

Public awareness of palliative care

Report of the findings of the first national survey
in Scotland into public knowledge and understanding of
palliative care

December 2003

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Foreword:

This report is extracted from the findings of a national survey undertaken by Jennifer Wallace on behalf of the Scottish Partnership for Palliative Care and in part requirement for the degree of M.Phil in Social Science Research, The Graduate School, University of Glasgow, September 2003.

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I. Introduction

Identifying public awareness of palliative care

This report outlines the findings of a national survey of public awareness of palliative care. The majority of social research on this subject explores the wishes of those already diagnosed with a terminal illness and their families, to ensure that services are designed to meet the needs of those affected. However, the exploration of palliative care has not extended, to date, to the knowledge and understanding of the Scottish population. It is this gap in knowledge that the research presented here aimed to fill, by attempting to identify current levels of awareness of palliative care within the Scottish population.

The research aimed to identify what are the current levels of knowledge of palliative care and what factors contribute to this knowledge. It also asked a number of additional questions relating to who respondents think should receive palliative care, what they think palliative care should consist of, when they would want information on palliative care and whether respondents feel that in the Scottish community there is sufficient discussion of issues surrounding death and dying.

Raising public awareness of palliative care

Why does it matter whether people are aware of palliative care? Discussing and planning for end of life care can be upsetting, and individuals may prefer not to be informed of the issues until a time when they might require such care. Research conducted by the National Hospice Foundation in America in 1999 highlighted the lack of discussion over end of life care:

The entire topic of how we want to be cared for when we are dying makes us uncomfortable. It's difficult for us to even think about having that conversation, and that's a problem. We must familiarize ourselves with the options now in order to make the best decisions later.

(Lazarus, S. 1999, www.hospiceinfo.org).

From the literature, there are three identifiable arguments for raising the public awareness of palliative care :

- improving access to services,
- empowering patients and
- involving communities.

Firstly, a lack of awareness of palliative care services can lead to negative impressions of end of life care and reduce doctors' willingness to recommend such care when necessary. As Gilhooly, Murray and Berkely (1991) point out:

Doctors might be reluctant to refer patients to hospices if they are viewed as 'death houses'.

(Gilhooly, Murray and Berkely, 1991, pg. 165)

Gilhooly, Murray and Berkely (1991) go on to discuss how these negative perceptions were also present within the public suggesting that individuals themselves may be less likely to accept such care if offered. Their findings were uncovered during exploratory interviews and suggest that lack of public awareness, and awareness within the medical profession, may reduce the likelihood of patients accessing these services.

The second, related, reason for improving public awareness of palliative care is linked to the 1980s and 1990s policy of increasing 'patient power', by informing patients of their choices and encouraging them to take an active role in their care. Croft and Beresford (1990) describe the attitude of the British medical profession as "*doing things to people rather than with people*" (1990: 5). Their 'liberational' model views health services as civil and human rights. This model is faced with an obstacle identified by many writers on the subject (see, for example, Croft and Beresford, 1990, Lindow and Morris, 1995), that of unequal power relationships between doctors and patients.

Within the medical model of disability (Oliver, 1990) this is seen as a product of the view of disabled people as 'deficient' and therefore allowing the medical profession to prescribe treatments that they, in their professional expertise, see fit.

This imbalance is described by Lindow and Morris as highly significant in the way that services are provided:

The judgements that workers in community care organisations make, whether they are based on a medical model of disability or on moral judgements about what someone 'should' be doing ... would not be so significant if it were not that professional expertise is often seen to be more authoritative than the judgement of the individual service user.

(Lindow and Morris, 1995: 9)

This imbalance began to be redressed following the reforms of the health service in the 1990s, most significantly with the introduction of a quasi-market in health care which allows individual service users to exercise choice in the services that they receive, and with the introduction of the 'Patient's Charter'. The Patients Charter includes the right to information on conditions and treatments, including information on the risks involved, detailed information on local services and information on complaint procedures (Farrell, Levenson and Snape, 1998: 19). However it does not discuss the information needs of those not currently using services or the population as a whole.

The importance of information for individuals is highlighted by a number of writers. Lindow and Morris (1995) note that the lack of information on services, by both service users and potential service users, means that the theoretical right to choice enshrined in the Patients Charter is not realised and the ability of individuals to exercise that choice is curtailed:

Lack of information is one of the main reasons for elderly people's indecision on many things which affect their lives. One never hears about too much information being given.

(British Pensioners Federation quoted in Lindow and Morris, 1995: 35)

Without this information, an individual's right to decide his/her own care plan is reduced, and as such individual empowerment cannot be achieved.

Thirdly, public awareness can be linked to notions of community involvement and empowerment. Palliative care, and in particular hospice care, came initially from voluntary sector hospices rather than National Health Service provision:

Charitably run hospices are set up and funded in large part by the local community. We market our skills and facilities in helping people to die with care and dignity and to live until they die. If members of the community find they do not have access to our services when and for as long as they need them, because theirs is not the right type of dying, or the right speed, or the right complexity, then they will understandably feel betrayed, and we risk losing their support.

