

Pain in the *Have Your Say* survey

“I want to live and die in an Ireland where I can get relief from pain, no matter where I am being cared for or what condition I have”

[People's Charter on Dying, Death and Bereavement in Ireland 2017]

Have Your Say series paper 4



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INTRODUCTION

The Irish Hospice Foundation's (IHF) *Have Your Say* project was launched in 2016, coinciding with the Foundation's 30th anniversary (as well as with the 100th anniversary of the 1916 Rising and proclamation of Irish independence). The project presented an opportunity for Irish people to reflect, reimagine and remember what dying, death and bereavement mean to them, and consider what they felt was important. A core part of the project invited people to complete a survey in their own words about what concerned them, and what they wished for themselves and those close to them, when they thought of death and grieving. The survey received almost 2,600 responses. From this, a [People's Charter on Dying, Death and Bereavement](#) was drawn up, reflecting the main themes and trends, and highlighting what was of real importance to people.

Among the worries and concerns of respondents, one stood out: by far the greatest fear expressed was the fear of pain.

This was the most prevalent fear among respondents both for themselves and when thinking of the deaths of loved ones. There were 1,677 mentions of pain – making it one of the most common significant words in the survey dataset – distributed among 1,200 individual responses. Its significance for respondents is more fully appreciated when considering the occurrence of ‘stand-in’ words, such as ‘suffering’ ‘distress’ or ‘symptom control’, which collectively occur an additional several hundred times. While phrases like ‘symptom control’ might suggest a respondent with a level of medical literacy, the majority of responses dealing with pain were blunt: simply the word itself, or short phrases such as ‘pain free’, ‘relief from pain’, as hopes, or ‘dying in pain’ as a worry.

The prevalence of fear of pain in the responses was striking, and somewhat surprising. It raises important questions about the source of the fear. It might be instinctive, because dying is associated with a lack of control, or it could be based on the perceptions and experiences of relatives of those who have died. Some fear of pain may be rooted in media representations of dying. Perhaps the most crucial question is: How justified or misplaced is this fear? It is justified if pain at the end-of-life is common, but misplaced if it is controlled in the great majority of cases. Lack of knowledge or misconceptions about the realities of end-of-life and palliative care may play a role here: some responses to the *Have Your Say* survey suggest abiding misconceptions among the public. And, as will be discussed, the fear could be based partly on misperceptions – a mistaken belief by relatives that a dying person is suffering or that common symptoms of death must cause pain. There is some evidence (McKeown et al. 2010) of differences between clinical opinion and laypersons’ perceptions regarding the presence of pain at the end of life, and these too must be addressed. What is clear from the *Have Your Say* data is that the fear is real, and is widespread, and that dying is associated in the public mind with pain. A greater awareness of that fear, and understanding of its possible sources, would benefit healthcare professionals involved in end-of-life care, and addressing it more openly have many benefits for the public.

PUBLIC UNDERSTANDING OF PALLIATIVE CARE

The ideal of hospice care promoted by Cicely Saunders, founder of the modern hospice movement, was the management of ‘total pain’ (see Clark 2014; Mehta and Chan 2008). Total pain, a phrase coined by Saunders, comprises not only physical but also emotional, psychological, social and spiritual pain. Successful managing of this totality was Saunders’ vision (and to these, one could add bereavement support for surviving relatives).

This comprehensive vision of ‘total’ pain control notwithstanding, the first focus of pain management must be physical pain. Spiritual or psychological ease is especially difficult when a person is in physical pain. This is indicated in some *Have Your Say* responses, which imagine reduction of physical distress as a necessary way of clearing the space for emotional support:

[To have a good death, each person deserves] ‘to meet their death in a way that reduces distress as much as is possible, and allows for each person’s emotional needs to be met.’

[When I think about living with advanced illness or approaching end of life, what matters to me is] ‘that I have pain relief which will allow me to cope with the emotional side of end of life.’

When people speak of palliative care, it most often refers to the control or relief of physical symptoms – of pain and other distressful symptoms associated with any particular, life-limiting condition (e.g. breathlessness). Granted, forms of emotional pain and existential distress can manifest themselves as physical pain; but the ‘palliation’ of pain and other physical symptoms is a primary object of palliative care. Despite continually improved understanding among the public of palliative care, there are certain abiding misunderstandings. Perhaps the most common is that palliative care is only for cancer patients. This is reflected in some comments from respondents to *Have Your Say*: ‘People with cancer have good care but chronically ill elderly have little help’, said one response; another: ‘It used to seem that only those with cancer would receive hospice support, but what about e.g. dementia, where a patient’s surroundings matter so much? Yet very few get the chance to die at home with palliative care’; this was echoed by another: ‘Currently palliative care seems to be mostly for cancer patients and the swifter terminal diseases. What about support (less intense perhaps) for those with the longer, more lingering, yet terminal diseases such as Parkinson’s, COPD etc.?’. Another response noted the community could support the dying by: ‘Widening hospice care from those with cancer to people coping with the end period of any illness, or just death from old age’.

