

Dying and Death in an Acute Hospital

Exploring the Views and
Experiences of Hospital Staff



Hospice *friendly*
Hospitals
PROGRAMME

Dying and Death in an Acute Hospital:

Exploring the Views and Experiences
of Hospital Staff

Focus Group Discussions with
Staff of Our Lady of Lourdes Hospital, Drogheda

A report prepared for the
Care for People Dying in Hospitals Project
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Our Lady of Lourdes Hospital, Drogheda March 2005

O'Mahony-Browne gratefully acknowledge the generous co-operation of the staff of Our Lady of Lourdes Hospital, Drogheda who contributed their time and ideas.

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Foreword

This report identifies issues and themes arising from research conducted among eight focus groups representative of all staff groupings in Our Lady of Lourdes Hospital in Drogheda. The research was undertaken on behalf of the *Care for People Dying in Hospitals Project 2004-2006* which was initiated by the Irish Hospice Foundation and was undertaken in partnership with the Health Service Executive – Dublin North East and the hospital. The purpose of this pilot project was to develop a comprehensive approach to the care of people dying in acute hospitals. A national *Hospice Friendly Hospitals Programme* has now been initiated and has been informed in part by the learning generated from this report.

The emphasis in the Focus Group discussions was on obtaining participants' actual experiences and perceptions of death and dying at the hospital. The result is a powerful documentation of the issues that concern staff, many of whom act in an advocacy role on behalf of patients who are dying and their families. The shortcomings identified and the frustrations revealed reflect genuine compassion, care and concern. They also reflect a need to urgently focus on issues such as spatial constraints, skills, services and support for staff as well as highlighting the need for organisational structures that support them.

These experiences are not unique to Our Lady of Lourdes Hospital. It is no coincidence that the first nationwide public opinion survey on attitudes and experiences of death and dying in Ireland showed high levels of concern about care of the terminally-ill in hospitals. Only 10% of Irish people would choose to die in hospital.

The issues raised by this report are profound and practical. They require serious consideration by policy and decision makers throughout the health services as well as the body politic. As a society we need to accept death as a dimension of life. We need to show maturity and take ownership of this sacred duty of care for those who are dying. One of the most profound indicators of a society's civilisation is how it responds to its citizens in their times of greatest vulnerability, at birth and death. Caring requires us not only to be present but to act as advocates to ensure that unnecessary suffering is not countenanced. More than half of all people who die in Ireland each year die in hospitals. It is time to recognise the significance of this simple fact and to face up to its many implications.

Introduction

This Report describes the findings of Focus Group¹ based research carried out by O'Mahony-Browne Research Consultants for the *Care for People Dying in Hospitals Project*. The project, which was initiated by the Irish Hospice Foundation, was undertaken at Our Lady of Lourdes Hospital, Drogheda and operated in partnership with the Health Service Executive-Dublin North East. The Focus Groups were conducted with hospital staff during November 2004 with a view to getting their detailed views and insights on policies, practice and procedures relating to dying, death and bereavement in the hospital.

The objectives of the Focus Group discussions were to:

- (i) provide an opportunity for consultation with hospital personnel about the project;
- (ii) ascertain staff views of the existing policies and practice relation to the care of people dying in the hospital;
- (iii) identify a range of potential areas for change and possible solutions which would inform the work of the Project Team and be brought to a future hospital review and planning day;
- (iv) inform the design of a detailed staff survey on current hospital practices and how these impact on people facing death in a hospital setting, their families and the hospital staff.

¹ *Focus Groups provide an opportunity for researchers to interact directly with the research target group. This allows the researchers to clarify and seek elaboration of responses. Focus Groups also allow participants to react to and build on the responses of other group members. A possible downside of Focus Groups is that the responses from individual members of the group are not independent of each other as would be the case in a one-to-one interview situation.*

Eight Focus Groups were organised which comprised representatives of the following hospital staff groupings:

Allied Health Professionals

Clerical and Administration

Consultants

Healthcare Assistants

Household Staff and Porters

Management Team and Nurse Managers

Non-Consultant Hospital Doctors

Nurses (to Clinical Nurse Manager 2 level)

Focus Group participants were self-selecting and the number in each group ranged from five to twelve participants. Some sixty staff members participated. Each Focus Group session lasted for two hours on average.

The themes explored in the Focus Group discussions were:

- current experiences of staff in handling death, dying and bereavement at the hospital;
- the implications of current practices and processes for patients, staff, families and the wider community;
- specific issues around death, dying and bereavement particular to different staff groups;
- general issues for all staff;
- what the hospital does well at present and what could be improved;
- adequacy of staff skill and experience in view of the realities of people dying that have to be faced on a day-to-day basis;
- supports required by staff.

The emphasis in the Focus Group discussions was on getting participants' actual experience and perceptions as distinct from broader generalisations. The researchers sought to work towards a consensus within the different groups on the various points made and, where this was not possible, to identify the range of perceptions around different issues. The content of the discussions was analysed by the researchers and distilled into a range of themes which formed the basis² of the present report.