(Praill, 2000, Pg 91)

The outcome of this has been to ensure that voluntary sector hospices and palliative care provision are accountable to the communities and populations that support them, as well as to the NHS boards to which they are accountable. Responding to the needs of the community is therefore an intrinsic element of hospice and palliative care.

Community involvement can be seen as more than staffing and funding. Community awareness and support is part of providing a holistic approach to end of life care for all, as David Clark (1997) concludes:

Public debate, education and understanding; community action and development; professional involvement and support: what could be more holistic?

(Clark, 1997: 190)

Previous research on public awareness of palliative care

To date, the public awareness aspects of palliative care have not received much attention from researchers in the field.

In 1987, three years before their definitive statement on the provision of palliative care, the World Health Organisation produced a small pamphlet on 'Palliative Cancer Care'. Amongst its many recommendations was a section on public education, reproduced here in full:

The public needs to know:

- *that Palliative Care will improve the quality of a patient's life, even through the cancer is incurable;*
- *that treatment exists for the relief of pain and for many of the other distressing symptoms that are*

- commonly associated with advanced cancer care;*
- *that there is no need for the patient to suffer prolonged intolerable pain or other distressing symptoms;*
- *how to obtain support from specialist Palliative Care services, should it become necessary and;*
- *where provision for day care and respite admission is available.*

(WHO, 1987: 21)

However, following this initial statement, no further statements from the WHO have discussed public education. This lack of action in this field led David Clark to note in an editorial:

I have been struck, amongst all the fascinating developments, by an interesting gap... overlooked in the hubbub is the neglected territory of public education. Who we might ask, has anything to shout about that matter?

(Clark, 1997: 181)

A large-scale study of public perceptions of end of life care was conducted in Canada by the Angus Reid Group in 1997 (Capital News Online, Feb 19th 1999). It showed that only 53% of respondents had heard of hospice palliative care, only 30% could define it and only 25% of those polled said they knew someone who had used or was using hospice palliative care services (Living Lessons Campaign, Canadian Palliative Care Association).

No such large scale investigation of public awareness of palliative care has been carried out in the UK. There are, however, a number of small scale research projects that throw light on the field of enquiry. In 2001 Help the Hospices commissioned a survey of public perceptions of hospices in the UK. Its aims were specifically related to marketing hospices and related only to hospice care rather than to the wide breadth of palliative care services. This research found a high awareness of hospice care in the UK (92% aware of the term hospice with 61% knowing of the existence of specific hospices). However, 68% of respondents were unaware of what palliative care is. This research also highlights that there is less understanding of hospice care amongst younger age groups and lower socioeconomic groups and suggests also lower awareness in Scotland compared to the rest of the UK (Help the Hospices, 2001).

Two surveys on public knowledge of hospices, carried out by interviewing people on the street in Glasgow and Aberdeen, were carried out in the late 1980s and early 1990s (Gilhooly and Murray, 1991, Gilhooly and McCann, 1988). Both surveys found low levels of knowledge of hospices, but suggested that women and older people were more likely to be aware of the services on offer. Both these surveys were carried out in areas with local hospices and explicitly linked to these hospices. No information is currently available on what those living in areas not serviced by local hospices know or think about hospices. It should also be noted that these surveys focused exclusively on hospice care, rather than the wider field of palliative care.

We can therefore confidently conclude that there is a gap in current research surrounding public awareness of palliative care. The only Scottish studies reported in peer review journals were carried out over 10 years ago and themselves did not cover the whole Scottish population, or the whole range of palliative care services.

Research aims and methodology

It is this gap in research and knowledge that this project aimed to fill, with an exploration of the public's awareness of palliative care. While further research on the field is necessary, this survey aimed to provide basic information from which ideas for future work, both research and policy, can be developed.

The broad aim of the research was therefore to explore current public knowledge of and attitudes to palliative care. The specific research questions addressed were:

