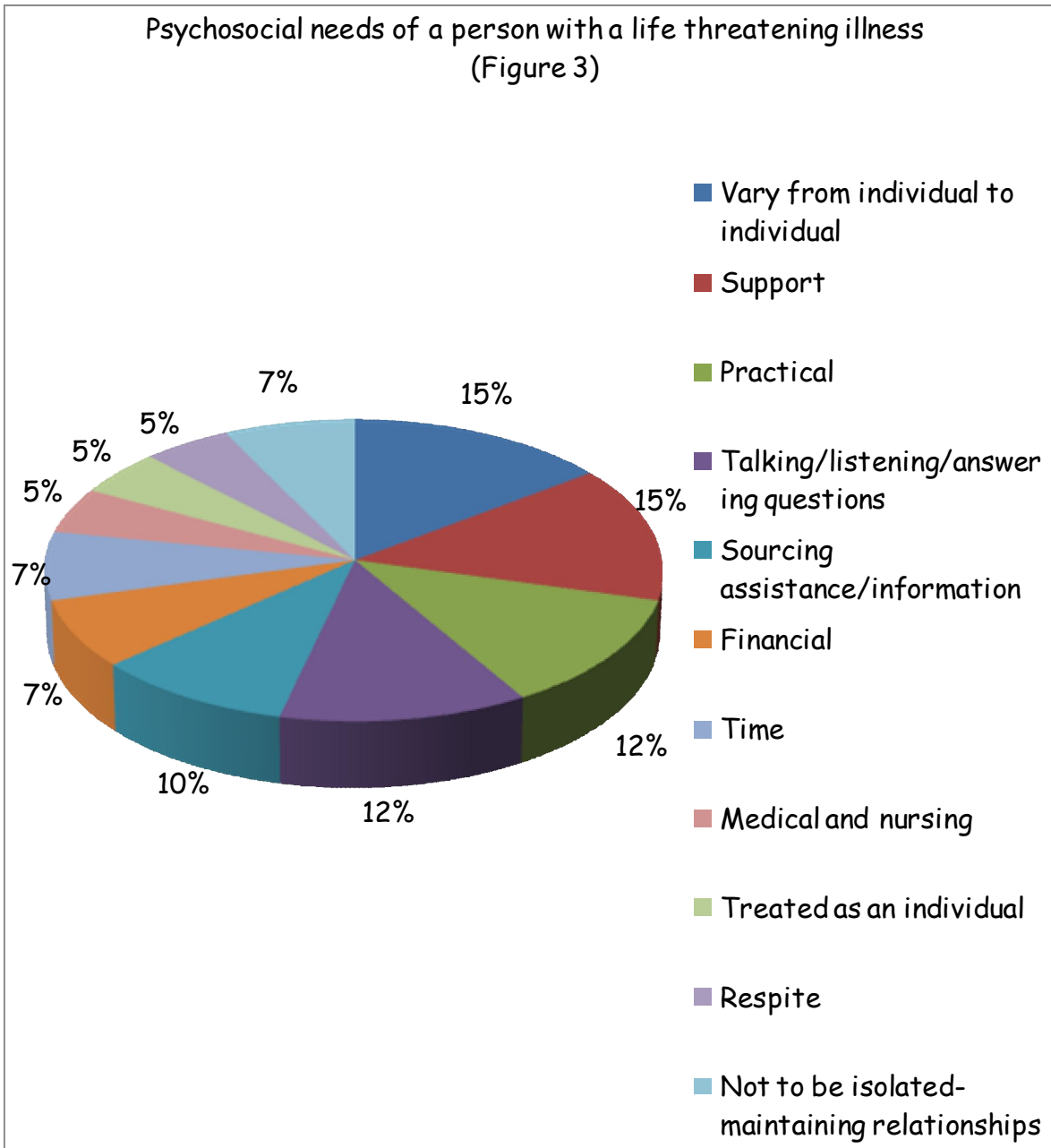
As part of a discussion of the psychosocial needs of people with a life threatening illness, a number of general comments were made. One participant cautioned that

'psychosocial needs may not be understood or expressed by the person, their family or those caring for them.'

Other people involved in this project discussed issues, such as the impact of communication between professionals and the influence of family structure on a person's psychosocial needs. However the most mentioned general comment was that psychosocial needs vary from individual to individual. This view is summarized in the following response: according to one group, that took part in the project, psychosocial needs are

'unique to each patient we meet. Not one size fits all. We go into farmers who do not wish to discuss anything. They are in total denial and that is how they are coping and you have to respect that..... There are some people who very much want to speak about it and derive benefit from groups.'

However, whilst it was acknowledged that needs vary from individual to individual participants were also able to identify some common themes.



The most mentioned psychosocial need, as illustrated by figure 3, is support. According to one participant

'people need generalist support from health and social care teams in the community and there should be specialist services to access at certain points.'

However the concept of support appears quite vague and participants' descriptions of what support means often touched on other needs, such as practical needs. Therefore the notion of support as a need appears to overlap with a number of the other needs that were also mentioned separately by those who took part in this project.

Practical needs were highlighted by a number of participants. Assistance with personal care and activities of daily living were the most mentioned practical needs by participants. However the practicalities of daily living, such as money, housing and mortgage loans were also mentioned. The importance of getting things in order was highlighted by one person who commented that people with a life threatening illness

'are more concerned about who they are leaving behind and how they can fix things for them.'

A number of participants discussed the need that people with a life threatening illness have to talk, ask questions and be listened to. According to one person who took part in this project

'there may be lots of things that a person wants to say but cannot say. It is having the support to do this.'

This view was supported by participants in a focus group who argued that

'people need to feel safe enough to ask questions that they may be afraid to ask because they think they are stupid.'

There was also a feeling that people needed to know that someone was taking an interest in them and that they could talk to someone outside of their family, if they needed to.

Sourcing information and assistance was also considered to be another psychosocial need of people with a life threatening illness by some people who took part in this project. In the opinion of one focus group

'people need to know where to go when they need help.'

Furthermore according to another participant people with a life threatening illness

'want to know about their illness as much as possible; the course of the illness, the side effects of medication.'

Therefore professionals need to know where people can go to get the assistance and information that they require.

Throughout this project the concept of 'time' was raised in relation to a number of different issues. When asked to identify the psychosocial needs of people with a life threatening illness, a handful of participants highlighted the need of people to have time, space and understanding. This is reflected in the response of one worker. According to her when someone has recently received 'bad news' they

'do need to know that they are not abandoned, but they might not need an overload of people. It's a balance.'

Similarly participants in one focus group argued that

'people need the time to discuss, talk about things and read through things at their own leisure. People are given a lot of information and they may not have time to process it psychologically. [It is about] giving people the opportunity to process things, giving people the chance to talk about the same thing over and over again until they have processed it. People may need to do this with a few people.'

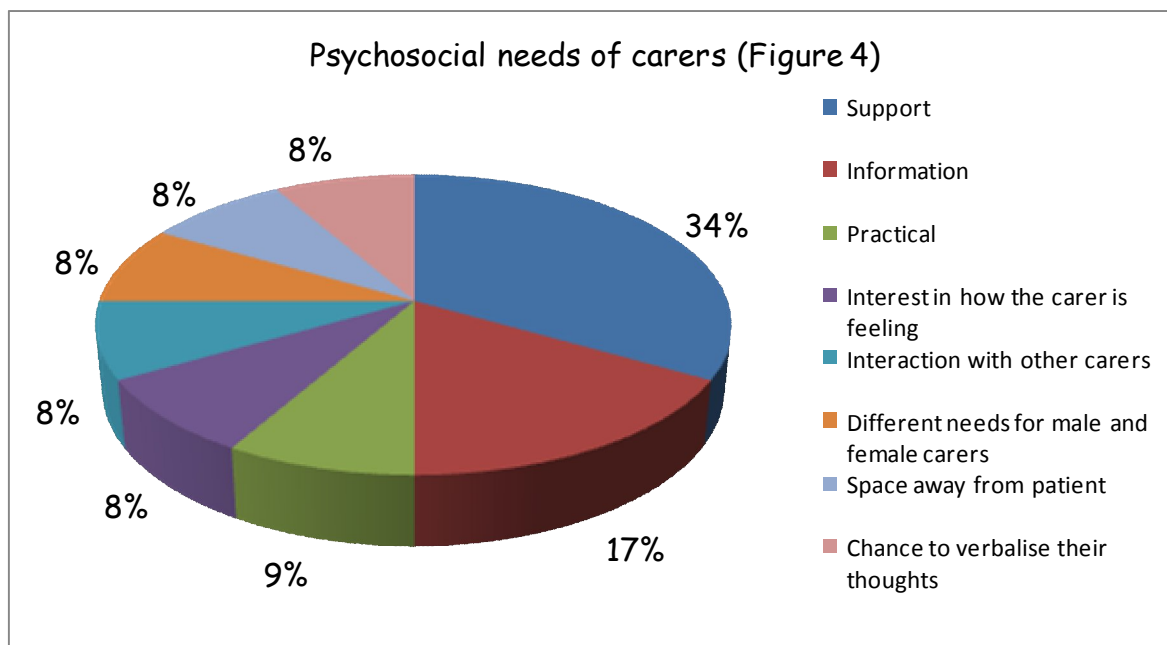
The psychosocial need of being able to maintain relationships and to have contact with others, so that they are not isolated was also highlighted by participants in this project. According to one person, some people with a life threatening illness need help to

'maintain relationships. [It can be] difficult for families to do this. They don't know how to respond.'

