



Beyond the questions

Shared experiences of palliative and end of life care

Thematic analysis of the first survey of the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance

Dr Annmarie Nelson

Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine

www.palliativecarepsp.org.uk

October 2016

Contents

Foreword	3
Report summary	4
Introduction	5
What did we ask and who answered?	7
What did we find?	8
1 Communication	9
2 Support	11
2.1 Bereavement	11
2.2 Financial support	12
2.3 Supporting families	13
2.4 Supporting staff	14
3 Service use	15
3.1 Access to services	15
3.2 Co-ordination and distribution of services	15
3.3 Out of hours and emergency support	16
4 Managing symptoms and medication	17
5 Understanding dying	19
6 Perceptions of palliative care	21
Discussion	23
Conclusion	24
Acknowledgements	25
Appendix 1 – Methods	26

Foreword



I was extremely privileged to chair the Steering Group of the Palliative and end of life care Priority Setting Partnership (PeolcPSP). The James Lind Alliance (JLA) has worked with many different Priority Setting Partnerships (PSPs) to set priorities for health research, but the PeolcPSP was one of the first to go beyond a specific condition to focus on such a broad, universal, and yet under-researched, area of healthcare.

The James Lind Alliance was conceived in 2004 to provide a framework for identifying ‘treatment uncertainties’ which could be checked against the evidence base and then prioritised. As the method has developed, the notion of treatment has evolved into a more general definition of ‘interventions’ – in other words, treatments, care and other actions that are designed to make a difference to patients and which can be tested and evaluated by research.

Inevitably, however, when Priority Setting Partnerships go out to patients, families and clinicians to ask them what questions they want research to answer, the issues that are important to them can extend beyond interventions and the realm of ‘interventional research’, i.e. research that aims to test and evaluate interventions. For a topic as complex as palliative and end of life care, it is not surprising that the issues raised via the survey were incredibly broad and varied.

People used it to share their experiences, aspirations and anxieties about palliative and end of life care. The PeolcPSP achieved its primary aim of identifying the interventional research questions and agreeing the top 10. Yet, we still had this wider dataset of questions and concerns – many of which were raised by patients and families. It was clear that its potential should not remain untapped.

It is a huge credit to the PeolcPSP Steering Group and team that additional time, expertise and resources were committed to exploring the full data set and presenting it in this report. The work undertaken has produced a series of themes that provide insight into the experiences of palliative and end of life care from personal and professional perspectives. It highlights issues in addition to the top 10, which have the potential to be addressed by social science research. It is also doing justice to the time people spent sharing their stories when they took part in the survey.

While Priority Setting Partnerships engage with the James Lind Alliance in order to identify clinical and other interventional research questions for funders and researchers to address, they may in the process discover other types of questions that might be answered by other types of research. The idea of losing these can be troubling. For future James Lind Alliance Priority Setting Partnerships, this report is a great example of how supplementary activities could potentially be undertaken to do something meaningful with that extra data. I am excited to be able to show Priority Setting Partnerships how they can still share that data with the research community and the wide range of research funders that exist, while highlighting an additional set of issues that are important to patients, families and healthcare professionals.

Katherine Cowan

Senior Adviser, James Lind Alliance

Report summary

This report presents a supplementary analysis of a public survey carried out by the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance (JLA) in 2013-14. The result of the original survey was a set of 83 ‘interventional’ questions, i.e. questions about treatments, care and other actions that are designed to make a difference to patients and which can be tested and evaluated by research. This set included a prioritised list of the top 10 questions for palliative and end of life care (see page 5) to address by better treatment, practice or management of care.

The PeolcPSP Steering Group realised that many of the respondents’ comments were less about research and instead focused on their personal experiences, or asked more general questions, unrelated to clinical care. The PeolcPSP Steering Group felt strongly that these responses should be included in a further analysis of the data.

We used a technique for analysis that grouped all of the responses by theme. We looked for similar patterns in the full set of 1,403 responses that could be grouped into similar categories, known as themes.

This report presents and discusses themes that cover: how we talk about death and dying, what we understand about death and dying and the place of palliative care, different types of support for families and healthcare professionals, how palliative care services are co-ordinated and distributed, and how we access services including care that is needed out of working hours.

The findings reveal respondents’ frustrations with lack of care and treatment, as well as with a lack of communication and understanding around death and dying. This has a huge impact on what we understand about the dying process and the grieving process of bereaved families. It is clear that further investment on service provision at the end of life is much needed. This should include alternative service models to address the priorities for care that patients and families find most important.

There was one theme, about perceptions of palliative care, which had not resulted in any interventional questions in the initial standard analysis, but includes important questions about what palliative care is and its wider role. It also includes questions asked about the balance of hope for a cure and the acceptance of dying.

Many of these issues will be best answered by research that is undertaken by social scientists to try to understand more about how we can improve the experience of death and dying for all. The results of the supplementary analysis illustrate many of the findings of the PeolcPSP. They also reinforce the call for further investment in palliative care research, in this case in particular about societal aspects of living with a terminal illness and ultimately the end of life.