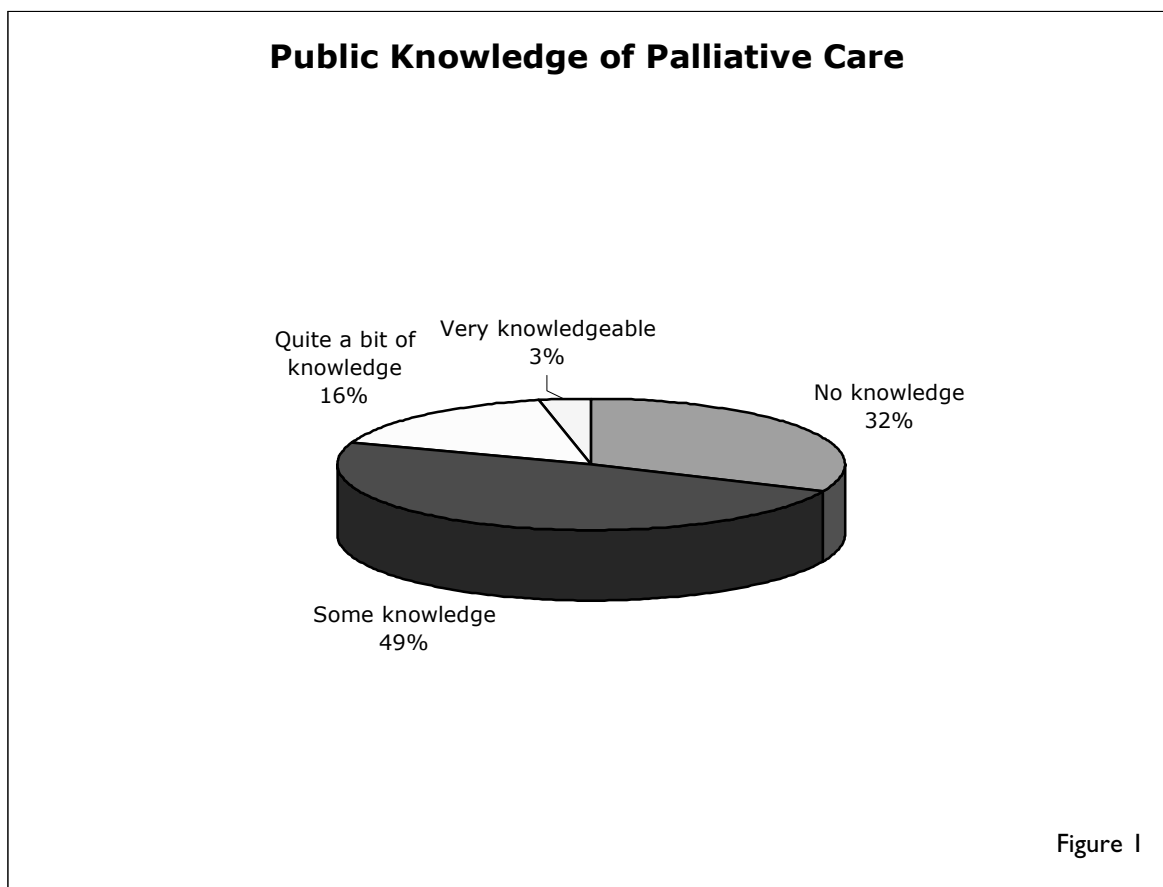
- to establish the current level of knowledge of palliative care
- to establish what factors contribute to knowledge of palliative care
- to explore attitudes towards palliative care.

The research was carried out through a postal survey. 3,000 individuals in Scotland were identified at random from the BT phone book (Scotland CD-ROM version). To ensure geographical representation stratified random sampling was used. Prior to the mailing of questionnaires, which were sent with a covering letter from the Scottish Partnership for Palliative Care, ethical approval for the research was granted by The University of Glasgow Ethics Committee. In total, 668 responses were received, a response rate of 22.3%.

2. Findings

Knowledge of Palliative Care

Overall the majority of respondents reported some knowledge of palliative care, with under a third reporting no knowledge. (Figure 1) Only a very small number of respondents reported a high level of knowledge of palliative care (n = 23, 3.5%).



Further analysis identified three variables with a significant relationship to knowledge of palliative care ($p < 0.05$):

- Work / ed in medical field
- Work /ed in palliative care
- Gender : women reported significantly higher levels of knowledge than men.

Of those who reported a level of knowledge about palliative care prior to receiving the questionnaire, the largest source of information was through a close friend or relative who had received care (n = 200, 30.2%), and the second largest source was working within a medical field (n = 87, 13.1%). In addition there were a small number of respondents who had themselves received palliative care (n = 7, 1.1%).

There were a large number of other responses (n = 61, 9.1%) which, for the most part, related to other caring professions such as social work (n = 7) or working for religious organisations (n = 4). There were also responses from people who work, or had worked as a volunteer for charities that provide palliative care (n = 9). The remaining responses cannot be categorised but include instances of people reading about it in books, finding information on the internet, or coming into contact with people who know about palliative care through their own work such as local grocers, researchers and owners of guest houses.

Who should receive Palliative Care?

Respondents were asked whether palliative care should be offered to people suffering from specific illnesses. (Figure 2)

