Psychosocial Aspects in Palliative Care

Communicating with the Patient and Family

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The dynamics surrounding the patient and family facing a death as the 'unit of care' is discussed. Aspects of communication, openness within the family, especially concerning children and teenagers, and factors that enable a family to function under the stress of a loved one's terminal illness are explored. The use of a genogram in palliative care to help to piece together the family dynamics and available support is fundamental to the care for the whole family.

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Since the 1960s there has been an increasing interest in the psychosocial aspects of palliative care. It could be argued that it has been the hospice movement that has helped to emphasize the importance not only of holistic care of patients but also extending that care to the family. Both of these aspects are now widely used in differing specialities of acute care. Within specialist palliative care, professionals commonly deal with a couple of fundamental issues of psychosocial care, namely: (i) how to use the time after a diagnosis of progressive, incurable disease, and (ii) how long the patient might have to live.

A useful analogy of the uncertainty of time (1, 2) with which both patient and family are faced after a diagnosis of advanced disease is portrayed in the play 'Shadowlands' (3), based around the latter part of CS Lewis's life. It involves his love for an American writer, Joy Davidman, and her subsequent death from cancer. The play gives insight into many of the dynamics involved in such a tragedy: dynamics about family, communication, spirituality and dying. CS Lewis, in his helplessness and shock at hearing the extent of Joy's cancer, asks the doctor how long she has to live. The doctor returns the question with the analogy of a train: 'Mr Lewis, he says, you're looking at a train standing in a station. It may not be moving right now, but trains move. That's how trains are'.

It is this aspect of the disease trajectory, with special attention to the psychosocial issues for patient and family, that this paper will look at, namely:

1. openness of communication between patient and family and our role as carers;
2. factors that enable families to cope with the dying of a loved one;
3. ways in which we can assess how a family is coping while caring for a loved one who is dying;
4. being aware of the 'vulnerable' within the family unit of someone who is dying.

OPENNESS OF COMMUNICATION ON EMOTIONAL AND EXISTENTIAL ISSUES OF DEATH AND DYING

Before examining some of the more obvious medical literature, there is much in the classical literature and the arts that deepens our understanding of some of the emotional/existential issues for the patient and family facing death. Edvard Munch is well known for his painting of the 'The Scream', which has been used often in palliative conferences to illustrate the sense of isolation that both terminally ill patients and indeed bereaved relatives might experience. Right from early childhood Munch's life was dogged with illness and death, and many of his pictures portray the anguish that he felt.

In his short story of 'The death of Ivan Ilyich', Tolstoy (4) gives a brilliant literary account of the 'lack of openness and collusion' in a family. In the book, Ivan struggles with the growing realization that he has something seriously wrong with him. His family and his doctor, not

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knowing what to say and believing Ivan does not want to talk about it, isolate him in a conspiracy of silence. They fail to realize that they cannot prevent Ivan's body from revealing the truth of what is happening. Ivan wants to scream out 'stop lying!' but he dares not. Instead, he ends his days in the agony of symptoms uncontrolled, isolated from the comfort of family and friends knowing what he is going through. Ivan could not bring himself to ask and, to Ivan, his doctor and family appeared preoccupied with living.

As specialists in palliative medicine we need to have our intuitive antennae alert to picking up clues and being proactive in our search for unspoken fear. This will give patients and their families opportunity to talk about what they are experiencing and how they are coping. Communication has to be a two-way scenario, it is not just about the giving of good or bad news. More importantly, it is about finding out how the patient and the family are, how much they understand, what questions they want answered and what information is being asked for (5). We need to be actively listening; listening to the words that are said, to what is *not* said, and at the same time observing the non-verbal communication. Listening and communicating like this is not just a mental process, it is also a feeling process. As Carl Rogers (6) details, 'the core personal skills of a good listener include: empathy, warmth and genuineness'. Openness of communication between patient and family is a lot easier to read and talk about than to do. Even in specialist palliative care there is a danger that we, too, avoid in-depth conversations. If we miss too many of these opportunities we begin not to see them.

Kearney (7) warns those of us in specialist palliative care about just becoming symptomatologists. He states that too often the emphasis of care is on the control of difficult symptoms, ignoring the psychosocial and existential issues of caring. Symptom control is very important, but should be used as a springboard for deeper communication. Its not for the doctor or nurse specialist just to sort out symptom problems and leave someone else the other problems. This is not holistic care. Having gained the confidence of a patient and their family through controlling difficult physical symptoms, that person is in a wonderful position to then explore some of the other issues. We have a responsibility to be holistic in our caring (8).

