

Experience of Bereavement

The perspective of family, carers and staff

in collaboration with



December 2017 to May 2018



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Foreword

I am pleased to present the 10,000 More Voices Regional report on the lived experience of Bereavement. The project encompasses the experience of family and carers following the death of a loved one. It also explores the professionals experience following end of life care. This is one of a number of work streams on the 10,000 More Voices work plan for 2018/2019. The 10,000 More Voices Initiative is commissioned and funded by the Health and Social Care Board (HSCB) and the Public Health Agency (PHA) to introduce a more person centred approach to shaping the way services are delivered and commissioned. It is based on the principles of Experience Led Co-Design, which have been adapted into a robust and systematic model, through which patients, clients, family members, carers and staff describe their experience of receiving and delivering health and social care in Northern Ireland.

In “Health and Wellbeing, Delivering Together” (2016) the minister outlines the importance of a “new culture of partnership, involvement and listening” within a quality health and social care system. Using the 10,000 More voices methodology is one of the ways in which we can begin to embrace a new culture of partnership and collaborative working by integrating the information we receive into shaping and delivering services for the future. This project has given valuable insight into the impact of bereavement on an individual, a family, a carer or staff members. At both a local and regional level this will inform organisations on actions to enhance services in the management of bereavement. This acknowledged the unique perspective of the people using services and also recognises the importance of listening to the experience.

This project demonstrates the real and difficult experience of bereavement. I would like to personally thank everyone who contributed through the 10,000 More Voices survey and for all of whom openly sharing with us their story. Each story is valuable and will shape the delivery of bereavement care within health and social care in Northern Ireland.

Mary Hinds, Director of Nursing and Allied Health Professionals, Public Health Agency

Acknowledgements

The Trust Bereavement Coordinators and 10,000 More Voices Facilitators would like to express their heartfelt thanks to the many people who submitted a personal experience of bereavement. We are aware that this may not have been easy; however the valuable contribution of so many has enabled this report to be as comprehensive and rich as it is. As one respondent said, *“Having the opportunity to complete this anonymous survey has helped me as I needed to share my experience about the breaking of bad news.”*

Thank you also to the large number of HSC staff who submitted a story about a workplace related death or a personal bereavement. These stories provided an important insight into the impact of caring for a loved one at end of life, returning to work following a personal bereavement and working in an environment where death is a regular occurrence. We also wish to acknowledge the input of the Project Steering Group, which provided direction for the implementation of the project. Membership of the steering group is included in Appendix 1.

Many extracts from the stories and free text questions have been included throughout this report, some of which have been edited to ensure anonymity of participants. If you are interested in discussing any of the information presented please contact one of the Trust Bereavement Coordinators or 10,000 Voices Facilitator (Appendix 1).

“Losing your mum is like someone taking the steering wheel from your car. You become lost, it was a dark time but I have learned a way to laugh when I think about her because she was very funny. In a funny way I can still sense her round me, I feel the strength she is giving me to enjoy life, love my kids, not take things too seriously. So, although I miss her like mad and always will her death recalibrated my outlook on life...basically life is for living and your health is your wealth, enjoy it while you’ve got it.”

“Life goes on even though you lose a loved one. It’s a different life, but it is one that you learn to accept and find other reasons to go on”.

Demographic information

*demographic detail refers to the patient reflected upon by the respondent



Trusts

277 respondents to survey with 104 from BHSCT, 39 NHSCT, 36 SEHSCT, 46 SHSCT, 27 WHSCT and 25 other (e.g. Hospice and Macmillan)

Gender

182 surveys related to female patients and 90 were male. 5 respondents preferred not to comment.

Nationality

243 patients were born in N.Ireland, 14 from England, 4 from Scotland, 7 from Republic of Ireland and 4 were outside the United Kingdom. 5 respondents preferred not to comment.

Disability

93 patients were identified to have a disability. 13 respondents preferred not to say.

Time of story

Experiences shared varied from more than 5 years ago (41 responses) to less than 6 months ago (77 responses); the greatest proportion of stories were between 6 months and 2 years.



Analysis of surveys

Recommendations highlighted in the report reflect the key messages from the following data sources contained in the surveys



Responses to bespoke survey designed in partnership with key stakeholders. Questions are analysed using SenseMaker[®] software

Key messages from within the staff stories.

Key messages from the service user narrative

New findings and areas of reflection from within survey responses

Focused questions e.g. "What could have improved your experience at or around the time of death?" and "What could have helped you in your bereavement?"

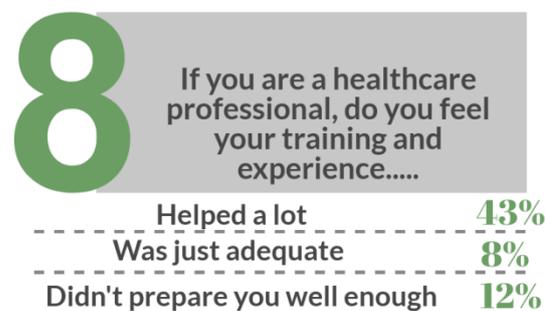
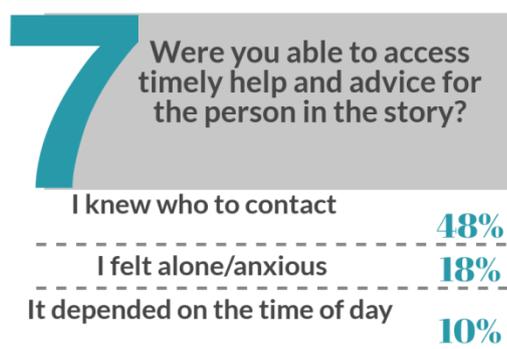
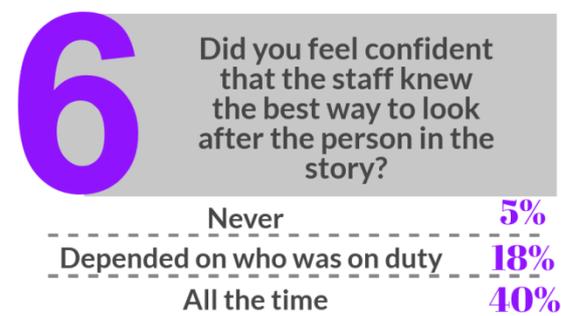
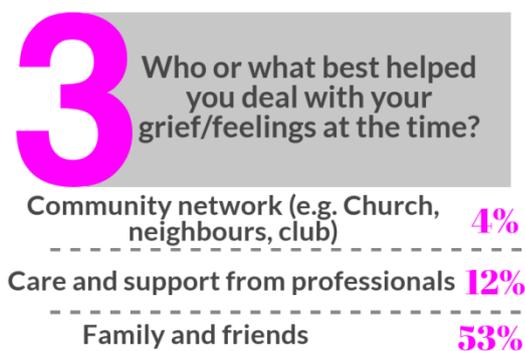
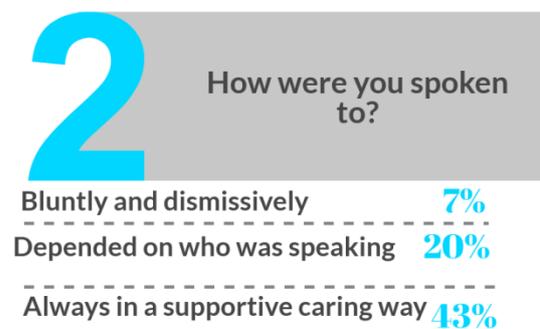
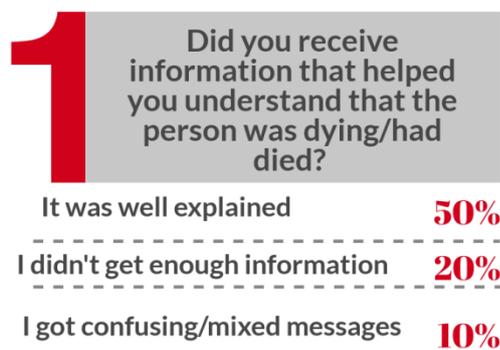
277 stories were shared. 216 were told by a family member (110 with a background in healthcare), 12 on behalf of a family members, 47 from the perspective of the health care staff delivering care to a patient. 2 respondents did not specify their connection to the story.



Data findings from patient stories using SenseMaker



*Percentages are reflective of the cluster responses only. They do not account for all responses scattered across a triad.



What was said

The following is an example of statements across the spectrum of strongly positive to strongly negative stories by patients and carers.



Worst day of my life, although the last 2 weeks he received great care from all the staff and were very helpful to myself and my 2 sons we never left his side day or night from the Wednesday until he passed away the Friday afternoon.

The care and compassion and communication with her family was poor at best and in all honesty I would be horrified if other families experienced this although not surprised.



We were provided with accommodation and made as comfortable as possible. When she passed away the most touching thing was that each member of staff on duty came in to pay their respects to her.

Their care, compassion and the way staff treated our mother from her first to last day in the home has been an enormous comfort to us. The way every care home should and could be.



When my husband was diagnosed...we were inundated with professional "help", social workers, OT, physiotherapists, etc. Once he died, all these people immediately disappeared. We have had no support or help.

The care that he received from the GP services, district nursing, cancer hospital and Marie Curie was excellent. I will never forget how they lovingly and willingly carried him and us as a family during his final months.



Key messages

Respondants were asked 2 open questions

- What could have improved your experience at or around time of death?
- What could have helped/did help you in your bereavement?

The following key messages summarise the responses

The standard of care provided to the dying patient has a direct impact on the family's journey of bereavement.

Training for both medical and nursing disciplines in the palliative symptom management and bereavement training.

A need to provide privacy for the patient and the family.

Patients who are actively dying should remain in the ward environment they are familiar with. Patients should not be moved between hospitals or wards.

Daily communication from senior staff on the patient's condition with time to discuss any treatment/care.

Practical arrangements for the family such as flexibility around visiting times, car parking validation, comfortable seating, refreshments.

Need for more consistent provision of written bereavement support at the time of death.

Better provision of palliative care in the community setting with package of care and access to district nursing.

A proactive approach to managing the patient at home with a key coordinator for daily contact.

Easier access to assistance during "out of hours" period including public holidays and weekends.



Recommendations

STRATEGIC: For HSCB/ PHA

In collaboration with HSC trusts the Regional Palliative Care board will consider and support recommendations in relation to bereavement support

- Review and development of training in all aspects of end of life care and bereavement, which should encompass all healthcare professionals who care for the dying patient and support those closest to them.
- Development of guidance to support staff, across all settings, to plan, implement and evaluate care for the dying patient, in partnership with those important to them (family, carers, close friends)
- Further exploration of the bereaved experience in relation to defined contexts such as loss through suicide, loss in pregnancy/miscarriage or loss in trauma

ORGANISATIONAL: For Trusts

- Staff who support dying and bereaved people receive communication skills training. This should include communication of emotional support to relatives when caring for a dying patient.
- Consistent provision of The Bereavement Information resource for all bereaved families in a hospital setting.
- Development of a protocol to support patients close to death to remain in the environment and nursing team that they are familiar with.
- Where there is a preference to die in the home setting, a planned discharge should be facilitated with direct communication with the primary care and community care teams
- A proactive approach to bereaved people in the period after death to signpost for advice or support in the community
- Promoting debriefing strategies in settings where staff are impacted by the death of a patient.
- Trusts should demonstrate good practices in relation to bereaved staff and those with caring responsibilities.

INDIVIDUAL: For all staff

- Family in attendance should be supported to stay and should have access to appropriate comfort measures in the ward setting .
- Reasonable measures should be taken to ensure a patient dying in hospital is cared for in a dignified environment.
- Dedicating time to speak to the family in attendance and recognition of the role that staff have in supporting the family at the start of the bereavement journey.
- Individual staff have a responsibility to provide Bereavement Information Resource in a timely manner to support families as part of end of life care.
- Individual staff have a responsibility to access training in relation to end of life care and bereavement care to support patients and their families



1.0 Introduction

1.1 Background

In 2009/2010 the HSC Bereavement Network conducted the second phase of the “NI Audit: Dying, Death and Bereavement: ***The experiences of bereaved people and those delivering primary care services***”. This audit provided rich and meaningful data with its messages and recommendations being used to inform the six standards (described appendix 2) in the HSC Services Strategy for Bereavement Care (2009). The standards are as follows:

- 1- Raising Awareness
- 2- Promoting Safe and Effective Care
- 3- Communication, Information & Resources
- 4- Creating a Supportive Experience
- 5- Knowledge and Skills
- 6- Working Together

Since their introduction and implementation, the standards have informed policy and practice development, training and resources to support bereavement care across all HSC Trusts.

It was agreed by the Regional Patient/Client Experience Steering Group that experience of bereavement would be included in the 2017/2018 regional work plan for 10,000 More Voices. The 10,000 More Voices initiative is commissioned and funded by the Health and Social Care Board (HSCB) and Public Health Agency (PHA) to introduce a more patient focused approach to improving the way health and social care services are shaped and delivered.

The overall aim of the Experience of Bereavement 10,000 More Voices Project was to capture the contemporary experience of bereaved people. This would enable measurement of the effectiveness of interventions and improvements since the introduction of the bereavement strategy standards and recommendations following the 2009/10 audit.