² *Pieces of text in parentheses included throughout the report are direct quotes from Focus Group participants*

Main Findings

The findings from the analysis of the Focus Group discussions are set out under ten broad headings:

- (i) dealing with dying in the acute hospital context
- (ii) overall care in the hospital
- (iii) the physical environment in the hospital
- (iv) diagnosing the dying state and communicating the diagnosis
- (v) palliative care
- (vi) post-death environment
- (vii) pastoral care team
- (viii) dying and death: general implications for staff
- (ix) current work practices in the hospital
- (x) supports required by staff.

Dealing with Dying in the Acute Hospital Context

The hospital focus on getting people well was seen by Focus Group participants as impinging on the care of dying people. There was a conflict of interest, even an ethical dilemma. As one participant noted, “time for dying patients and their families is a real issue.”

Several participants felt that a focus on the “terminally-ill” state was only beginning to emerge in the hospital. Some participants expressed the view that the “dying state” was still not fully acknowledged in the hospital as a legitimate diagnosis. “Dying as a clinical state is not recognised in the acute hospital setting.” It was felt that more clarity around the diagnosis of a person as “actively dying” was needed.

Planning for dying and death in the hospital was regarded by some staff as totally inadequate. Some Focus Group participants felt strongly that services for those dying and the relatives of dead persons fell well short of a desirable standard. The focus in acute medicine was on treating people rather than dealing with the reality of dying. The inherent tension between letting people die and “doing everything we can” was an ongoing challenge. It was pointed out that the safe option in the acute hospital was to “do everything” that could be done to avoid any perception of not having explored all possibilities.

Fear of litigation was seen as a significant factor shaping the care-of-the-dying ethos. Some participants said this increased the suffering of a dying patient and postponed the family facing the fact that a relative was in fact dying. It was noted that families sometimes had unrealistic expectations and that this could present problems for medical staff.

It was pointed out that planning for dying, as distinct from recuperation, required different priorities. For example, in terms of nutrition, the emphasis needed to be on comfort and maintenance. It was important to have family agreement that food should not be pushed on the patient on the basis that “you won’t get better if you don’t eat.” The cut-off point for treatment was seen as important for people’s comfort. The key issue noted was whether one was prolonging life or prolonging death. For example, when is ongoing “aggressive” treatment valid? Some Focus Group participants regarded tube feeding in specific instances as a huge issue that had not been addressed fully or systematically in the hospital.

In cases where patients are reluctant to accept that they are

dying, the situation becomes more difficult for staff, relatives and other patients in the ward. Also, some Focus Group participants stated that on occasions they felt bullied by family members to act against their own better judgement. It was noted that there were no protocols to guide and support staff dealing with such situations.

There was a general recognition among Focus Group participants that, in addressing issues of death and dying in the hospital setting, cognisance needed to be given to the fact that there were diverse dying-related situations. These included terminally ill in-hospital patients, trauma and casualty-related deaths, people discharged to die at home, still-births and miscarriages.

While there are some common factors, each of these situations presents different challenges and requires different responses. It was noted, for example, that people who have had miscarriages have needs that have to be dealt with in a particular way. Frequently they require time to come to terms with what has happened and, as a result, grieving may be delayed. It was also pointed out that dealing with children dying from Cystic Fibrosis presented particular difficulties which required particular responses.

Focus Group participants perceived that people who died in the hospital were seen by families and relatives as having received good care. However, participants noted that people generally did not want to be sent to die in the hospital³. As one participant put it, “one bad story influences broader community perceptions.”

³ Research shows that people express a preference for dying at home. See, for example, Weafer and Associates, *Nationwide Survey on Death and Dying*, The Irish Hospice Foundation, 2004

The physical environment and lack of space in the hospital was seen as giving a bad impression. It created stress for bereaved families despite the best efforts of staff to mitigate existing constraints.

Focus Group participants who were not directly involved with dying and death as part of their daily work stated that they regularly encountered issues around death and dying. For example, administrative staff are frequently the first point of contact in emergency situations and regularly deal with dying and death-related queries and processes. This aspect of the work is not adverted to in their job specifications. No specific training in this regard is provided and no specific provision is made for debriefing.

Medical Intervention

A number of issues were raised about continuing medical intervention when there was no chance of recovery. A particular problem arose when the palliative care approach was not put in place soon enough. Families sometimes continued to demand aggressive interventions, including resuscitation.

Arrest Protocols and Resuscitation

While, in theory, there were steps to be followed, participants noted that in practice they could by their very nature be chaotic. Staff are not necessarily trained or equipped to deal with such emergencies but are expected to manage. The situation is more complicated when the resuscitation status has not been fully clarified. Dealing with an arrest situation was seen as more difficult for medical staff to deal with outside regular hours because they could not consult immediately with senior colleagues.