Introduction

The Palliative and end of life care Priority Setting Partnership (PeolcPSP) carried out a public survey of patients, carers, health and social care professionals, family members, friends, volunteers and members of the public to identify unanswered questions in palliative and end of life care. The process followed a method developed by the James Lind Alliance (JLA), where questions are prioritised for research by patients, carers and health and social care professionals. People who responded to the survey talked about their experiences of the care, support and treatment of people with a terminal illness who might be in the last years of their life.

The James Lind Alliance approach to setting research priorities is to identify ‘interventional’ research questions¹. That covers treatment, practice or management of care designed to improve health and/or wellbeing. Following this approach, the PeolcPSP formulated 83 questions from which the top 10 research priorities were identified and agreed by representatives of all the groups surveyed. The final project report was published in January 2015² and work is being done to tackle the questions by funding relevant research.

Table 1: Top 10 research priorities for palliative and end of life care (2015)

- 1** What are the best ways of providing palliative care outside of ‘working hours’ to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.
- 2** How can access to palliative care services be improved for everyone regardless of where they are in the UK?
- 3** What are the benefits of advance care planning and other approaches to listening to and incorporating patients’ preferences? Who should implement this and when?
- 4** What information and training do carers and families need to provide the best care for their loved one who is dying?
- 5** How can it be ensured that staff, including healthcare assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?
- 6** What are the best ways to determine a person’s palliative care needs, then initiate and deliver this care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn’s disease, Parkinson’s disease, dementia, and stroke)?
- 7** What are the core palliative care services that should be provided no matter what the patients’ diagnosis is?
- 8** What are the benefits, and best ways, of providing care in the patient’s home and how can home care be maintained as long as possible? Does good co-ordination of services affect this?
- 9** What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff they have contact with, and does this improve quality of palliative care? Would having a designated case co-ordinator improve this process?
- 10** What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson’s disease, brain tumour (including glioblastoma) or head and neck cancer, for example?

This was the first wide-ranging Priority Setting Partnership not based on a particular condition and it was difficult to ask a narrow question without restricting people's experiences and comments. So, for the purpose of prioritisation, we followed the JLA method, as published, but we recognised the importance of those broader non-interventional questions. We took the opportunity to explore and understand the full dataset once the prioritisation exercise was complete.

It became clear very early in the process that not all of the survey responses could be translated into questions which might be answered by interventions. Many people described their experiences and raised more

general questions, eg about the purpose of palliative care. The PeolcPSP Steering Group felt strongly that these responses (which are referred to as 'out of scope' of the original survey analysis) should not be lost and that the voices of all people who took part in the survey were heard.

This report explores all the responses to the first PeolcPSP survey, giving individual examples. It uses thematic analysis of the data to supplement the standard James Lind Alliance methodology for identifying all emerging themes from the survey responses (see Appendix 1). We have included the words of those surveyed to illustrate the most common themes.

What did we ask and who answered?

The survey was open from 9 December 2013 to 16 May 2014. It asked two big questions:

- 1 What question(s) do you have about care, support and treatment for people who are in the last few years of their lives that could help them to live as well as possible?**

This could also include question(s) about care and support for current carers or families.

- 2 What question(s) do you have about care, support and treatment for those rapidly approaching the end of their lives?**

This could also include question(s) about care and support for current or bereaved carers, or families looking after someone at the end of their life.

We received 1,403 responses from different groups of people. The details are provided in Table 2. Some of those surveyed chose several ways of describing themselves, for example as

a bereaved carer / family member / friend and a professional working with people in the last few years of life.

Table 2: Numbers and percentages of different groups responding to the PeolcPSP survey – multiple answers were possible

Respondent	Number	%
I am in the last few years of my life	59	4
I am a carer or family member or partner or friend of someone in the last few years of their life	176	13
I am a bereaved carer or family member or friend	494	35
I am a professional working with people in the last few years of life	680	48
I am a volunteer working with people in the last few years of life	43	3
I am a member of the public who has an interest in the subject	181	13
Other	142	10

What did we find?

Palliative and end of life care has long been associated mainly with the care of people with cancer, but this is changing. More and more awareness is growing that there are many conditions which could benefit from a link to palliative and end of life care³.

In our survey, respondents mentioned many issues relating to living with different types of cancer. However, a large number of other conditions were also mentioned, showing a great need for knowledge of palliative and end of life care in illnesses other than cancer. Conditions mentioned included dementia, motor neurone disease, lung disease including chronic obstructive pulmonary disease (COPD), multiple sclerosis, Parkinson's disease, stroke, frailty and organ failure (kidney, liver and heart).

The overarching themes that emerged from the survey responses were:

1 Communication

2 Support

2.1 Bereavement

2.2 Financial support

2.3 Supporting families

2.4 Supporting staff

3 Service use

3.1 Access to services

3.2 Co-ordination and distribution of services

3.3 Out of hours and emergency support

4 Managing symptoms and medication

5 Understanding dying

6 Perceptions of palliative care

The remainder of the report highlights the main issues encountered within each of the themes and gives examples of relevant responses from carers, health and social care professionals or patients. Quotes are taken verbatim.

1 Communication

All groups of respondents discussed their experiences of communication with health and social care professionals, along with the services they received, during palliative and end of life care.