Analysis of the data has identified new issues arising in end of life and bereavement care, therefore the recommendations in this report will inform all regional work in this area, for example the bereavement strategy which continues to shape services and care provided by HSC staff to dying and bereaved people.

Throughout the report excerpts from stories have been included *in italics* as examples to illustrate the results. The words of bereaved people will speak more powerfully than any statistic. These voices will encourage all those providing end of life and bereavement care, to commission and deliver care of the highest standard as is described by many of those who have shared their

experience. There are also opportunities to learn from the stories which reflect areas for improvement. The rich information from this project is also relevant to all organisations, outside of the health service -any service which works in the area of palliative and end of life care such as local councils and Funeral Directors. Alongside the health services, these also services have a privileged position to positively impact upon service users who experience bereavement.

1.2 Context

Our understanding of grief has evolved in recent years from being viewed as a primarily emotional, individual process to being seen as one in which important cognitive, social and existential adjustment to the loss takes place (Hibberd 2013). Grief is a normal essential response to the death of someone with whom the grieving person had a close relationship. Each person's grief, its impact and their reactions are unique and very personal. Sudden or unexpected death, especially in traumatic circumstances, or a death out of turn i.e. when a baby or child dies, can have a particularly profound impact (Keese et al. 2008; Dokha, 2014).

The process of making sense of the death and integrating the experience into the person's life story as they move forward is viewed as a central feature of grieving and one that contributes to adaptation following loss (Neimeyer & Anderson 2002, Neimeyer et al 2014). Grief is shared with others, such as family members and community, and takes place within the traditions and rituals of the culture and society to which the deceased and the griever belongs.

Following the audit of bereaved peoples' experiences in 2009/10, a number of initiatives have been introduced, including the following:

- Care after death and bereavement training
- Use of a symbol to create a quiet,
- Respectful environment for families
- Pro-active follow up support after certain deaths

However, alongside this Health and Social Care organisations face many additional pressures and challenges, which have the potential to compromise the delivery of optimal end of life care

Increasingly, our society is being reintroduced to death and dying following a period when the deconstruction of family and community networks led to many people dying without the support that once was a cultural norm. (Sallnow & Paul, 2015). Our population demographic now requires Health and Social Care to deliver an ever more encompassing service and the Department of Health (DoH) has identified the need to revisit the roles and responsibilities of individuals, families, communities and government within a reformed system of support (DoH December

2017). In addition, recommendations in the O'Hara Report (2018) which investigated and reported hyponatraemia related deaths in Northern Ireland, require organisations and staff to review and revise their guidelines and practice in relation to bereavement care (O'Hara, 2018).

Within this report there are defined recommendations for commissioners of end of life and bereavement care, the Health and Social Care Trusts (HSCTs) and health and social care staff that have a professional and moral responsibility to deliver safe, effective, compassionate, respectful and holistic care to dying people and their families.

2.0 Methodology

The 10,000 More Voices initiative asks people to tell us what was important to them in their individual experience and to describe their overall feelings by “telling their story”, using Sensemaker® methodology. This approach blends together qualitative and quantitative data, with patient stories providing a rich source of information from which we can identify themes and trends.

In keeping with the principles of Experience Based Co-Design, which underpins the 10,000 More Voices initiative, a workshop was facilitated for key stakeholders, including bereaved people, to co-design the survey tool for the project. Following collection of the stories, a further workshop provided an opportunity for key stakeholders to assist in the analysis and interpretation of the information and to identify themes and trends which would form the basis of the recommendations going forward.

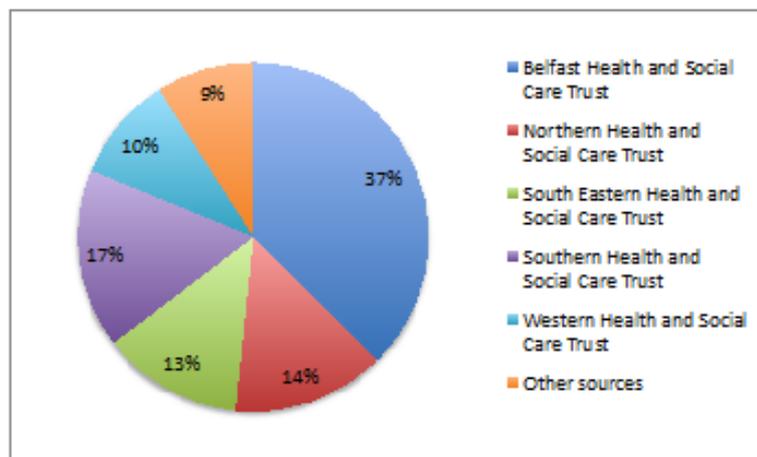
3.0 Results

The survey included a range of demographic questions, triads (questions which are designed in a triangle format) and dyads (questions which offer 2 responses across a continuum), multiple choice questions and open questions to explore the respondent's story.

3.1 Context of the stories

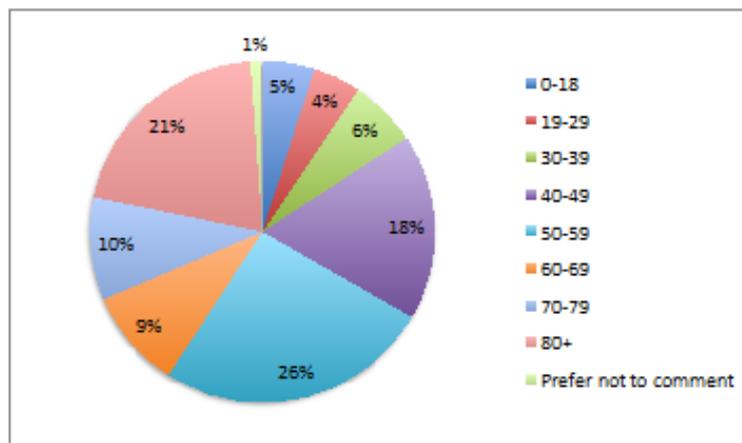
To assist in understanding of the data the following charts illustrate the context in which the stories occurred. Appendix 3 of the report is a complete breakdown of the demographics of the respondents, as governed by Equality Act (2010). In total there were 277 responses across HSCTs and other areas such as, Hospice and MacMillan. The breakdown of responses by Trust/area is shown below:

Chart 1 Response by Trust



The survey was open to all people who have experienced bereavement. Chart 2 shows the age of the patient reflected upon in the story.

Chart 2: The age of the patient the respondent reflected upon in their story



Respondents were asked “how long ago did the person in the story die?”. As illustrated in Chart 3, the greatest proportion of respondents (60%) shared a story from within the past 2 years. Chart 4 shows the setting in which the experience occurred – 51% took place in the hospital setting and 30% of stories related to dying within the person’s home.

Chart 3. Time passed since person in the story died

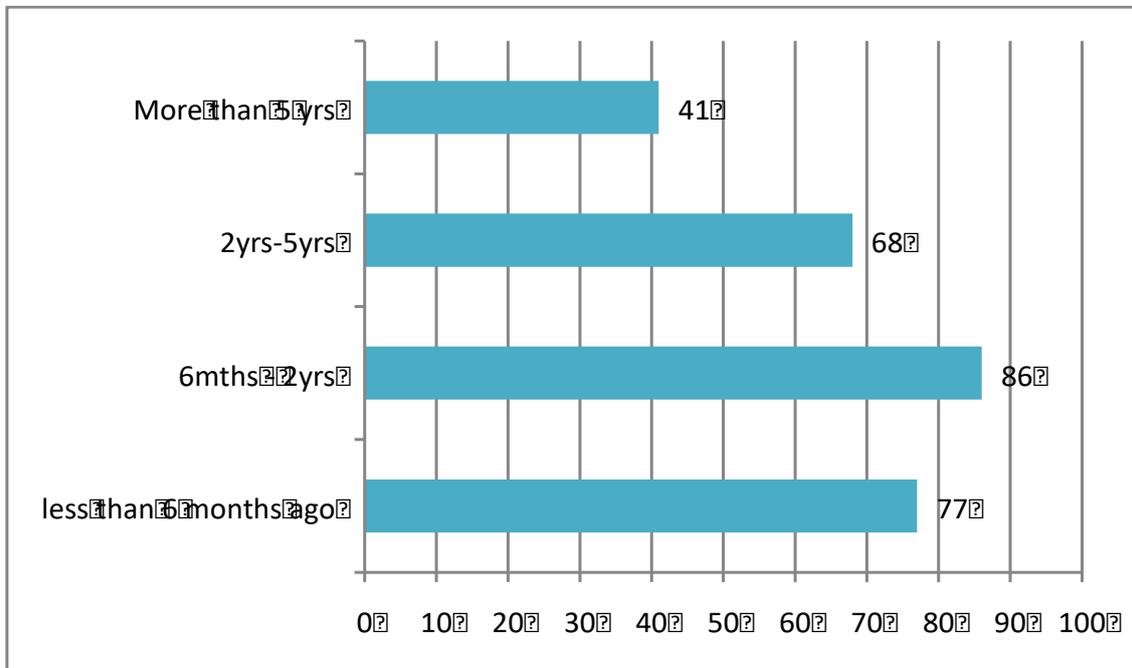
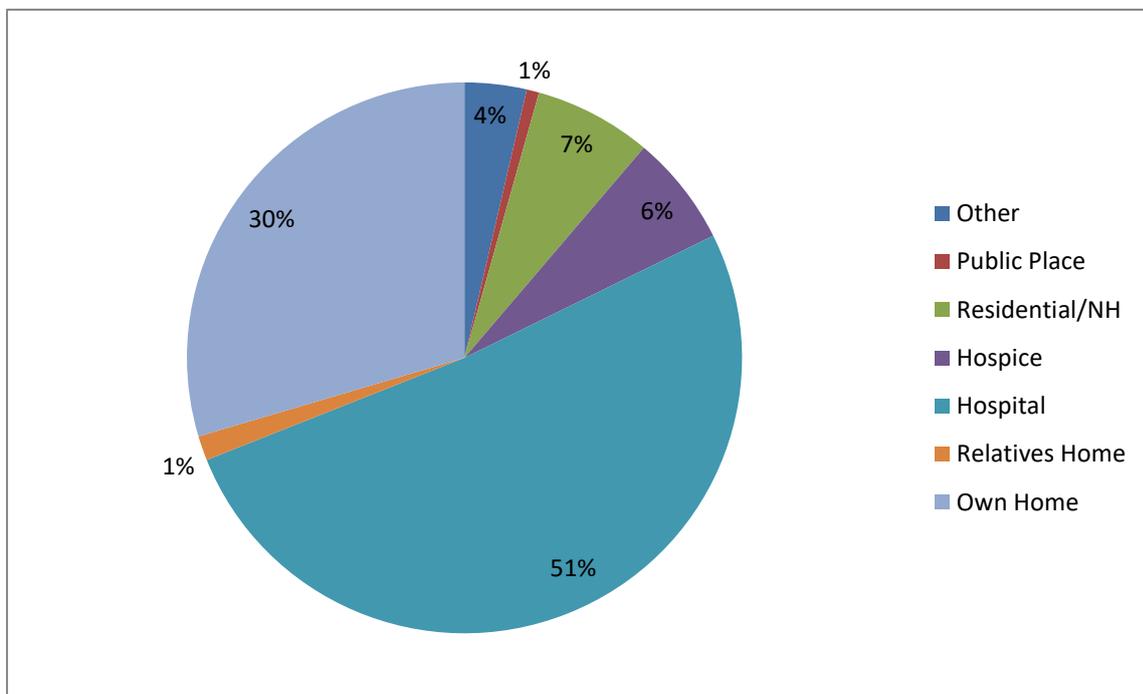


Chart 4: Response to question “Where in the story did the person in the story die?”



Where the person in the story had been admitted to hospital/hospice there was a range of length of stay prior to death as shown in Chart 5. The greater proportion of respondents did not know if this was place where the person wanted to die as demonstrated in Chart 6.

Chart 5 Response to question

"If the place of death was hospital/hospice/residential/nursing home, how long was the person there before they died?"