A handful of participants also identified the financial needs of people with a life threatening illness. It was acknowledged that worries over how to meet mortgage repayments, claiming benefits and dealing with debt can all cause distress for those involved. Housing, empathy and spiritual needs were also all mentioned, however each one was only identified by one person involved in the project

Interestingly when asked to identifying the psychosocial needs of people with a life threatening illness a couple of participants mentioned medical and nursing needs. Shipman et. al.'s (2002) definition of psychosocial care explicitly excludes 'needs for clinical care' as part of the meaning of the term. Therefore, whilst medical and nursing needs have been identified as psychosocial needs by a couple of people involved in this project, it is difficult to include them in an understanding of the psychosocial needs of people with a life threatening illness, as they do not seem to fit with the agreed definition of psychosocial support for this project.

Psychosocial needs of carers of people with a life threatening illness



Although people were asked to discuss the psychosocial needs of people with a life threatening illness and those of their family, a much smaller number of participants commented on what the psychosocial needs of carers are in comparison to the number of people who discussed the needs of the person with a life threatening illness. Nonetheless it is still possible to create a picture of what the needs of carers might be (figure 4). Similarly to the needs of people with a life threatening illness, the most mentioned psychosocial need of carers of people with a life threatening illness is that of 'support.'

Different aspects of 'support' were highlighted by those involved in the project. A couple of workers commented that one of the psychosocial needs of carers is support, but did not elaborate any further on this. Whereas a couple of other participants provided more detail about what they meant by 'support.' One participant identified that carers need emotional support. According to her, carers need emotional support above practical help as

'People often assume, and they assume wrongly, that it is the practical side of caring that is quite difficult. From my experience I think it is the emotional impact of caring that has the greatest effect on carers.'

Another worker elaborated on why carers need support. In her opinion carers need support, as having a life threatening illness effects the whole family.

In contrast to the opinion of the participant who emphasized the emotional support needs of carers, another person who took part in this project did highlight the practical needs of being a carer, as she argued that

'practical needs should be taken care of, so families do not have issues with [things like] money, Mum needs help with a bath. [We should] smooth the way for them.'

The need for information was mentioned by a couple of participants when discussing the psychosocial needs of carers of people with a life threatening illness. One person involved in this project was of the opinion that

'people look for timescales; people want to know how long they will be in this caring role.'

This view was supported by another participant who emphasized the need for carers to have information so that they have some sense of feeling in control.

Space away from the patient, an interest in how they are feeling, a chance to verbalize their thoughts and interaction with other carers were each mentioned by one participant as other psychosocial needs of carers of people with a life threatening illness. Interestingly one person involved in the project also argued that the psychosocial needs of male and female carers are different. According to this worker the perception of society is that

'It is okay to be female and give up your work to look after someone, but being male and doing that, that is still not socially acceptable.'

This, therefore, has an impact upon the psychosocial needs of male and female carers and, in many cases, makes them different.

In addition to identifying the psychosocial needs of carers of people with a life threatening illness, some participants also made general comments about the experience of being a carer. The overwhelming impression from these comments is that being a carer is difficult. This is summarized by the comment of one person who took part in this project. In her opinion

'people do not realize how difficult caring can be, how restrictive it can be. Few carers present saying 'oh I am so happy at taking on the carers' role,' most present by admitting that they did not know how hard it was going to be.'

According to another participant the focus is always on the patient, not the carer, which means that the carer can feel voiceless and pushed aside. Participants also discussed the losses that carers face.

Which psychosocial needs are met by participants and the projects that they are involved in?

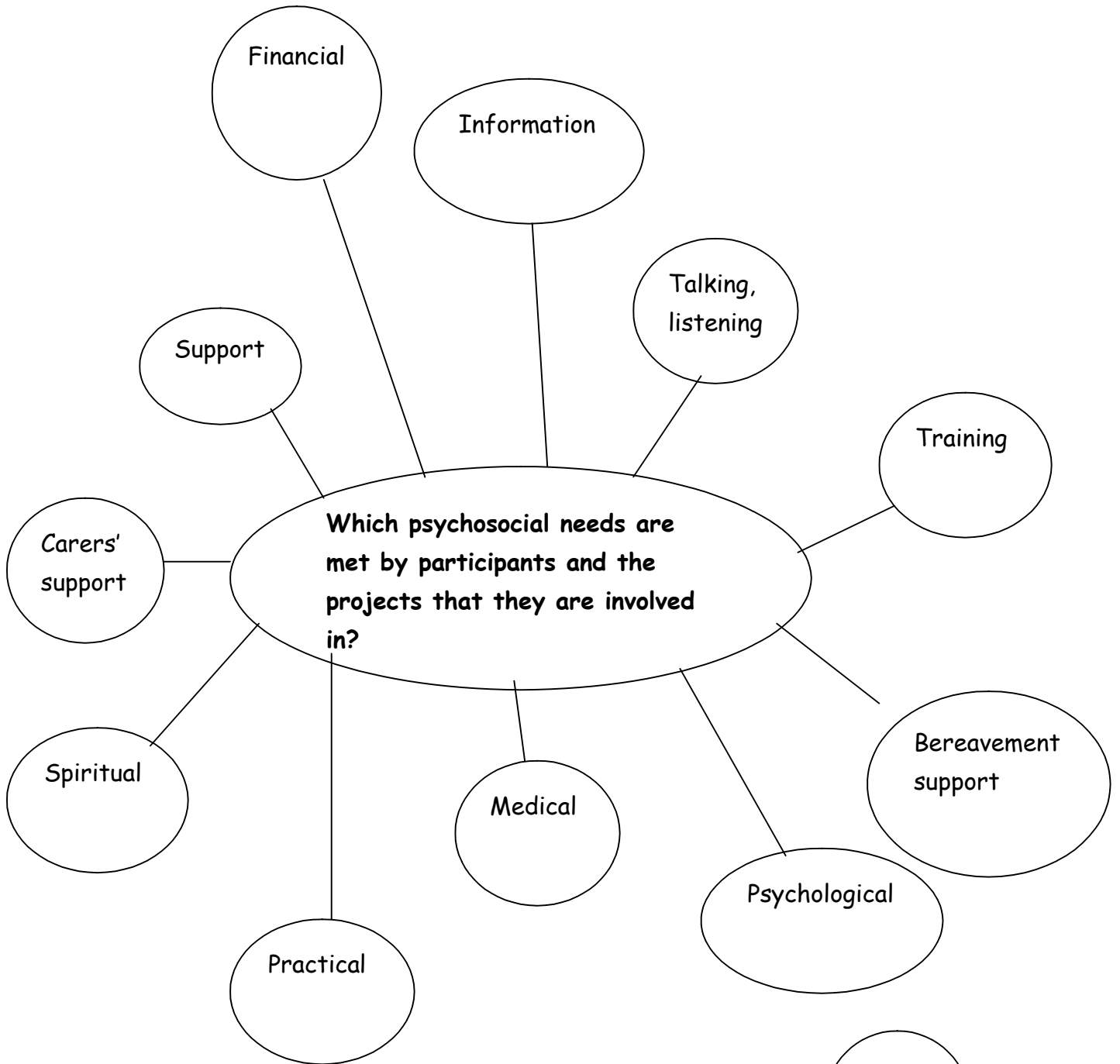


Figure
5

As illustrated by figure 5 when asked to identify which psychosocial needs they met, participants identified a broad range of needs. A number of these needs correlate with the aforementioned psychosocial needs of people with a life threatening illness and their family.

Interestingly, although only a handful of participants actually identified the psychosocial needs of family members of a person with a life threatening illness when discussing psychosocial need, the most mentioned psychosocial need met by participants, or the projects that they worked on, was that of carers' support. One person involved in this project stated that

'we are available for carers. We offer some counselling for their loss, explain the process of what is happening.'

Similarly another participant described their role in meeting carers' support needs arguing that

'the carers are under just as much stress. [We] include them in the conversation; make sure they are okay.'

A further person involved in this project stated that

'often we do not provide a lot of support but it is a big thing for the family to know that we are there.'

Information and advice was the second most highlighted psychosocial need that participants thought they, or the project that they worked on, met. Workers met the need for information and advice in a number of ways including providing people with a life threatening illness with information on their illness and signposting other services that could be accessed.

Financial needs were also amongst one of the most mentioned needs met by people involved in this project. A number of participants help people with a life threatening illness to apply for benefits. Interestingly a couple of workers also mentioned that they have been involved in encouraging people with a life threatening illness to update their will.