Another common misunderstanding is that palliative care is only for the very final stages of life – the last day or two before death is expected. In fact, palliative care can be recommended for anyone with a life-limiting illness who would benefit from expert management of pain and other symptoms; patients can also move in and out of palliative care. The American Society for Clinical Oncology guidelines now recommend integration of palliative care into treatment of advanced cancer, and a broad conception of palliative care is promoted in Ireland’s National Cancer Strategy (Smith et al. 2018; Department of Health 2017: 96).

Finally, there is a common, negative perception about palliative care, which equates it with ‘giving up’, conceding that hope is gone (Hawley 2017). In reality, palliative care can be recommended in tandem with other treatments, complementing them to manage symptoms.

The ideas that palliative care is for cancer only, or only for the very end of life, are among the main palliative care myths identified by the All-Ireland Institute of Hospice and Palliative Care (See AIIHPC Palliative Hub, n.d.). The AIIHPC coordinates Palliative Care Week on the island of Ireland with partner organisations including the IHF each year. There is evidence that public understanding continues to improve, but also that these and other misunderstandings persist – including among some healthcare professionals – and addressing them should be a definite point of national healthcare policy.

The fear of pain at end of life is likely based partly on misconceptions about palliative care. The expansion of palliative services, and the greater integration of palliative care into health planning, should be accompanied by further, coordinated efforts at public education which recognise and address the fear of pain.

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MANAGEMENT OF PHYSICAL PAIN

The importance of pain relief is acknowledged in international, collaborative statements such as the Lisbon Challenge (Radbruch, Payne et al. 2013) and Prague Charter (EAPC 2012; Radbruch, Lima et al. 2013). These call on governments to implement health and social care policies that will ensure the relief of suffering through adequate access to patient-centred palliative care in any care setting, throughout the world, and even advocate for enshrinement of palliative care as a human right. The World Health Organization meanwhile notes that ‘most, if not all, pain due to cancer could be relieved if we implemented existing medical knowledge and treatments’ (Amon and Lohman 2011).

While global inequities in access to palliative care services (including to medicines) are well documented (Conner and Bermedo 2014), the development of palliative and hospice care in advanced western societies means, according to some involved in these services, that very few people now face unmanaged pain at end of life. This is a position taken strongly by some professionals with literary or media profiles, including two of the most public faces and voices of palliative care, Sallie Tisdale and Kathryn Mannix. Tisdale for example has stated that research in hospice and palliative care suggests that only about one in a hundred people suffers uncontrolled pain while dying (2018: 84) – but it is not clear what research this figure is based on, and it would almost certainly be disputed. Similarly, the neurologist Sara Manning Peskin writes in a popular piece:

'Some symptoms, like the death rattle, air hunger and terminal agitation, appear agonizing, but aren't usually uncomfortable for the dying person. They are well-treated with medications. With hospice availability increasing worldwide, it is rare to die in pain' (Manning Peskin 2017). Kathryn Mannix offers a reassuring account for UK patients. In a blogpost for Marie Curie UK reporting a session with students in which she outlined the late stages of the dying process, regardless of condition, she closes with the comforting advice to the reader: 'We all need to understand how gentle the process of normal human dying is; in an odd way, it's good news' (Mannix 2019).

Such assurances, in popular forums, from professionals with public profiles, are an important part of spreading knowledge of end-of-life care. Mannix's blogpost, however, prompted a response from another writer and nurse with experience in hospice settings, which took issue with its optimism and insisted there was no 'normal' process of dying, Sarah Malik's counter-post asked: 'How can we possibly compare someone with sickle cell disease dying from a severe vaso-occlusive crisis, in pain that cannot be controlled while in a busy ward environment, to another in a hospice who has slipped, seemingly comfortable, into a minimally conscious state?' It further reminded of the inequities of access to palliative care in the UK, and that 'sometimes, despite the determined efforts of the best palliative care available, it isn't always possible to take away the pain and the suffering of a dying person' (Malik 2019). There are inequities in access to hospice care in Ireland, and specialist palliative team staffing in hospitals is not at recommended levels.

