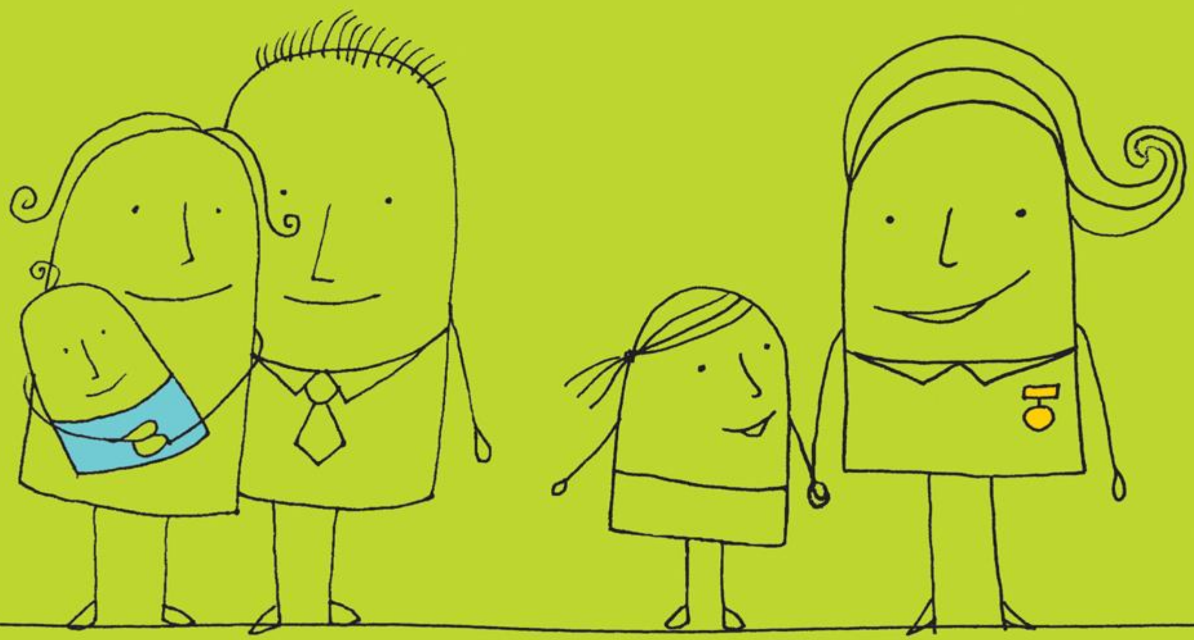
Patient and Client Council

End of life

Key issues arising from complaints about end of life care experience – Year 2

April 2017



Content

Foreword

Dear Reader**,**

Compassionate care at the end of life has improved significantly over the last few years. There are many examples of excellent practice across health and social care and there is recognition that compassionate care at the end of life can help the grieving process for bereaved families.

Opportunities for more open and earlier conversations about the choices and preferences of patients and their families are essential if the needs and wishes of families are going to be realised. Responsibility for creating these opportunities is not confined to health and social care but to society as a whole.

Care at the end of life is an important element of all care. The evidence in this report describes how the care received at this time can have a significant impact on patients and their families.

This report identifies some of the issues raised by service users through our Complaints Support Service. There were three key areas highlighted: communication, coordination of care between health care staff, patients and their families and training for staff who are providing end of life care. These were reported issues for end of life care for both unexpected deaths and patients who were terminally ill.

These global issues are not new and a lot of work has already been completed to find solutions to these complex areas of care. I hope the information in this report will help to ensure that the voice of service users is included in the discussions to find sustainable solutions.

Yours sincerely**,**

Maeve Hully

Chief Executive

1. Introduction

The Patient and Client Council (PCC) 2016/17 business plan states the following:

> ***The Patient and Client Council will seek to understand the key issues in relation to the end of life care experience.***
>
> This will be the second phase of a two year project which will explore people's recent experience of end of life care.
>
> The Patient and Client Council will report to key stakeholders in HSC on the key issues in relation to the end of life care experience.

This report describes the second phase of a two year project exploring key issues in relation to end of life care. The first phase, a scoping exercise conducted in 2015-2016, presented the current context in Northern Ireland and identified that significant work had already been undertaken in policy development, service delivery and commissioning of end of life care.