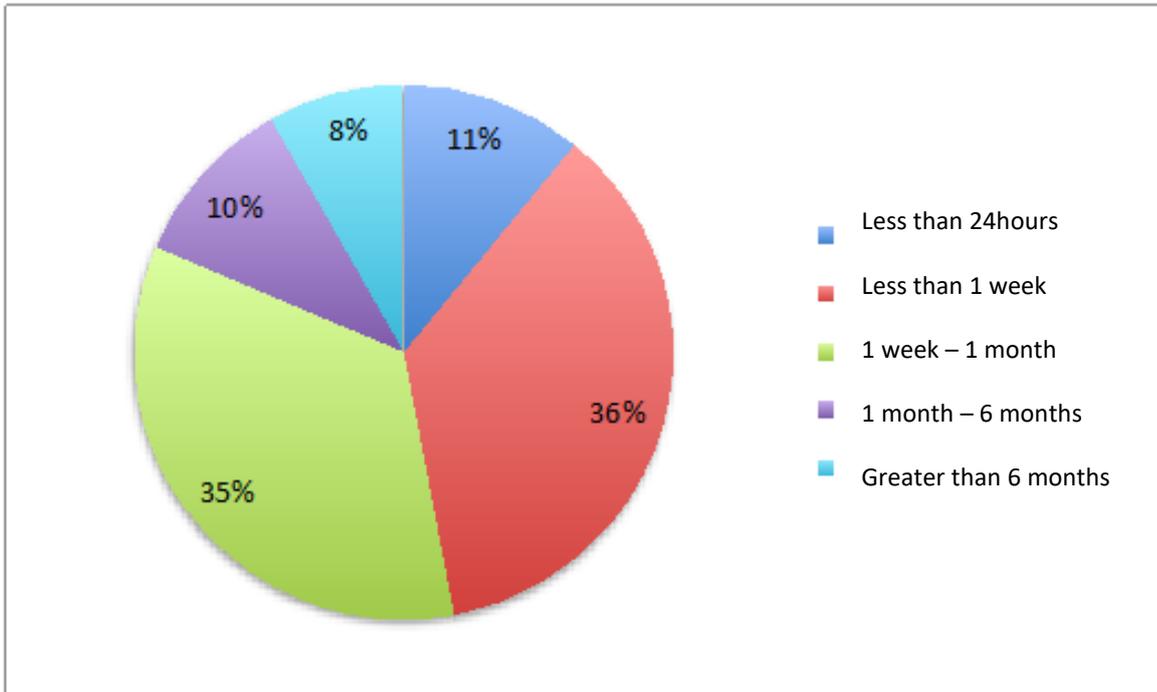
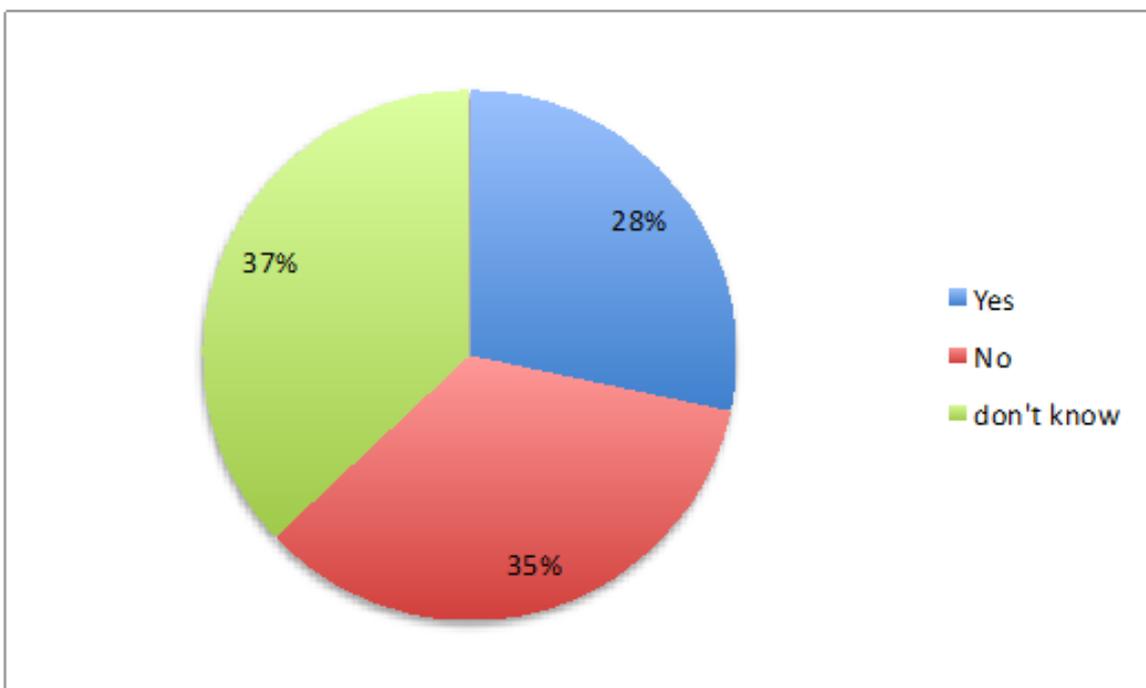


Chart 6 Responses to the question "Is this where the person wanted to die?"



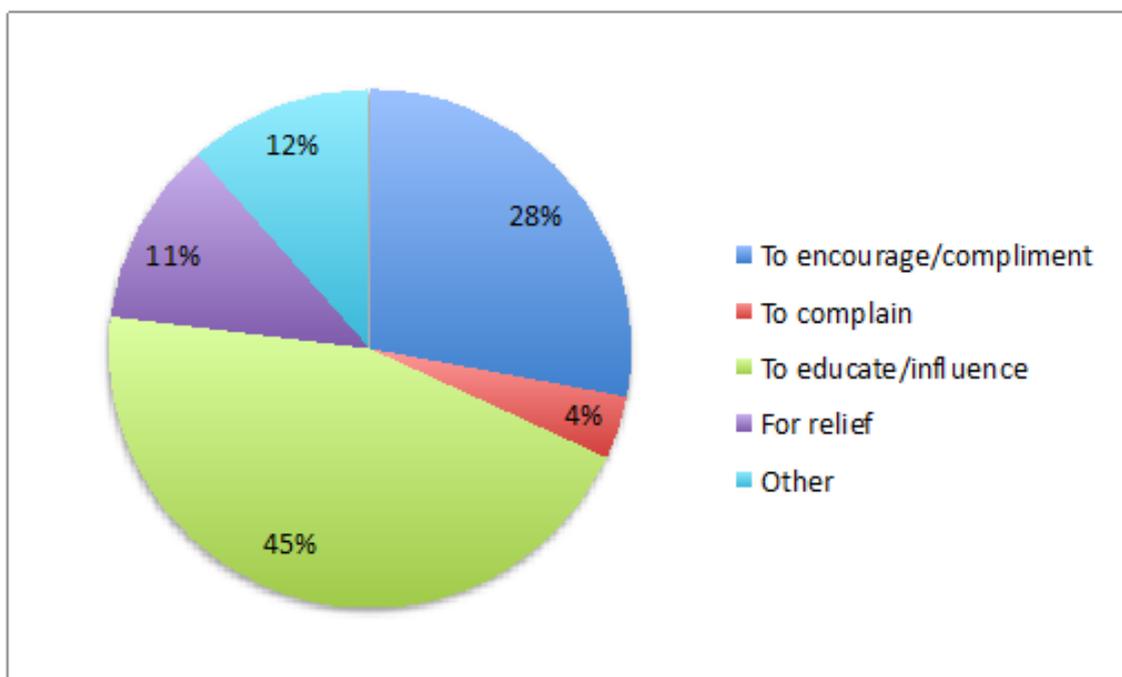
Within the stories shared there was a wide range of conditions in relation to cause of death. Three most common cause of death in the stories were cancer, heart disease and respiratory disease which are reflective of the leading causes of death in Northern Ireland (NISRA, 2017). In table 1 “other “ relates to any illness outside of the list defined in the survey.

Table 1: Response to the question “If known, what was the cause of death in the story?”

Cancer	112
Other	73
Heart Disease	33
Respiratory Disease	24
Alzheimer’s/dementia related	20
Stroke	9
Trauma	8
Suicide	5
Genetic disorder	2
Still Birth	2
Neonatal death	2
Miscarriage	1

Respondents’ motivations to share their story within the 10,000 More Voices project varied. The greatest majority told their story to educate and influence others in the delivery of bereavement care. Also 28% of respondents wanted to encourage and compliment the service they received. This is demonstrated in Chart 7

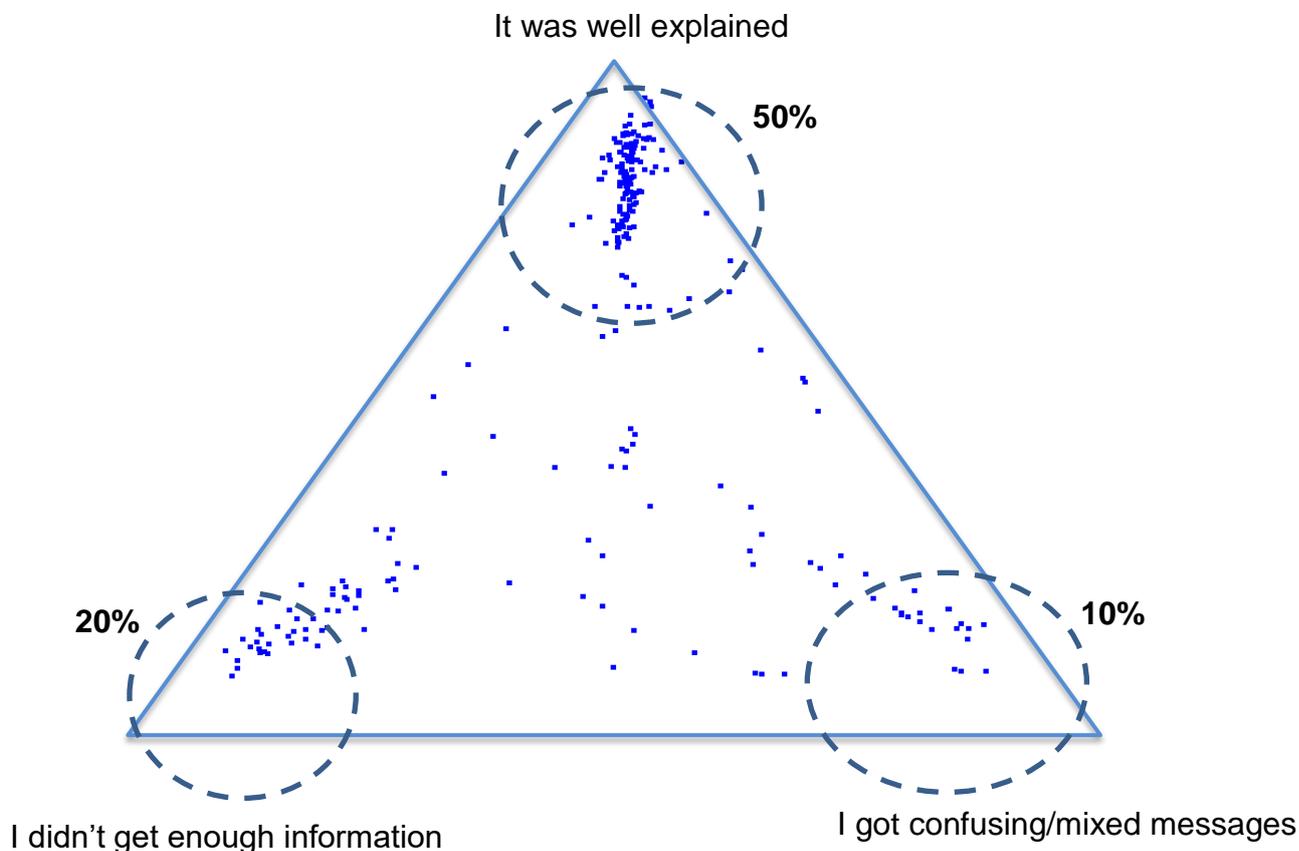
Chart 7: Response to the question “why did you tell your story?”



3.2 Responses to Triad questions and analysis

3.2.1 Question 1: Did you receive information that helped you understand that the person was dying/had died?

243 responses



Discussion/Interpretation

The largest cluster of responses to this question (50%) indicated that 'It was well explained'. Within the narrative respondents described open and honest communication from both nursing and medical staff. There was also recognition of how difficult information sharing was for staff, in particular sudden deaths or the death of a child.

There were two other significant clusters, one accounting for 20% of the responses, at the 'I didn't get enough information' apex and another 10% at the 'I got confusing/mixed messages' apex. Within the stories respondents shared concerns regarding the lack of communication in relation to "Do Not Attempt Resuscitation" and lack of clarity regarding test results or plan of care. Respondents shared anxiety around unanswered questions and their concerns not being heard. For both these clusters the majority of respondents rated the overall experience as negative or

strongly negative. This reinforces the importance of clear, transparent communication with family to support them in the bereavement journey.

Examples of what respondents said

It was well explained

“Mum and I were very grateful for the frank and sensitive discussion with the doctor.