Overall Care in the Hospital

The general perception was that staff met basic medical, human and care needs within the time and resource constraints operating in the hospital. While some participants regarded the care provided as excellent, it was also noted that much depended on staff “on the floor” and on the attitude and approach of individuals. The “kindness of what you say and do” was identified as the key factor. A number of participants made the point that “care on wards is only as good as the person doing it – it depends on who you get.” Some participants referred to isolated cases of bad practice – people being left in wet pads or not having their toileting needs dealt with quickly enough. The point was also made that some staff did not like intensive caring and/or were just not good at it.

Caring for the Dying

There was a general recognition that the hospital should be able to meet the needs of the dying and the bereaved with sensitivity and that the dead should be treated with the utmost respect. However, it was acknowledged that frequently the hospital currently fell short of this goal for a variety of reasons. Staff are fully committed to providing the best service possible and are often distressed when they are unable to achieve this. Some participants referred to the satisfaction of a ‘job well done’ in caring for a dying person and noted that the biggest stress was when things could have been done better. They might not have been done better because of either the hospital system or the response of the patient and his/her family. Participants instanced people being unnecessarily moved within the hospital before actually dying or the person not being fully informed of his/her dying status.

While the palliative care approach was universally seen as most welcome and useful, facilities for death and dying were generally regarded as patchy throughout the hospital. Some units were regarded as having good practices, protocols and facilities and as managing difficult situations sensitively and appropriately. Other units were regarded as less well equipped and much of this was seen as arising from work pressures, bed shortages and lack of private space. As one participant put it, “patients dying in six-bedded units is a nightmare for staff.”

It was noted that, frequently, staff individually and/or collectively built up a strong rapport with a person who had been there for a while and that this contributed to an environment of “total care to the end.” It was also stated that a dying person sometimes built up a rapport with other patients, for example, in a six-bedded unit, and that people in that situation “really connect” with one another which, it was felt, helped the dying person. It was noted that an outcome of this was that other patients in the unit experienced a sense of loss at the stage when a dying person was moved into a single room for the last few days of his/her life. This was another aspect of dealing with death and dying that staff had to manage.

The Physical Environment in the Hospital

The general view that emerged was that the management of dying and death was, to some extent at least, determined by the physical environment of the hospital. In a general sense, it was noted that the physical configuration of the hospital, the décor and the level of cleanliness, and the general facilities, all impinged on the way staff could respond to the needs of people dying and those who were bereaved.

The hospital's physical space is under severe pressure due to the location of more and more services without provision of commensurate extra space. The reality is that there are too few rooms to cater for dying people. The availability of single rooms where patients who are dying can be transferred, and/or where families can be brought, was universally regarded as making a major difference in dealing and coping with dying and death in a sensitive and adequate manner.

To that extent, the experience in public wards and Casualty was perceived by Focus Group participants as different from that in private/semi-private accommodation and children's units.

Space and Privacy

It was pointed out that there was a general lack of privacy for both patients and families in both public wards and in Casualty – “private space for families of people on public wards is totally inadequate.” This becomes more acute when a person is dying or has just died. An example was given of a man who died in a public ward, surrounded by his family, but with a football match commentary blaring in the background. This can appear very insensitive and callous to families.

It was also noted that the lack of a dedicated room for dying patients caused distress for other patients. For example, it can be traumatic for children to watch the death of another child from Cystic Fibrosis. Also, the sight of a small white coffin being carried out can be upsetting for women awaiting childbirth. Staff were deeply concerned about these issues. The age and circumstances of a child's death all bring about their own challenges in an under-resourced situation with the space constraints.

Reference was made repeatedly to the absence of provision for a “cup of tea” for families and “nowhere to bring families to talk to them.” It was said “you should not have to talk to families in crowded corridors or clinical rooms. “With a couple of exceptions (for example, a room outside ICU and a room on the Children’s Ward), Focus Group participants stated that there was nowhere in the hospital to talk in private to people. This aspect of care was seen as totally haphazard and as not being addressed in any systematic manner. Also, it was pointed out that a comfortable sitting room for families was required. “There are no quiet rooms, resource rooms, crying rooms.” “No place to bring relatives”, was a recurrent theme as was the fact that “rooms previously used for the terminally-ill and dying are now offices.”

Public Wards

Space was regarded as a real issue on public wards. For example, trying to cope with the care of terminally-ill people behind screens was seen as totally unsatisfactory for patients, relatives and staff. Basically, there was not enough space for toileting and washing and changing beds and, as one participant put it, “curtains are not sound-proof.” One participant referred to the whole process as “warehouse dying.” The lack of space for families on public wards was referred to by one participant as “horrific.” The syndrome of families of dying or dead people “standing around” on corridors or walk-through areas was highlighted as most unsatisfactory.

Staff felt that when people were dying families needed a completely private room but that this could not usually be provided in public wards. Several participants referred to the need for a dedicated ‘dying room’ in all units. The situation on

public wards was regularly contrasted with that in other wards where there was more space and where a single room was normally available for a person dying.

Casualty

The lack of space in A & E was frequently mentioned as was the design and general layout of the area. The Casualty area was universally regarded as too cramped and was described by one participant as “chaotic.” It was noted that there was nowhere to bring someone who was dying or for repose after death. While the resuscitation room was used when available, “there is always a concern that this will be needed for another patient.” Space for families in Casualty, or for breaking bad news, was reported as being “non-existent”. It was stated that, despite the best efforts of staff, people were traumatised by the poor quality service arising from the physical layout.