Care received at the end of life is a significant and important element of all care and the evidence describes how the care received at this time can greatly impact patient and family/carer experience of end of life. The growing recognition of the importance of high quality end of life care has resulted in extensive research being completed by a wide range of stakeholders and service providers. The PCC scoping exercise in 2016 confirmed this.

The scoping exercise identified a number of obstacles to providing high quality end of life care as highlighted from published research. These issues included:

Capacity and timeliness of discussions

With the increasing age of the population comes the risk of dementia and one of the biggest barriers to planning end of life care with regards to the patient is a lack of cognitive capacity. Therefore end of life care discussions need to take place in a timely manner and cannot be left until it is too late and the person no longer has the capacity to make a decision. [1]

Relationships

As a society we do not talk openly about death and dying with relatively few adults having discussed their preferences for care with relatives or friends, making it difficult for wishes to be met.[2] As a result there is often reluctance to talk about death and end of life care when the time comes.[1] Therefore it is important to build up trust between health and social care staff and patients and to form good relationships to be able to talk about such matters.[3]

Sharing and availability of information

On occasions when end of life care or advance care plans exist the information is not always shared between all relevant parties.[4] Unforeseen medical scenarios and clinical need were also seen as barriers to fulfilling certain advance recommendations.[1]

The carers of patients who are nearing the end of their lives play a significant role in enabling them to die in their place of choice, and carers should be empowered to participate in end of life care-planning and decision-making. One way of doing this is to provide appropriate and timely information and signpost them to alternative or additional services if necessary and appropriate.[5]

Training

In order to provide each individual with the opportunity to discuss end of life care, training for staff needs to be implemented more widely.[4, 6-10] The evidence shows that where staff have received training they are more confident and knowledgeable in having conversations and providing care for those nearing the end of life. Having staff who are more knowledgeable and able to recognise someone who is dying will help to avoid unnecessary hospital admissions and enable individuals to remain at home to die rather than moving them to hospital unnecessarily.[8, 11, 12] This will help to fulfil more fully the wishes of those in the end of life care stage who would prefer to die at home or in a hospice.

Much of the research identified in the scoping exercise was concentrated on palliative and end of life care where death had been expected. The experience of end of life care where death is sudden or unexpected was less well documented. In addition, the scoping exercise did not uncover any recent research into people's experience of end of life care in Northern Ireland.

The PCC Complaints Support Service handled 55 cases regarding end of life care in 2015/2016. It was agreed by the PCC Board that an exploration of the complaints received would add value to the discussion on people's experience of end of life care in Northern Ireland. This approach was endorsed by partners already working in this field Including the All Ireland Institute of Hospice and Palliative Care (AIIHPC), the Commissioner for Older People Northern Ireland (COPNI), Marie Curie, the Public Health Agency (PHA), the Regulation and Quality Improvement Authority (RQIA), Queen's University and Ulster University.

This report is a summary of the PCC desk top exercise.

2. Methods

This was the first time that the PCC has undertaken an in-depth review of complaints cases for a particular health and social care issue. The PCC Complaints Support Service has important intelligence on key issues experienced by patients and the public accessing Health and Social Care services. As such, a review of complaints cases related to end of life was thought to be a good approach to identify these issues.

To identify PCC Complaints Support Service cases related to end of life issues a key word search using terms such as “death”, “deceased” and “DNR” was applied to anonymised cases from April 2015 to March 2016. Two members of the research team agreed on the inclusion of all identified cases. Anonymised case summaries were then prepared for all relevant cases.

For the purposes of this report, end of life care refers to cases where a complaint was made in regards to how an individual was treated in the days and weeks up to their death. The cases analysed include people who were already on an end of life pathway as well as those who were suddenly taken ill and died unexpectedly.

The cases identified from the search were of varying degrees of complexity and the Research team only had access to anonymised summaries of each case. In order to fully explore the issues of each case the research team interviewed PCC Complaints Support Officers about cases in their area. The aim was to gather their perspective on the core issues emerging from end of life cases.

A topic guide was developed for use in the PCC Complaints Support Officer interviews in order to promote consistency of the information being gathered. Questions focused on exploring: the underpinning issues of each case; the outcome that the client was seeking when they approached the PCC and what expectation they had of the PCC; how the organisation/professionals at the source of the complaint engaged with the client through the complaints process; what the outcome of the case was, if known; and, what learning the PCC Complaints Support Officer thought could be taken from the case.