Communication around decision-making was a major concern. In particular, whether or not to tell someone that they are dying, when to have such a conversation, and how best to support patients and families to understand the impact of this. Some respondents felt strongly that they and their families were able to make informed choices about care and treatment at the end of life. However, others felt that they did not receive enough information and wanted more involvement in making decisions about treatment. In some cases, family members felt excluded from decision-making.

Many of those surveyed had concerns about advance care planning, their preferred place of care at the end of life, spirituality and psychological and social needs, as well as counselling and other therapies.

“Why are we given no information about what support can be offered in the home by the local CCG? (Clinical Commissioning Group) In the middle of the countryside it feels like a decision to die at home is a decision to die unsupported and in fear and pain.”

Bereaved carer/family member/friend; carer/family member/partner/friend of someone in the last few years of their life.

“Why did we only get the opportunity to draw up an Advance Care Plan at the point where it really needs to be implemented, when many of the questions are too distressing to ask as death gets closer?”

Bereaved carer/family member/friend; carer/family member/partner/friend of someone in the last few years of their life



Kieran Dodds/Marie Curie

“Though my husband has been ill for many years with COPD which we know is terminal, only recently I have been told that he probably only has a couple more years to live. I don’t know how to deal with this information. Should I tell him, other family members, what should I do with this information? The consultant has not referred us to anyone for palliative care, I don’t know what to do.”

Carer/family member/partner/friend of someone in the last few years of their life.

“How can I bear my feelings of grief and anger at my death sentence? Who can help me?”

Professional working with people in the last few years of life.

“I would strongly prefer to die at home rather than in a hospital or hospice. How do I set about trying to optimise my chances of this happening?”

Respondent in the last few years of their life.



2 Support

Support was a major theme. This theme was further divided into sub-themes according to the type of support (bereavement or financial support), and the people needing that support (families or staff).

2.1 Bereavement

Many respondents offered thoughts and experiences on losing loved ones. These included factors which they felt made their experiences worse as well as suggestions for how to make things better for others who are experiencing loss. Respondents highlighted the need for better information and availability of bereavement care in routine practice. They also highlighted a need for evidence on what kinds of bereavement support are best and for which groups of people.

“I have experienced the loss of two members of my family; one person died at home with the support of our GP, District Nurses, carers and Marie Curie nurses. I recovered emotionally from this experience quicker as I felt my mother had the best of care and support and I was not as physically exhausted as when my sister-in-law died. My sister-in-law died in hospital, she was put on the Liverpool Care Plan - this was not explained fully to my brother-in-law and the whole experience has left him emotionally fragile and requiring our support.”

Bereaved carer/family member/friend

“We had plenty of help during palliative care but had nothing afterwards, would have been nice to have had some support after husband died.”

Carer/family member/partner/friend of someone in the last few years of their life

“... it was a huge shock after caring for my husband for 24 hours a day for 20 years to lose him. Not only did I lose my husband but also my whole purpose to live myself. He was also my “full time job”. I felt totally lost when I lost him. We had regular contact with various professionals when he was alive ie DNs, the hospice, dieticians, stoma nurse, speech therapist, GPs (very regularly). Suddenly, when my husband died, all this stopped. My income also stopped the day he died as he was in receipt of disability benefits. I felt totally lost and abandoned.”

Bereaved carer/family member/friend

“The psychological loss of someone to dementia illness begins early in the illness which may be many years before their death. When will care and support for carers and their families be offered in the same way as those dealing with, for example, cancer illness?”

Bereaved carer/family member/friend; carer/family member/partner/friend of someone in the last few years of their life



Simon Rawles/Marie Curie

2.2 Financial support

Concerns about finance were related to funding availability, access to care provision and personal financial support. Respondents commented that families and patients should not have to prioritise financial issues at the end of life.

Survey participants highlighted a lack of suitable financial support and benefit packages for patients and carers, including home care. They felt that there was little co-ordination between health and social care benefits schemes. The financial support available across different diseases and the poor understanding of long-term conditions were major issues.

“Why more financial support isn’t made available for people caring for loved ones in their homes. They are saving the NHS thousands by taking on this caring role yet there is little financial help along the way. Of course this isn’t viewed as a job to the family but more help should be made available.”

Bereaved carer/family member/friend/volunteer working with people in the last few years of life

“I worry about working and caring for my husband when he becomes very ill. I can take some carers leave one week a year, but I know this will not be enough. Part time work would mean a pay cut, it is a worry.”

Carer/family member/partner/friend of someone in the last few years of their life

2.3 Supporting families

Many people talked about the support needs of families when patients are approaching the end of life. Concerns were expressed about accessing available support with calls for increased provision of: support for the emotional wellbeing of families, support that enables family-based care at home and professional support and equipment in the home. Respondents called for improvement in several areas:

- Better co-ordination of care packages
- Improved communication between families and health and social care professionals
- More focused responses to the needs of different family carers.

“As a carer to my husband when he was dying, I would have liked more to have made more informed decisions, based on his illness. I found it impossible - we had a baby and a toddler at the time he was dying and I felt utterly alone. Everything I did was a struggle and a fight. It was bad enough watching my beloved husband die, but insult was added to that by being made to feel that our wishes were not being listened to.”