While the A&E team were regarded as working well together and supportive of each other, there was a very strong feeling that the situation was much more stressful for staff than it should be because of the lack of reasonable facilities.

Transfer to Mortuary

The means of transferring a body from a ward to the mortuary was seen as presenting real difficulties and current provision was universally regarded as totally inadequate. The trolley transfer process was regarded by one participant as horrific – “everybody knows that this is a dead person.” The situation was regarded as even more problematic in the case of dead children who had to be transferred for post-mortems. Parents were understandably sensitive about parting with their child immediately after death.

It was felt that this can cause great and lasting trauma.

The general view of participants was that current arrangements for transfer from wards was totally unacceptable and needed to be reviewed urgently. It was felt that some better method could be found, even in the short-term.

Mortuary

There was a broad consensus that the mortuary chapel urgently needed refurbishment and that practices and procedures needed to be urgently reviewed. Some Focus Group participants felt that the maintenance and cleaning of the mortuary was far from satisfactory and that families were additionally traumatised by this. As one participant put it, “the mortuary should be treated as a sacred space.” The mortuary waiting room was seen as totally unacceptable by some participants.

Environmental Noise

A general issue of environmental noise in the hospital was identified by some Focus Group participants. This arose from day-to-day activities, such as:

- hoovering
- hammering/drilling
- broadcasting of Mass
- listening to others dying.

It was noted that the noise levels of day-to-day ward routines disturbed dying patients and that families were often upset by this.

Diagnosing the Dying State and Communicating the Diagnosis

It was pointed out that the onus was on the primary consultant to make the diagnosis, to tell patients and communicate this to staff. However, it was felt by some participants that there were situations where “nobody calls it” and that this caused problems. Another participant commented that there had to be a defined point in time when invasive procedures, such as taking blood for analysis, should cease. The situation is obviously complicated in cases where the patient or his/her family wants “everything done.” It was noted that doctors received little training to equip them to deal with complex situations such as this.

It was suggested that there were extremes in how diagnosis of dying was presented – it depended on the skills and practice of the individual consultant and it was felt that some consultants were not trained in this complex task. The bedside manner of some doctors was seen by some participants as less than satisfactory. There can be communication problems where English is not the first language of either the staff or patients involved. Also, there may be difficulties arising out of different cultures and different attitudes to death and dying on the part of non-national doctors or patients.

Some participants pointed out that people might only gather a little from what the consultant said and that many people were reluctant to hear what was actually said. Patients and their families may not always know the questions to ask to get the information they want. The point was also made that sometimes the consultant might assume that people chose not to pursue an

issue because they preferred not to know any more, but that this might in fact not be the case.

While the consultant communicates the diagnosis to the patient and his/her family, the reality is that relatives tend to approach junior staff or regular ward staff for elaboration and clarification. There may be a perception that the latter have more time and/or can explain things better. The onus of explaining the details of the diagnosis to people thus sometimes falls on less experienced members of staff who may not have the skills or experience and, indeed, may not be sure of their own role and responsibility. This can be difficult for the staff involved. As already stated, patients may only gather a little from what a consultant says and families are also sometimes reluctant to hear what is actually said. As one participant put it, “nobody teaches you how to communicate with people in such situations.” Particular problems can arise when staff are “caught off guard” by family members, for example, on a corridor or when they are dealing with another case.

Dealing with families can be particularly problematic when different family members have different views, for example, in relation to resuscitation. Also, families may collude in denial and want hospital staff to do the same when dealing with the patient.

The view was expressed that the onus was on the hospital to involve the family as much as possible and the notion of “don’t tell him/her” was widely regarded as “no longer a runner.” The consultant’s therapeutic contract and primary relationship is with the patient and after that with families and significant others. The situation where families do not want the person told

is a very challenging scenario, particularly where the person him/herself appears reluctant to want to know the diagnosis. Legally, the patient is the only one with the right to information and, while significant progress has been made in this regard, some participants felt that there were still situations where families rather than patients (perhaps, inadvertently) were told the full diagnosis. It was noted that nurses were more and more taking on the role of patient advocate of his/her right to know. However, one participant expressed the view that sometimes “people are still referred to palliative care who don’t even know they are dying.”

It was pointed out that the process of preparing people should begin at out-patient stage where opportunities were provided for people to ask questions and to seek elaboration. Many people may be reluctant to talk about the implications of the diagnosis and physicians need to help people to get over this block. Building up trust with patients was regarded as essential in this context. This was more difficult in situations where people came into hospital late in the disease process, either from another hospital or having been cared for at home until a crisis arose.

Palliative Care Unit

Changes arising from the palliative care unit approach were generally regarded as very positive. It was also noted that the unit facilitated a multi-disciplinary approach and gave people options and choices.