Six interviews were completed, one with each of the PCC Complaints Support Team. Interviews lasted approximately one hour and were recorded and transcribed verbatim. Two members of the research team independently analysed the transcripts in order to identify key themes in relation to end of life complaints cases.

3. Key issues identified from end of life cases

The PCC Complaints Support Service handles issues from across the range of health and social care (HSC) services including issues involving end of life care. These are explored in this report. In total, anonymised case summaries were prepared for 55 end of life cases.

While preparing the case summaries it became clear that there was considerable diversity between cases with regard to the circumstances of how people had died and the illnesses they had, however, there seemed to be a core set of concerns that people were raising. The principal concern was about the quality of treatment and care in end of life care. Within this two key issues arose, the need for better coordinated care and the issue of perceived neglect/complacency. The issue of delayed diagnosis and misdiagnosis was also highlighted by clients as was a lack of understanding of the cause of death. Finally, although fewer in numbers, there were a subset of complaints where the key issue was around pain management.

A common thread which ran through all complaints was the issue of poor communication. It is evident from analysing the cases and speaking to the PCC Complaints Support Officers that if there had been open and timely communication between complainants and staff then a proportion of cases could have been addressed earlier and may not have escalated to submission of a formal complaint.

Tables 1-3 give an overview of the age groups of deceased subjects of complaints, the Trust area the complaint was associated with and the key concerns clients raised.

Table 1: Summary of complaints by age of subject

Age of subject of complaint	**Number of cases**
Younger than 16	**2**
16-25	**5**
26-35	**2**
36-45	**-**
46-55	**-**
56-65	**4**
66-75	**11**
76-85	**5**
Over 86	**2**
Unknown	**24**

Table 2: Summary of complaints by Trust area

Trust area	**Number of cases**
Belfast	**13**
Southern	**9**
Northern	**8**
Western	**8**
South Eastern	**7**
GP	**9**
NIAS	**1**

Table 3: Summary of complaints by key concern

Key area of concern	**Number of cases**
Need for improved communication	**55**
Quality of treatment and care	**38**
Perceived neglect/complacency	**30**
Lack of coordinated care	**8**
Delayed diagnosis/misdiagnosis	**10**
Lack of understanding/access to medical records	**9**
Pain management	**4**
Note: Does not add to 55 as some cases coded as more than one key issue.	

Need for improved communication

Poor communication was a common thread which ran through all end of life complaints cases that were dealt with by the PCC Complaints Support Service. Issues ranged from underlying misunderstanding, miscommunication or a failure to communicate meaningfully at all. As a result in many cases the primary role played by the PCC Complaints Support Officer was to re-establish communication pathways between complainants and HSC staff so that the issue could be resolved. There were two aspects of communication which impacted negatively on end of life cases, poor communication at the stage of death and poor communication during the complaints process.

Poor communication at the stage of death

In a significant proportion of cases it was clear that clients had not been prepared that their family member was coming to the end of their life. In one case, where a client had highlighted this within their complaint, the Trust involved explained to the family that they had discussed with the patient that they were nearing end of life. However, the client felt that even when it came to the stage of death no one had explained to the family that their relative was going to die.

In another case, part of the complainants issue was that a junior doctor had come to pronounce their relative dead but didn't introduce themselves or speak to the family when they came into the hospital room. When the client had raised the issue at the time they were told by other staff that they didn't know which doctor the client was referring to. This led the client to believe that the staff were protecting the doctor from a complaint being made directly against them rather than taking the clients concerns on board.

It was also clear that family dynamics are not always taken into consideration by HSC staff when communicating with a family. In a number of cases which were dealt with by the PCC Complaints Support Service a cause of concern was that staff had never met with the family as a whole to determine who they needed to speak to. An example of this was a case where staff had been communicating with an elderly relative who had memory issues and had not been able to relay the information to the family, as such, the family were not aware of certain issues in their relative's care.

Poor communication during complaints process

A distinct challenge faced with end of life complaints is that families are often faced with barriers to successful communication, particularly in relation to accessing information, as the individual at the centre of the complaint is no longer living. As a result, end of life complaint cases can become very prolonged.