“The honesty of all the health professionals about his prognosis was so valuable and important to us.... For me honesty is the most important thing in a situation like this”

“The staff in the Emergency Department were excellent, the doctor on night shift when he was admitted explained how ill he was. We were helped to understand what was happening so in the end all was very dignified”

I didn't get enough information

“My concern is that on the night that my husband died resuscitation was not discussed with the family. We did not know what was happening in resus and we waited for at least two hours plus until we were given information”

I got confusing/mixed messages

“Whilst giving us a positive outlook and plans for further treatment the consultant seemed to relay a very conflicting story to our GP when she advised there would be no more treatment”

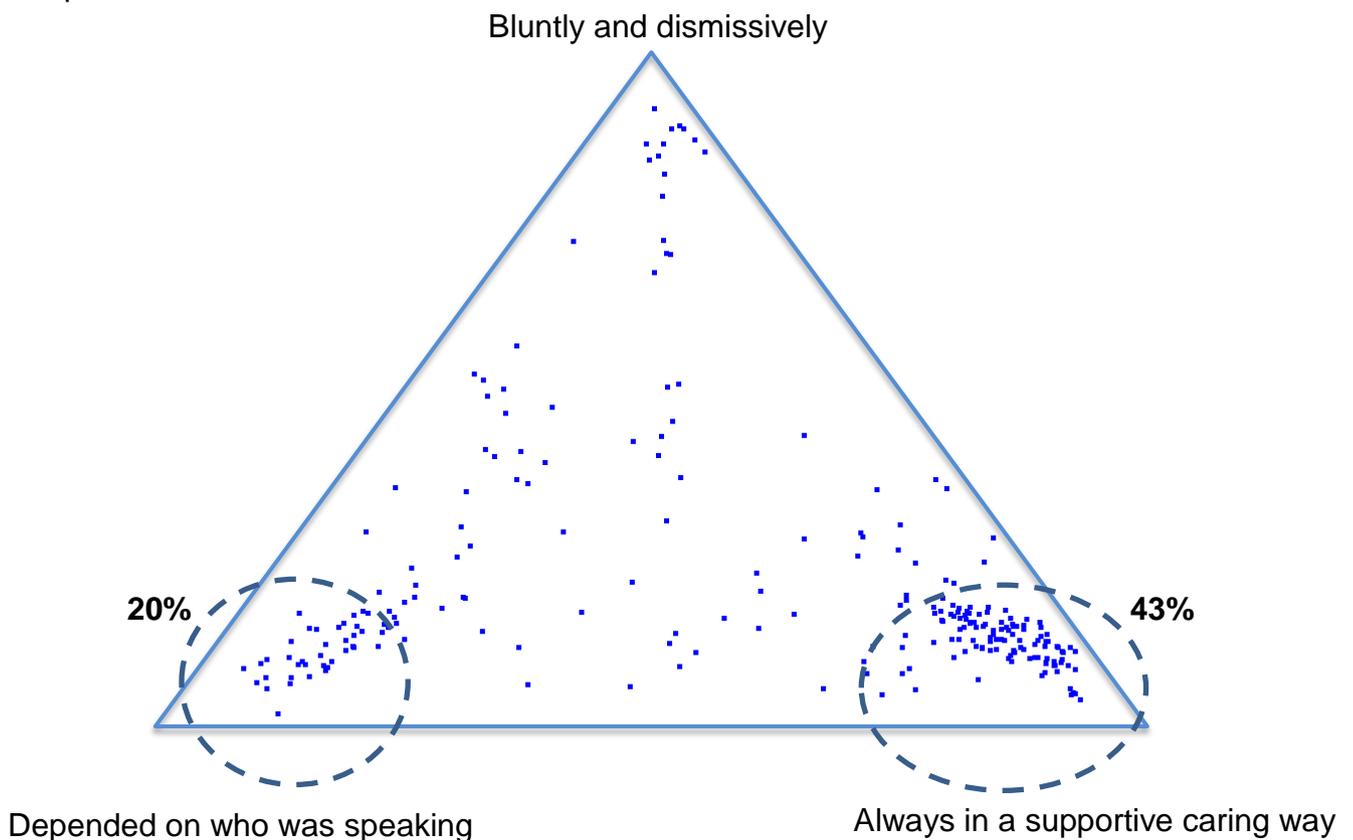
“Communication between medical staff needs to be better and doctors should not speak to family without all the facts”

Main messages from the Narrative

- Good communication helps people understand that a person is dying or has died, and prepares them for what is to come. Honesty without bluntness, enables families' plans and the planning of appropriate care for a patient and their family
- Listening to and consulting with the experts, i.e. family and patient themselves, helps HSC staff understand and manage expectations, and helps patients and families better understand the situation. This is important in decisions around the plan of care for the patient
- Confusing and mixed messages can contribute to an unrealistic understanding of the situation and false hope
- When people do not get information that allows them to prepare for death, bereaved people express regret about lost opportunities with the dying person

3.2.2 Question 2: How were you spoken to?

244 responses



Discussion/Interpretation

The responses to this question were scattered widely across the triad. There were two significant clusters, one (43%) around the 'Always in a supportive and caring way' apex, the other (20%) at the 'Depended who was speaking' apex. There appears to be an extremely wide variation in the way respondents perceived they had been spoken to. As communication is a central component in creating a supportive experience around the time of death, this is recognised as an area for improvement.

Examples of what respondents said

Always in a supportive caring way

"My mum was made to feel that her illness mattered and that she was cared for. The most underrated aspect of patient care is talking and understanding"

"My family were kept well informed of all facts during this time. All staff in the ward treated both my late father and our family with honesty, dignity and respect."

“I would just like to say all the staff were very compassionate caring and thoughtful...the doctors and nursing staff were extremely thoughtful as well as the catering and domestic staff also.”

“The nurse who looked after Dad during his time in ED was fantastic the male nurse talked Dad through every part of his care advising of medication he was receiving, admission plan and he generally talked to Dad about same interests they both had in common”

Depended on who was speaking

“Coming from a nursing background I was very shocked by some of the staff's attitudes. The night mum passed away there was an SHO on the ward who completed all the paperwork and was so kind and thoughtful”

“I said that I wanted to speak to the doctor... The nurse replied it's not the policy in this unit for doctors to speak to relatives on a daily basis. Through my tears I quietly but firmly replied ... I'm not just a relative I'm her mummy please tell the doctor that I would like to speak to him. Thankfully the doctor did speak to me and he also allowed me back into my daughter's room where I belonged”

Bluntly and dismissively

“I lost a baby 6 months into pregnancy... When I asked about counselling I was told to go and look up the yellow pages. My treatment and experience was terrible in the NHS. It would have helped to have more information, more compassion/empathy, more respect, more help”

“This shall stay with me for the rest of my days. When I asked the district nurse why this happened I was informed she didn't like my attitude”

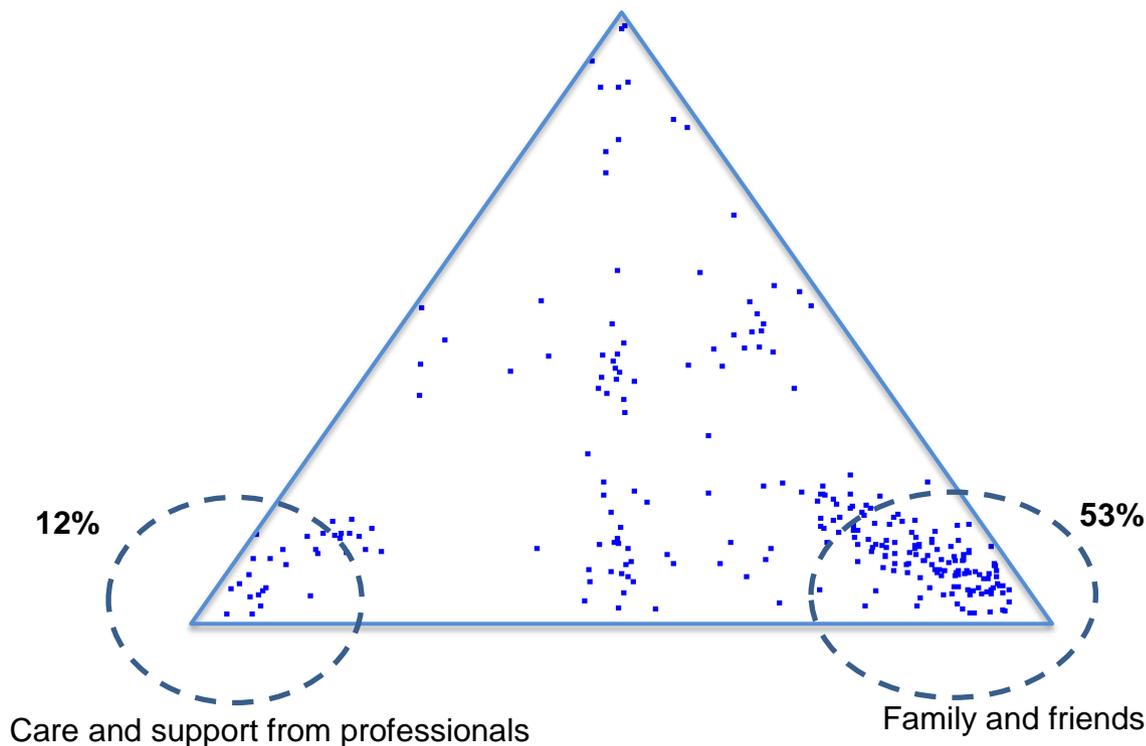
Main messages from the Narrative

- Bereaved people appreciate healthcare professionals speaking to dying people and to them in a supportive and compassionate way, this has a positive impact on their experience and their memories of the care provided
- When patients and bereaved people perceive that HSC professionals have spoken to them bluntly and dismissively, they report that the memory “will stay with them for the rest of their days”
- Some bereaved people described an experience when not all staff displayed a supportive and compassionate attitude, this was upsetting and made the situation more difficult for them

3.2.3 Question 3: Who or what best helped you deal with your grief/feelings at the time?

255 responses

Community network (e.g. Church, neighbours, club)



Discussion/Interpretation

The response to Question 3 spread across the triad. Responses placed in the centre identify that all three aspects of the triad helped in dealing with grief. It is known that family and friends is what helps and supports people most when they have been bereaved so it was no surprise that this largest cluster (53%) was found at the 'Family and friends' apex.

Research from the Irish Hospice Foundation (IHF) shows that a number of bereaved people require additional professional support and this too was reflected in the responses where 12% of the responses focused on care and support from professionals (Appendix 4). The circumstances around the death varied greatly within this cluster. Deaths due to trauma, suicide and miscarriage or still birth are represented in small numbers. Stories are from relatives who cared for their loved one at home during a terminal illness reflected upon the need for additional support following their death.

Examples of what respondents said

Community network

"We had really good support from our own church and this continues for us"

“The support and love of family and friends, the support love and care of the pastoral support team in our church and our ministers”

“In the following days the community supported my family and myself as only country people can do.... We talk about my father a lot and laugh about old times and remember him in all that we do. This definitely helps to manage the pain of our loss”

Care and support from professionals

“I didn't realise it at the time as I was so numb but I would never have made it this far without it. I contacted Cruse Bereavement and it saved our lives. We all had counselling individually and took part in the Get Together project”

“We received a call from the Trust liaison for families bereaved by suicide. He made sure that we had access to information regarding our situation support groups and counselling. Suddenly we felt much less alone and helpless”

“We were invited some months later to attend a Remembrance Service to remember the passing of all patients who had died that year. It was beautiful and comforting to us all”

“Cruse changed my never-ending journey of anger, abandonment, sadness and torment into a road of recovery.”

Family and friends

“The support and help I received from my friends and family kept me getting up every day”

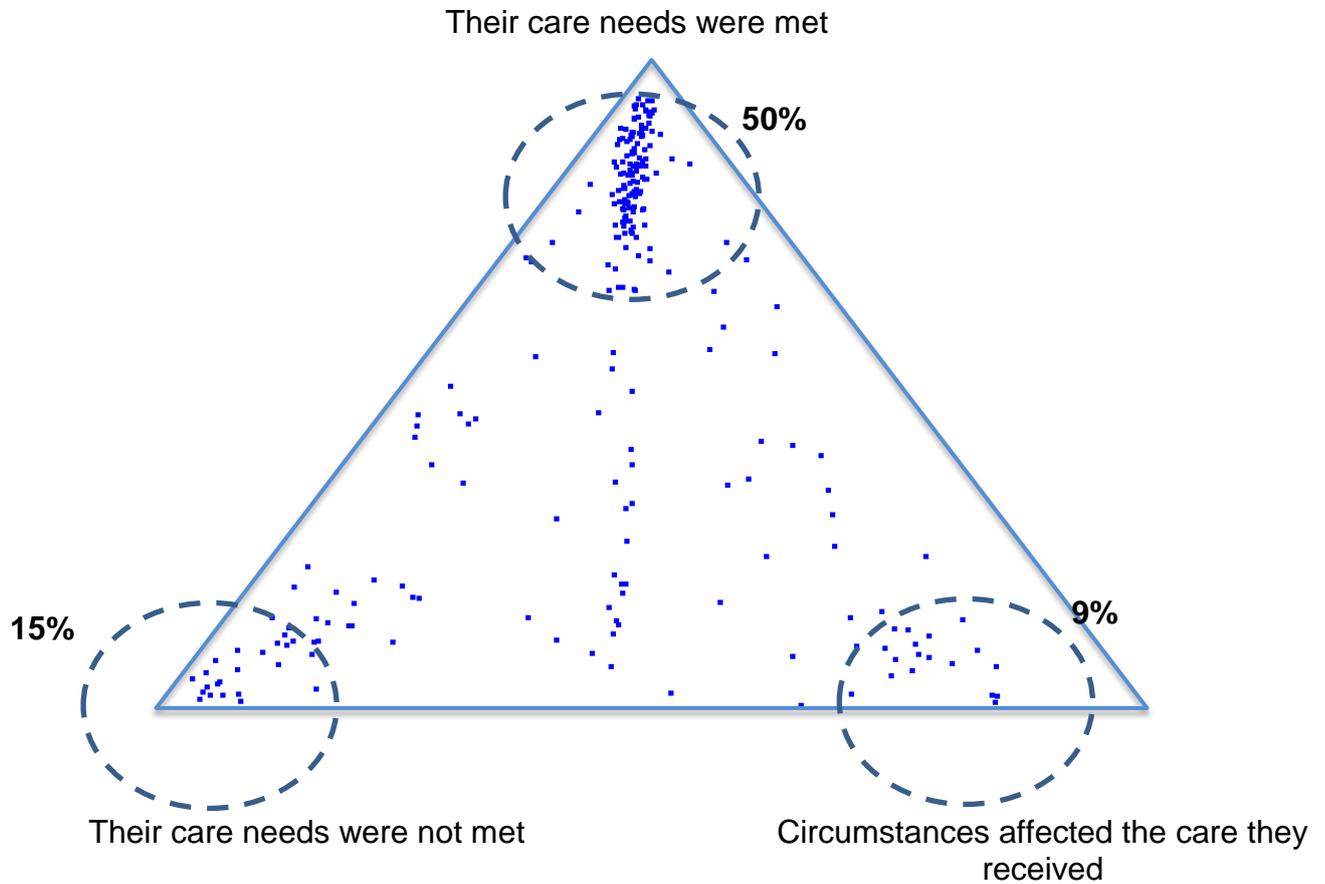
“Our life was shattered. We did not know how to take the next steps forward. We were lucky to be surrounded by family and friends who were incredibly supportive and loving”