Malik's points are made forcefully, and like Mannix's, in the interest of public education. Some research does suggest that Tisdale's estimate of 1% of terminal cases with unmanaged pain might oversell the effectiveness of end-of-life care (Smith et al. 2010; Wilkie and Ezenwa 2012; Kobewka et al. 2017; Baillie et al. 2018). There is also the issue, mentioned by Malik, of inequities in access to palliative care. Generalist palliative care – that is, adequate pain relief provided by a medical professional not necessarily specialist or hospice care – may not be available to those who need it (Murtagh et al. 2014), and there is international evidence that it is less accessed by minority populations (Johnson 2013; Nawaz 2014). Perhaps another driver of the fear of pain at end of life so evident in the *Have Your Say* responses is a general perception of an inadequate health service – so, even if a person understood palliative care and what it could provide, they would not be confident it would be available to them if needed. Regular reports of waiting lists for services and the unavailability of beds in hospitals influence the perception, expressed by one *Have Your Say* respondent: 'The health service always seems like it's ready to collapse. How do they deal with people dying on corridors in A&E? What must that feel like for that person, and their families?'

It is possible the more optimistic views reflect the perspectives (and experiences) of specialist palliative care professionals, where those with generalist palliative training are more reserved about the quantum of unmanaged pain and symptom burden at end of life. These differing views serve well to highlight the difficulties the layperson faces in understanding what to expect. The reservations evident in Malik's response to Mannix also suggest some professional disagreement about how facts about death and dying should be communicated to a patient or the public. Further, the highly optimistic statements of Tisdale, Manning Peskin and Mannix would seem, given the evident prevalence of fear of pain at end of life, to hint at some level of disconnection between clinical opinion and public understanding.

The association between dying and pain is prevalent enough that any layperson would likely conclude that common experiences must lie behind it. This leads one to the question: Are there some people dying in pain when they should not be? Are there deficits in palliative care provision, and generalist training, which mean that people are dying with pain that ought to be managed? There would seem to be lack of expert consensus on the issue.

This apparent lack of consensus indicates a need for agreed outcome measures in end-of-life care, addressing management of pain and other symptoms. Though gathering data and eliciting feedback from palliative patients or bereaved relatives pose obvious challenges, without agreed metrics and standards for quality improvement, end-of-life care services cannot adequately measure their effectiveness. There may be reservations, stemming from US experience, about setting pain management as a core KPI, as it incentivises over-prescribing of strong opioids; this has been particular concern in the US (see IASP 2018; Berterame et al. 2016; Bruera and Del Fabbro 2018). These acknowledged reservations only mean that open collaboration and dialogue between clinicians and researchers is important, whether in methods of treatment or measurement of pain and its successful management (Colvin and Rice 2019). Such agreement on metrics will build consensus on what constitutes best practice in end-of-life and palliative care, and assist in public information and education; this can only serve the public well, and help to address anxieties about pain that the Have Your Say data show us are so prevalent.

FEAR, PERCEPTION – AND MISPERCEPTION?

This fear that the dying process is a painful one, so prominent in *Have Your Say* responses, has similarly emerged as an area of concern among the public in the IHF's public engagement programme of café conversations.

It was noted that the hard questions have to be asked about whether some people are dying with avoidable pain. We know that not all pain can be banished from the dying process; but we equally know that, where palliative care is integrated into a national system, pain at end of life should be much more manageable for a variety of conditions. Ireland is, in international terms, relatively advanced; it was ranked fourth in an international ranking of palliative care based on a study conducted by The Economist Intelligence Unit in 2015. So, while the hard question of whether there is avoidable pain for some people at end of life needs to be raised, a question also has to be asked whether fear of pain at end of life is often misplaced, or even based on common misperceptions.

Manning Peskin assured in her New York Times contribution (quoted above) that certain symptoms 'appear agonizing, but aren't usually uncomfortable for the dying person'. This statement implies that much of the fear of pain at end of life may be based on a misperception by carers and relatives of the suffering of a dying person. While the reported experiences and the opinions of relatives can never be discounted, there is, evidently, often some discrepancy between clinical opinion and public perception regarding levels of pain or discomfort.

Relatives' perceptions may of course vary. A major study of bereaved relatives carried out in the Mater Hospital and St James's Hospital noted that 'while pain is managed well for the majority of patients, for others, it does not appear to be the case' (Ó Coimín et al. 2017: 74). There is however an apparent tendency for relatives to perceive greater levels of pain in patients – rightly or wrongly – than do doctors and other medical staff. A 2010 IHF report on dying in hospital showed that, when compared with the opinions of doctors and nurses, relatives' perceptions of a patient's death registered higher levels of pain, breathing difficulties and anxiety (McKeown et al. 2010); another report showed that 13% of patients' relatives perceived their loved one was in pain all or most of the time during their last week of life (McLoughlin 2015: 17). It is noteworthy however that proxies such as relatives can tend to rate distress higher not only than doctors, but also than patients who self-report pain (Rand and Caeils 2015)

It may be the case that misperception or lack of understanding plays a role in a tendency of relatives to overestimate the pain or distress of loved ones. This in itself highlights a serious issue, and a need to support and prepare relatives and carers for their loved ones' deaths. Any gap between clinical perception that pain is well managed at end of life in all but a very small number of cases, and bereaved relatives' perception that a far higher proportion of patients endure uncontrolled or constant pain, would indicate this. It would also suggest a need for better communication with patients and families as well as with the public. Carers and relatives may feel disempowered by a lack of knowledge about the dying process and whether a loved one is suffering (Baillie et al. 2018). The perception that a loved one died in great pain no doubt contributes considerably to the distress of surviving relatives; if there are misperceptions about symptoms in play, it is important that better communication and education about the dying process addresses these (McKeown et al. 2010; Office of the Ombudsman 2014).