Bereaved carer/family member/friend

“I cared for him (father) for 16 weeks, while continuing my job as a hospital consultant physician and supporting two teenagers. The care involved personal care, laundry, cooking and making beds for multiple visitors and being a personal assistant. I was relieved by Marie Curie Nurses for four nights only and my children and husband did some nights so I could sleep. I suffered severe back pain from trying to catch him as he fell. We kept to his wish of staying and dying at home. Although I kept saying I was finding it difficult to cope, there was no other support available. As a doctor, I know how to keep going long after I am too tired, but after his death it took many months of specialised help for me to recover. If I had had more idea of what it involved and more support during the process I suspect I could have avoided the resulting problems for me. As an oncologist, I am familiar with end of life planning, but found the actuality of experiencing it without adequate support extremely challenging.”

Bereaved carer/family member/friend;
professional working with people in the
last few years of life



Alex Rath/Thinkstock

2.4 Supporting staff

A number of survey respondents suggested the need for provision of support – to staff who care for patients towards the end of their life and for the families of those patients. Both professionals and family members expressed concerns about professionals' wellbeing. Many respondents expressed concern over a lack of support, education and training for staff who are caring for patients with a terminal diagnosis and their families.

“How much training do clinicians (particularly consultants) receive about discussing death/dying, emotional support, and caring language? Is there an ongoing professional development requirement for this?”

Member of the public who has an interest in the subject

“In the nursing home I often feel unprepared and lacking confidence about providing end of life care to people with illnesses such as MS and MND. How can I develop these skills - are there specific skills required to care for these people at the end of life?”

Professional working with people in the last few years of life

“Palliative care is still aimed largely at cancer patients. I am dying from liver disease. The issues I face therefore are working with Drs and nurses who are cancer care specialists but not expert in liver issues. Also cancer tends to be more stable whereas liver, kidney and other such issues can be very erratic. You can be at death's door one week and then ok again the next. I have not found my palliative care nurses helpful. They just want to chat but I need someone who can help me with practical problems I am facing.”

Respondent in the last few years of life

“Are staff caring for those in need of palliative care happy in their jobs, are they supported and given the right training and equipment to make their jobs as meaningful as possible? Is crying allowed? (Sometimes carers find it hard when a person they are caring for cries, they need to be supported and trained to meet the emotional needs that come with sad times.) Is laughing allowed?”

Carer/family member/partner/friend of someone in the last few years of their life

3 Service use

Service use was another major theme and was divided into three sub-themes to reflect concerns and experiences across three different areas:

- Access to services
- Co-ordination and distribution of services
- Out of hours and emergency support

3.1 Access to services

Difficulties in accessing specialist or routine services, equipment and therapies were mentioned frequently. This included the timing for introduction of these services, along with specific types of care and facilities. Many respondents were concerned with the lack of service provision for palliative and end of life care patients, their carers and families. The survey responses also highlighted the frustrations of some healthcare professionals about patients' and families' inability to access the services.

“Is respite care so impossible to organise?”

Bereaved carer/family member/friend; member of the public with an interest in the subject

“Why are things so slow? We found services and equipment arrived late, when condition was deteriorating too fast, no one jumped ahead in preparation.”

Bereaved carer/family member/friend; health professional with an interest in the subject

“When a patient is in a hospice or hospital they have access to equipment suitable for their needs, electronic beds, moving mattresses, hoists etc., will all this be available should the patient want to stay at home? This could include exercise equipment and aids to keep the patient mobile as long as possible.”

Bereaved carer/family member/friend (has a family member who has just passed away and another relative who has just a short time to live); member of the public who has an interest in the subject

3.2 Co-ordination and distribution of services

Many respondents called for joined-up or integrated services. There was concern that patients' quality of life and death may be severely affected by the lack of co-ordination between health and social care providers. Many suggested that a keyworker or central hub might help to co-ordinate palliative and end of life care services.

Many people voiced concerns about the poor quality of care and support provided. The availability of trained and skilled care staff for patients and families was seen as a significant issue.

Respondents felt that palliative and end of life care services were not allocated fairly. Some described it as a 'postcode lottery' where patients may receive certain services if they live within a specific area. Others talked about a lack of palliative and end of life care for patients with non-cancer diagnoses, or discrimination against certain populations by age, sexuality, disease, nationality or rurality, amongst others.

“Who is responsible for me, the whole of me? Who is going to coordinate the care?”

Retired nurse in the last few years of life; carer/family member/partner/friend of someone in the last few years of life; member of the public who has an interest in the subject

“The whole support system needs to be co-ordinated more fully, too many agencies all operating differently and not always communicating with each other.”

Bereaved carer/family member/friend

“Why can't we have one nominated person to oversee all angles of a patient's care? It can be very disjointed when so many professionals think they are right”

Professional working with people in the last few years of life

“Patients suffering from cancer seem to have a lot of support networks/provision, whilst those with other life-limiting illnesses, eg motor neurone disease or multiple sclerosis, seem to be less well off in comparison.”