Main messages from the Narrative

- Most bereaved people are helped by a number of support networks. Most often family and friends provide bereaved people with the support they need to cope with their loss
- The community in which bereaved people live also provides an important source of support
- Some bereaved people have greatly benefitted from the follow-up support of healthcare professionals as reflected in IHF model Levels of Bereavement (appendix 4).
- People who were bereaved in a traumatic way (accident, suicide, miscarriage or still birth) described their need for additional support and appreciated a proactive approach whereby someone contacted them

3.2.4 Question 4: Did the person in the story receive the care they needed?

251 responses



Discussion/Interpretation

There was one significant cluster in this triad, where 50% of respondents felt the patient received the care they needed. Each of these respondents rated their overall experience as positive or strongly positive. Conversely 15% of respondents felt the care needs of the patient were not met and rated the overall experience as negative or strongly negative. Therefore, there is a strong association between the importance of meeting the patient's needs and the overall journey of bereavement.

Examples of what respondents said

Their care needs were met

"They looked after him with dignity and cared for us as well"

"The staff were helpful but unobtrusive in her last hours. She was kept free of pain and anxiety in her last days, which was so important to us. In the last few days the staff still cared for her,

washing her drying her, and brushing her hair. They even put on her favourite nightdress on the last day. Their care, compassion and the way staff treated our mother from her first to last day in the home has been an enormous comfort to us”

Circumstances affected the care they received

“When my mum was diagnosed with pancreatic cancer my dad and I decided to nurse her at home and we both were assured that support would be there for us. Unfortunately, I felt that it was unavailable to us unless I fought for it, and it was a constant battle to do this”

“Unfortunately on the second last day daddy was moved. He was dying. ...There was no privacy and I felt my elderly father, who had never been sick in his life and had always worked hard to take care of his family and community members, was just abandoned to die with no respect or dignity”

Their care needs were not met

“One unfortunate episode occurred in a ward in which my dad lay for 3 days without washing...this distressed him terribly, as did the lack of communication or care from staff”.

“The 24 hours before she died was horrendous. She was in pain; the nurses and doctor did their best but admitted they were not trained to deal with late stages of cancer”

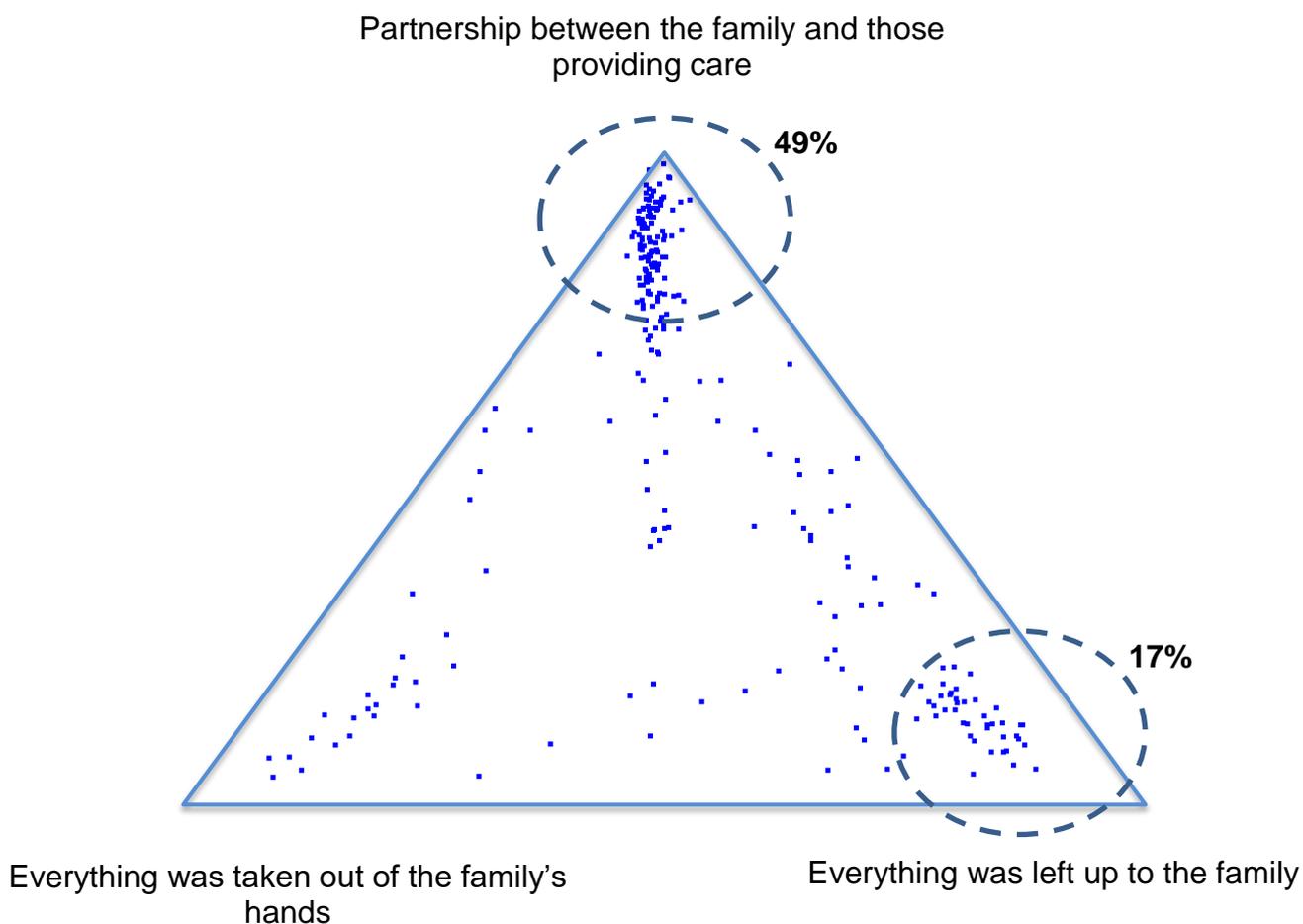
“...it was the family who had to ask if there was nothing that could be done to make him more comfortable, ease the pain and make him less distressed. It was only then that pain relief was administered.... the family who spent the time at his bedside were really left to it with no guidance or support”

Main messages from the Narrative

- When people perceived that the needs of their dying relative were well met they reported this as a positive experience and on reflection are taking comfort from it e.g. well managed symptoms, compassion, respect and dignity
- Those stories where respondents reported care needs not being met, described distressing situations such as unmanaged pain, lack of basic nursing care, lack of privacy, unanswered requests for help and times when staff appeared to be unaware of the particular care needs of dying people and their families
- When participants indicated that circumstances affected the care received they described lack of timely support for caring for a relative at home, moving dying patients from one ward to another and lack of privacy when people died in an open ward

3.2.5 Question 5: Which of these best describes family involvement prior to or after death?

248 responses



Discussion/Interpretation

Family involvement is an important component of end of life care (Wright et al, 2008). It is encouraging that the largest cluster (49%) is at the 'Partnership between the family and those providing care' apex. 9% of respondents felt everything was taken out of the family's hands. It is important to note that these stories related to a sudden cardiac arrest or cardiac arrest secondary to an acute admission and highlights the difficult circumstances around such events. Respondents also reflected upon the lack of communication on the severity of their loved one's illness and also a lack of engagement with the family prior to the event. In the opposite apex 17% felt that everything was left up to the family. These stories relate to meeting basic needs, especially in relation to caring for those people dying in the community. The scatter of responses may have been the result of confusion due to the question asked, as family involvement may have differed 'prior to' and 'after death'. This limitation has been noted for exploration within future projects in relation to dying and bereavement.

Examples of what respondents said

Partnership between the family and those providing care

“Even when the doctors had the awful role of telling him his days and weeks appear to be numbered they gave him the chance to stay in control, he was the one to tell the medical team he did not want to die on a ventilator nor did he want resuscitated”

“...On the last admission it was agreed by the family and medical staff that it was more disruptive to admit her to hospital and therefore she would remain in the nursing home... it was very peaceful and she slipped away in her sleep”

“We were made a part of that unit, the single occupancy ward was the ideal thing for my husband, he was so comfortable and relaxed. We got support from the staff who were the best, nothing was too much for them.”

Everything was taken out of the family's hands

“We spoke to the Doctors and made them aware of my mother's situation however the Consultant decided that he would give her antibiotics as he felt he could get her back on her feet... We felt she was put through unnecessary pain and suffering because, as a family, we were not listened to.”

“If we/I as a family were told his health was that dire someone would have been there staying with him keeping him company so he would know that he wasn't alone. This regret I still live with. Why weren't we contacted earlier?”

Everything was left up to the family

“Against the hospital's wishes, as the care package wasn't in place, we brought him home and he got 4 days at home before he passed away”

“All of the support services I was promised ... I had to keep ringing to ask when they were coming to see mum. They also arrived when it was too late and she was unable to co-operate with them... The district nurse was really lovely but she only came out when I specifically requested”

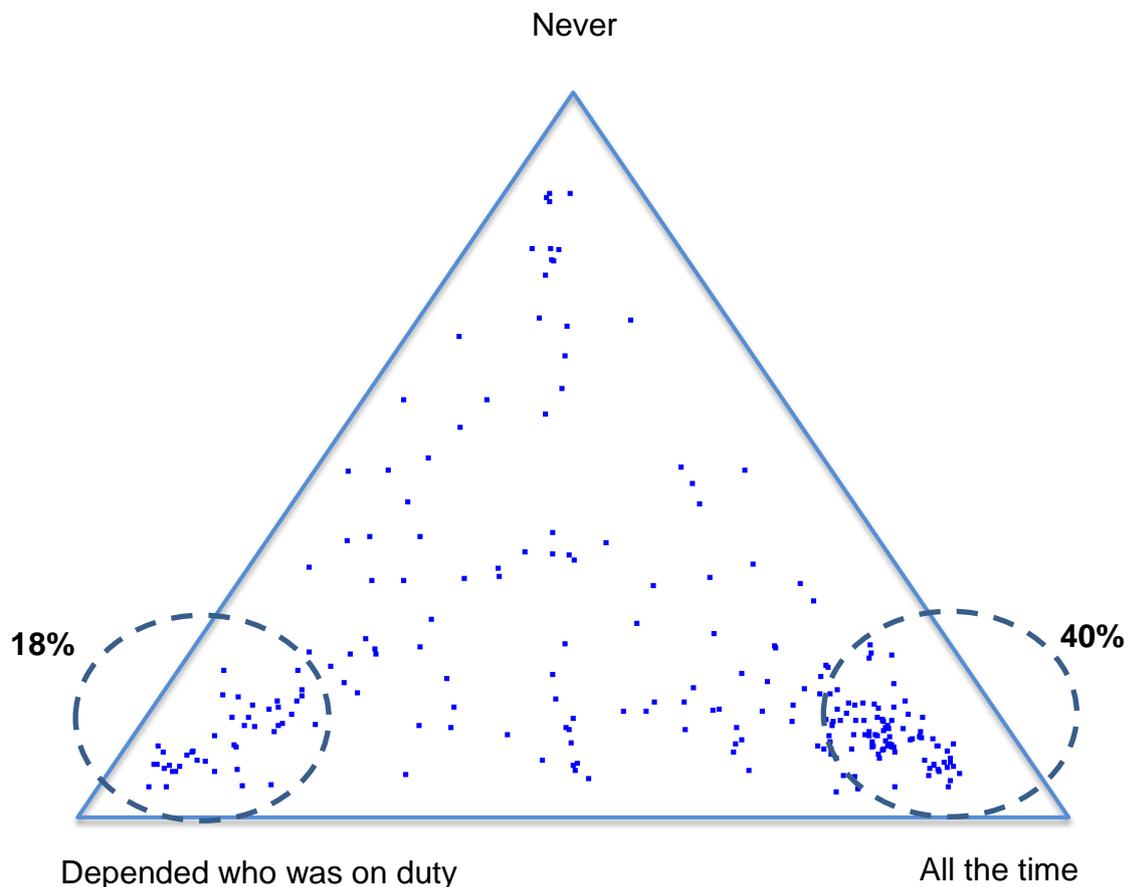
“We had not been anticipating discharge so there were no preparations made in the house for her coming home. I was alone... I never slept..... and I am left with the guilt that no matter how much I was able to do, it was not enough for her needs.”