Rathbone et al. (9) use a method of self-evaluated assessment by asking the patient and family to identify and grade the major problems as they perceive them. In this way one does not follow one's own agenda, for example: how is your pain? How are you sleeping at night? What level do you rate your fatigue? Instead, one is listening to what is worrying the patient and the family the most. This is a method that makes it considerably easier to pick up some of the more psychosocial and existential issues of care. Powazki & Walsh (10) describe the psychosocial assessment of 150 patients using a profile that assesses the physical, cognitive, social and emotional dimension of both patient and caregiver.

FAMILIES AS THE UNIT OF CARE AND ISSUES OF COPING

One of the central beliefs within the hospice movement right from its inception in the 1960s is that the family is the unit of care. Thirty years on, across the spectrum of community and hospital healthcare, there is greater awareness of the needs of the terminally ill patient: the need to control symptoms and the importance of answering questions truthfully. We are also aware of our need to speak to relatives and answer their questions. But, do we connect the two? Do we really consider the patient and the relatives as a 'family', *together*, making the time to organize a family meeting? Or do we see them as two identities, as the patient and the relative coping as best they can, sometimes in semi-isolation. From a hospital point of view, the ward environment is often not conducive to the concept of families. Is it perhaps that the word 'family' generates a greater feeling of intimacy than the word 'relative', thereby making the meeting of a family more emotionally draining and therefore something to be avoided in the hustle and bustle of a busy ward situation? Although more challenging, it is very important to have the fuller picture that the family dynamic can give. What happens to a patient has a direct impact on all members of the family, not only the spouse, but also the children and indeed the parents of the patient in some situations.

The importance of a family meeting cannot be emphasized enough and in some circumstances can make a considerable difference to how families cope, e.g. obtaining the right resources for the home if the patient can be discharged (11). In a study looking at the care of terminally ill patients and their families on medical wards in a London teaching hospital, over one-third of the families had not spoken to a doctor since the day of patient's admission some 14 days previously. Fifty per cent of relatives interviewed felt that the information given was inadequate. More than 50% of the relatives reported that the patient had already spoken to them about dying but they had been caught by surprise and did not know what to say. In response, they either changed the subject or pretended not to have heard. In asking for more information from the ward nurses, relatives were often not given the required information as the nurses felt that it was the doctor's job (12).

The way in which a family manages the overwhelming threat of having a loved one die often depends on how well a family has coped with the balancing act of adjustments that they have already had to make during the family's life cycle (13). To maintain a degree of balance in all the ups and downs of life, members of the family develop specific roles and ways of coping and communicating. It is how well these are developed within the context of each individ-

ual family network that will often determine how well they cope in a crisis. Levitt (14) has detailed six factors that will enable a family to function under the stress of a loved one's terminal illness, namely:

1. the ability to work as a cohesive unit;
2. prior successful experience of handling stress;
3. the existence of a large and flexible coping repertoire;
4. the absence of a major period of instability resulting from family developmental issues;
5. the availability of outside support that the family wants;
6. a willingness on the part of the family to perceive a difficult period as potentially growth producing.

Despite the desperate sadness of losing someone who is very close, some people can find meaning in such a situation (15). This in part may clarify the final factor of Levitt's point above. However, sometimes there is an accumulation of stress that will hamper a family's ability to manage the illness; for example, families already struggling with developmental changes (e.g. adolescence), career changes, ill or ageing parents, or financial hardships. Any of these will cause a family to be more vulnerable. As healthcare professionals we need to recognize these difficulties and in some way ease communication. This may necessitate separate interviews to explore both patients' and relatives' anxieties prior to an opportunity to express the anxieties more honestly together.

Besides the emotional strain of living with the threat of a terminal illness hanging over a family, and the importance of communication, there is the adjustment of changing roles as the disease progresses. Even if there is complete openness and honesty within a family, it is none the less sometimes difficult to accommodate the necessary role adjustment. Any role shift is likely to place added burden on the other family members. Younger people assume an adult responsibility earlier than anticipated. For the patient, maintaining their role within the family is vital. However, inevitably an adjustment has to take place and sometimes this can cause upset and anger, with the outcome of reducing communication within the family.

Stedeford (16) graphically portrays the anger engendered between couples over adjustment to a changing role. What may seem a triviality of adjusting to not being able to drive a car any longer can be an inevitable threat. The anger over the loss of role experienced by the one who is ill is often taken out on the other person who has to resume the role of the driver rather than on the disease and on death. With explanation of what is happening and helping to 'redirect the anger' (16) to the actual threat (i.e. death) a better understanding of all that is involved can be re-established.