Professional working with people in the last few years of life

“Why is less help and support provided if the diagnosis includes dementia? If the diagnosis is solely cancer, greater assistance received. The reality is a greater level of support is needed if there is the dual diagnosis of cancer and dementia.”

Bereaved carer/family member/friend; carer/family member/partner/friend of someone in the last few years of their life

“I am a trans man... (words omitted for purposes of anonymity) My body, especially my genitals are different from ordinary guys. I worry about receiving care from untrained carers, especially for bathing and toileting and post toilet cleansing (omitted)... How can I ensure that any end of life carers receive training in advance of providing personal care if it comes to needing that.”

Respondent in the last few years of their life; carer/family member/partner/friend of someone in the last few years of their life; bereaved carer/family member/friend

“How can we increase Marie Curie support to patients and their families of varying nationalities? My experiences so far are that we cannot always offer the care needed within our communities in the patient’s preferred language and sometimes only language especially in deepest west Wales where a lot of the patients are very elderly and first/only language Welsh. This is also true of patients from different countries and nationalities.”

Professional working with people in the last few years of life; bereaved carer/family member/friend; carer/family member/partner /friend of someone in the last few years of their life

3.3 Out of hours and emergency support

Many survey respondents talked about the need for 24-hour and out of hours care. Most of these responses consider access to home care support and services to be a key priority. In particular, respondents struggled to understand why services were restricted outside normal working hours and were frustrated about this.

“Why does most support stop on a Friday? Palliative care is about delivering service 24/7 365 surely?”

Professional working with people in the last few years of life

“Families often report - that they feel unsupported at home. Unable to access a GP or palliative care services over bank holidays or if their own palliative care CNS is on holiday.”

Professional working with people in the last few years of life

“There is a severe lack of continuity, no weekend care from GP or Mac Nurses and why does end of care life treatment have to be given by charity? We have NHS which lets down those that need help in their final stage of illness.”

Bereaved carer/family member/friend

“Access to information, support and help 24/7 is essential, so why isn’t this the case? Amazingly enough, people don’t just feel sicker between 9am - 5pm Monday to Friday. Even if it was just a telephone support network, to let the patient know they have someone to speak to and that help is close to hand.”

Bereaved carer/family member/friend



Chris Renton/Marie Curie

4 Managing symptoms and medication

The responses and questions within this report highlight that many professionals and carers have questions regarding the most appropriate methods of assessing and managing symptoms, as well as medications in palliative and end of life care. Responses from families and healthcare professionals were about coping with symptoms, including pain, breathing difficulties, agitation, nutrition and hydration. The respondents talked about managing symptoms in the right way to ensure the best treatment and care for the patient. Many patients raised concerns that their symptoms and medications would not be managed well if they remained at home:

“I want to die at home, who will help me and my family with medications and symptoms? If I get frightened I do not want to go to hospital but who will help me?”

Professional working with people in the last few years of life

Some talked about conditions other than cancer, and were concerned that end of life services were not fully equipped to manage a range of diseases including chronic obstructive pulmonary disease (COPD), motor neurone disease and Parkinson’s disease.

“Parkinson’s Disease - as a GP I have some patients who are in residential care and reluctant or unable to attend hospital appointments. There is a visiting specialist nurse service but the nurse is inexperienced and will only visit very occasionally. All Parkinson’s medications in the BNF have the caution “should only be initiated or adjusted by a specialist”. This is impossible in practice. How can GPs be facilitated to improve care for this group of vulnerable patients?”

Professional working with people in the last few years of life

Others discussed broader issues in terms of the appropriateness of interventions such as pain control, sedation, hydration and nutrition at end of life.

“What is best / common practice with pain management? Does excessive morphine dosing hasten death? Is excessive morphine ‘deliberately’ used to hasten / ease death?”

Bereaved carer/family member/friend;
professional working with people in the last
few years of life

“When people are sedated, are they really unaware of pain / what is being done to them / voices of those they love / extraneous noise from adjacent patients and ward activity? Or are they trapped in a situation where they are aware, but cannot tell us? How do we know? How do we know when a person is unconscious rather than sedated?”

Carer/family member/partner/friend of someone
in the last few years of their life; professional
working with people in the last few years of life

“It is unethical to use sedatives to relieve my mother’s obvious distress. (Despite her advanced decision form clearly stating that she accepts any medical intervention aimed at alleviating pain and distress, even if it shortens her life.) I was told by a registrar that the BMA ethics only allow sedatives to be used to prevent people harming themselves or others. I dispute this. A sleeping pill is a sedative isn’t it? Palliative care uses sedatives.”

Carer/family member/partner/friend of someone
in the last few years of their life; member of the
public with an interest in the subject

“What support do people who are dependent on artificial support for feeding/respiration get when they face decisions around continuing/withdrawing support?”

Professional working with people in the last
few years of life

“My father lost his swallowing reflex eight days before he died. For the last 6 days of his life he had no food or liquid - apart from any moisture on oral care sponges. Would he have suffered from hunger and thirst?”

Bereaved carer/family member/friend



Kieran Dodds/Marie Curie

5 Understanding dying

The responses within this theme from professionals, patients and families alike highlighted the taboo or stigma of dying and the need to raise societal awareness to uncover the mysteries of death.