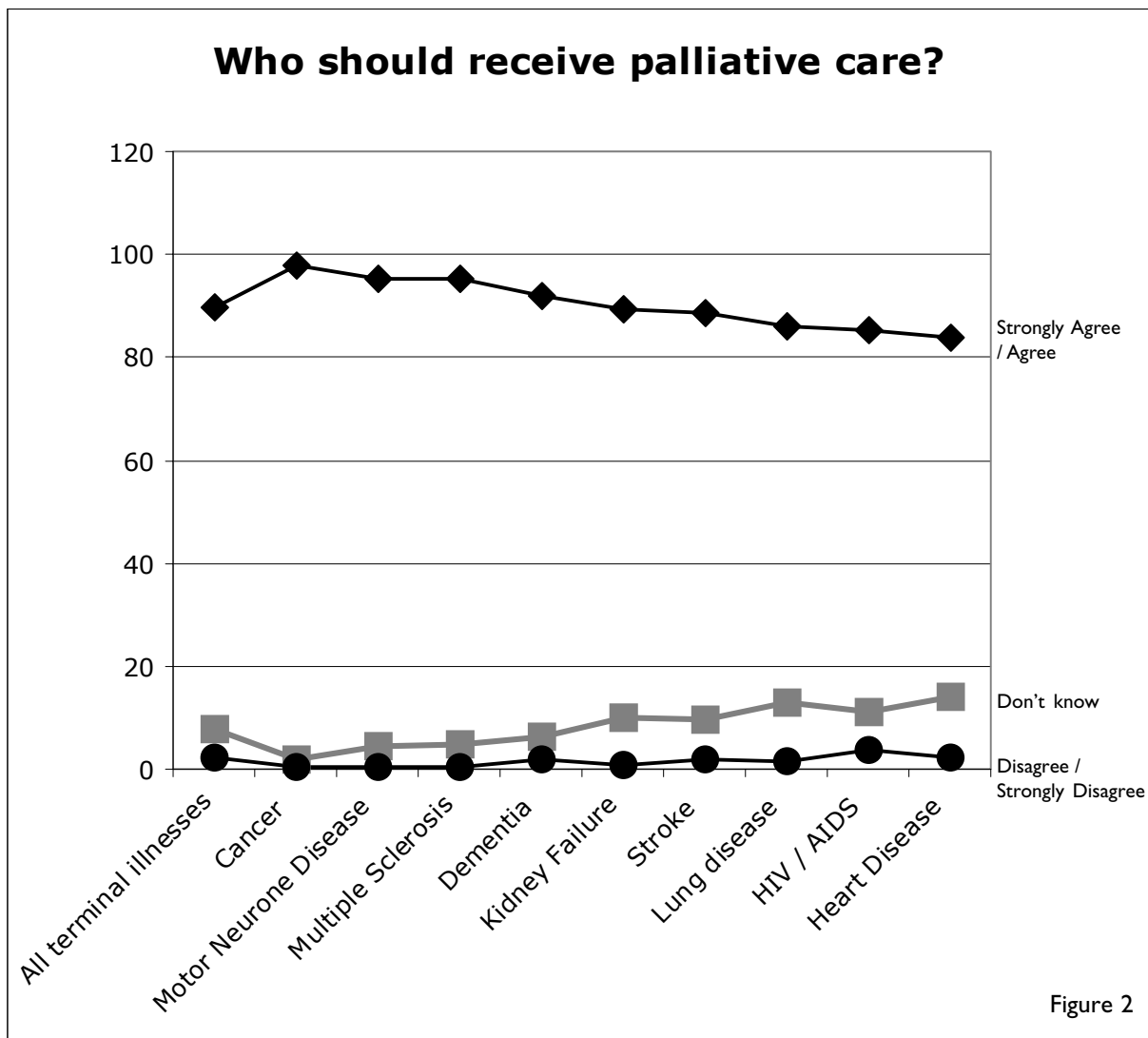


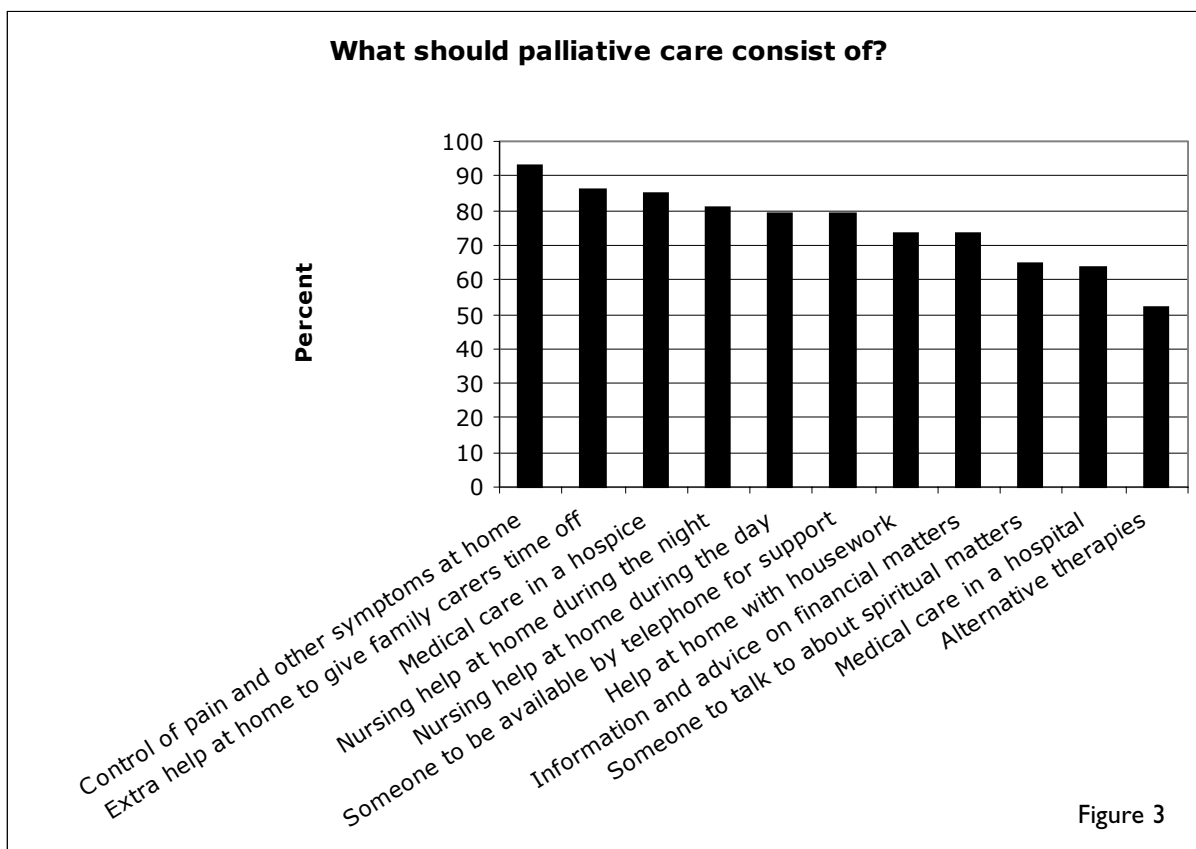
Figure 2

The vast majority of respondents (almost 90%) feel that palliative care should be offered to all those who have terminal illnesses. However, when asked about specific illnesses there appears to be a defined hierarchy within people's perceptions of need. For example, palliative care for individuals with cancer prompts not only agreement of the need for palliative care (97.7%) but the vast majority of individuals who responded 'strongly agreed' with provision for this group (77%).

Overall, very few respondents reported disagreeing with offering palliative care to those with specific diseases. Of these, HIV / AIDS elicited a more negative response with 20 individuals stating that palliative care should not be offered in this case. However this remains a very small percentage of respondents (3.7%). More common were individuals stating that either they did not agree or disagree, or that they did not know whether palliative care should be offered in the case of specific illnesses. In the case of heart disease and lung disease these 'unsure' options rose to (12.8 and 14.1% respectively).

What should palliative care consist of?

Respondents were asked to choose from a list of services what they thought should be offered to those suffering from incurable diseases and their families. (Figure 3 overleaf)



None of the options for services for terminally ill people were supported by fewer than 50% of respondents, showing a high level of approval for such services. In particular, pain control and extra help to give family carers time off were deemed necessary by over 85% of respondents.

While hospice care was felt by many to be an important component of care (84.7%), less wanted hospital care to be available (63.3%) suggesting that care in less formal surroundings was preferable for many people.

Advice and support were also seen as important, whether spiritual (64.7%), financial (73.2%) or practical (73.6%). In particular, individuals seemed supportive of a telephone advice line for people with terminal illnesses (79%).

Income has some impact on the services that people feel should be offered to those with terminal illnesses. For example, those with incomes over £25,000 were more likely to respond positively to the suggestion of offering alternative therapies and someone to talk to about spiritual matters.

These findings suggest that those on above average incomes are more likely to respond positively to services which could be described as 'luxuries'. This hypothesis is supported by the fact that there is no correlation between income and the main medical services such as pain relief and hospital care.