PCC Complaints Support Officers identified that the majority of long running complaints in their caseload were to do with end of life. In fact one PCC Complaints Support Officer explained how they had had to start a process of sending out monthly requests to the complaints manager in their Trust area in order to chase up long standing cases. Causes of delay sometimes included the requirement by the Trust that responses are signed off by senior management. This is in itself, while meant to ensure appropriate responsibility and awareness of complaints by senior management, can have the effect of delaying a response. Unfortunately, the PCC Complaints Support Officers identified that clients often equate the delay in response with a lack of openness and honestly on behalf of HSC services. In addition, for many clients delayed responses to their complaint mean they feel unable to get closure. For some, getting written correspondence more than a year down the line means they have to read details of their family member's death and often this reliving of events leads to more questions which can extend the complaints process even further. PCC Complaints Support Officers felt that if clients were better informed of the stage of their complaint and updated to any delays, including the reason for the delay, that this communication could significantly improve their satisfaction with the HSC complaints process.

From their experience the PCC Complaints Support Officers felt that official processes should be put in place for relatives of deceased patients to have the opportunity to speak to consultants and/or other clinical staff to get clarification on any concerns they may have. They also suggested that for clients who feel their family member was let down by medical staff it may be more appropriate for them to have the option to meet with a mediator. In one Trust a face to face meeting is offered routinely to any complainant with a concern about the death of a relative and they felt this was a successful approach in dealing with a substantial proportion of complaints. However, some PCC Complaints Support Officers explained their frustration that while many face to face complaint meetings are very successful, often the written notes of the meeting which are sent out after do not reflect the client's understanding of what was discussed and agreed at the meeting. This means that while clients may be accepting of the meeting's outcomes at the time and feel that they have reached some kind of resolution, when they read the formal response they can feel misled and can wish to pursue or reopen a case. PCC Complaints Support Officers explained that this can be the case in complaints across HSC services but that it is most common in end of life cases. PCC Complaints Support Officers also highlighted that those preparing responses to end of life complaints need to be mindful of the client who is receiving the correspondence, their emotional status and the impact the response may have on them.

Importantly, the issue of client's grief can also be a complicating factor influencing communication between complainants and the HSC services. Often it can be very difficult for a client to look objectively at the case to allow them to successfully identify their issues, especially when it comes to written correspondence. In addition, it should be noted that some cases go on for a long time because clients may halt the process, before resuming the complaint at a later stage, for example the anniversary of their family member's death prompts them to revisit the complaint.

Quality of treatment and care

Perceived neglect/complacency

Across the cases examined there were a number of instances where the complaint made focused on the failure of staff to act in an appropriate and/or timely manner from the complainant's perspective (n=30/55 cases). In one particular case the client felt their family member had died due to a lack of attention to their basic needs during their admission and had sought independent medical opinion which had supported this point of view.

Cases regarding issues of perceived neglect or complacency, however, were not as clear cut as they may have first appeared and highlight the complex nature of some end of life complaints. For example, in one case a family had brought a complaint to the PCC Complaints Support Service because they believed that doctors had failed to treat a relative with a terminal condition. However, following the death of the patient it was only through making a complaint that the family were informed that the patient had not wanted any intervention.

Lack of coordinated care

Many clients (n=8/55 cases) who contacted the PCC Complaints Support Service regarding an end of life case described how a lack of coordinated care negatively impacted on their relative's death. In these cases while some clients understood their family member was facing death, they believed the circumstances of their care either hastened this process or reduced the quality of life that they experienced at end of life. One example was where a patient had been treated by two Trusts in the lead up to their death. The client stated that it was the family who contacted another hospital directly to check what the referral process was and chased up results of diagnostic tests in order to get the patient moved more quickly to a more specialised department. The family felt that although they had been continuously told that their relative was being treated as an urgent case this was far from the impression that they were given due to a significant delay from their relative's admission to hospital to getting them access to the specialist ward. The client was taking the case to the Ombudsman as they believed there should be better communication pathways between the Trusts to ensure that when patients meet the criteria for onward referral this is expedited.

A further instance of poorly coordinated care was a case where a family claimed that an elderly patient in their last days of life was discharged home without an appropriate care package in place. The family had felt that this had negatively impacted the quality of life of their relative experienced in their final days.

Delayed diagnosis/misdiagnosis

In ten out of 55 cases the complaint was about delays in obtaining the correct diagnosis and/or treatment and care. This category mainly concerned GPs. In some cases clients claimed that the GP had not sent their family member for tests even though they had been frequent attenders presenting with consistent symptoms. Complaints regarding an apparent delayed or missed diagnosis of cancer accounted for the majority of the cases. In these cases clients believed that if appropriate actions had been taken at the time then their relative may have been able to access treatment which could have saved or at least prolonged their life.