Main messages from the Narrative

- Many stories describe the sensitive attention healthcare professionals gave to the individual needs and wishes of families at end of life or after death.
- Respondents who reported being involved in the care planning and decision making for their loved one; and had the support they needed to provide some of that care themselves, valued being involved.
- Stories which highlight the positive benefits of family involvement, reinforce the need for healthcare professionals to work in partnership with those who are significant to the dying person
- When families felt their views or knowledge of the patient or situation were not sought or considered they reported feeling helpless, not listened to and have been left with regrets
- For families caring for loved ones at home the importance of support to meet basic needs was highlighted. Those who described an ongoing battle to get the support they needed stated that this was an added burden for them at an already difficult time and a negative impact upon their health and wellbeing.

3.2.6 Question 6: Did you feel confident that the staff knew the best way to look after the person in the story?

240 responses



Discussion/Interpretation

The responses to this question were scattered widely across the triad with the largest (40%) being clustered around the 'All the time' apex. Stories clustered around "Depended who was on duty" and scattered across the triad reflected, not only on the individual, but also access to specialist teams/services for symptom management such as pain and agitation. Within the triad a large number of stories acknowledged that staff did their best to support end of life however it was perceived that they did not always have the knowledge and skills to meet the needs of the patient. Research on end of life care and complaints from relatives has shown that bereaved people's perception of the care delivered to their loved one has a significant impact on their bereavement journey (Whitehouse, 2013). This shows an important link in the experience of the bereaved families and their journey after the death of a loved one and reinforces the importance of staff knowledge and skills in this area.

Examples of what respondents said

All the time

"The nursing care he received was fantastic the nurses got to know my Dad and remembered him on each admission. My father's Haematology Consultant was a wonderful, caring individual whom my father had so much faith and confidence in. He would not leave the room until my father firmly understood the information he was giving him, the same regarding us (the family)"

Depended who was on duty

"Mum was eventually admitted despite, within earshot, a dispute between clinicians as to which patient she should be, medical or surgical"

"Some doctors and nurses showed incredible care and compassion and seemed to instinctively know the right things to say or do so as to make things better not worse"

"She was in pain – the nurses and doctor done their best but they admitted they were not trained to deal with the late stages of cancer. She died on the day she was to move to the Hospice"

Never

“...We are left with a feeling that he didn't get proper care and there was no sense of his condition being actively treated

Main messages from the Narrative

- When respondents felt confident that care was good all the time they described caring individuals who treated the patient and family with respect through good communication and involvement, who managed symptoms well and made the family feel the patient was valued
- For some people the experience was dependent on who was on duty and the availability of particular members of staff/specialist teams
- A small number firmly indicated that they never felt confident that their loved one received the care they needed, giving examples of unacceptable care that could be seen as neither safe nor effective. Some respondents had made formal complaints about care

3.2.7 Question 7: Were you able to access timely help and advice for the person in the story?

243 responses



Discussion/Interpretation

Responses to this question produced three distinct clusters, the largest cluster (48%) was at the 'I knew who to contact' apex. The two smaller clusters (18% and 10%) were found at the 'I felt alone/anxious' and 'It depended on the time of day' apexes respectively. Stories in these apexes described someone dying across a range of settings, from community to acute hospital or hospice. The stories highlighted a frustration around lack of access to someone who could answer their questions or explain the plan of care. This supports the recommendation that when dying people are being cared for at home it is very important that family carers can contact a professional for help or advice when required and when a dying person is in hospital it is important that the patient and family have access to professionals who know them, and listen and respond to their needs.

Examples of what respondents said

I knew who to contact

"I contacted Out of Hours again to request the Acute Care at Home team as my Dad was known to them, in order to be proactive not reactive. This team provided an excellent service ...antibiotics their response was both timely and caring. I can only commend this team both in terms of their professionalism and their inclusive approach"

"We were really looked after extremely well as a family and my dad's care was excellent. No matter what time of day it was there was always someone available to us. Macmillan nurse explained everything to us as well, it was a very special time for us as a family"

It depended on the time of day

"Unfortunately, when we rang GP out of hours to declare his death. We had to ring back 3 hours later as we hadn't heard anything and it was another 7 hours before we had someone come to our house and certify his death"

Caring 24 hours a day for an elderly relative with no care package (it was during the Christmas period and understandably this could not be arranged yet) as she just wanted to come home to die.... Community services require looked at."

I felt alone/anxious

“I feel we would have benefited from someone being there each day to support and guide us even to call in once a day for 10 minutes. This would have encouraged us and let us know that we were doing everything right instead of a constant battle on the phone to try and get everything sorted. .”

“Unfortunately we were not met by any medical staff ... we asked on numerous occasions to be met by medical staff to get an update and understand the diagnosis or tests that were being carried out, to no avail”.

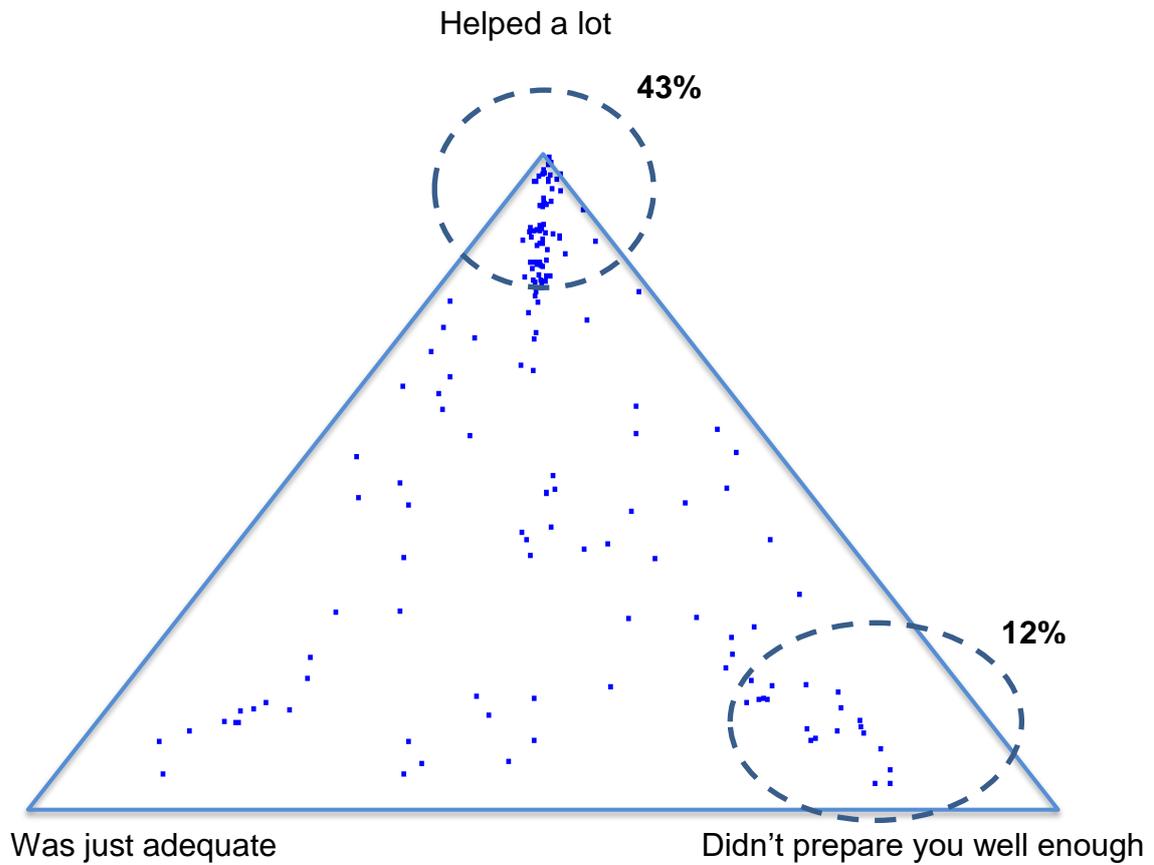
“As a carer and mother of young children I felt isolated and alone even though I did have a network of friends. I felt that the health care did not have any resources available to care for young children of dementia sufferers or young dementia sufferers’ themselves”

Main messages from the Narrative

- When families had a point of contact for advice, support and information they described an experience that was made easier for them by the professionals with a responsibility for the patient.
- Those participants who had family members working in healthcare valued their knowledge on how to access the services they needed
- When people had difficulty accessing the professionals they needed to speak to for support or advice, they felt alone and anxious
- Those people who stated that the time of day affected the availability of help and advice, often described difficulties in the “out of hours” period

3.2.8 Question 8: If you are a healthcare professional, do you feel your training and experience.....

157 responses



Discussion/Interpretation

Health and social care staff contributed 56% of the stories received and shared stories from a personal and professional perspective. They highlighted the importance of support from colleagues and managers. Many reflected upon stories of deaths in the workplace that demonstrated the emotional impact of caring for the dying patient. In Question 8 healthcare professionals were asked whether their training helped them manage the experience they described. This question produced one main cluster (43%) at the 'Helped a lot' apex. Training should cover all aspects of caring for patients and families at end of life; however, some staff reported difficulties with communication and dealing with emotional distress.

Examples of what respondents said

Helped a lot

"I suppose I should consider it a privilege and my nurse training/experience has taught me that we cannot save everyone and that we can care for the dying"

"I along with my sister cared for my mother at home for the last 12 weeks of her life. She had a wonderful end of life care because my sister and I were from nursing backgrounds and could provide her with the care required. I was so glad that we could keep her at home"

Was just adequate

"I wish I had more training in how to speak to patients / families in distress"

"I find it easy to tell bereaved families the process that will follow coroner etc. following their relative's death. Where I find difficulty is regarding the emotional care of bereaved families and knowing the best way to support them...I feel that bereavement care should become mandatory training within the Trust"

"As a midwife, unfortunately, I have to deal with pregnancies where the outcome is not what was hoped for all too often. It is a very emotional time for myself and all the midwives who have to deal with this but we feel we have to hide a lot of this emotion and be strong to support mum, dad and family. This in turn makes it even more emotionally draining."

Didn't prepare you well enough

"I was very upset for the family, I was trying to remain professional but was crying saying that I was 'so sorry we couldn't save her' I felt embarrassed that I couldn't control my emotions / at times I couldn't speak much as I was trying not to cry"

"I am a healthcare assistant; I experienced a death on the ward recently. It was such a shock for all the staff as she had seemed clinically well and was due to go home that morning...Because it was quite shocking it would have helped to discuss it, review it and reflect on it to grow and evolve from this sad experience."

Main messages from the Narrative

- Dealing with death in the workplace has an emotional impact on staff and some felt their training was just adequate or didn't prepare them well enough to manage the grief of bereaved families, and their own emotions. They highlighted the importance of time to reflect as a team following a death of a patient
- In relation to personal experience some staff provided end of life care for a family member and have taken comfort from that; others found it challenging emotionally and physically to look after close family members. It is evident that looking after a family member is challenging at times, even for staff with experience and skills

In addition to the training, a number of stories from health professionals described the challenge in returning to work following a personal bereavement and primarily the process to manage absence and the importance of a supportive line manager. Whilst this is an intensely personal experience, a compassionate and flexible approach from employers can ensure that the impact on both the individual and the organisation is minimised.' (LRA Guidance, 2015). The word cloud illustrates the emotion and experiences of staff and supports the key messages relating to returning to the workplace following personal bereavement.

Main messages from the Narrative

- The importance of a process to manage absence following personal bereavement which is sensitive to the needs of the bereaved member of staff, as supported by Labour Relation Agency (2015) "Managing death in the workplace. A Good Practice Guide"
- The line manager is key to signposting to resources of support and providing continued communication with the Occupational Health team.
- Supportive measures, such as flexibility and the opportunity to talk are important to ensure the staff can return to work with limited additional stress.

lost sympathy daily
thankful forgotten
vulnerable compassion
grieving tearful breathe
counsellor stress ready
anxious support human
demand dark
depressed cared
painful progress everyday
quick listen
counselling
angry

3.3. Response to Dyads

Within the survey there were two questions known as dyads which explored when the respondent experienced compassionate care. For both questions the clusters, illustrated below, reflected an overall positive experience in relation to compassionate care

Dyad 1: Question 9: Did the person in the story receive compassionate care?

256 responses



Dyad 2: Question 10: Were you supported in a compassionate way?

257 responses



Analysis of the stories at the end of the spectrum indicated lack of compassion, reflected upon stories of uncoordinated care following a terminal diagnosis, a lack of sympathy or empathy by staff when delivering bad news to the families, lack of resource in primary care and a family who were not listened to when they raised concerns. These stories highlight key areas in delivering compassionate end of life care to patients and their families.