A handful of participants stated that they met people's support needs and people's need to talk and be listened to. According to one participant she meets people's needs by talking

'on a one-to-one basis about what their concerns, feelings, problems are and do my best to address these but usually that involves the other members of the team'

Similarly another person involved in this project identified that they give people

'the chance to discuss their problems, reassurance that they will cope with things as they arise.'

Bereavement support was identified by a couple of participants as a need that they met. Similarly practical care and training were also highlighted by a couple of people involved in this project as needs that they met. The following needs were each identified as needs they met by only one participant each: psychological needs, spiritual needs and medical needs.

Although in a discussion of psychosocial needs met by participants it was only mentioned by one person involved in this project, it is interesting that medical needs were highlighted at all. It is apparent from this that it is very difficult to draw a line between what should be classed as clinical and what should be seen as coming under the remit of psychosocial care. In this case the participant linked the provision of medical care to enabling people to be able to live more independently. Therefore it is difficult to judge as to whether this should be considered to be a psychosocial need that the worker meets or a clinical need, which according to Shipman et. al.'s (2002) definition does not fall under the realm of psychosocial care.

It is important to note that some of the needs that participants mentioned (see figure 5), which they or the project that they are part of meet, may not be met across all areas and illnesses. A number of people who took part in this project only work with people with a specific illness and/or in a certain area of Aberdeenshire. Whilst in some cases patients with an illness that does not come under the remit of one worker will fall under the remit of another, this may not always be the case.

However specific areas of unmet psychosocial need were highlighted by some people who took part in this project. Care was identified as one area of unmet psychosocial need. One participant commented that the care that is provided does not always meet people's individual needs as according to her

'a big thing for clients is that no-one will cook for them now; it is frozen meals or nothing. It is a big thing if someone wants a home cooked meal in the last stages of life and cannot.'

Interestingly place of death was also identified as an unmet psychosocial need by participants. According to people who took part in this project a significant proportion of people still end up dying in hospital, which in the words of one participant is

'not a place where holism is very easily found.'

Housing and spiritual needs were also acknowledged by one person each as psychosocial needs that go unmet. In the opinion of one participant

'I don't think we are good at doing spiritual; I don't think spiritual needs are as well met.'

Throughout the project it was apparent that there was a perception amongst those who took part that the psychosocial needs of people with a non-malignant illness were unmet more frequently than those of people with a malignant diagnosis. This is captured in the answer of one participant when asked whether psychosocial needs go unmet:

'I suspect there are a number of people living in the community with advanced illness. I think probably cancer patients get a higher level of intervention and support, perhaps than people with non-malignant illness. I don't know, to me it is a bit of an unknown. I think that is probably true.'

When asked why she thought this was the case she replied that

'the priorities are seen as providing meals, personal care when there are limited resources. I do not know how much time there is for conversation, letting people know they can talk if they want to talk about things.'

When she was asked if she thought that this level of support and communication was provided to cancer patients, she replied

'generally.'

Carers were also recognized as having unmet psychosocial needs. One person who took part in this project was particularly gloomy in her analysis of whether any psychosocial needs of carers of people with a life threatening illness go unmet. In her opinion

'I think all of them do. I know that sounds a horrible generalization, but I think that from the bottom of my heart.'

However this did not seem to reflect the general opinion of those who discussed the unmet psychosocial needs of carers. Instead people highlighted particular unmet needs. Respite care was identified as being an unmet psychosocial need of carers by some participants. According to one person who took part in this project

'respite care is few and far between.'

This view was supported by another worker who commented that there is

'no suitable respite....[There are] limited places for younger people.'

Bereavement care was also recognized as an area of unmet psychosocial need. This was summarized by one participant, who argued that

'after someone has died the agencies pull out and the person who is left is left alone.'

Another person involved in this project argued that carers should be supported for as long as they need to be after their caring role has ended, as they may have coped with the situation well whilst they were caring for someone, but they may find it difficult when the person has passed away and they are no longer in the caring role.

Another significant area of unmet psychosocial need for carers is that of information. According to one participant

'sometimes people are left to look for information. Sometimes they find it, and sometimes they do not find it and then they ask me. I do not feel the best person to ask, as I am not an expert.'

Why do the psychosocial needs of people with a life threatening illness go unmet?

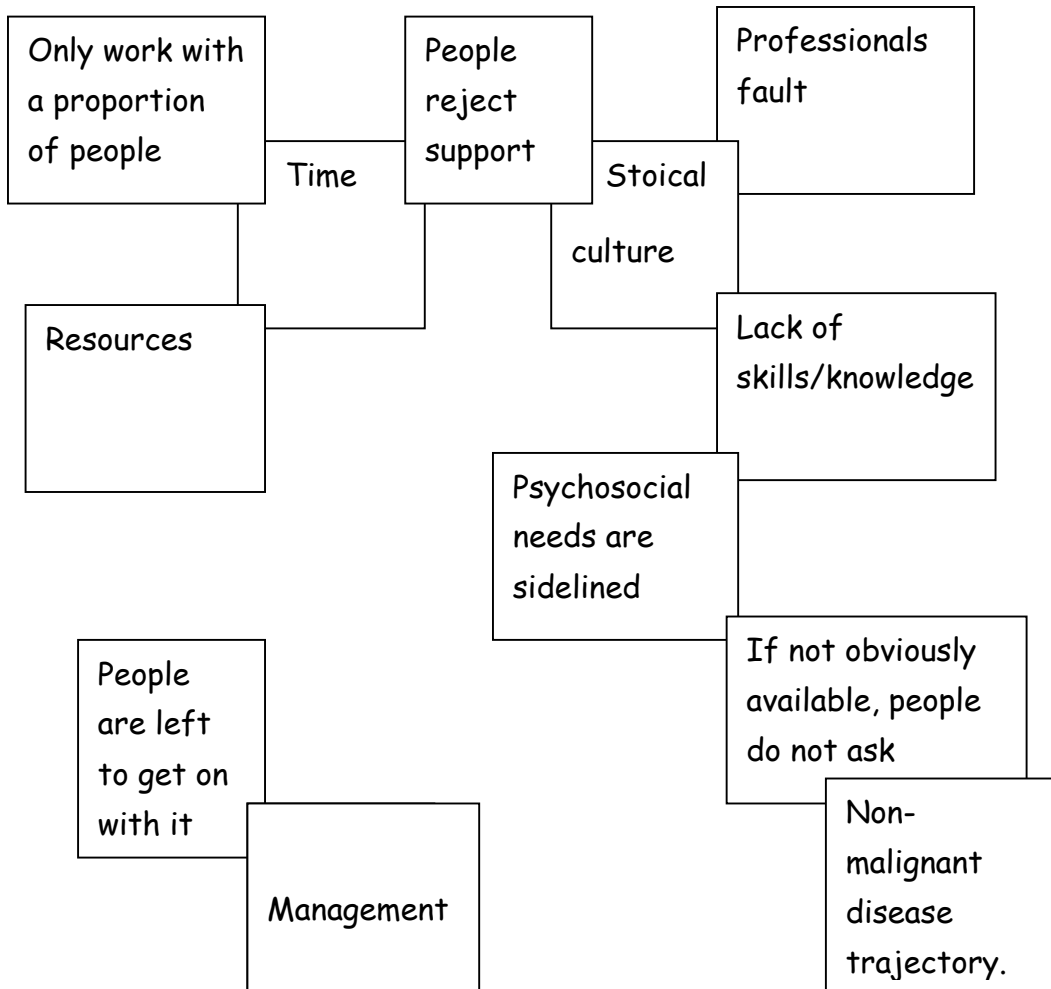


Figure 6

As illustrated by figure 6 a broad range of reasons were suggested by participants when discussing why psychosocial needs of people with a life threatening illness go unmet. One of the most frequently mentioned reasons why people's psychosocial needs went unmet was resources. This was summarized by one person who stated that

'some psychosocial needs do go unmet. It comes down to a lack of resources.'

Linked closely with resources is time, which was cited as another reason why the psychosocial needs of people with a life threatening illness go unmet. According to participants in one focus group

'psychosocial needs could go unmet either because the service isn't there or because people would struggle to be able to meet those needs in the sense of having enough time to give to the person.'

This view was supported by another worker who, when asked if any psychosocial needs go unmet, answered

'I think the answer to that question is yes and a lot of that relates to time.'

A number of people who took part in this project were also of the opinion that psychosocial needs of people with a life threatening illness go unmet because, as a worker, they only work with a proportion of people. As part of their remit, a number of participants only work with people with a certain illness or with people from a particular area of Aberdeenshire. Therefore it appears that it is possible for some people to fall through the net and not have their psychosocial needs met.

According to one worker she tends to only be involved

'with more complex cases. These people tend to have a high level of contact with professionals.....[Therefore] for other people who are

not seen as complex, they may not have access to the same psychosocial support.'

Similarly another participant, discussing the limits of her remit, conceded that

'we don't see everyone, [it] depends on where someone lives, and depends on who their primary care team is.'