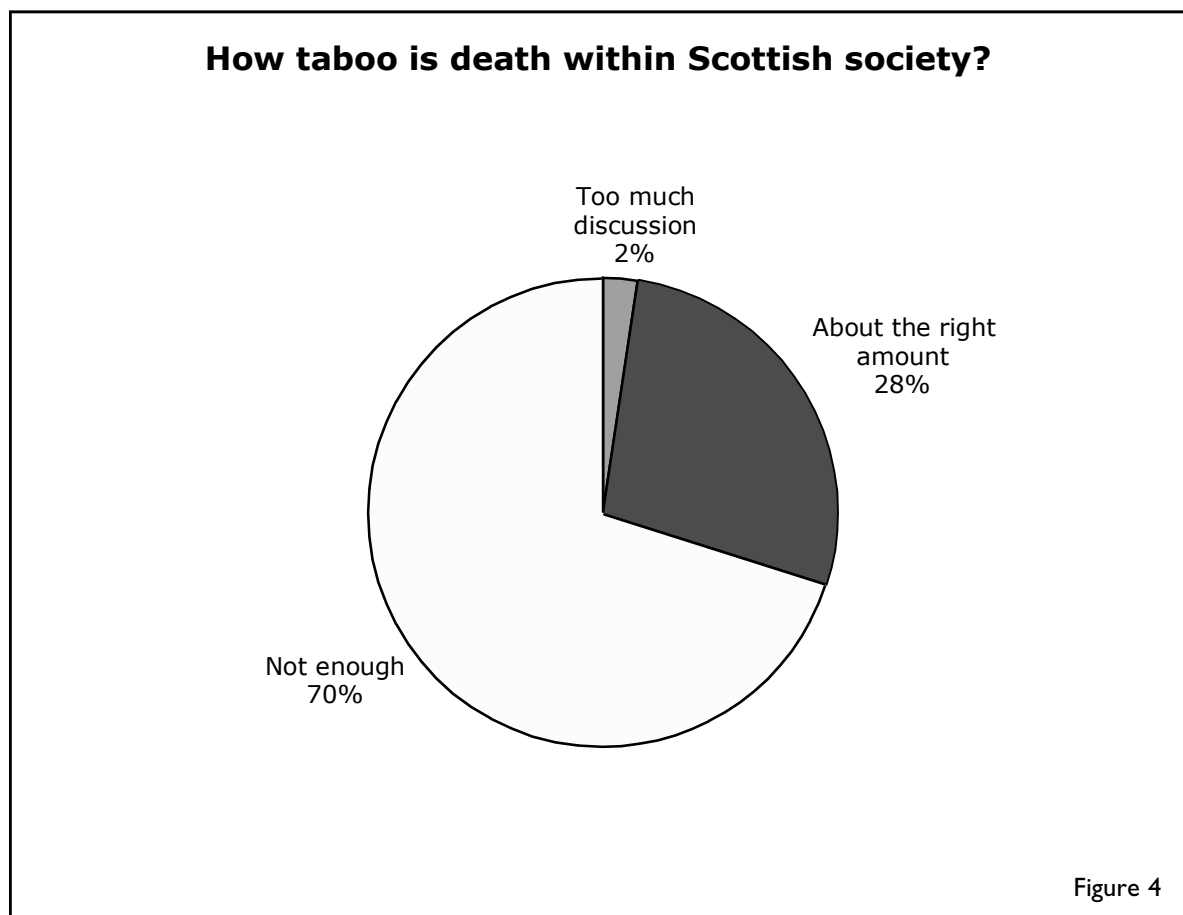
In addition, those who have quite a bit of prior knowledge, or who are very knowledgeable, about palliative care are more likely than expected to agree that someone to talk to about spiritual matters should be available to those suffering from incurable illnesses.

In a subsequent open question, the majority of respondents cited pain relief as important in end of life care (67%), with many stating this as their first, most important service (43%). The second most common service requested for end of life care was family support (34.2%), including respite services, support services and someone for family to talk to.

Respect or dignity were also commonly cited, with a similar percentage of respondents citing this across first, second and third choices (23% overall). When discussed in open answers this often revolved around being in control of the services offered and being treated as a human being by staff.

Almost a fifth of respondents (19.9%) highlighted that they would like to be able to stay at home for as long as possible, in some cases stipulating that they would like to be able to access nursing care at home or administer their own medication. This is also mirrored by the low numbers of respondents who stated that they would like hospital care (13 respondents overall, 2.1%). More individuals seemed to view hospice care favourably with 9.9% overall stating that they would like this service to be available to them.

How 'taboo' is death within Scottish society?



Respondents were asked whether they thought that as a community, we discuss death and dying enough. (Figure 4) The responses to this question show that the overwhelming majority of respondents did not feel that Scottish society discusses death and dying enough. Additional (unsolicited) responses to this question threw light on individuals' concerns:

Discussion is usually laced with fear and embarrassment. Not enough talk that is constructive.

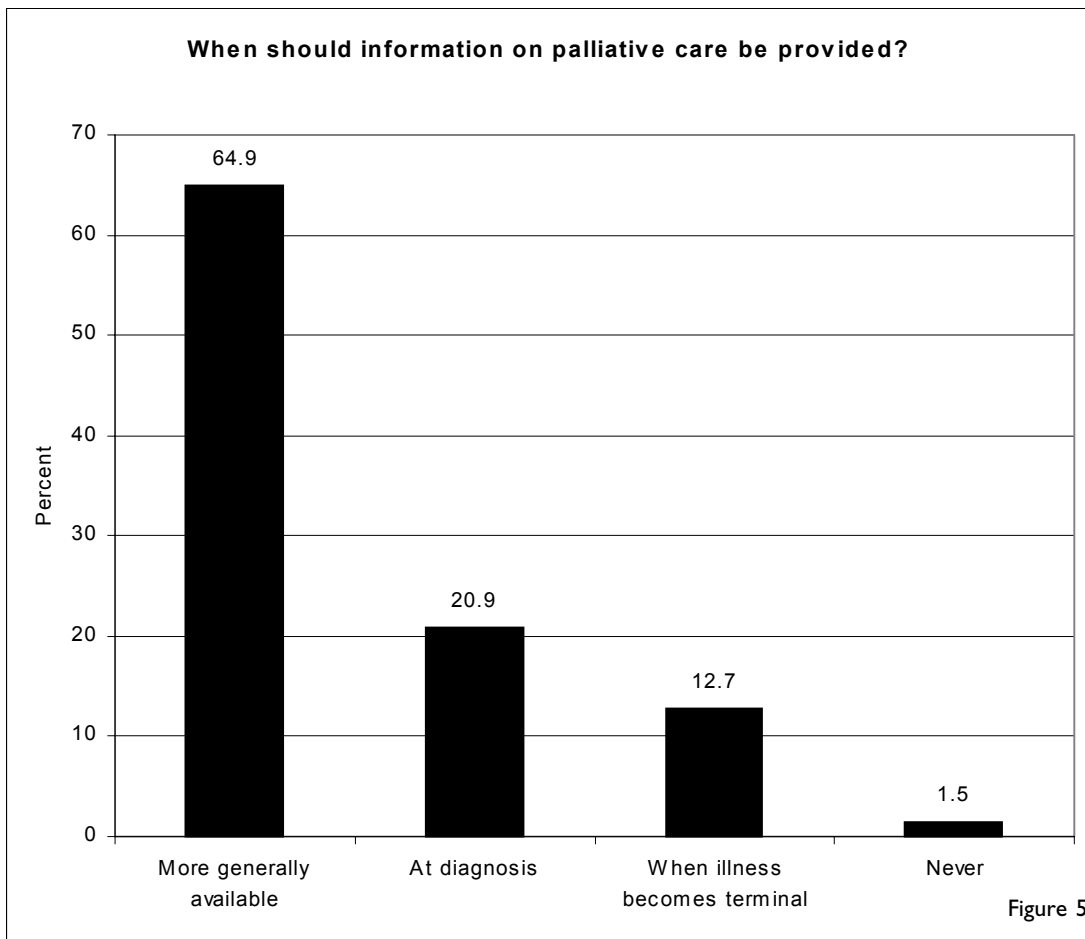
Too much pseudo respect and false sentimentality, not enough reality. We are all going to die one day so there's no point pretending otherwise.