Examples of what respondents said

“Now I really see the nurses as the key workers and co-ordinators of our daughter’s care. They liaised between the other professionals and always kept us updated. They treated our daughter with total respect and enabled her to have a dignified and peaceful death... continued to provide support during this past year keeping regular contact, always listening, affording us time to express emotions - they have signposted to counselling services”

“One nurse in particular was exceptional in that she treated my partner with respect and dignity both before his death and following same in removing lines drips etc. speaking to him as if he were still able to hear her. This was so comforting for me in that she recognized him as a human being, a person whom she had gotten to know in a very short space of time, her empathy was exceptional”

3.4 Responses to multiple choice questions on information

3.4.1 Written information

Standard three of the HSC Strategy for Bereavement Care (2009) states that people who are dying and those affected by bereavement will have access to up to date, timely, accurate and consistent information. Within 230 responses to question 11 (a), 78 respondents received written information, 152 did not receive any written information as demonstrated in Chart 8, indicating a need to explore the dissemination of resources in each trust.

Chart 8: responses to Question 11(a):

Did you receive written information (e.g. Bereavement booklet) after the death that helped you with practical requirements and arrangements and outlined what support is available to you?

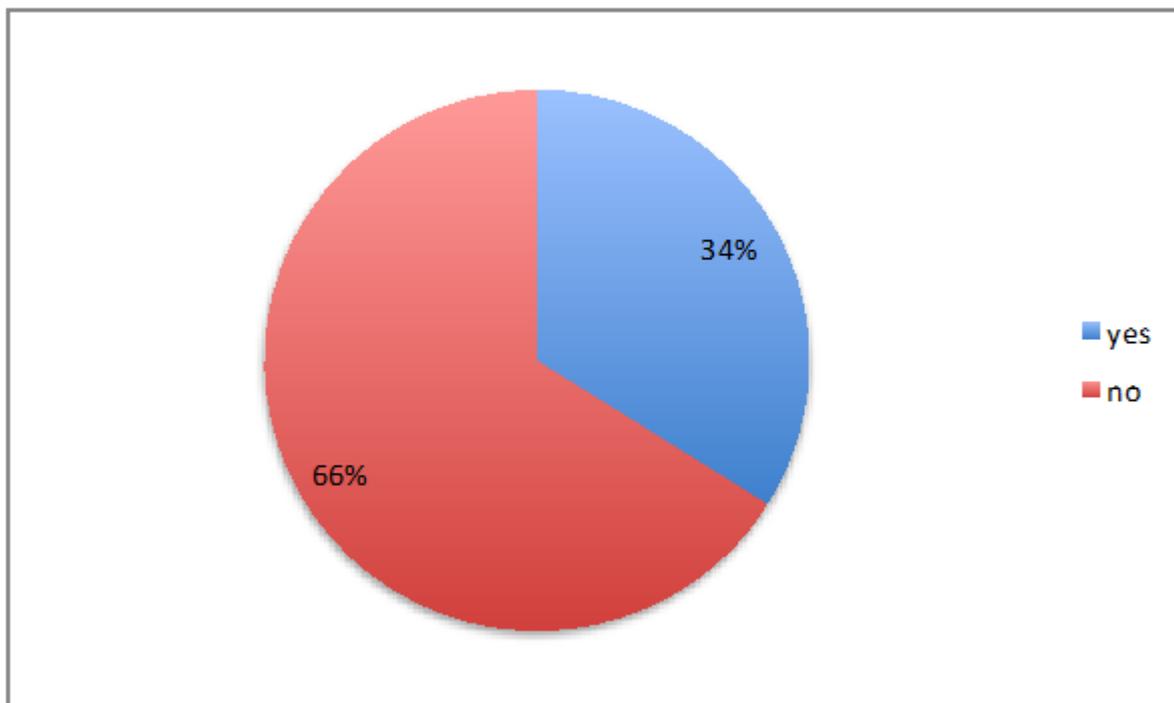
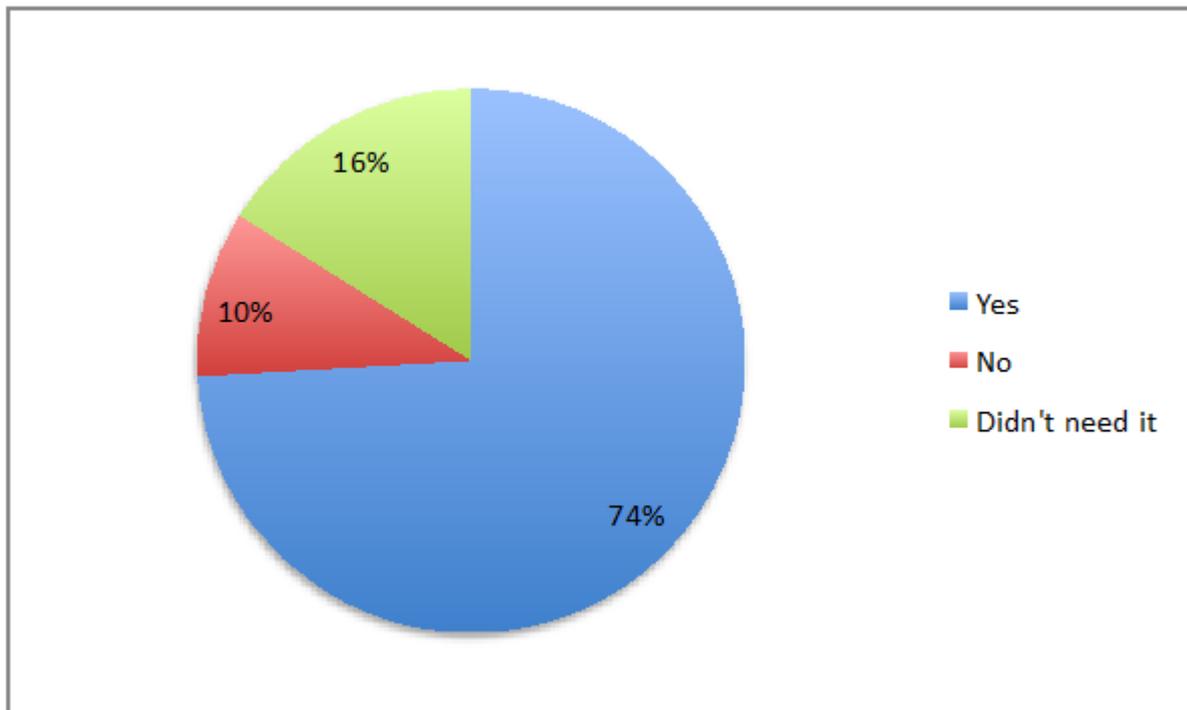


Chart 9: responses to Question 11B: Was the information helpful/useful?



Of the respondents who received written information the majority (78%) identified it as helpful/useful (refer to chart 9); This supports the focus for Standard three, that the information will be helpful to the particular needs of the recipient and consistent with their needs, abilities and preferences.

3.4.2 What matters to you

Respondents to the survey were asked to rate what was most important in relation to end of life and bereavement care. Table 2 shows compassion, respect and dignity were recognised as the most important aspect of bereavement care; (Respondents could choose more than 1 option)

Table 2 Response to the question “Which of these things is most important to you?”

Aspect of bereavement care	Number of responses
Compassion/Respect/Dignity	162
Well Managed Symptoms	95
Communication & Information	90
Being involved in decision making	51
Choice about place to die	28
Not Sure	8

3.5 Key messages in open questions in relation to bereavement

After telling their story and completing questions and triads respondents were given a second opportunity to contribute free text when asked what could have improved their experience at or around the time of death; and what helped or could have helped them with their bereavement. The two open questions were:

- 1- What could have improved your experience at or around the time of death
- 2- What could have helped/did help you in your bereavement?

In the survey 42% of respondents answered the open questions. Of those who did 16% of respondents provided evidence of the positive experience they had, for example simple kindness, privacy and compassion, receipt of a sympathy card and bereavement information. All responses to these questions, provided valuable information about the care delivered to dying people and their families, about who and what helped them at the time of death and afterwards and the impact of these measures on a bereavement journey.

Sudden/Unexpected death

From review of the demographics and also the story 38% of stories related to a sudden or an unexpected death. In the instance of trauma and suicide (5% of stories) respondents found the experience very challenging as illustrated from the following quotes

“I wasn’t there when he died – I wish I could’ve been there”

“nothing would prepare you for the sudden death of someone you love”

However, some very practical measures were suggested to support families in such circumstances

- Access to public information such as helplines and leaflets to support the family after leaving the hospital
- A directory of local Funeral Directors and practical advice on what to do when a death is sudden.
- Guidance on financial matters
- Engagement in clinician’s decisions regarding “Do Not Resuscitate” and presence of the family.
- Better access to bereavement counselling and a proactive approach to those bereaved by sudden death.

Death following progression of illness

For a larger number of responses, the experience related to an illness which had progressed over an extended period of time. The following improvements are reflective of the environment where the experience occurred.

51% of the answers related to a death in the acute hospital ward setting and highlighted particular need:

- **Training** for both medical and nursing disciplines in the palliative symptom management (in particular pain and agitation) and bereavement training.
- **Privacy for the patient and the family.** Side rooms were indicated as being important to support privacy and dignity in positive stories shared. Where a side room was not available respondents suggested the importance of somewhere private for the families to meet.
- **Patients who are actively dying should be allowed to stay in the ward they are familiar with.** The patient should not be moved between wards or hospitals.
- **Daily communication between senior staff and patient/family** on the patient's condition with time to discuss any treatment/care
- **Improved practical arrangements for the family** such as flexibility around visiting times, car parking validation, comfortable seating, refreshments
- **Provision of written bereavement support at the time of death.**

29% of the answers related to a death which occurred in the patient's home or relative's home; They highlighted the need for

- **Better provision of palliative care in the community setting** with package of care and access to district nursing to support families to care for their loved one at home
- A proactive approach to managing the patient at home with **a key coordinator for daily contact**
- **Easier access to assistance during "out of hours" period** including public holidays and weekends.

3.6 The Overall Experience

The final question of the survey asked respondents to provide an overall rating in relation to their experience. Almost half (49%) of respondents highlighted their experience as being positive or strongly positive. This is encouraging for staff involved in delivering end of life care and bereavement care.

Chart 10: Responses to Question 23: How would you rate your overall feeling about the story?

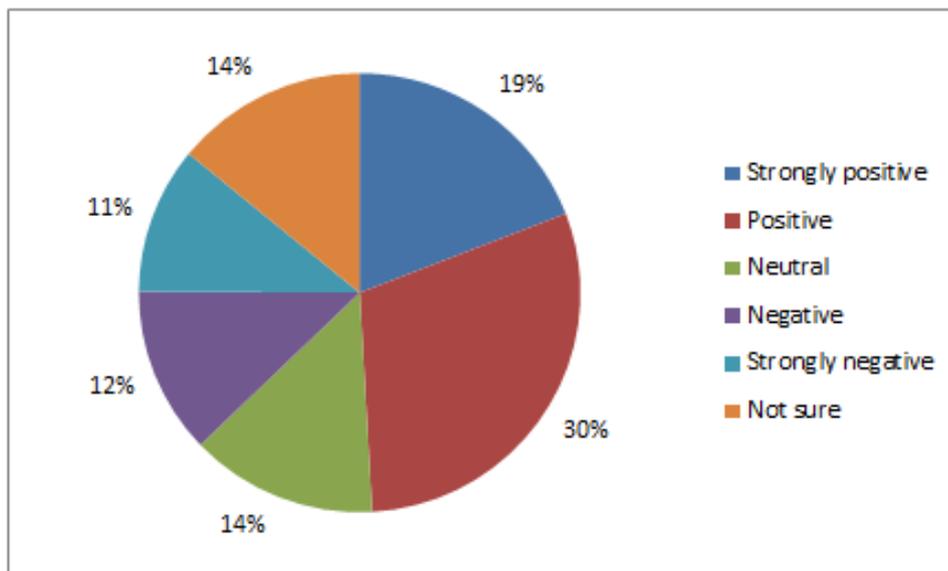


Chart 10 also illustrates that a significant proportion of respondents felt their experience was negative or strongly negative. The key elements of all the stories have been analysed and both the positive and negative messages have informed the recommendations.

4.0 Recommendations for action

As the majority (73%) of people who submitted a story did so either to “compliment” or “educate/influence”, it is important that health and social care staff, organisations and commissioners honour the messages in their stories, and take steps to continue to improve end of life and bereavement care services.

STRATEGIC CONTEXT: For HSCB/PHA

- Review and development of training in all aspects of end of life care and bereavement, as defined in national and regional standards. Training should encompass all healthcare professionals who care for the dying patient and support those closest to them.
- Development of guidance to support staff, across all settings, to plan, implement and evaluate care for the dying patient, in partnership with those important to them (family, carers, close friends)
- Further exploration of the bereaved experience in relation to defined contexts such as death in the acute hospital setting, loss through suicide, loss in pregnancy/miscarriage or loss in trauma.
- In collaboration with HSC trusts the Regional Palliative Care board will consider and support recommendations in relation to bereavement support

ORGANISATIONAL CONTEXT: For HSC Trusts

- Staff who support dying and bereaved people receive communication skills training. This should include communication of emotional support to relatives when caring for a dying patient.
- Compliance to the provision of Bereavement Information Resources to bereaved families, following death in the hospital setting. Trusts should audit compliance on a monthly basis with documented evidence of subsequent actions to support compliance.