Although it is important to highlight the influence of the limit of professionals' remits upon whether the psychosocial needs of people with a life threatening illness are met, some people who took part in this project were also keen to point out that sometimes the psychosocial needs of people go unmet because people decide to reject support. Furthermore the impact of the stoical culture of Aberdeenshire was also acknowledged as having an influence upon whether psychosocial need is met.

According to one participant

'one of the difficult things is when people do not accept services, they can only be offered.'

Another worker reflected that people who are referred to her are not always ready to meet her. On these occasions she is left asking who follows up these people and ensures that their psychosocial needs are met?

The influence of north-east stoical culture was summarized by one participant who argued that the

'stoical culture up here- pride, upbringing, means that people will not complain and reveal problems because it is not the done thing.'

Therefore people's psychosocial needs can remain unmet as they soldier on without assistance. Professionals have a tightrope to walk in such situations, as the same worker goes onto say that

'you may need to dig, but you need to be careful not to cause upset or be seen to be prying.'

A number of participants conceded that on occasions it can be a professionals' fault that people's psychosocial needs are not met. In the opinion of one person who took part in this project the psychosocial needs of people with a life threatening illness can go unmet because there is a

'hesitancy amongst care professionals to discuss issues, such as where someone would like to die.'

Psychosocial needs also go unmet because, in the words of one participant,

'there is also the thing about people not thinking it is their role, even within a multi-disciplinary team. No-one may think it is their role to address these sensitive issues, so they are left.'

Professional may also lack the skills and/or knowledge to meet people's psychosocial needs, which can result in them going unmet. According to participants in one focus group

'if you don't know what is out there or there is not something out there then you make do. You either skirt around the issue or you try to do something about it yourself. You may miss things out because you don't know about them.'

In some situations workers suggested that psychosocial needs are unmet because people are left to get on with it. A couple of participants were able to recall times when they knew of a person with a life threatening illness who, in their opinion, did not receive the assistance that they should have done. The suggestion was also made that if people do not know what is available then they do not ask and, therefore, do not receive so their needs go unmet.

There was also an acknowledgement by a few participants that psychosocial needs of people may go unmet because they are often sidelined, as other aspects of palliative care take precedence. According to one person who was involved in this project the

'physical always seems to take over. The psychosocial side of things is less well done.'

Although only mentioned by a handful of participants, there was a strong feeling, amongst those who did discuss it, that management was one reason why the psychosocial needs of some people with a life threatening illness go unmet. According to participants in one focus group

'management look at things differently [to those on the frontline].'

There was a feeling amongst workers that the service that they were providing was a task focused service. Therefore whilst individual professionals appear to place importance on things like building up relationships with individuals, which sometimes involves being, as much as doing, the perception amongst workers is that only the doing is valued by those in authority, as it can be more easily measured.

A number of other reasons, such distance, the influence of family and a decline in social conscience, were also given as explanations as to why psychosocial needs of people with a life threatening illness go unmet. However each of these were only mentioned by one participant.

Some workers also drew specific attention to the reasons why the psychosocial needs of people with a non-malignant life threatening illness go unmet. According to participants who commented on this the uncertain disease trajectory of many non-malignant conditions had a significant impact upon when support was provided to someone with a non-cancer diagnosis. In the opinion of one participant the

'problem with non-malignant conditions is that there is a less clear trajectory-people can get better when you think that they are going to die.'

Similarly another person who took part in this project commented that

'the difficulty with some of these non-malign illnesses is deciding at what point you go from trying to cure the patient to purely palliative care. [It is] very much a judgment call.'

Service provision

A number of people who took part in this project raised the issue of multi-disciplinary working when discussing service provision. Multi-disciplinary working, when mentioned, was spoken of in a positive light and was seen as an important factor in providing a good standard of holistic care to people with a life threatening illness.

However one of the most highlighted aspects of service provision by participants was the inequalities that exist in the system. A considerable number of workers drew attention to the variable service provision that is perceived to exist across Aberdeenshire and to the different referral processes in operation.

In the opinion of participants in one focus group

'We are better off here than a lot of places....I think we are quite well provided for, I don't think we have any major problems. We are usually able to find something.'

Whereas workers in another focus group were of the opinion that their region of Aberdeenshire was 'left out,' as other areas of the local authority had access to more resources.

According to the feedback gathered from participants there appears to be variation in the referral process for different areas of Aberdeenshire and/or different life threatening illnesses. This view was summarized by one worker who commented that it

'depends on the referrer's awareness of what services are available as to whether someone will be referred on.'

There was also a strong feeling amongst some people who took part in this project that service provision is 'haphazard' and structure is lacking. In the opinion of one participant

'it is all haphazard, there is no cohesive overview of psychosocial needs and any attempt to address them at a strategic level tends to be as and when discovered.'

This view was supported by another worker who commented that

'structure is lacking. Links, [which benefit service provision], are there through personal experience.'

This has an effect on service provision as

'with some patients there will be all professionals trying to meet psychosocial needs, [whereas with] others it may be missed out. [There] needs to be more clarity over who does it and when they do it and when you step in and out.'

Service provision

Please see appendix 7 for a full record of service provision.

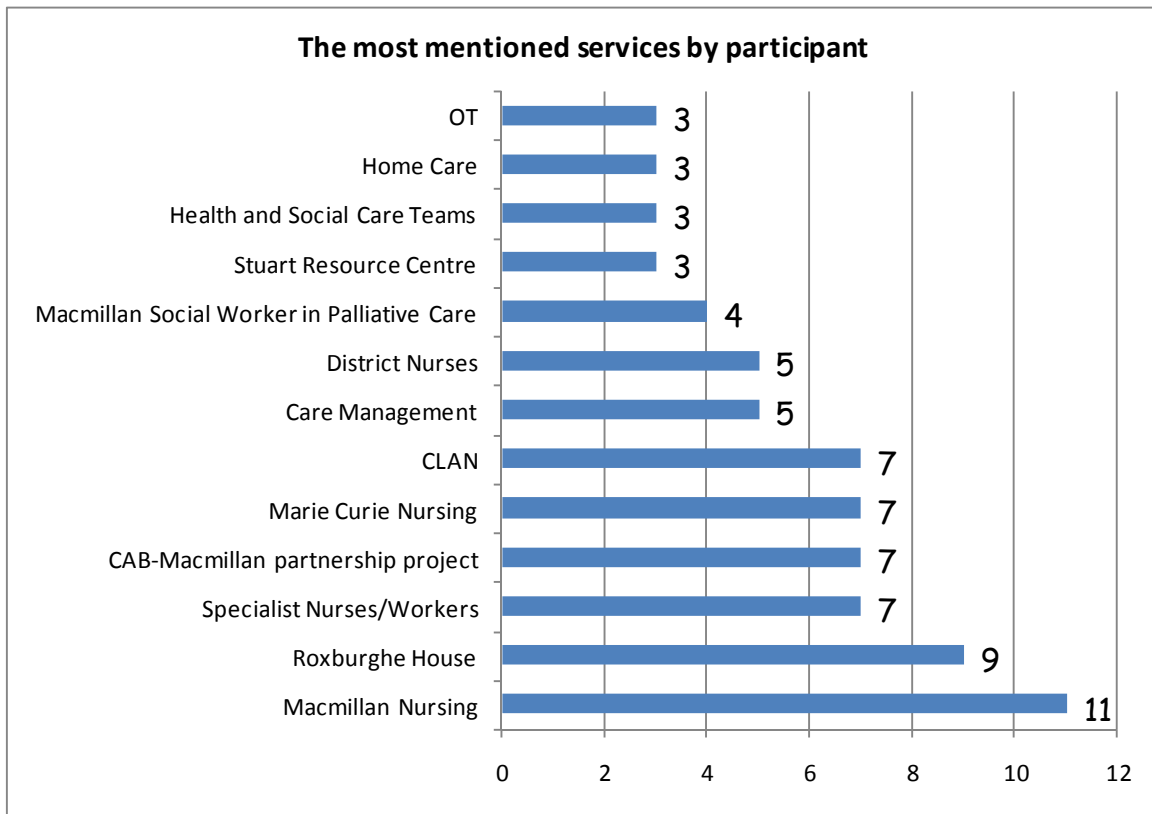


Figure 7

Whilst appendix 7 lists a wide range of services across Aberdeenshire, only thirteen services, illustrated by figure 7, were mentioned by three or more participants. All the other services that are recorded in appendix 7 were either only mentioned by one or two people or were not mentioned at all and were identified by the author.

Although the majority of services listed in appendix 7 can be accessed by both people with a malignant and a non-malignant life threatening illness, five out of the

top six most mentioned services, as illustrated by figure 7, are either exclusively or predominantly for people with cancer. Moreover these services are high profile and reach across the whole of Aberdeenshire. (It should be noted that the constitution of Marie Curie has recently been changed to include more people with non-malignant illnesses, however at present the majority of their caseload continues to be people with cancer. Similarly whilst there are occasions when Macmillan nurses will undertake work with people with non-malignant conditions, the majority of their caseload is with people with cancer).