Age had a significant impact on whether people felt that there is enough discussion of death and dying in Scottish society, with those over 60 years old less likely to respond that there is too little discussion of these issues.

Those who work in a medical field were more likely than expected to feel that there is not enough discussion of death and dying in Scottish society, though it is interesting to note that working in palliative care did not influence the response to this question.

When should information on palliative care be provided?

Respondents were asked when, if they had an incurable illness, they would want information about palliative care to be provided. (Figure 5)



The majority of respondents would like more information on palliative care to be generally available (64.9%). Of those who did not want information to be generally available, 20.9% wanted information at diagnosis of a life-threatening condition with only 12.7% wanting to wait until such a condition became terminal. Overall a very small percentage (1.5%) did not ever want information on palliative care.

Analysis of the impact of gender shows that women were more likely to want more information to be generally available than men, who were more likely to want information at diagnosis.

3. Discussion

In this section, the findings presented above are discussed in more depth and suggestions are offered for possible future research in this area.

Public knowledge of palliative care

This study elicited the views both of sections of the public who had prior knowledge of palliative care, and those who did not. In relation to the factors which contribute to knowledge of palliative care, it is perhaps unsurprising that working in a medical field or in palliative care increases knowledge of palliative care itself. It is also unsurprising that awareness of the experience of a close friend or family member also increases knowledge of palliative care.

This study also confirms the impact of gender already identified by Gilhoony and Murray (1991) and Gilhoony and McCann (1985), with women in general having a higher level of knowledge of palliative care. This relationship holds even when we control for the effects of other variables such as working in palliative care or in a medical field.

Public attitudes to palliative care

The findings referred to in the previous section throw light on what the general public thinks about palliative care. Most interesting is that the vast majority, over 90%, feel that palliative care services should be offered to all those with terminal illnesses. This research therefore supports the expansion of palliative care services into non-malignant diseases. However, there is also some evidence of a minority view that 'all terminal illnesses are equal but some are more equal than others', with heart disease, lung disease and HIV/AIDS all receiving less positive support than the other diseases listed. This could perhaps be interpreted as suggesting that a minority of the Scottish population are less likely to agree with the provision of palliative care services for those who could be seen as contributing to their disease through lifestyle choices (for example through lack of fitness, unhealthy eating and smoking and through engagement in 'risky' behaviours such as intravenous drug use and unprotected sexual activity). This finding should be interpreted with caution, however - the low numbers indicate that this is not a majority view, and ethical considerations must intervene in any suggestion that negative public perceptions might be used as a basis for the development of a strategy for health services.

In relation to what palliative care should consist of, support for family was seen as an important component of palliative care services, which suggests that the public desire care services for those with terminal illnesses to take account of family considerations. Similarly, over 70% of respondents agreed that information on benefits and financial matters was important as was practical help with housework. Respondents therefore saw end of life care as not confined only to medical matters such as pain relief or medical services, but extending also to the more practical everyday concerns of individuals and families.

Public attitudes to discussion of death and dying

As discussed in the introduction to this report, individualistic societies are not good at discussing death, finding the issue upsetting and difficult to confront. This research supports this view, with 70% of respondents stating that we do not discuss death and dying enough. By stating that there is not enough discussion of death and dying, individuals are also stating an opinion that there should be more discussion, with the implication that a more open attitude to these issues is desired by a majority of the Scottish population. This assertion is supported by the finding that 65% of respondents would like more information on palliative care services to be generally available.