Many respondents expressed frustration with uncertainties around prognostication, lack of support for carers, difficult communications, recognising when death is near, and the inability to make appropriate preparations in time. A great number of respondents felt that a better understanding of what to expect would have reduced distress. This was emphasised by many survey respondents who had poor experiences of end of life care.

“I care for my wife who as I do desires to remain at home and only go into care as a very last resort. She seems to have a nagging question ‘I don’t know how to die’. She feels unable to elaborate on the statement.”

Carer/family member/partner/friend of someone in the last few years of their life

“Why is it still so difficult for professionals working in the acute setting to recognise when someone has begun to die and therefore delay referral to specialist palliative care where appropriate? Why is education/training in caring for the patient in the last days and hours not a mandatory session for all staff with a refresher every two years?”

Professional working with people in the last few years of life

“How does one know when the time is near? What are the signs?”

Bereaved carer/family member/friend

“Is it very hard to know when an illness is ‘terminal’? We had no idea how close my husband was to the end of his life - either that he had weeks to live or, at the end, days. This would have helped to know, also his sons weren’t able to get to the hospice to see him before he died as ran out of time (he had bowel cancer and died five months after diagnosis, aged 47).”

Bereaved carer/family member/friend

“I have terminal bowel cancer, first diagnosed four years ago. I have very little idea of what my final periods will be like, whether I will suddenly become very ill, how long that is likely to last, whether it will be the cancer or an opportunistic infection that actually kills me and what my needs for care are likely to be. I understand that professionals can only make guesses about all this but I find them oddly unwilling even to discuss what is probable.”

Respondent in the last few years of their life

“I did not know what was involved in dying until a Marie Curie Nurse gave me a booklet one day before my mum died. I was scared. I knew she was dying but I did not know how it would happen. Had I known in advance I would have been able to help more I’m sure of it. My mum wanted to stay at home and I was alone with her. It was terrifying and without the support of the Marie Curie Nurses I would not have coped. Someone should have told me about the course that was being adopted by the doctors and why and what it involved. Someone should have told me that equipment could have been brought to the house to ease going to the toilet and bed sores. Someone should have told me that I could access Marie Curie Nurses to help at night. All of these things I found out about at the last minute. I needed to know weeks in advance.”

Bereaved carer/family member/friend

“With terminal kidney failure my 92-year-old father had to struggle on until he eventually died of pneumonia. He was allowed the morphine drip but nobody was able to tell me when he would last be conscious enough to say a proper goodbye, so he died alone in his care home and was carted off to the wrong undertaker because nobody wanted to speak about him actually dying. A miserable end to a long and relatively happy life. Why on earth cannot the last few days of a life be managed as thoroughly as every other conceivable aspect of one’s life?”

Bereaved carer/family member/friend

“How can a patient like me with terminal cancer work out where they are on their journey to end of life? Sometimes clinicians are reluctant to answer the question ‘how long have I got?’”

Respondent in the last few years of their life

“How can we change still further the problematic social stigma of death and dying?”

Professional working with people in the last few years of life



Simon Rawles/Marie Curie

6 Perceptions of palliative care

This theme focuses on difficult ethical areas of end of life care. Many people asked about the purpose of palliative care and terminology, while raising the difficult topics of assisted dying and euthanasia. Others commented on whether it was right to use aggressive or ineffective treatments in the transitions between active management of disease, palliation (ie treatment) of symptoms and end of life care.

“I never knew that palliative care could be just for very poorly patients, not always people on the brink of death. My husband received palliative care at [names hospital]. Could more people be made aware of this? It might help reduce people’s stress when palliative care is first mentioned.”

Bereaved carer/family member/friend

“Do you save people’s lives?”

Member of the public who has an interest in the subject

“What is a hospice, surely it’s not just for the last few days of my life!?”

Respondent in the last few years of their life; bereaved carer/family member/friend; professional working with people in the last few years of life; member of the public who has an interest in the subject

“My mother and father were terrified by the word hospice and would not consider receiving help from a ‘death centre’. I would like more research on use of terminology in palliative and end of life care.”

Professional working with people in the last few years of life



Layton Thompson/Marie Curie

“How carers can cope with decisions by their loved one to hasten end of life by refusing food, drink or medications that would almost certainly prolong life.”

Bereaved carer/family member/friend who works for a charity supporting people with a life-limiting condition

“How to identify best practice to ensure cancer patients are correctly informed that future treatments are palliative and will not offer them a false sense of hope/cure?”

Bereaved carer/family member/friend; professional working with people in the last few years of life

“I have concerns about patients in the last years of their lives having interventional medicine prioritised over care. I am a hospital doctor and I have seen over the years how it has become more difficult to discuss with colleagues let alone patients and relatives that further investigation and treatment is unlikely to alter outcomes and perhaps should not be done.”

Professional working with people in the last few years of life

“Don’t give people false hope. Be realistic and honest.”

Bereaved carer/family member/friend

Discussion

This supplementary analysis has enabled a thematic approach to the PeolcPSP respondents' concerns, including the responses previously assessed as being out of the scope of the standard James Lind Alliance priority setting process.