Those services which either exclusively or predominantly serve people with non-malignant illnesses, such as the Stuart Resource Centre and Specialist Workers, for example the Parkinson's' Disease Nurse Specialist, are Aberdeen City based and often involve only one worker covering a large geographical area of Aberdeenshire. Therefore whilst at first glance services seem to be fairly equally distributed between those serving people with malignant illness and those serving people with non-malignant illnesses, further examination reveals that this is not the case.

Consideration of the data in appendix 7 also reveals that whilst there are many similarities in service provision across Aberdeenshire there are some differences. The differences in service provision across Aberdeenshire can be broken into two groups: larger scale services and smaller scale services that have grown up in a particular place. The most notable difference in larger scale services in Aberdeenshire is the existence of a Macmillan Social Worker and a Community Dementia Team in central Aberdeenshire only. The other differences that exist in service provision tend to involve smaller scale services that only serve one community, such as the Banff and Buchan Counselling Service or the community ambulance at Portlethen.

Service gaps

A number of suggestions were made by participants as to where the gaps in psychosocial services existed. However throughout the project it was apparent that the area that most people drew attention to was gaps in the provision of services for people with a non-malignant illness.

Care and respite was the most frequently mentioned gap in psychosocial service provision. Members of one focus group commented on the difficulty that they had getting care in a particular area that they worked in. Whereas, other people who took part in this project were concerned at the difficulty that they had getting overnight care. This view is summarized by one participant who commented that

'there is not enough overnight care.'

Workers also highlighted the lack of respite care in their responses.

Access to the Marie Curie Nursing service was another area that was highlighted as a gap in psychosocial service provision. According to participants in one focus group

'Marie Curie is only available the night before someone dies... You cannot get them to do respite.'

This view was supported by another worker who stated that the District Nurses that she worked with were having difficulty getting Marie Curie nurses when they needed them. Furthermore this particular person thought that the situation had got worse since Marie Curie had stopped organising their nursing service locally.

A handful of participants also drew attention to the gaps that exist in transport provision. Workers in one focus group argued that

'sometimes the services are there, but it is the transport to services that is the problem.'

Day care, carers support and support for children with ill parents were each highlighted as gaps by a couple of people who took part in this project. According to participants in one focus group there is

'not a lot of support for children whose parents are ill.'

This was also the view of workers in another focus group who argued that there is a significant gap in psychosocial service provision

'where children are involved and one of their parents is unwell.'

One member of this group went on to recount the difficulty she had had trying to get support for children of one of her clients who was dying.

In addition to the gaps in psychosocial support detailed above, a number of other areas where service provision was lacking, such as family therapy and counselling, were also discussed by one participant each.

A number of comments were made throughout this project about the gaps that exist in psychosocial service provision for people with a non-malignant life threatening illness. There was a strong feeling that inequalities exist between service provision for those with malignant and non-malignant life threatening illnesses. According to one participant

'cancer has had a high profile and there are a lot of things available for cancer. Most people would know a support group for cancer, they know about CLAN, how to access alternative treatment and how to get your parking paid for when you are in the ANCHOR unit. But people who have a life threatening illness that is not cancer, they do not get that high profile service, they get a raw deal. Even the general public are probably not aware what that diagnosis means for them.....people have a general idea of what cancer is, but if it is another terminal illness, people will ask 'well, what is that?'

It was apparent that some people found this inequality difficult to work with, as one participant commented that

'it is hard, I suppose, when you are working with loads of different folk when there is that difference [access to services], depending on what is wrong with them.'

One participant put forward a reason why this apparent inequality in psychosocial service provision for people with malignant and non-malignant life threatening illness exists. In her opinion

'it is not that people with non-malignant illness do not get palliative care, it is that they do not get specialist palliative care.'

Therefore whilst people with non-malignant life threatening illness are cared for by District Nurses, GPs and Health and Social Care teams it is more difficult to access the specialist services provided by Macmillan Nursing and CLAN, for example, for this group of patients. As a result of this, people with a non-malignant life threatening illness are often reliant on the support provided by home carers, as they do not have access to more specialist services. However, as people who took part in this project pointed out, these services are commissioned on a task-orientated basis and consequently there is, according to participants in one focus group

'very much an emphasis on the physical.'

Hence it is debatable whether carers are routinely meeting the psychosocial needs of people with a non-malignant life threatening illness; thus raising the question how much attention is paid to the psychosocial needs of this group of people.

Throughout this project it was also highlighted that psychosocial service provision for people with a non-malignant life threatening illness seems to be poorly organised and planned. In the view of one participant

'the pre-emptive, planned, organized care that we offer cancer patients is not being offered because they do not have cancer.'

This opinion was supported by another worker who argued that

'if you've got cancer there are probably very well defined support mechanisms and there is a clear pathway. I don't think there is for

people with non-malignant conditions. I think it depends where you are and it depends on who your team of professionals are.'

There was also a thought amongst workers that there was a lack of resources for people with a non-malignant life threatening illness. According to one participant

'the resources are not always there for a patient who does not have a malignancy.'

As a result of this, according to a number of people involved in this project, it was more difficult to support a person with a non-malignant life threatening illness than someone with a malignancy. This lack of resources seems to, in part at least, stem from the existence of cancer only services. Participants in one focus group expressed the opinion that the services provided by CLAN to people with a malignant illness would benefit many of the younger people with neurological conditions that they worked with, yet these people were not able to access the services as they did not come under its remit.

Furthermore a handful of participants also discussed the difficulty that they have accessing a DS1500 for people with non-malignant conditions. The DS1500 appears to be the gateway for people with a life threatening illness to access free personal care, if they are younger than 65 years of age. However, according to workers in one focus group,

'doctors can be reluctant to issue a DS1500 for non-malign conditions.'

Therefore, once again, people with a non-malignant condition find themselves at a disadvantage.

A number of participants also commented on the experience of people with specific conditions. The plight of the young chronic sick was highlighted by a number of people who took part in this project. There was a general sense that psychosocial services were particularly lacking for this group of people. This view is summarised by one worker who argued that

'there is nothing for them at the moment.'

Participants drew attention to both the difficulty in getting care for the young chronic sick and the lack of appropriate respite places for these people.

The experience of people with dementia and respiratory illnesses were also frequently discussed. People who took part in this project often drew comparisons with the way in which cancer patients were viewed in contrast to those with other conditions, such as dementia. According to one participant

'dementia is a big area, but it is not discussed or thought about in the same way as cancer.'

Services workers would like

Towards the end of the interviews and focus groups that were conducted participants were asked to identify what services they would like to see provided to meet the psychosocial needs of people with a life threatening illness in Aberdeenshire. The responses to this question are summarised in figure 8