- Development of a protocol to support patients close to death to remain in the environment and nursing team that they are familiar with. Patients should not be moved to another ward or hospital setting at this time
- Where there is a preference to die in the home setting, a planned discharge should be facilitated with appropriate support to address the needs of the patient and family, including an appropriate care package. This is supported with direct communication with the primary care and community care teams to support the family.
- A proactive approach to bereaved people in the period leading up to (in the case advance progression of an illness or life limiting conditions) or after death to signpost for advice or support (for example a sympathy card, provision of a bereavement booklet, specialist bereavement services or charitable support).
- Additional support should be made available for those who have experienced a traumatic or sudden bereavement. It is also important to signpost families to bereavement support organisations that offer more focused support for the bereaved in the community.
- Promoting debriefing strategies in settings where staff are impacted by the death of a patient
- Trusts should demonstrate good practices in relation to bereaved staff and those with caring responsibilities (for example bereavement policy, training for line managers)

INDIVIDUAL: For all staff in HSC

The following recommendations relate to the individual's responsibility when delivering end of life care and how they support the bereaved.

- Family in attendance should be supported to stay and should have access to appropriate comfort measures in the ward setting (for example comfortable chair, car parking, flexible visiting)
- Reasonable measures should be taken to ensure a patient dying in hospital is cared for in a dignified environment – a side room is identified as important in provision of privacy and

dignity. Where a side room is unavailable ward staff should focus upon other methods such as a corner bed space, minimal interruptions, available space for families to meet.

- Dedicating time to speak to the family in attendance and recognition of the role that staff have in supporting the family at the start of the bereavement journey.
- Individual staff have a responsibility to provide Bereavement Information Resource in a timely manner to support families as part of end of life care.
- Individual staff have a responsibility to access training in relation to end of life care and bereavement care to support patients and their families

5.0 Conclusion

The 10,000 Voices Experience of Bereavement Project 2017/18 provides a wealth of information about the personal experiences of bereaved people. The voices of those who told their story will not go unheard if commissioners, Health and Social Care Trusts and individual health and social care practitioners are willing to listen to what respondents have told us, acknowledge the importance of the themes, and act upon the recommendations contained within this report.

The revision and publication of the HSC Strategy for Bereavement Care reflects and strengthens the obligation to provide an end of life and after death experience that enables and supports healthy grieving. The key messages from the people who told us their story is integrated into and helps to inform this strategy. Future studies will focus on the profile of the patient and the family member. This will enable deeper analysis of the age profile of the bereaved and the complexity of the needs of the bereaved.

No one is immune from death and bereavement, and research shows that how people are cared for and supported at such a time may contribute positively or negatively to their experience. Patients and those important to them deserve, and should expect, to be cared for by skilled, compassionate and respectful staff.

Appendix 1

MEMBERSHIP OF PROJECT STEERING GROUP

Project Group	
Christine Armstrong	Regional lead, 10,000 Voices
Vi Gray	WHSCT 10,000 Voices Facilitator
Colin Jackson	BHSCT 10,000 Voices Facilitator
Loretta Gribbon	PHA
Corinna Grimes	PHA
Heather Russell	BHSCT TBC (Project Lead)
Anne Coyle	SHSCT TBC
Paul McCloskey	SEHSCT TBC
Carole McKeeman	WHSCT TBC
Gwyneth Peden	NHSCT TBC
Jack Moore	Chaplain NHSCT
Edel Corr	Patient Support Lead SHSCT
Lisa McGrattan	Service User/ NHSCT representative

Trust Bereavement Coordinators and 10,000 More Voices Facilitators

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Appendix 2

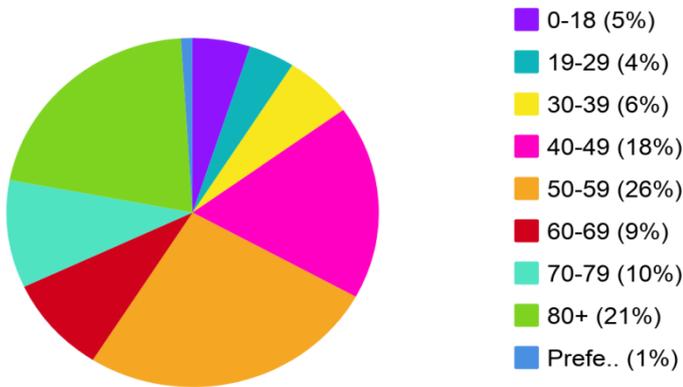
HSC SERVICE STANDARD FOR BEREAVEMENT CARE (ref: GAIN(2010) Northern Ireland Audit: Dying, Death and Bereavement. Phase 2: The experiences of bereaved people and those delivering primary care services)

- 1- **Raising Awareness:** That Health and Social Care staff will be suitably trained to have an awareness and understanding of death, dying and bereavement. Staff should also acknowledge the fact that grief is a normal process following loss, and that needs vary according to an individual's background, community beliefs and abilities
- 2- **Promoting Safe and Effective Care:** That all Health and Social Care staff who have contact with people who are dying and/or with those affected by bereavement will deliver high quality, safe, sensitive and effective care before, at the time of and after death according to individuals' background, communities, beliefs and abilities
- 3- **Communication, Information and Resource:** That people who are dying and those who are affected by bereavement will have access to up to date, timely, accurate and consistent information in a format and language which is appropriate and will be helpful to their particular circumstances consistent with their needs, abilities and preferences. Staff will remember that the availability of written or other information does not negate their personal support role
- 4- **Creating a Supportive Experience:** That those who are dying and their families will be afforded time, privacy, dignity and respect and, wherever possible, given the opportunity to die in their preferred environment with access to practical, emotional and spiritual support based on their individual needs, abilities and preferences
- 5- **Knowledge and Skills:** That Health and Social Care organisations recognise the value of a skilled workforce by ensuring that those coming into contact with, or caring for people who are dying and those affected by bereavement are competent to deliver care through continuing professional development; and by having systems in place to support them
- 6- **Working Together:** That good communication and coordination will take place within and between individuals, organisations and sectors, to ensure that resources are targeted efficiently and effectively and that there is integration of care to meet the needs of people who are dying and their families, friends and carers.

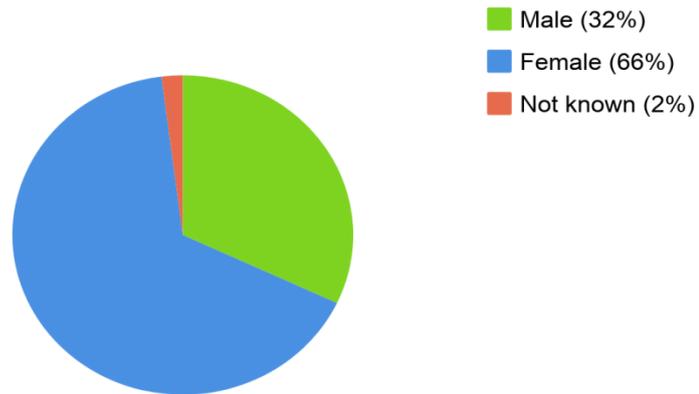
Appendix 3

Summary of standard demographic questions relating to the patient (mapped to Equality Act 2010)

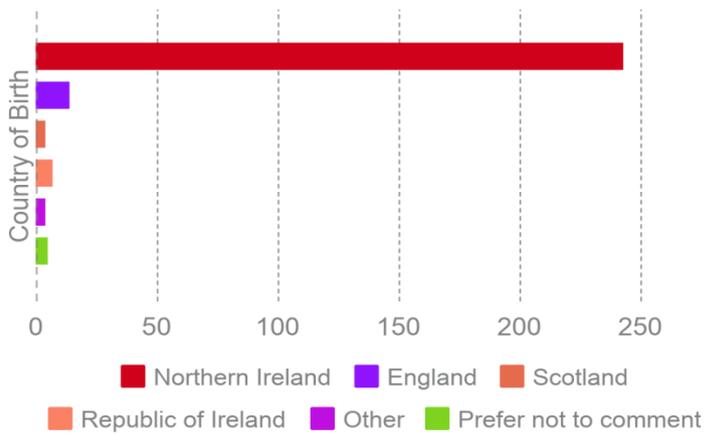
1 - Age of Respondents



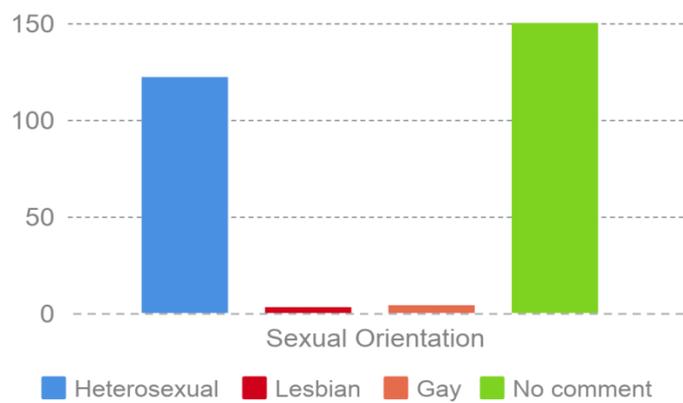
2 - Gender of Respondents



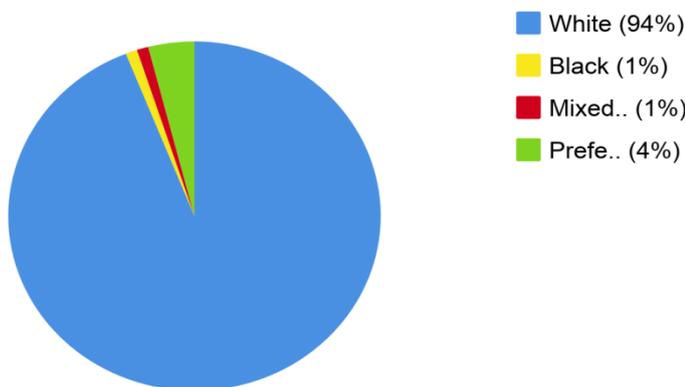
3 - Country of Birth



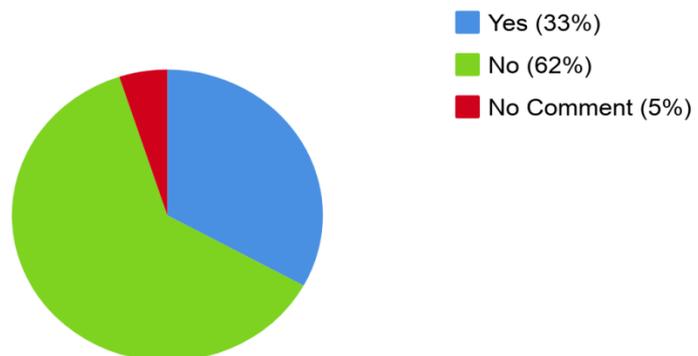
4 - Sexual Orientation



5 - Ethnicity

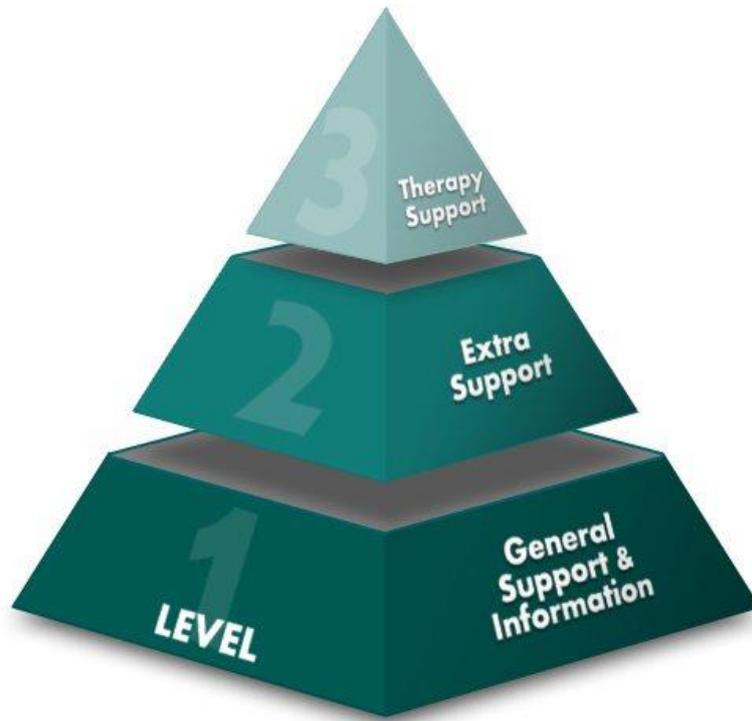


6 - Disability



Appendix 4

Irish Hospice Foundation Model of Support in Bereavement Care



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