A study which asked bereaved relatives' about perceptions of quality of end-of-life care in hospitals and hospices found that hospice care was better rated, to a statistically significant degree, on eight of thirteen selected variables measuring satisfaction with care outcomes. While there were no significant differences in perception of pain or symptoms like breathlessness in the different settings, pain control was rated better by relatives whose loved one died in a hospice. It is perhaps significant that another of the variables on which hospice care scored higher for bereaved relatives was effective communication (Addington-Hall and O'Callaghan 2009). This study was published ten years ago, and management of pain in healthcare settings has no doubt improved. A report published in September 2019, however, estimating the prevalence of unrelieved pain in palliative patients, still shows better ratings for pain relief in hospices as against home or hospital; it also notes discrepancies between the amount of self-reported unrelieved pain and the assessment of its prevalence in clinical judgement (Zamora et al. 2019: 8).

The report from The Irish Longitudinal Study on Ageing (TILDA) of the end-of-life experiences of older people, conducted via a questionnaire administered to surviving relatives of deceased study participants, noted that 50% of participants experienced 'regular pain' in the last year of life (May et al. 2017: 11). It should be noted, however, that it was not asked whether the pain was adequately managed or treated; 'regular pain' need not mean debilitating pain, or that was more significant at end of life, and the figure does not necessarily indicate shortcomings in the management of avoidable pain.

Any discrepancy evident between relatives' and medical professionals' perceptions of patient discomfort or pain suggests that these professionals must address the issue of communicating the realities of what is happening and, as far as possible, what is to be expected during the dying process. This should apply regardless of the care setting – whether a patient is in a hospital, a hospice, at home or in residential care. Without such communication, with patients and carers and with the public, misunderstandings not only about the dying process but about end-of-life care options will be perpetuated, and the belief and fear that death and pain go together continue to prevail.

CONCLUSIONS

'Everyone has access to hospice and palliative care' – this, regrettably, also numbers among AIIHPC's identified myths about palliative care. Positive recent developments relating to palliative care in healthcare policy in Ireland – the publishing of the Adult Palliative Care Services New Model of Care, and the commitment to improved and expanded palliative services under the Sláintecare implementation plan – provide a platform for improving services and for addressing deficits in service provision, information provision and public understanding. There remain deficits in specialist and generalist palliative care. As with other health and social care services, the so-called 'postcode lottery' applies also to hospice care, with inequities nationally in access to inpatient specialist units (hospices, which will only ever serve a minority); and there is not yet sufficient resourcing of generalist palliative care in other settings. Adequate end-of-life care requires sufficient investment in and staffing of palliative resources for all healthcare settings, and for management of pain and symptom burden associated with any life-limiting illness, as well as work toward a consensus about patient outcome measures, quality indicators and metrics for improvement of care. This is becoming recognised and accepted, and we would encourage open collaboration nationally in the development of agreed measures for Ireland, and their gradual integration into palliative care policy.

As has been made clear above, there are also urgent informational, educational and communicational deficits regarding palliative care which need to be addressed. First, patients, family carers and relatives should be aware of what is available. They should further be able to understand what is happening in the dying process, and know what might be expected. National initiatives such as Palliative care week are to be commended and supported.

Finally, all aspects of the evidently widespread fear of pain need to be acknowledged, for the sake of patients and for relatives. Understanding palliative care may alleviate some fears, but effective communication with the public on a range of general issues is crucial. If, for example, it is the case that very few now die with unmanaged pain, this should be communicated to the public – without suggesting that all pain can be controlled. If feelings among relatives that a loved one died in pain are often based on misperceptions and lack of medical knowledge, this is certainly something of which medical professionals should be acutely aware and ready to address. If there is a disconnection between clinical opinion and public perception, this similarly should become a focus of education both of the public and professionals – and which would benefit both with more open dialogue. If the ideal of total management of total pain is to be realised, alleviation not only of end-of-life pain but of the fear of it – especially if that fear is uninformed – in patients and among the public, is required.



Note: We invite comment and discussion on the topics covered in these papers. Please contact paul.omahoney@hospicefoundation.ie with any queries or comments.

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