Lack of understanding/Access to medical records

Several clients found themselves left with unanswered questions after their relative's death and wanted information so that they could get clarification about how their family member died. In these cases they contacted the PCC Complaints Support Service for assistance in getting access to medical notes (n=9/55 cases). For example, in one case a family had received a death certificate for a relative that cited conditions as the cause of death which they felt the GP had not made the patient aware of, as a consequence the client wanted help in obtaining their family member's medical records.

Clients who come to the PCC Complaints Support Service for help in obtaining medicals records have often faced difficulties in getting records released. A number of clients were not informed about how to access records by HSC staff or they were not informed as to their rights to receive notes of a deceased family member.

Pain management

Pain management was a primary concern in a small number of cases (n=4/55 cases). In one case brought to the PCC Complaints Support Service a family had felt their relative was receiving optimal patient management when they were being cared for at home by specialist palliative care nurses, however, when admitted to hospital their medication was reduced and the patient was in a distressed state when they passed away. Another client highlighted within their complaint that they had had to ask staff to provide pain medication to their relative in advance of nursing procedures and felt that this was something that staff should have noticed without them having to flag the issue.

4. Conclusions and recommendations

The death of a family member is a distressing experience. For people who feel that the treatment and care their relative needed was sub-optimal, making a complaint adds a further dimension to that distress.

This exploration of the cases handled by the PCC Complaints Support Service provided insight into some of the key issues experienced by patients and their families in relation to end of life care. The concerns identified reflect the ongoing issues described in global research that has been completed over the last decade. Poor communication and lack of coordinated care are recurring themes. The ongoing distress felt by families who have been dissatisfied by the end of life care of a relative and the often-protracted nature of complaints resolution were key findings from this work.

Complaints about end of life care form an important part of the work of the PCC Complaints Support Service, particularly in terms of time taken in trying to obtain a potential resolution for the client. It can be argued that having appropriate communication pathways in place so that people can access the right information at the right time, could potentially prevent at least some concerns developing into a formal complaint.

The approach used in this project, to explore intelligence coming from the PCC Complaints Support Service was a method which had not been used before by the organisation. While it was successful in identifying a number of key issues reported by clients with experience of end of life care there are limitations to this approach. As the PCC is not responsible for investigating complaints it is unclear whether all of the complaint issues explored can be substantiated. The fact that these are people’s perceptions of the care received at end of life is important. Another complicating fact of this approach is that only anonymised case summaries could be reviewed in order to maintain client confidentiality, this could mean that the complexity of these cases was not fully explored.

The following recommendations can be made as a result of this project.

Recommendation1

Measures which improve communication between staff, patients and their families at end of life should be introduced.

Recently the new guideline ‘Care of the deceased patient and their family: A Guideline for Nursing Practice in Northern Ireland’ [13] has been published. The aim of the report is to promote a holistic perspective on all the processes associated with care after death and to provide guidance on the delivery of safe, effective and sensitive care for deceased patients and their bereaved families. Encouragingly the document emphasises the importance of communication and highlights how communication at end of life should be clear, unambiguous, compassionate and supportive; and, that communication with patients and families should be undertaken in a private space with professionals who have appropriate communication skills. This type of guidance should be cascaded to other healthcare professionals who may interact with patients or families at end of life.

Recommendation 2

Separate and appropriate arrangements to ensure effective communication with families regarding any concerns leading up to end of life should be available. In addition, formal processes to allow relatives to meet with clinical staff after a relative’s death to discuss any concerns or get clarification on issues should be available. Some Trusts already routinely offer this. Providing a means by which bereaved people can provide feedback on their experience of health and social care services should be explored, for example The National Survey of Bereaved People (VOICES) England.

Recommendation 3

Training in end of life care should be cascaded to all staff so they are able to prepare and support patients and families.

Recommendation 4

Undue delay in resolving complaints about end of life care cause distress to families. Service providers should ensure an appropriate priority is given to these complaints.

Next steps

This report describes the second phase of a two year project which explores the end of life care experiences of people who were supported by the PCC Complaints Support Service during 2015/16. There are important messages for service provider’s, commissioners and policy makers which will be presented for discussion and agreement in the context of future planning of end of life care at a future meeting of the Regional Palliative Care Programme Board. The findings from this report have already been fed into a planning workshop for work being undertaken by the Public Health Agency through the 10,000 Voices project exploring the experience of bereavement.

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