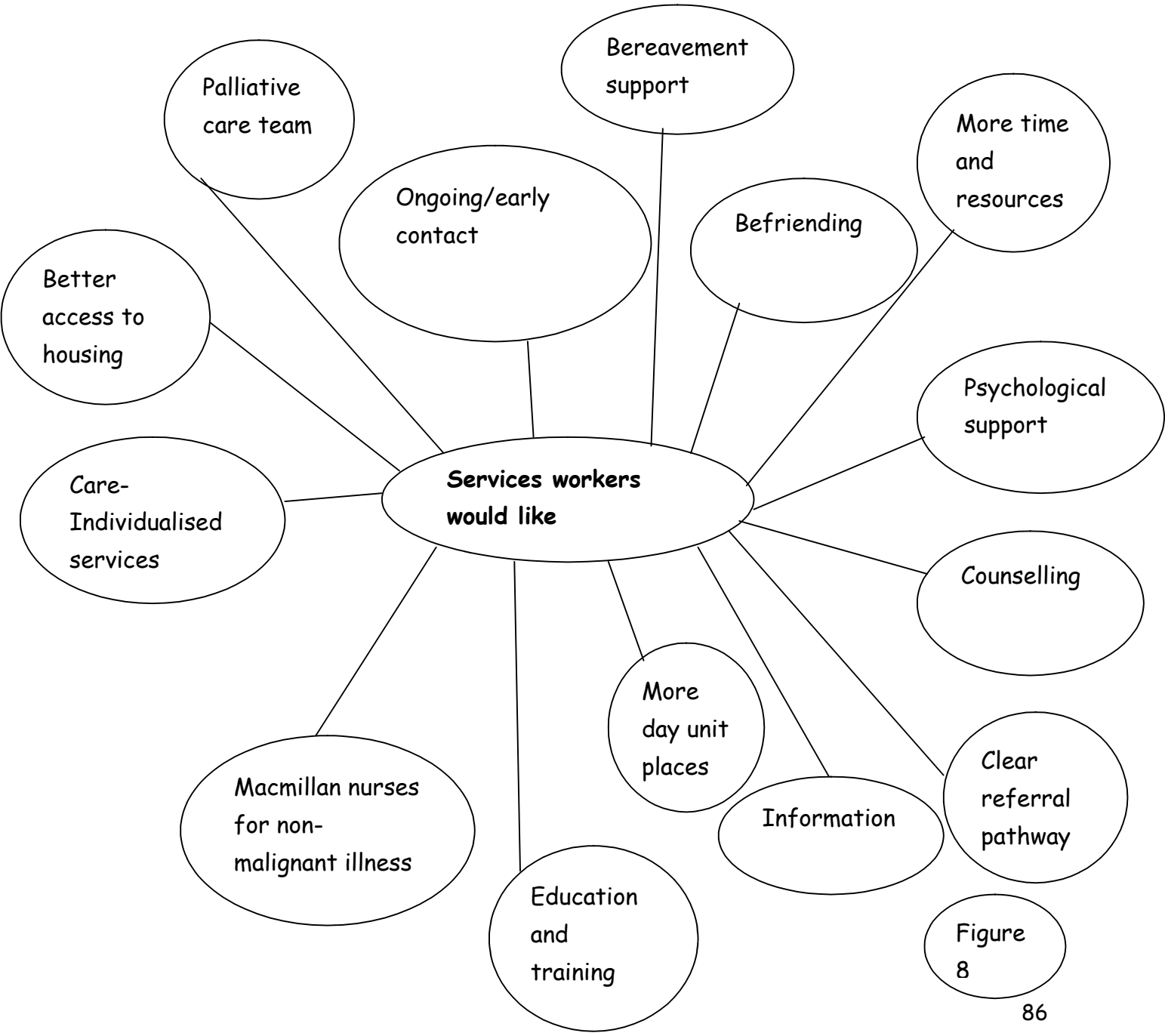


Figure 8

A number of participants suggested that they would like to see a difference in the way in which care is provided to people with a life threatening illness. There was a call for more individualised services, as according to one worker we need

'more people to provide care tailored to people's needs: the generation of people we have been looking after have been less demanding in their expectations than the next generation who have led outgoing lives and have higher expectations.'

Workers would also like to see more 24 hour care at home to allow people to die at home, if that is their wish, and more appropriate respite care.

Interestingly one of the most mentioned changes to service provision that workers would like to see is earlier and ongoing contact with people with a life threatening illness. Linked in with this is participants call for more time and more resources so that they are able to pop into people to see how they are doing without feeling the need to justifying why such a visit is necessary. In the opinion of one worker

'if community care is going to do what it promised then we need more time and more resources.'

There was also a call amongst some participants for a specific palliative care worker or team whose remit would be to meet the psychosocial needs of people with a life threatening illness across Aberdeenshire. One worker stated that they would like to see a

'comprehensive service [involving] health, local authority and voluntary agencies for anyone affected by an advanced, progressive illness.'

Similarly another participant would like to see a person employed to work with people with a life threatening illness who had

'skills in physical, emotional and psychological needs.'

In addition to this workers in one focus group suggested that it would be good to have a

'travelling alternative therapist who could visit people in their own homes who are too ill to get out and about to things.'

The remit of this worker or team would also extend to providing support to staff. According to participants in another focus group we

'need debriefing for carers. [We] need someone whose remit is to provide psychosocial support for the client and debriefing and support for the carers.'

Information was another area that was identified by participants when asked what services they would like to see to meet the psychosocial needs of people with a life threatening illness. One worker commented that it

'would be useful to have a website which has all the information on organizations and support for a particular illness for a particular area.'

Similarly another person who took part in this project argued that

'we need to know what is available in other parts of the Shire. There may be good practice in other areas. It might be good to get an overall feel of what is available out there, what could be different ways of working and accessing help directly for our staff as well as service users.'

Participants also called for a clear referral pathway so that they know who should be involved in each case.

A number of people who took part in this project identified psychological support and counselling as services that they would like to see for people with a life threatening illness and their carers, both formal and informal. According to one worker it

'would be good to be able to refer client, family and carers to counselling. Carers do a very tough role....[we only] offer them debriefing at the moment if they need it.'

Another participant argued that there is also a need for family therapy services, as

'life threatening illness can have a big impact upon family dynamics,. Certainly with the more dysfunctional families it would be very useful to get a family therapist in.....dysfunctional cases are not very common, but when they do come up they can be very challenging for all concerned and you have to muddle through it.'

Although some people involved in this project called for more psychological support for people with a life threatening illness, one worker did sound a note of caution, arguing that

'getting one hundred extra psychologists may not be the answer.'

According to this worker

'it is about dealing with people, listening to them, helping them.....[they] may not need any more than that.'

Education and training was also highlighted by a handful of people as an area where they would like to see an improvement in services. According to a participant in one focus group

'I think training is very important. If we are going to use the carers, and we do use them more and more, then we need some background.'

In addition to the above suggestions, a few people also argued that they would like to see Macmillan nurses for people with a non-malignant illness, better bereavement support, befriending, more day unit places and improved access to housing for people with a life threatening illness. There were also a number of suggestions that were made by one participant only, such as CLAN for people with

a non-malignant life threatening illness, a resource like the Oaks in Elgin and better transport.

Feedback from presentations of the project's findings

During the week commencing Monday 18th August three presentations were held across Aberdeenshire. Thirty six people attended these events in Peterhead, Inverurie and Stonehaven. Although some of those who attended these sessions had participated in the study, a number of people had not. The main aim of the presentations was to share the project's findings and ascertain if these reflected wider opinion.

The vast majority of the feedback received at these presentations confirmed the aforementioned findings. However a few additional points were highlighted by those who attended these feedback events. These included:

- The issue of rurality.
 - It was argued that there are few carers available in rural areas, so keeping people trained and in the job is an issue.
 - The suggestion was put forward that people in the local community are often the main sources of support in remote, rural locations.
 - The possibility of providing a mobile palliative care team was suggested.
- The need for generic workers.
 - It was suggested that rather than more specialists, there is a need for care workers to have more of a generic role.
- Continued project funding.
 - It was suggested that funding could be sourced from organisations, such as the Motor Neurone Disease Society, MS Society and Macmillan Cancer Relief, to follow up areas of further research.

CONCLUSIONS

The main findings to come out of this project can be summarised into the following points:

- 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 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.
- 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. These include: support, practical needs, the need to talk and be listened to, sourcing information and assistance, time and financial needs.
 - Carers were identified as having their own psychosocial needs. These include: support, information and space away from the patient.
 - Interestingly when asked to identifying the psychosocial needs of people with a life threatening illness a couple of participants mentioned medical and nursing needs. This once again suggests that some participants, at least, were unsure about what psychosocial care is.
- 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.
- 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. These included: lack of time, lack of resources, stoical culture of the area, professionals fault and 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.
- Participants were able to identify a large number of services to meet the psychosocial needs of people with a life threatening illness in Aberdeenshire.
 - There was a general feeling that good multi-disciplinary working took place across Aberdeenshire, which contributed positively to service provision.
 - Workers pointed out that there were inequalities in service provision.
 - Although a similar number of services were identified for people with a malignant and a non-malignant life threatening illness, the majority of the most mentioned services could only be accessed, either predominantly or exclusively, by people with cancer.
- According to participants significant gaps exist in the provision of psychosocial services to people with a non-malignant illness.
 - Considerable attention was paid to the inequitable service for people with a non-malignant life threatening illness.

- This links in with the aforementioned finding that workers thought that the psychosocial needs of people with a non-malignant illness go unmet more frequently than those with a malignant condition.
 - According to participants the DS1500 form is used as a tool to decide if a person under 65 years of age receives free personal care. Although it appears that some doctors are prepared to complete this form for a person with a non-malignant, life threatening illness, this does not always seem to be the case. Thus indicating a significant inequality in service provision between people with malignant and non-malignant conditions.
 - Workers also identified gaps in the general provision of psychosocial services to people with a non-malignant illness, such as care.
- Participants identified a number of services that they would like to see to meet the psychosocial needs of people with a life threatening illness.
 - Services suggested included a difference in the way care is provided, earlier and ongoing contact with people with a life threatening illness, a palliative care worker/team that covers the whole of Aberdeenshire whose remit would be to meet the psychosocial needs of people with a life threatening illness and psychological support and counselling.

Limitations

One of the most significant limitations of this piece of work has been time, given the scale of the project. If there had been more time and more personnel working on this topic then a more comprehensive piece of work could have been undertaken. The author would have liked to have interviewed more people, included service users in the study and had more time to analyse the data that has already been gathered.

It is possible that with more time to analyse the existing data a more comprehensive picture would have emerged. For example, it would have been useful to compare and contrast the answers given by participants who work predominantly with people with a non-malignant, life threatening illness and those who work with

people with a malignant condition. This further analysis would have gone part way to more fully answering some of the original objectives of the project. Instead all the participants' answers were taken together and no such comparison was undertaken.