Future research possibilities

Only a small amount of research has been carried out to date into public knowledge and public opinions of palliative care. This study therefore suggests a number of future research possibilities. The findings in relation to discussion of death and dying could be expanded by qualitative research such as focus groups or in-depth interviews which would allow for an exploration of how greater openness and discussion of such subjects could be fostered. Similarly, the findings in relation to the desire for further information on palliative care do not show how people want this information to be provided, which will be crucial if the palliative care field is to embark on a large-scale information provision strategy.

4. Conclusion

The specific research aims of this survey into public awareness of palliative care in Scotland -

- to establish the current level of knowledge of palliative care
- to establish what factors contribute to knowledge of palliative care
- to explore attitudes towards palliative care

appear to a considerable degree to have been met.

In addition, the survey findings confirm many of the existing views and policies within palliative care and point to possible directions and challenges for future development.

In particular there is confirmation:

- for the Scottish Partnership for Palliative Care's policy of promoting increased access to palliative care for all on the basis of need and not diagnosis
- that the general public's grasp of, and desire for the delivery of, a holistic concept of end of life care which embraces the physical, practical, social, spiritual and emotional needs of individuals and families may be considerably greater than has been realised
- that a majority of people would like to see issues of death and dying more openly addressed in Scottish society
- that a majority of people would like information about palliative care services to be more generally available.

Each of these brings with it a range of challenges for palliative care in the future including:

- * How can we best approach the challenge of incorporating palliative care into services for people with non-malignant progressive disease?
- * How can we ensure that holistic end of life care is available for people living and dying in their own homes and in a range of care settings?
- * How can we best encourage a greater openness in society to issues of death and dying? In what context and with and by whom could such discussion best be introduced?
- * How can we make information about palliative care more generally available in a manner, which will meet the needs of individuals? How can we ensure that it is in the right form, in the right place, and at the right time? Can we find an approach which recognises the different needs of people in different circumstances and with different levels of knowledge and awareness?

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Appendix A: Questionnaire

PUBLIC AWARENESS OF PALLIATIVE CARE

SECTION I: WHAT YOU KNOW ABOUT PALLIATIVE CARE

1. Before you received this letter how would you describe your level of knowledge of Palliative Care?

	Please tick only one
No knowledge	
Some knowledge	
Quite a bit of knowledge	
Very knowledgeable	

2. If you had heard of Palliative Care before receiving this letter, where did your information come from?

	You can tick more than one box
Have personally received Palliative Care	
Close friend / relative received Palliative Care	
Distant friend / relative received Palliative Care	
Neighbour received Palliative Care	
Friend discussed it	
Relative discussed it	
You work in Palliative Care	
You work in a medical field	
Radio	
Television	
Newspaper	
Magazine	
People collecting money	
Other (please describe)	

If you have ticked more than one, which source was most important in informing you about Palliative Care?

--

SECTION 2: YOUR OPINIONS

3. Do you think Palliative Care should be offered to people suffering from the following illnesses?

Please tick one box for each condition.

	Strongly agree	Agree	Do not agree or disagree	Disagree	Strongly disagree	Don't know
Cancer						
Kidney failure						
Motor neurone Disease						
Dementia						
Stroke						
Heart disease						
HIV / AIDS						
Lung disease						
Multiple sclerosis						
All incurable diseases						

4. Which of the following do you think should be offered to those suffering from incurable diseases and their families?

	<i>You can tick more than one box</i>
Control of pain and other symptoms at home	
Nursing help at home during the day	
Nursing help at home during the night	
Alternative therapies such as aromatherapy, reflexology, reiki etc	
Someone to talk to about spiritual matters such as hopes, fears, anxieties and beliefs	
Someone to be available by telephone for advice and support to patients and families	
Help at home with housework, shopping, transport etc	
Extra help at home to give family carers time off	
Information and advice on benefits and financial matters	
Medical care in a hospice	
Medical care in a hospital	

5. If you had to rank the three things which you would want out of end of life care, what would they be?

1
2
3

6. Do you think that as a community we discuss death and dying

	<i>Please tick only one box</i>
Too much?	
About the right amount?	
Not enough?	

7. If you had an incurable illness, when would you want information about Palliative Care?

	<i>Please tick only one box</i>
I would not want information at any point	
I would like more information to be generally available	
I would only want information to be provided if diagnosed with a life threatening illness	
I would only want information if a life threatening illness became terminal	

SECTION 3: ABOUT YOU

In order to find out whether different groups of people have different opinions we would like to ask some basic information about you.

8. How old are you?
(please tick one)

Under 20	
20 – 29	
30 – 39	
40 – 49	
50 – 59	
60 – 69	
70 – 79	
80 and over	

9. Are you male or female?
(please tick one)

Male	
Female	

10. What are the first 4 digits of your postcode (i.e. EH1 2)?

--

11. How many people in each of these age ranges live in your household?
(please tick one)

Under 20	
20 – 29	
30 – 39	
40 – 49	
50 – 59	
60 – 69	
70 – 79	
80 and over	

12. Please indicate your annual household income (before tax).
(please tick one)

Under £10,000	
£10,000 – £24,000	
£25,000 – £39,000	
£40,000 – £59,000	
Over £60,000	

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