The broad questions asked in the PeolcPSP priority setting process produced interventional questions in five themes, reflecting the respondents' experiences and priorities. This supplementary analysis adds a further important theme; 'Perceptions of palliative care'. This theme did not appear at all within the standard James Lind Alliance process, as no interventional questions could be identified within it. This shows the strength of the supplementary qualitative approach taken here in reflecting all areas of concern of the survey respondents.

When considering the range and frequency of the 83 longlisted questions that could be taken forward for research², it is clear, and not surprising given the emphasis on care interventions, that the majority of questions fall within the 'Managing symptoms and medication' theme (32 longlisted questions). This is followed by 'Service use' (27 longlisted questions).

'Service use' is also the major theme emerging from the supplementary methodology. It further expands on issues around equity and professional roles. 'Communication' (which has produced three longlisted questions) is the second largest theme and captures several ethical or moral dilemmas experienced by the survey respondents. The 'Support' theme (18 longlisted questions) further illuminates the questions within the PeolcPSP longlist. However, it also includes issues around financial support, which was not covered by the original longlist.

Many of the questions highlighted by this thematic approach will be best answered by social scientists using non-interventional research designs for earlier stage work into knowledge, attitudes and perceptions of the overarching topics. In terms of the PeolcPSP top 10 questions, the number one priority is out of hours care with the published question comprehensively covering all of the issues expressed by respondents. However, a thematic analysis of this area further uncovers the experiences, attitudes and anger of healthcare professionals, families and patients at this frustrating lack of resource.

The respondents of the PeolcPSP survey were asked to respond to big questions. In return, they gave big answers often with highly personal narrative accounts in illustration of their concerns. The dual approach of the PeolcPSP protocol and the thematic approach described in this report has appropriately explored the entire dataset in recognition of the time and personal effort given by the survey respondents.

Conclusion

The focus of the James Lind Alliance process was to establish respondents' priorities for interventional research. This exercise has explored the full data set, which future Priority Setting Partnerships might consider exploring in addition to their standard priority setting plan which identifies interventional questions. However, it must be acknowledged that this type of analysis is a resource-intensive exercise and requires researchers with the appropriate skills.

It is striking that there was one theme, about perceptions of palliative care, which had not resulted in any interventional questions in the initial standard analysis, but includes important questions about what palliative care is and its wider role. It also includes questions asked about the balance of hope for a cure and the acceptance of dying.

Many of these questions will be best answered by research that is undertaken by social scientists to try to understand more about how we can improve the experience of death and dying for all. The results of the supplementary analysis reinforce the call for further investment in palliative care research, in this case in particular about societal aspects of living with a terminal illness and ultimately the end of life. This supplementary analysis has been supported by the Economic and Social Research Council (ESRC) and we hope that more social science research funders will come forward to invest in the topics described in this report.

Inevitably, the wide-ranging topic of palliative and end of life care has revealed many sensitivities requiring thoughtful treatment of the survey data. Looking forward, this approach could be considered for future priority setting exercises in similarly complex or broad areas, such as mental health or the elderly.

Recent reports confirm that palliative and end of life care is an under-resourced and under-researched specialty. Funding for research in palliative and end of life care in recent years is below 0.7% of the total spent on cancer research in the UK⁴ and end of life care research represents 0.16% of health-related research⁵ in the UK.

A recent report from the London School of Economics and Political Science (LSE) *Equity in provision of palliative care in the UK*⁶, commissioned by Marie Curie, describes the shortage of specialist palliative care services and the difficulty in accessing social care. This is further confirmed by the findings of this report.

More than 110,000 people affected by terminal illness in the UK are missing out on the care and support they need each year. Seven out of 10 carers say that people with a terminal illness don't get all the care and support they need⁷, while only 15% of health and social care professionals think people with a terminal illness have their care needs adequately met by emergency services.

Much of the content of this report is focused on service provision and it is clear that further investment is much needed. This should include alternative service models to address the priorities for care that patients and families find most important.

The PeolcPSP has already made an impact in highlighting the need for further investment in palliative care services and research. We very much hope that this supplementary report continues to highlight the attention required for services to ensure that more people are able to access the help they need.

Acknowledgements

We are extremely grateful to the survey respondents for sharing their opinions, thoughts and emotions about really difficult experiences.

We thank the research team (Jordan Van Godwin, Dr Stephanie Sivell, Dr Jessica Baillie, Dr Emily Harrop, Dr Despina Anagnostou, Rosie Nelson and Dr Anthony Byrne) for the sensitivity and skill they showed in collating

the themes from a large and complicated dataset, and Katherine Cowan from the James Lind Alliance for her guidance throughout the process. We thank Dr Sabine Best and Dr Angela McCullagh for providing helpful comments on this report.

Finally, thanks go to all the co-funders and stakeholders of the PeolcPSP, in particular the ESRC who gave funding to produce this report.