Another limitation of this project is that there are some notable gaps in knowledge as the author was not able to interview all the people that were identified as stakeholders at the start of this piece of work. The author made contact with as many stakeholders as possible; however a number of these people did not take part in either interviews or focus groups for a variety of reasons. This had a particular impact upon the data that was gathered about people with a non-malignant illness, as some of these illnesses appear only have contact with a handful of workers and in some cases it was not possible to interview these workers. Therefore the information that was collected as part of this study was not complete.

At the start of each interview and focus group, with the exception of the short interview schedule (appendices 2-6), participants were asked to define psychosocial care. As highlighted in the findings, a number of people had difficulty defining this term. However no prompts were given, therefore all subsequent answers that participants gave were based on their understanding of psychosocial care as previously expressed. Therefore it is possible that, had prompts been given or a definition of psychosocial care been shared with workers later on in the interview, they would have given different answers to the later questions.

As a result of these limitations the author has only been able to provide an introduction to the topic, which has left a number of avenues still to be pursued and further research to be undertaken.

Recommendations

At the beginning of this project a number of aims were set down. One of these aims was to draft plans for action to fill identified gaps in service provision. As this project has progressed it has become apparent that there are no easy solutions to fill the gaps that have been identified. Moreover it seems that a step before this needs to be completed as there are a number of questions that remain unanswered and aspects of psychosocial need and service provision that require further examination as a matter of priority. Hence there is still a considerable amount of work that needs to be done before fully informed suggestions can be put forward for service provision. As a result, areas of further research are listed first to provide an insight into the work that still needs to be undertaken. The recommendations for service provision that follow are tentative ideas as to how things could then be taken forward.

Areas of further research

Further research needs to be conducted into psychosocial need, as a number of questions remain, which this project has not been able to adequately answer.

- 1) How do people with a life threatening illness view psychosocial need? What needs do people highlight? Do people think their psychosocial needs are more, less or as important as their other needs, such as the need for clinical care?
 - This would involve a more in-depth scan of the literature in this area followed by research conducted with people with a life threatening illness.

- 2) Are the psychosocial needs of people with a non-malignant illness the same as those with a person with a malignant condition or are there significant differences?

- It is possible that a further detailed analysis of the data collected in this project would shed some light on this. However for a more comprehensive answer to this question further research would need to be conducted with people with both a malignant and a non-malignant life threatening illness.

Additional research needs to be conducted with people who work with informal carers and informal carers themselves, as this project was not able to cover this area in the depth that is required.

- 1) The author came away with the impression that carers face a number of challenges and frequently do not feel supported in their role. However carers' support was amongst one of the most frequently mentioned psychosocial needs that participants met. Therefore more research is required in this area to ascertain whether the author's impression is accurate.
 - Is it possible that carers psychosocial needs are being met, but their expectations of support are too high? Or could it be that workers think that they are meeting carers needs, but in reality are not, as the services that are available are either not adequate or fit for purpose?

Research also needs to be undertaken with paid (formal) carers.

- 1) One of the findings from this project suggests that formal carers are often the main people providing support for people with a non-malignant life threatening illness.
 - Are formal carers meeting people's psychosocial needs?
 - Is there an unspoken expectation that meeting people's psychosocial needs is part of their role?
 - Do carers receive training to meet the psychosocial needs of people with a life threatening illness?

- If this is part of the role of carers why are services commissioned on a task-orientated basis?
- Are we expecting carers to do too much or are we underestimating the skills that they have?

Although this project has examined service provision across Aberdeenshire from the perspective of professionals involved in palliative care, further research needs to be conducted with people with a life threatening illness to gain their opinion on service provision and service gaps.

- 1) Do people with a non-malignant life threatening illness want access to the same services as people with a malignant condition, or do they require a different pattern of service provision to meet their needs?
 - Do people with a non-malignant life threatening condition actually want on-going support from professionals in palliative care, when they are diagnosed with a non-malignant life threatening condition, as this may span an indefinite period of time, due to the nature of the condition?

Furthermore additional research needs to be conducted into when a life threatening non-malignant illness is deemed to have entered its palliative stage. This has considerable implications upon the ability of people with a life threatening illness to access services, which are often reserved for people at the palliative stage in their illness.

- 1) If certain services are only available to people in the last few months of life, how do we ensure equitable access to these services for people with a non-malignant life threatening condition given the difficulty in ascertaining when the end of life is near for this group?

There also needs to be further research into the perceived inequalities in service provision across Aberdeenshire.

- 1) Do psychosocial needs go unmet in certain areas of Aberdeenshire because of different patterns in service provision; for example does the existence of a Macmillan palliative care social worker and a community dementia team in central, but not in north and south, lead to inequalities on the ground? Or can psychosocial need be met equitably across Aberdeenshire using different patterns of service provision?

Recommendations for service provision

As a number of participants did not seem confident with the term psychosocial care it is apparent that there needs to be agreement and education across all services (health, local authority, voluntary and private sector) as to what it means.

- There needs to be an acknowledgement that psychosocial care is important and should be an integral part of palliative care.
- The workforce needs to be encouraged and supported to provide psychosocial care to all people with a life threatening illness.

There needs to be agreement between professionals from all sectors at a local level as to 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.
- A clear referral pathway should be created so that workers are aware of what assistance is available in their area and how it can be accessed.
- A map of service provision should also be published and kept up-to-date so that workers and people with a life threatening illness are aware of what services are available across Aberdeenshire. Prior to this map being formulated there may need to be dialogue with some of organisations concerned to ascertain exactly what they provide in terms of psychosocial support for people with a life threatening illness, so that workers are accurately informed as to what is out there.

For those professionals who are already confident in providing psychosocial care, they need to be given the time and manpower to fulfil this role and the work that they do in this area should to be acknowledged as valuable.

- Best practice in psychosocial care needs to be praised and ways of working shared with other workers/teams.
- For those workers who do not feel confident in providing psychosocial care to people with a life threatening illness, training needs to be provided.

In addition to this, there also needs to be clarification and education about the DS1500 form. At present the DS1500 form seems to be used as a way of distinguishing who, under the age of 65 years, receives free personal care.

- To ensure equity in service provision for both people with a malignant and a non-malignant life threatening condition, workers need to know when to request a DS1500 form to ensure that all patients, who fit the criteria, receive free personal care.
- There also needs to be clarification regarding when a DS1500 should be issued, so that medical staff issue DS1500 forms in a uniform way across Aberdeenshire.

Moving service provision forward

There needs to be a frank and honest discussion amongst policy makers and those involved in service provision about the inequalities that exist in service provision for people with a non-malignant and a malignant life threatening illness. The existence of voluntary and private organisations, which provide a significant amount of psychosocial care to people with a life threatening illness, has had implications for equity in service provision, as many of these organisations only work with people with certain illnesses.

- There needs to be an acknowledgement of the services that these organisations 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 organisation to ascertain if they plan to follow Marie Curie's example and wide their remit to include the care of people with a non-malignant illness.

If organisations continue to opt to provide psychosocial care to people with particular illnesses then other forms of service provision will need to be examined to sit alongside these services.

- Based on the findings from this project, such service provision should include workers who can provide counselling, financial advice, meet practical needs, such as commissioning care, and provide complementary therapies. In addition to this, provision of support to those working with people with a life threatening illness, including both formal and informal carers would be required.
- Service provision should be accessible to anyone with a life threatening illness, malignant or non-malignant. It would also need to be accessible to people from all areas of Aberdeenshire.

The views expressed in this report do not necessarily reflect those of Aberdeenshire Council, Aberdeenshire Disability Action or NHS Grampian.

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APPENDICES

Appendix 1

Steering group members

Stuart Watts (Social Work Manager (Community Care), Aberdeenshire Council)

Yvonne Macdonald (Executive Officer, Aberdeenshire Disability Action)

Alistair Kerr (Macmillan Social Worker, Aberdeenshire Council)

Dr. Sally Lawton (Senior Lecturer in Palliative Care (Nursing))

Dr. David Carroll (Associate Specialist in Palliative Medicine and GP Facilitator for Palliative Care, NHS Grampian)

Appendix 2

Interview schedule (for people who predominantly work with people with a malignant illness)

- 1) Can you tell me a little bit about your job and the client group that you work with?

PROBE: Can I just clarify; do you predominantly work with people with a malignant or a non-malignant life threatening illness?

- 2) How do you define 'psychosocial care?'

- 3) In your experience what do you think the psychosocial needs of a person with a life threatening illness and their family are?

- 4) You have just mentioned a number of psychosocial needs, which of these needs do you meet?

- 5) In your opinion do any of the psychosocial needs that you mentioned earlier go unmet?

6) Are you aware of any other services that meet the psychosocial needs of people with a life threatening illness that you are unable to meet?

7) What services would you like to see provided to meet the psychosocial needs of people with incurable, advanced, progressive cancer in Aberdeenshire?

8) You say that you predominantly work with people with cancer. Could people with an advanced, progressive non-malignant illness access your service?

PROBE: If not, are you aware of a similar service for people with an advanced, progressive non-malignant illness?

9) Are there any other issues that you would like to raise?