The focus in the palliative care approach is on helping people to maximise the time they have left and on helping people to

manage and cope. Death and dying are part and parcel of the palliative care approach. It was felt that in many instances this was best achieved in the home setting rather than in the hospital.

The option to die at home was now becoming a reality for many people. It was noted that as a matter of best practice this option should be offered to people where feasible on the basis that this might be the least stressful option. One view was that it was rare that “somebody cannot die at home.” However, people in the dying state already in hospital are frequently reluctant to go home, despite the fact that most people have a preference for dying at home. They may not want to put further stress on their families and/or may feel that in the hospital setting they would be more in control of the situation and have better access to supports, for example, pain control. Families frequently feel that they would not be able to cope for various reasons:

- timescale not clear
- people working full-time
- fear of not getting supports such as oxygen and pain control
- conflicting views within families.

One participant expressed the view that the reticence about going home to die arose because “we underestimate our ability to cope with people who are dying.” While technical support is important in caring for someone dying at home, the human caring element is the essential component. At times of stress people may not always fully realise this. Focus Group participants felt that the palliative care approach could empower both patients and families to cope in the home environment.

Post-death Environment

The after-death situation in the hospital was generally associated with “a lot of things happening at the same time.” This is particularly true where there is a sudden death, whether on a ward or in Casualty. This can be difficult and traumatic for staff, especially for those with little experience, and for relatives. The following were some of the comments made by Focus Group participants:

- “You’re trying to find somebody to take care of the family”
- “families tend to be in shock – even when the death is expected”
- “It is distressing for other patients”
- “Relatives don’t know what to expect or do”
- “There is chaos in casualty”
- “Other patients’ needs have to be catered for”
- “The corridor [narrow] is blocked by people bereft and crying.”

The comment was also made that in the post-death situation, it was difficult for staff to “just be there” for relatives. It was felt that there was a perception that “if you do not have a specific task, you probably shouldn’t be hanging around and that you should get back to your regular work.” Some participants also referred to a perceived taboo against hospital staff physically touching or holding someone grieving and/or in shock.

The situation is particularly difficult in cases where organ retrieval has to be carried out. The person is already dead but kept on a ventilator and relatives and staff have to wait for a Transplant Team to carry out retrieval. There are a lot of emotional feelings around and it was pointed out that staff were

not really equipped to deal with these. There was also a problem in relation to where the body could be brought after the retrieval procedure. There were difficulties with returning the body to the ward and the mortuary, in its present condition, was seen as a far from satisfactory option.

Sudden Death: Breaking Bad News

Deaths of people in A&E associated with accidents or out of hospital cardiac arrest or trauma deaths were regarded as very distressing for staff: parents, siblings, spouses, partners, boyfriends/girlfriends have to be told. While an experienced member of nursing staff was generally delegated to prepare waiting relatives for the worst, the breaking of the actual news was still difficult.

It was noted that there was no opportunity for the staff to establish a rapport with families of people who were dead on arrival or who died in casualty, as would usually happen in the case of an in-patient where staff would have got to know families over time. Breaking the bad news to relatives was seen as being much more difficult for staff in situations where there was no previous contact.

Some participants took the view that breaking bad news to relatives was an integral part of the job and had to be done in a respectful and professional manner in every post-death context without dwelling on or over-emphasising one's own feelings.

Dealing with the Dead Person

Some participants expressed the view that appropriate procedures for dealing with the body of the dead person immediately after death (for example, closing the eyes and mouth) were not always observed. Similarly, it was felt that the transportation of the dead person to the mortuary was not always carried out with appropriate respect and dignity.

The reality reported was that frequently beds had to be cleared very soon after death; the hospital would be literally waiting for a bed to deal with an emergency admission. This meant that families might not be able to say their goodbyes in a dignified manner and might be hurt and offended and further traumatised as a result. Also, this was seen as putting enormous pressure on ward staff who very much wanted to give a more sensitive and respectful service.

Deceased Person's Belongings

The practice of returning a deceased person's belongings in a plastic bag was referred to as offensive, particularly to people already traumatised by sudden death. The point was made by several Focus Group participants that it should not be difficult to find a more respectful way of doing this.

Pastoral Care Team

The pastoral care team was universally regarded as playing a vital role and “filling many gaps” in relation to death and dying in the hospital. The team was seen as providing an excellent service and, as one participant put it, “the hospital would get a

desperate reputation if the pastoral care team were not there.” The service acted as a support for patients and as a “cushion for families.” “They are there when needed” and “can be called on at any time.”

The pastoral care team was also available for support and debriefing of staff, as required.

A number of participants stated that, while the pastoral care team did its best and provided a valuable service, a comprehensive approach was required to cater for the very complex needs associated with dying and death in the hospital. For example, the point was made that there was a clear need for a long-term bereavement counselling service which was different from pastoral care. It was also noted that a changing, more broadly-based religious ethos in society had to be adequately catered for in the hospital context.

Some Focus Group participants expressed the view that the role of the pastoral care team was somewhat taken for granted by hospital management and that there was a perception that the team could and did cater for all support and counselling requirements, which was not necessarily the case. The provision of more resources for the support and counselling aspects of hospital care for the dying and bereaved was regarded as essential by some participants.