Glossary

BMA	British Medical Association	JLA	James Lind Alliance
BNF	British National Formulary	LSE	London School of Economics
CCG	Clinical Commissioning Group	MND	Motor Neurone Disease
CNS	Clinical Nurse Specialist	MS	Multiple Sclerosis
COPD	Chronic Obstructive Pulmonary Disease	NHS	National Health Service
DN	District Nurse	PeolcPSP	Palliative and end of life care Priority Setting Partnership
ESRC	Economic and Social Research Council	PSP	Priority Setting Partnership

References

- 1** *The James Lind Alliance Guidebook*, Version 6, February 2016, available from jla.nihr.ac.uk/jla-guidebook/ accessed 1 March 2016.
- 2** *Palliative and end of life care Priority Setting Partnership (PeolcPSP) Final Report*, 15 January 2015, available from www.palliativecarepsp.org.uk/finalreport/ accessed 1 March 2016.
- 3** Fallon M and Foley P, *Rising to the Challenge of Palliative Care for Non-malignant Disease*, *Pall Med* 26, 99 (2012).
- 4** *Marie Curie's Contribution to Palliative and End of Life Care Research Funding in the UK – An Analysis of the NCRI Cancer Research Database, 2002-13*, available from mariecurie.org.uk/ncri accessed 23 May 2016.
- 5** UK Health Research Analysis 2014 (UK Clinical Research Collaboration, 2015) ISBN 978-0-903730-20-4 hrcsonline.net/pages/uk-health-research-analysis-2014
- 6** London School of Economics (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*, www.pssru.ac.uk/archive/pdf/4962.pdf
- 7** On behalf of Marie Curie, Ipsos MORI interviewed a quota sample of 1,067 adults aged 16-75 online who had cared for a family member, friend or neighbour who was, or is, terminally ill in the last three years.

Appendix 1 – Methods

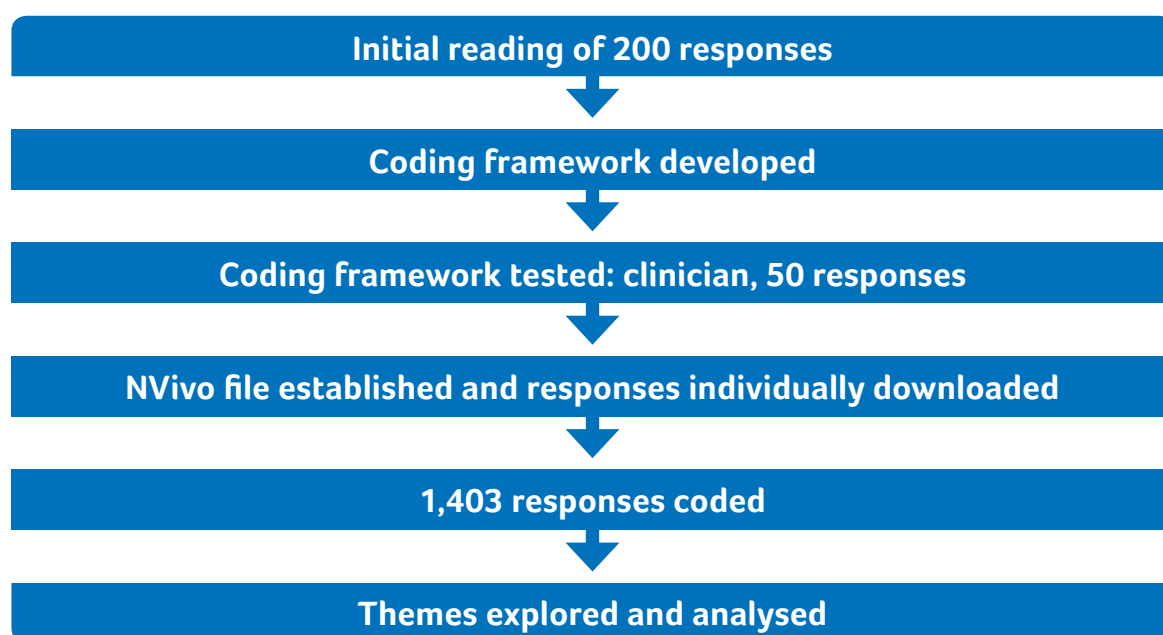
The Marie Curie Palliative Care Research Centre (MCPCRC) at Cardiff University was responsible for analysing the information in the PeolcPSP dataset to explore the worries, questions and experiences of a wide variety of people.

Managing and coding the data

We looked at each comment in full. To organise the information, we developed a series of categories that best described the comments. Then, we grouped all the responses into similar categories and sub-categories. This is called thematic analysis. To do this, we firstly developed what is known as a coding framework.

Coding framework

To create the coding framework, we first reviewed 200 printed copies of the survey responses. The framework was then tested on 50 survey responses by a doctor to confirm that it reflected the data accurately. After this, researchers entered the coding framework into a software programme (NVivo) to help catalogue the data. They then systematically coded the survey responses.



For more information contact:

If you have any queries or comments, please contact the Project Co-ordinator on peolcsp@mariecurie.org.uk

For more information on the project process, news coverage and partners and to download the full report, go to www.palliativecarepsp.org.uk



@PeolcPSP

Palliative and end of life care
Priority Setting Partnership

SUPPORTED AND GUIDED BY



IN PARTNERSHIP WITH