As health professionals, it is crucial to remember that we are there to help rather than to take over. Helping a person, a couple or a family to regain control of what often seems to them to be an uncontrollable situation can call for reasonably innovative thinking. In some circumstances it may mean taking a more direct initiative, such as admitting a patient for respite care because of a family's exhaustion. However, this is always with the intention of handing back the control and autonomy to the family once the immediate crisis has passed. We have to be able to let go of what Smith (13) calls being the 'saviour'. 'A fear of how to get off the see-saw should never prevent one from trying to balance out the crisis a family is feeling under the threat of a lived one's terminals illness. However, to stay standing on the see-saw with the family without trying to hand back the control with the added support of the healthcare team may well lead to difficulties of their own as time goes on' (13).

ASSESSING FAMILY SUPPORT

Sketching out a family tree or genogram (17) with a patient who is terminally ill is a practical way of establishing what support there is within the family. By drawing a genogram with the patient one can determine what support there is or is not within the family. It also identifies who might be at risk in the family and whether extra specialist support in the form of nurse specialists, social workers or psychologists might be helpful.

The following case study and family tree (Figure 1) of a 45-year-old man, Simon, who had carcinoma of the lung is an example of the importance of understanding the situation from the family viewpoint.

Case study 1

Simon was married. He and his wife had a 6-year-old son, Jamie, who was conceived 14 years after being told they would never have children. The child was understandably very precious. On both sides of the immediate family there was little support. Simon had a sister and mother, but his own father had died 2 years previously from cancer. There had been several deaths in the family: Simon's father-in-law had died 2 months ago from cancer, and his brother-in-law had died from a road traffic accident 11 months previously. His wife had requested to see someone after their son had asked her whether 'Daddy was going to die?' 'No, of course not!' she had said quickly and then regretted it. She felt that she had betrayed his trust in her. The family lived 60 miles away from the hospital where Simon was now a patient and she was facing the situation that 'if Daddy wasn't going to die', why was she staying at the hospital. Simon was extremely ill and it was anticipated by the doctors that he might not live the weekend. The wife was very strong; she had to be to have coped so well with all the recent losses that she had been through. As we compiled the family tree together, she suddenly realized the impact of the losses on Jamie, who had seen both grandparents and an uncle die within the last 2 years:

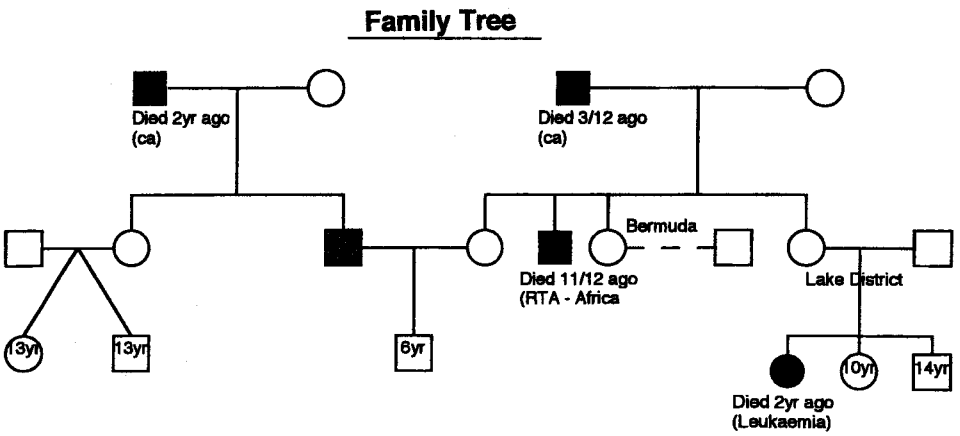

Fig. 1. Family tree.

all male in gender. For him this was a large majority of his acquaintances, and now Daddy was ill: was he to die and if so what about me and Mummy? I never specifically saw Jamie but guided Simon's wife how to talk further with Jamie, giving her booklets to help to back-up what we had talked about together.

Often the best people to talk to children are their parents, but they often need considerable guidance and help from professionals to know how to start such a difficult conversation. Even dealing with children facing a grandparent's death needs to be handled well, especially if the child has a strong relationship with their grandpa or grandma. Most of a young child's attachment will be towards one or both parents and the immediate family. Unlike an adult, who often has a considerable number of attachments to various friends, the young child's perception of his or her world and the important people in it is greatly reduced. If a parent is to die then a major part of the child's security is taken away. Furman (18) writes, 'The younger the child, the less he is differentiated from his parent … and the more he needs the surviving parent's help in differentiating himself and his own fate from that of the dead parent'. In this remarkable study of childhood bereavement (18) there are many examples of recognizing the grieving process in a child as young as 2 years old. A further case study from my own experience highlights this.