Dying and Death: General Implications for Staff

Dying and death were seen as presenting a number of challenges and difficulties for staff. These ranged from informing people

about a diagnosis to dealing with the aftermath of a sudden or traumatic death. The overall situation is complicated as sometimes patients and relatives do not differentiate between different staff roles and responsibilities. For example, Health Care Assistants may be asked questions that they are not in a position to answer. Sometimes individual staff members may be landed in complex situations that they have to try to deal with, for example, a patient may ask “how do you die?” It was also noted that in some situations staff could take a “lot of hammering” because relatives might believe that the hospital did not do enough. It may be that people take their own guilt or anger out on the hospital. Some Focus Group participants felt that little thought was given at the planning level to the need for de-briefing and individual support for staff in such situations.

The reality reported was that staff, including doctors, sometimes got close to patients and their families and that this inevitably had an emotional impact when the person died. It was generally acknowledged that where a rapport had been developed, there was a limbo after a person died – “you just go home.” It was noted that staff, even at arms length, got upset.. This might depend on where an individual was at in his/her own life. A person was likely to react differently if s/he had had a recent bereavement. The point was also made that it could be difficult for a staff member to come back after time off and find that a person s/he had been caring for over a period of time had died. This was seen as especially difficult when no other staff member had remembered to pass on the information.

It was noted that “dying affects the whole ward,” including staff. Death in a public setting is traumatic for other patients, and staff

have to deal with this aspect of the situation as far as time allows.

The point was made repeatedly that there are no systematic procedures in place for staff achieving closure after a person had died. While staff talked informally about a death, mostly there was no structured de-briefing in place. It was acknowledged that there was a counselling service available to staff but people might not be aware of it, or might not want to use it, for reasons of confidentiality.

It was felt that there should be provision for de-briefing, for example, opportunities for staff to explore the issues around death and dying in particular instances and the personal impact these had on the staff involved.

Support for Bereaved Families

Support and follow-up for families who have experienced trauma associated with death was regarded as hit and miss – it very much depended on the skills of the individual staff members involved and the time they had available to deal with specific situations, for example, helping a family to come to terms with and cope with a still-birth.

The point was made that staff generally might tend to identify more with the patient than with relatives and as a result the needs of family members might not be catered for. Some Focus Group participants expressed the view that usually people just wanted space to sit down and talk rather than an intensive counselling type approach. However, while there was a need for staff to help people to deal with bereavement, as one participant put it, “if you got embroiled in all the problems that families have to deal with in the post-death situation, you would be a wreck.”

Current Work Practices in the Hospital

Teamwork and Multidisciplinary Working

Focus Group members reported that teamwork varied from unit to unit within the hospital. It was seen as very good in some units. However, it was felt that teamwork depended on individual relationships rather than on systems. It was also noted that some areas were more dependent on temporary staff than others and that this could impinge on a team approach. The point was also made that a staff member who made an error could frequently be left on his/her own to deal with the fall-out.

It was stated that while multidisciplinary working was desirable as a concept, the reality in the general hospital setting was that it was very scarce and ad hoc. Most staff were already overstretched in carrying out their own duties and responsibilities. "Where would you find time to fit in a multidisciplinary team meeting, even once a week?" It was also noted that some disciplines were much more overstretched than others. There was a broad consensus that links between different disciplines tended to be dependent on the consultant and/or on individual relationships.

Some Focus Group members stated that on occasions a difficulty could arise for individual staff when their own perception of a patient's need differed from that of other staff. This might happen where a staff member felt unnecessary procedures were being carried out on a dying person or where s/he felt the full diagnosis might not have been communicated to the patient.

Communication

In-house communication was generally regarded as good but occasionally there were systems failures which could have a significant knock-on effect. The latter were felt by some participants to arise on occasions because of a lack of clarity about responsibilities.

A number of participants expressed the view that the voice of people on the floor was not always heard by hospital management and that an overall understanding of the pressures and needs of frontline staff might not be reflected as strongly as it should be in the planning of services.

Work Pressures

It was noted that staff morale could sometimes be low because of pressures of work. Staff regularly do not have time to deal adequately with all their caring responsibilities. One view expressed was that it was acknowledged that doctors did not have time and that other staff were left to “pick up the pieces,” particularly in respect of helping patients tease out and come to grips with a diagnosis.

There was also a view that the emphasis on administrative procedures might be undermining the basics of caring. As one respondent put it, “form-filling has taken over.” Another participant pointed out that documentation was an essential element of the hospital service – “if it’s not written down, it didn’t happen.”

It was pointed out that many staff had acquired high-level skills in dealing with the dying through experience but that issues around space, time and privacy affected their ability to do the job as well as they could.

Some participants felt that there was insufficient support from administration/management for clinical staff. The key question for administration was referred to by one Focus Group participant as “how many empty beds in the unit to-day?”