Appendix 3

Individual interview schedule (for people who predominantly work with people with a non-malignant illness)

- 1) Can you tell me a little bit about your job and the client group that you work with?

PROBE: Can I just clarify; do you predominantly work with people with a malignant or a non-malignant life threatening illness?

- 2) How do you define 'psychosocial care?'
- 3) In your experience what do you think the psychosocial needs of a person with an advanced, progressive, non-malignant illness [or specific illness name] and their family are?
- 4) You have just mentioned a number of psychosocial needs, which of these needs do you meet through your day to day work?
- 5) In your opinion do any of the psychosocial needs that you mentioned earlier go unmet?

- 6) Are you aware of any other services that meet the psychosocial needs of people with advanced, progressive non-malignant illness [or specific illness name] that you are unable to meet?

- 7) What services would you like to see provided to meet the psychosocial needs of people with advanced, progressive non-malignant illness [or specific illness name] in Aberdeenshire?

- 8) You say that you work with people with [name of illness]. Are you aware of a similar service for people with other non-malignant illnesses in Aberdeenshire?

- 9) Are there any other issues that you would like to raise?

Appendix 4

Individual interview schedule (for people who predominantly work with informal carers)

- 1) Can you tell me a little bit about your job and the client group that you work with?

PROBE: Can I just clarify; do you predominantly work with people who are caring for someone with a malignant or a non-malignant life threatening illness?

- 2) How do you define 'psychosocial care?'

- 3) In your experience what do you think the psychosocial needs of the carers of people with a life threatening illness are?

- 4) You have just mentioned a number of psychosocial needs, which of these needs do you meet through your day to day work?

- 5) In your opinion do any of the psychosocial needs that you mentioned earlier go unmet?

- 6) Are you aware of any other services that meet the psychosocial needs of the carers of people with a life threatening illness that you are unable to meet?

- 7) What services would you like to see provided to meet the psychosocial needs of the carers of people with a life threatening illness in Aberdeenshire?

Appendix 5

Short interview schedule

- 1) In your experience what do you think the psychosocial needs of people with a life threatening illness and their family are?
- 2) Which of these psychosocial needs do you meet through your day to day work?
- 3) Which other services do you access to meet the psychosocial needs of people with a life threatening illness and their family?
- 4) Where are the gaps?
 - What services would you like to see provided to meet the psychosocial needs of people with a life threatening illness in Aberdeenshire?

Appendix 6

Focus Group Schedule

- 1.) Can I begin by asking everyone to share their name, occupation and how long they have worked for the team?

 - 2.) Can you tell me a little bit about your job and the client group that you work with?

 - 3.) How do you define psychosocial care?

 - 4.) In your experience what do you think the psychosocial needs of people with a life threatening illness and their family are?

 - 5.) You have just mentioned some of the psychosocial needs of people with a life threatening illness what service provision are you aware of in this area of Aberdeenshire to meet these needs?
- 'Where are the gaps?'
- 'What about people with a non-malignant life threatening illness? What services are you aware of for this group of people? Where are the gaps?'

6.) What service would you like to see provided to meet the psychosocial needs of people with a life threatening illness in Aberdeenshire?

7.) Are there any other issues that you would like to raise?

Appendix 7

Table of current service provision

Area (N/C/S/Shire wide/City based)	Which Client Group? (Malignant/Non-Malignant)	Service (Voluntary/LA/Health)	Mentioned by participants (number of participants who mentioned it)
North	Non-malignant (Dementia)	Alzheimer Scotland (Voluntary)	Yes (2)
North	Malignant and non-malignant	Counselling-Banff and Buchan counseling Services and a Fraserburgh GP	Yes (1)
North	Malignant and non-malignant (for carers)	VSA carers centre (Voluntary)	Yes (1)
North	Malignant and non-malignant (for carers)	VSA carers support groups (Voluntary)	Yes (1)
North	Malignant and non-malignant	Fraserburgh and District Advice Centre	Yes (1)
North	Malignant and non-malignant	Citizens Advice Bureau (Voluntary)	Yes (2)
North	Malignant and non-malignant	Benefits Officer	Yes (1)
North	Non-malignant (Dementia) For carers	Collieburn Day Hospital Carers' Support Group	No
North	Malignant and non-malignant	Crossroads Caring for Carers (Voluntary)	No
North	Non-malignant (Dementia)	Day Care Services for people with dementia	No

		(Aberdeenshire Council)	
North	Non-malignant (Dementia) and carers	Old Age Psychiatry Team (Health)	Yes (1)
North	Non-malignant	COPD project	Yes (1)
North	Non-malignant (Dementia)	Peterhead Committee for Aged and Infirm	No
Central	Malignant and non-malignant (for carers)	Carers Support Workers-Gordon Rural Action (Voluntary)	Yes (1)
Central	Malignant and non-malignant (for carers)	Carers Support Groups-Gordon Rural Action (Voluntary)	Yes (1)
Central	Malignant and non-malignant	Advocacy Service	Yes (1)
Central	Malignant and non-malignant	Auchmacoy Unit (Ellon)	Yes (1)
Central	Malignant and non-malignant	Computers in Inverurie	Yes (1)
Central	Non-malignant (Dementia)	Dementia Team (Aberdeenshire Council)	Yes (1)
Central	Non-malignant (Dementia)	Support workers (through the dementia team)	Yes (1)
Central	Non-malignant (Dementia)	Gordon Dementia Services (day club)	No
Central	Malignant and non-malignant	Benefits Officer	Yes (1)
Central	Malignant	Cancer support groups (Voluntary)	Yes (2)
Central	Malignant	Macmillan Social Worker in Palliative Care (Aberdeenshire Council)	Yes (4)
Central	Malignant	Palliative Day Care in	Yes

		Ellon at the Auchmacoy Unit	(2)
Central	Malignant and non-malignant	Take-A-Break (Voluntary)	No
Central	Malignant and non-malignant	School Nurse and School Counsellor	Yes (1)
South	Non-malignant (Dementia)	Alzheimer Scotland (Voluntary)	Yes (1)
South	Malignant and non-malignant	Crossroads	Yes (1)
South	Malignant and non-malignant (for carers)	VSA Carers Centre (Voluntary)	No
South	Non-malignant (Dementia)	'Forget me not' club	Yes (1)
South	Malignant	Cancer support group (Voluntary)	No
South	Malignant and non-malignant	Charity grants (Deeside)	Yes (1)
South	Malignant and non-malignant	Community Ambulance (Portlethen)	Yes (1)
South	Malignant and non-malignant	Befriending Scheme (Kincardine)	Yes (1)
Shire wide	Malignant	www.cancerservices.info Cancer Information Project (Voluntary)	No
Shire wide	Malignant and non-malignant (for carers)	CRUSE (Voluntary)	Yes (2)
Shire wide	Malignant and non-Malignant	Care Management and Social Services (Aberdeenshire Council)	Yes (5)
Shire wide	Malignant and non-malignant	District Nursing Service (Health)	Yes (5)
Shire wide	Malignant and non-malignant	General Practitioners (Health)	Yes (2)

Shire wide	Malignant and non-malignant	Health and Social Care Teams (Health and Aberdeenshire Council)	Yes (3)
Shire wide	Malignant and non-malignant	Care homes	Yes (2)
Shire wide	Malignant	Grampian Macmillan-CAB partnership project.	Yes (7)
Shire wide	Malignant and non-malignant	Home Care (Aberdeenshire Council)	Yes (3)
Shire wide	Malignant and non-malignant	Care agencies (Private)	Yes (2)
Shire wide	Malignant and occasionally non-malignant	Macmillan Nursing Service (Health)	Yes (11)
Shire wide	Malignant and non-malignant	Marie Curie Nursing Service (Voluntary)	Yes (7)
	Malignant and non-malignant	Occupational Therapy (Aberdeenshire Council)	Yes (3)
	Malignant and non-malignant	Physiotherapy (Health)	No
Shire wide	Malignant and non-malignant	Speech and Language Therapists (Health)	No
Shire wide	Malignant and non-malignant	Church groups (Voluntary)	Yes (1)
Shire wide	Malignant and non-malignant	Housing (Aberdeenshire Council and Voluntary)	Yes (1)
Shire wide	Malignant	CLAN (Voluntary)	Yes (7)
City based	Malignant and occasional non-malignant	Roxburghe House (Health)	Yes (9)
City based	Non-malignant	Horizons	Yes (1)

City based	Non-malignant	Specialist Nurses and Specific Condition Workers: Motor Neurone Disease Worker, Parkinsons Disease Nurse, Rehabilitation Nurse, MS Nurse, Huntington's Disease Workers	Yes (7)
City based	Non-malignant	MS Society (Stuart Resource Centre) (Voluntary)	Yes (3)
City based	Non-malignant	Parkinsons Disease Society	Yes (1)
City based	Non-malignant	Scottish Huntington's Association (Voluntary)	Yes (2)
City based	Non-malignant	Scottish Motor Neurone Disease Association	No
City based	Non-malignant	Terrence Higgins Trust	No