Case study 2

I had been asked to work alongside the team caring for a 32-year-old woman who had been diagnosed with carcinoma of the kidney. I had spoken several times with her and her husband, helping them to talk more openly about what was happening. They had a 3-year-old son, Peter. Because they lived outside the city we asked a local hospice to support them at home, and a few months later she died in the hospice near her home. Ten days after she had died, I rang to see how the family was and spoke to the grandmother. She told me what had happened the day before, something that I will never forget. She had collected Peter from playschool as usual. She had opened the front door of the house and Peter had run down the hall into the lounge. As he went into the lounge he knocked his right elbow on the door and fell to the floor crying. The grandmother ran to pick him up and sat with him on her knee on the settee. She asked him to show 'nanny' where it hurt. Instead of rubbing his elbow, he rubbed his heart. He was probably too young to be able to put into words what he was feeling but being given the opportunity to express what he was feeling was so important, not only to Peter but also to his grandmother. They then both cried together.

Children are not overwhelmed by emotion as long as the expression of grief is not overwhelming the adult. The very fact that the adult is expressing the grief is an important role model for the child.

Anticipating a death is painful but, in general, having warning of the event helps one to prepare for bereavement. A considerable number of excellent books for children (19–23) and teenagers (24) is available to help them to speak about the feelings associated with the dying of a parent. The building of 'memory boxes' while the ill parent is still reasonably well and able to visit places with the family can be a useful way of collecting things that, at a later date, can provide the child with tangible memories. The memory boxes are built as a natural part of enjoying the time together. Just as one takes photographs to remind one of a memorable occasion, the collecting is being done a little more pro-actively in the light of advanced disease. The whole purpose of collecting does not need to be spelled out at the time to the children, but can be done in preparation for the children in the light of the parents being told about advancing disease. The drawing of pictures with younger children may help them to start expressing what they want to say or ask.

Much of society still considers that children are too young to understand a great deal about death and dying. Children who are not given accurate information will often

try to make up a story to fill in the gaps (25) or hide themselves away in a fantasy world. Some believe that this may have been the stimulus behind CS Lewis's children's books. If children have been excluded from being involved with what has been going on, especially if they have had a strong relationship with the dying person, it may become difficult for them to accept the death. Being honest with a child who is asking difficult questions and the showing of emotion are not detrimental as long as the child feels a sense of control in the situation: a hand being held or an arm around them. For a child to be excluded from a family interview will only make them feel isolated and alone: children are always aware of the atmosphere around them even though they might pretend otherwise.

AWARENESS OF THE VULNERABLE CHILD IN A GRIEVING SITUATION

Kliman (26) examines situations that may exacerbate the vulnerability of a grieving child. Kliman lists eight circumstances where, if two or more occur together around the time of the death of a parent, the child may be in danger from psychological disturbance later in their development:

1. the child has suffered a loss under the age of 4 years;
2. the child already has psychic behaviours;
3. there has been a change of environment;
4. the surviving parent develops pathological grief;
5. there is increasing physical intimacy with the surviving parent;
6. a death has been caused through the birth of a child;
7. the family has concealed the disease from the child;
8. terminal illness has resulted in physical deformation or psychic problems.

As healthcare professionals who have access to research and information, we have a duty to pass on and to help families cope with dying. In the past certain community rituals were passed down and supported people through the death of a loved one. Now, more and more the same support is not available. Patients and families are seeking help and information and we need to be equipped with the necessary advice. The work that can be done *before* someone dies is fundamental in helping a grieving family to cope. However, it is not about taking over but more about empowering and helping a patient and family to regain some control. Smith (13) argues very convincingly the importance of preventive healthcare by caring for the patient within the context of the family, not only helping to reduce the suffering for the family but ultimately being more cost-effective by preventing post-death grief pathology.

In summary, therefore, it is important that awareness of the family unit as a whole is considered. A good family assessment should be performed alongside other health professionals such as social workers. Caring for the dying patient and his or her family requires the efforts of the whole multi-disciplinary team: the nurse, social worker, the doctor and the chaplain. In the UK, where young children are involved, we would seek help from a health visitor who would follow the family up in the community alongside their general practitioner or community doctor. Sometimes the discipline matters less than the skill that a certain health professional may have in order to give the necessary support and care. Finally, it is how we communicate with the patient in the context of the family that hopefully allows death to become 'the discreet but dignified exit of a peaceful person, from a helpful society, without pain or suffering and ultimately without fear' (27).

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