Good Practice

Focus Group participants identified a number of good practices in respect of death and dying. One example was one-to-one support for a mother where there was a pending stillbirth. Another example of good practice noted was the practice on the paediatric ward of bringing a child back to the ward for a prayer service. The holding of an annual memorial service for children who died during the year was also mentioned. In cases of stillbirth, the post-natal check-up was seen as providing an opportunity for staff to encourage people to reflect on and talk about their experience.

Supports Required by Staff

Staff reported regularly experiencing stress in respect of dealing with death and dying. The main cause of stress was identified as arising from the scarcity of resources and the related lack of capacity within the hospital. This was exacerbated by the vagueness of protocols, some of which were perceived as arising out of a lack of overall support for the state of dying in the acute hospital setting. The point was made by a number of participants that a lot of energy was used diffusing stress which resulted from having to cope in pressurised situations where protocols were vague.

It was also noted that it could be stressful for staff when a person for whom “they did everything” was going to die. As already

stated, a major stress for staff could arise when things could have been done better but were not because of either the hospital system or the response of the patient and his/her family.

Another area of stress noted was where some treatment was taking place that a staff member was not comfortable with and/or could see no point in, for example, continuing medical interventions for someone in the dying state. It was pointed out that staff needed to be helped to cope with situations where they felt that procedures were unnecessarily invasive, for example people who were clearly dying being brought for X-rays.

It was noted that the death of a pre-birth viable baby, while relatively rare, was extremely difficult for parents and could, therefore, be traumatising for staff.

Some of the stress experienced was seen as arising from the fact that people usually came into the job with little experience or training in dealing with difficult and complex dying situations. It was pointed out, for example, that the hospital system presumed that “you have already experienced someone dying,” which frequently was not the case.

It was stated that professionals as individuals sometimes did not have adequate support, particularly in relation to the legal aspects of caring for the dying in particular situations.

There was no formal system of de-briefing for staff after a death and, as already stated, mechanisms to help staff deal with difficult experiences tended to be informal and ad hoc. As one participant put it, “there is no support except what we give one another” and “we get ourselves through it.” There was a broad consensus that more provision for de-briefing for staff in more

complex cases of death was needed and that this should be more structured and organised.

It was noted that , with few exceptions, staff were either not aware of and/or did not use the counselling service available to staff by appointment. It was not entirely clear why this was the case but one view was that it was regarded by staff as too removed from the day-to-day reality of the hospital and, therefore, was not considered as an option. Another view was that, because the only available information to staff about the service was a contact telephone number, people might be unsure about its status, with particular reference to its confidentiality.

Skills/Training

Training for staff was generally regarded as totally inadequate. It was stated that frequently new staff did not have enough experience/skills to carry out their job properly, for example:

- handling and lifting dying patients
- dealing with corpses with dignity and respect
- communicating with patients and relatives
- dealing with stressful post-death situations

General Issues Arising from the Focus Groups

A number of general issues emerged from the analysis of the Focus Group discussions which can be summarised as follows:

- Planning for dying in the hospital is inadequate in terms of space, physical environment and staff skills, training and supports.
- Staff who interface with patients/families often have least input into policy formulation. Staff on the floor feel that management does not always see things from a care perspective in relation to people dying.
- Policy development and planning is seen as being carried out by personnel who spend least time in the actual hospital/ward caring environment.
- The palliative care approach is felt to be still not fully understood by patients or staff, including doctors.
- While the method and approach used in breaking bad news is of paramount importance in terms of both supporting people and how the hospital is perceived, no facilities are provided for this purpose.
- It is acknowledged that multidisciplinary working with appropriate delegation is an important prerequisite in caring for the dying – however, with notable exceptions, multidisciplinary working is underdeveloped within the hospital setting.
- There are major concerns about the use of spatial resources – Focus Group participants felt that administrative requirements were given priority before the needs of dying patients and their families for privacy.

Addressing the Issues

The following suggestions were put forward as ways of addressing some of the issues identified.

- There is a need to urgently review the overall approach to death and dying in the hospital with particular reference to the allocation of space, training and supports for staff and the development of good practice throughout.
- Good practice in relation to dying and death currently operating in some units should be extended and systematically applied throughout the hospital.
- There should be single rooms dedicated to dying patients on every floor.
- Private/comfort areas should be made available throughout the hospitals for relatives and to facilitate interactions between staff and relatives.
- There is a need for an agreed set of values, principles and ways of working based on a clear and shared vision of policy and practice around dying and death in the hospital.
- The hospital system needs to support and encourage individual responsibility and initiative within a stronger overall care for the dying and bereaved ethos.
- Joint staff/management committees should be established to develop clearer protocols around issues identified as problematic:
 - communicating diagnosis
 - clarifying state-of-dying status
 - resuscitation

- dealing with situations involving organ retrieval
- dealing with bereaved families in the case of sudden or traumatic death.
- Personal supports for staff dealing with death and dying are currently under-resourced and need to be enhanced.
- The mortuary/chapel of rest should be revamped and a clear-cut distinction made between this space and the morgue. Consideration should be given to having a designated area in the mortuary for children. In the short-term the overall décor and appearance should be improved as a matter of urgency.
- More training and skill enhancement on breaking bad news should be provided.
- Regular de-briefing sessions should be integrated as part of day-to-day working.
- The following specific provisions should be introduced:
 - a better system for transferring bodies from wards to mortuary
 - the provision of a Moses basket for carrying the body of a dead child to the mortuary
 - the availability of colourful rather than clinical sheets for laying out the bodies of children
 - provision of flowers for use when bodies are being laid out
 - provision of a suitably designed container for a deceased person's belongings.

Synthesis of Main Findings

The inherent tension between the needs of an acute hospital and the needs of people dying and their families is a day-to-day reality. Planning for dying in the hospital is inadequate in terms of space, physical environment and staff skills, training and supports. The development of policies and practices appropriate to people in the dying state is an ongoing challenge. This requires full recognition of the dying state as a legitimate diagnosis. The palliative care approach, while seen as a most positive development, is still not an integral part of the hospital system. Also, some Focus Group participants expressed the view that a separate hospice unit was essential.

There was a general consensus among Focus Group participants that the physical environment and structure of the hospital was unsatisfactory in many respects and presented significant difficulties for staff in dealing with death and dying in a sensitive and respectful manner. Physical design and lack of private space are very real issues, particularly in public wards, A&E and in the mortuary. Background noise, crowded corridors, and having nowhere to talk to families were recurrent themes. Current practice for the transfer of bodies from wards to the mortuary was regarded as totally unsatisfactory.

There was agreement that staff for the most part dealt as well as possible with the situation of death and dying in the hospital within the constraints noted above. Difficulties arising from space constraints and occasional system failures were lessened to some extent by the efforts of individual staff members.

Focus Group participants identified a number of good practices in respect of death and dying in the hospital. However, this varied from unit to unit and was regarded as depending on individuals as distinct from being an integral part of the hospital system.

It was suggested that there were extremes in how diagnosis of dying was presented to patients and families – it depended on the skills and practice of the individual consultant and it was felt that some consultants were not trained in this complex task.

The pastoral care team was universally regarded as playing a vital role and “filling many gaps” in relation to death and dying in the hospital. The team was seen as providing an excellent service to patients, relatives and staff. It was suggested that there was a clear need for a more comprehensive bereavement counselling service, particularly in relation to sudden and/or traumatic deaths. This was seen as different from pastoral care. Also, a changing and more broadly-based religious ethos in society at large must be adequately catered for in the hospital context.

Staff reported regularly experiencing stress in respect of dealing with death and dying. The main cause of stress was identified as arising from the physical environment in the hospital and the scarcity of resources and the related lack of capacity within the hospital. This was exacerbated by the vagueness of protocols, some of which were perceived as arising out of a lack of overall support and provision for the state of dying in the acute hospital setting. Morale among staff can sometimes be low because of pressures of work. Staff regularly do not have time to deal adequately with all their caring responsibilities, particularly supporting bereaved families.

Systematic de-briefing for staff after a death was not done generally or systematically but tended to happen informally and to be somewhat “hit and miss.”

The need for more training for all staff around the whole area of death, dying and bereavement was generally acknowledged. Staff not directly involved with patients, for example, administrative staff, need to be provided with appropriate training to enable them to cope with death and dying situations that they have to deal with from time to time.

Support and follow-up for families who have experienced trauma associated with death was seen as very much depending on the skills of the individual staff members involved with the particular case and the time they have available.

While there may be a negative perception of the hospital in the wider community, Focus Group participants felt that people, in practice, were happy with how their dying relatives were cared for in the hospital. However, the limitations of the physical environment and the lack of private space in some sections of the hospital were seen by Focus Group members as inevitably having a negative impact on how people experienced dying and death in the hospital. The best efforts of staff could not fully compensate for these limitations.

Concluding Comments

Five key points were identified from analysis of the Focus Group discussions:

First, the overall impression that emerged from the analysis was that the physical capacity and resources of the hospital were greatly overstretched and that as a result dying and death in the hospital setting did not receive adequate recognition.

Second, there was a clear picture of a staff uneasy about the fact that the hospital frequently did not deal adequately with the dying and the bereaved. In many instances, things that could and should have been done did not happen. This undermined staff morale, both individually and collectively, and sometimes resulted in additional stress in an already pressurised work environment.

Third, there was a clear sense of staff feeling disempowered. While dealing with this may appear daunting, it is important to break the cycle of disempowerment by selecting a small number of achievable goals that would improve services, for example, the re-configuration of the A&E area and the re-decoration of the mortuary.

Fourth, the goodwill and skills of staff may be undermined by a hospital system that was regarded as overstretched and, therefore, lacking the capacity to respond adequately and equitably to the day-to-day needs of people dying and their families. This is an issue which needs to be addressed.

CONCLUDING COMMENTS

Fifth, there is a pool of talent within the hospital that could be purposefully used for in-service staff training in dealing with dying, death and bereavement in the acute hospital setting.

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in partnership with the Health Service Executive

